

**A Qualitative Study of Hope
And the Environment of Persons Living with Cancer**

by

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The purpose of this naturalistic study was to explore and describe the impact of factors from the internal and external, human and non-human environments on the hoping process utilized by persons living with cancer. Given the nature of difficulties encountered by persons living with cancer, a sense of hopefulness is deemed to be especially important in managing life with this diagnosis. Using semi-structured interviewing and a purposive sample of fifteen persons living with cancer, positive and negative factors from the total environment were explored. Special attention was given to the impact of health care providers and health care environments on participants' hoping processes. Current perceived level of hopefulness on a one to ten scale was elicited from each informant revealing a high level of hopefulness for the group (mean=9.37). Participants were asked to rank their positive hope influencing factors by importance for the internal (self) and external (human and non-human)

environmental domains and overall. Data were audio taped and transcribed. Analysis and interpretation of data revealed four broad theme categories for hope influencing factors from the internal environment -- personal characteristics, uplifting thoughts, sustaining beliefs, and self care. Human relational groupings, other than health care providers, revealed six broad themes including encouragement, companionship, love, gifts, communications, and role modeling. For health care providers, broad themes were competence, caring and compassion, and recognition and respect. For the external non-human environment, six broad theme categories emerged from the data, including pleasant environmental stimuli, symbols, comfort, safety, power, and surrogates. Three to six sub-themes were developed under each broad category. Two theoretical models were developed to explain the hoping process. One was developed prior to gathering data and involved an integration of attachment/loss, need satisfaction/deficit, and developmental growth. This theory was supported by the data. Another theoretical perspective emerged from the data suggested by the difficulty expressed by participants in ranking their sources of hope. The importance of various factors and perceived level of hope were reported to vary with time and circumstances. The second theory explained hoping as a dynamic cyclical process of emergence and growth across time. The results of this study have implications for nursing education, practice, and research. Most important is the potential for increased knowledge of the hoping process to assist nurses in enhancing the well-being and holistic health of persons living with cancer.

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CHAPTER I

INTRODUCTION TO THE STUDY

An anonymous author quoted in Brownlow (1993) has emphasized the value of hope to human life. "It has been said that man can live about forty days without food, about three days without water, and about eight minutes without air--but only one second without HOPE" (p. 9).

A young nurse, disabled by chronic illness, has described the development of hope in a personal account of recovery and renewal after the shock and pain of a life-threatening diagnosis:

Hope strangely began to emerge in my heart and mind from seemingly nowhere--almost like a bulb planted in the soil of the dark night of my being and soul--called forth by the promise of warmth and light. It was like experiencing the springtime of my soul, as new thoughts began to bud, new dreams were born, and new directions sprang forth in the perfect timing of the seasons of my life and living (Lewis, 1985, p. 30).

With this newborn hope, she began to envision fresh perspectives on life, with new thoughts, dreams, and directions. Hope was described as an essential resource for the process of reconstructing her life anew.

How did hope emerge in this young patient's heart and mind? Consider her image of a bulb growing out of the cold, dark soil. With a bulb, what initiates and sustains its growth? Is it the strong roots, the substance of the bulb, the quality of the soil, the warmth and light of sunshine, the rain; or the care of the gardener who fertilizes, waters, and cultivates? For a human being, what inspires and sustains hope

during illness or other difficult times? Is it the internal environment (the self), the external environment (other persons or non-human factors), or a combination of all these which facilitates the emergence and maintenance of hope?

Problem

Illness presents a person with numerous challenges, changes, and difficulties to overcome. A positive, hopeful outlook is an important resource to help the person transcend troublesome times. Literature suggests that loss of hope may even lead to death (Frankl, 1959; Engel, 1968; Seligman, 1975/1992, 1990). Little is known about the nurse's role in aiding the mobilization of hope, an apparently invaluable resource. First, it is necessary to understand the process by which hope is gained and maintained or lost during illness. Given the nature of human beings, each with self-awareness and perspectives on the world, it is logical to begin the investigation with individual persons, asking each for his or her unique perception of how hope emerges, is sustained, or lost during illness. With this knowledge, nurses will be better prepared to design strategies to promote hope and prevent hopelessness in our most vulnerable clients, those experiencing illness.

Background and Significance

Every day millions of Americans face living with chronic, acute, and terminal illnesses. Nurses encounter these patients in all phases of illness, recovery, and dying. Nursing care is delivered in diverse health care environments, from highly specialized hospital intensive care units to a variety of community and home care settings.

In the current health care arena, with mushrooming technological interventions, increased acuity levels of hospital patients, cost containment measures, and personnel reductions, nurses are confronted with doing more with less (Green, 2001, Rinard, 1996, Willmann, 2001). It would be easy for some nurses, especially those managing multiple "high tech" treatment modalities to become engrossed in the physiological aspects of illness care (Peplau, 1995). A perceived lack of support from the health care delivery system has been described by patients struggling to maintain hope during serious illnesses (Hall, 1990). In Hall's study, some participants even described the feeling that caregivers had "robbed" persons of their hope. Ethics, education, tradition, and standards of practice remind nurses of their professional responsibility to provide holistic care that facilitates healing for the whole person-- body, mind, and spirit (American Nurses Association [A.N.A.], 1985; A.N.A., 1995; Chitty, 1997; Dossey, Guzetta, & Kenner, 1992; Dossey, Keegan, Guzetta, & Kolkmeier, 1988; Erickson, Tomlin, and Swaim, 1983; Kozier, Erb, Berman, & Burke, 2000; Lindeman & McAthie, 1999; Lindberg, Hunter, & Kruszewski, 1998; Nightingale, 1969).

Given the nature and direction of changes in the health care delivery system, it is especially important for nurses to recognize and assume their key role in promoting holistic health, to bring about healing for the human mind and spirit, as well as for the body. Facilitating hopefulness and preventing hopelessness are very much a part of

holistic care and healing, aimed toward the goal of holistic health, the optimum possible well-being of body, mind and spirit.

The linkage of hope to health--physical, mental, and spiritual--is evident in the literature of many disciplines. The "survival value" of hope has been professed by many authors, scientists, and practitioners (Cousins, 1989; Engel, 1968; Farran, Herth, & Popovich, 1995; Frankl, 1959; Garrison & Sheperd, 1989; Hutschnecker, 1958; McGee, 1984; Seligman, 1975/1992, 1990; Siegel, 1988; Swindoll, 1996). Hafen, Frandsen, Karren, and Hooker in their book, The Health Effects of Attitudes, Emotions, and Relationships (1992), cite evidence from multiple research studies and personal accounts of hope as a predictor of health, a healing factor, and a survival factor in human life. Kenner, Guzetta, and Dossey (1985) point out a practice observation of many experienced critical care nurses. The critically ill patient who gives up, consumed by feelings of hopelessness and helplessness, frequently shows rapid physiological deterioration. Two authors, Engel (1968) and Seligman (1975/1992), have discussed this "giving up" phenomenon, a hopeless-helpless state, which places a person at great risk for illness or even death.

Norman Cousins, a journalist, has written a brilliant work, Head First: The Biology of Hope (1989), in which he extols the "healing power" of hope in a personal illness and recovery story. Stricken with a painful and life-threatening collagen disease, Cousins designed a program of viewing humorous films. This produced hearty laughter that relieved his pain, promoted rest and miraculously resulted in

reversal of his illness. He was so affected by the experience, that he redirected his life work into medical education and research on body-mind connections.

The majority of nursing research on hope reported in the literature to date has been undertaken to define the concept, determine its dimensions, describe its meaning to clients, or describe its relationship to other variables. Studies of a similar nature have been replicated in different age groups and diagnoses (Dufault & Martocchio, 1985; Farran & Popovich, 1990; Herth, 1993b; Hinds, 1984; Hinds & Martin, 1988; Owen, 1989; Stoner & Keampfer, 1985). Little research in nursing has been undertaken either to determine the process by which hope is gained, maintained, or lost during illness or to determine the nurse's role in this process. In a recently published book, devoted entirely to the concepts of hope and hopelessness, nurse authors Farran, Herth, and Popovich (1995), each having years of experience in hope research, concluded as follows. "Despite increasing interest in the concepts of hope and hopelessness, little evidence has been derived from clinical research to guide nurses in selecting appropriate strategies to mobilize, enhance and support hope or to prevent or diminish hopelessness" (pp.105-106).

Given the pervasive importance of hope to health, it is important that the scientific body of knowledge for the nursing profession contain adequate guidelines describing the nurse's role in inspiring and sustaining hope in clients. The present study sought to expand current knowledge of hope-influencing factors and the hoping process experienced by clients during illness.

In exploring the multiple factors that might affect a person's hoping process, the broadest approach to the investigation is deemed to be from an environmental perspective. All influencing factors within the self (internal environment) and surrounding a person (external environment), human and non-human, are open to consideration as potentially impacting the hoping process. Several nursing studies have linked hope to internal human resources, e.g. self esteem, and external human resources, e.g. social support (Coward, 1996; Foote, Piazza, Holcombe, Paul, & Daffin, 1990; Piazza, Holcombe, Foote, Paul, Love, & Daffin, 1991; Vandercreek, Nye, & Herth, 1994). However, there has been little research on hope from the standpoint of the non-human environment and its impact on the hoping process. Three studies were found which looked at only one aspect of the non-human environment, "setting of care"--home, hospital, hospice, or nursing home--and its relationship to hope (Herth 1989, 1990a, 1993b). The results were inconsistent as far as which setting was associated with highest hope. The paucity of studies in this area indicates a need for greater consideration of setting as well as other aspects of the non-human environment as they impact the hoping process.

The importance of environment to the discipline of nursing is found in the writings of key historical figures. In revisiting the teachings and observations of Florence Nightingale, founder of modern nursing, her concern with the impact of the environment on health was noted over one hundred years ago. In her book, Notes on Nursing (1969, originally published in 1860), she described the benefits of fresh air,

light, warmth, quiet and cleanliness. She recommended placing the patient's bed by the window for a view and allowing the room to be filled with "brilliance of colour", a variety of beautiful objects, green plants, and cut flowers. In the forward to the modern reproduction of Notes on Nursing, Dolan (1969) notes, "the entire physical environment was of primary importance to Miss Nightingale" (p.vi). "Put the pale withering plant and human being into the sun, and, if not too far gone, each will recover health and spirit" (Nightingale, p.87). It is unknown how such environmental interventions might impact the patient's hoping process. In some types of hospital environments (intensive care units) these aesthetic interventions are prohibited, with patients' flowers and plants decorating the nurses' station.

An environmental perspective on nursing phenomena is supported by many nursing scholars and theorists since Nightingale. These authors suggest that nurses need to consider the impact of the total environment on persons (Chitty, 1997; Ellis, 1982; Erickson et al., 1983; Flaskerud & Halloran, 1980; Lindberg et al., 1998; Schuster & Brown, 1994; Woods & Catanzaro, 1988). "Our focus is to make the total environment as conducive as possible to meeting the client's needs and promoting the client's welfare" (Erickson et al., 1983, p. 140). Environment is one of the four meta-paradigm concepts (person, health, environment, and nursing) in the discipline of nursing (George, 1995). "Contemporary nursing science emphasizes a holistic understanding of human beings in interaction with their environments." (Woods & Catanzaro, 1988, p. ix).

In the present research study, environment is conceptualized as internal/external and human/non-human in order to differentiate self (internal) from person-to-person interactions (external human), and other non-human factors impacting the hoping process. As stated above, the non-human environment has received little attention as a source of hope in nursing research. Furthermore, little has been written about the interface of all environmental factors on the hoping process--human (internal and external) and non-human (other living things, settings of care, physical and metaphysical surroundings).

Purpose

The purpose of this naturalistic study in nursing was to explore and describe the impact of factors from the internal and external, human and non-human environments on the hoping process utilized by persons living with cancer. Special attention was given to the behavior of nurses and other health care personnel as it impacted the individual's hoping process. The person-environmental interaction afforded a unique perspective on the hoping process not found in previous research. The nursing practice theory, Modeling and Role Modeling (Erickson et al., 1983), provided the theoretical orientation, philosophical foundation, and methodological guidance for this study. The findings of this study will provide nurses with a broader based understanding of the total environment as it influences the hoping processes of persons living with a diagnosis of cancer. With this knowledge, nurses will be better prepared to facilitate hope and prevent hopelessness in persons experiencing such

illness. In addition, the results of this research will serve to sensitize caregivers from multidisciplinary backgrounds to individual patient experiences of hope in various health care settings.

Theoretical Orientation

Theoretical background for this study comes from the nursing grand theory, Modeling and Role Modeling (Erickson et al., 1983). Modeling and Role Modeling is also a practice theory, including specific intervention guidelines designed to be applied directly to practice. In part, the theory was inductively derived from the authors' nursing experiences, vividly illustrated with multiple client anecdotes. Another strength of Modeling and Role Modeling is the unique synthesis of theoretical bases from human development (Erikson 1963, 1982), needs (Maslow 1970), stress (Selye 1976), and object relations (Bowlby 1969/1982), all of which are relevant to nursing practice. Familiar to most nurses, the synthesized theoretical bases are made more meaningful and applicable when explicated from the authors' distinctive nursing perspective, accompanied by clinical examples.

As the title indicates, Modeling and Role Modeling theory emphasizes *modeling* (developing an image and understanding of the client's world, as the client perceives it) and *role-modeling* (facilitating and nurturing the individual in attaining, maintaining or promoting health through purposeful interventions). The emphasis on client's perspective suggests qualitative investigations (Lock, 1990; Tipton, 1992). Major concepts of Modeling and Role Modeling philosophy include those related to

human nature--holism, health, adaptation, affiliated-individuation, self care, lifetime growth and development; and those related to the role of the nurse -- facilitation, nurturance, and unconditional acceptance (Erickson et al., 1983). The authors have defined nursing as follows:

Nursing is the holistic helping of persons with their self-care activities in relation to their health. This is an interactive, interpersonal process that nurtures strengths to enable development, release, and channeling of resources for coping with one's circumstances and environment. The goal is to achieve a state of perceived optimum health and contentment (p. 49).

Theoretical linkages are proposed between developmental task resolution, basic need satisfaction, object attachment and loss, and adaptive potential. The authors relate the theory to implementation of the nursing process, proposing five aims of intervention (build trust, promote positive orientation, promote client control, affirm and promote strengths, and set mutual health-directed goals). Nursing actions are suggested for each aim, grouped according to the basic needs hierarchy of Maslow (1970).

The authors of Modeling and Role Modeling embrace the human developmental theory of Erik Erikson (1963), tracing the origins of hope to the earliest stage of life and resolution of the "Trust vs. Mistrust" task. Hope is the "virtue" and drive the "strength" that results from favorable resolution of this first stage of development. A preponderance of trust over mistrust in the human personality is theorized to result in the enduring attitude, the psychosocial resource, known as hope.

Since Modeling and Role Modeling theory views growth and development as a lifetime process, early origins or deficits of hope are not final (Erickson et al., 1983).

Modeling and Role Modeling (MRM) theory provides fertile ground for nursing inquiry. Three central theoretical linkages are proposed by the authors:

(1) The relationship between completion of developmental tasks and basic-need satisfaction, (2) the relationships among satisfaction of basic needs, object attachment and loss, and developmental growth, and (3) the relationship between one's ability to mobilize coping resources and need satisfaction (Erickson et al., p. 86).

These propositions suggest relationships that may explain the development and renewal of hope. The model found in Figure 1., entitled "Development and Renewal of Hope," was synthesized from ideas in MRM theory.

The first MRM proposition links resolution of developmental tasks (e.g. trust vs. mistrust) with basic need satisfaction. The authors assert, "the degree to which developmental tasks are resolved is dependent on the degree to which human needs are satisfied" (Erickson et al., p. 87). The basic (or survival) needs described by Maslow (1987) include *physiological* (oxygen, hydration, nutrition, warmth, sleep, taste, smell, activity, exercise, comfort, sex, touch); *safety* (security; stability; dependency; protection; strength in the protector; freedom from fear, anxiety, and chaos; need for order, law, and limits); *belongingness and love* (contact, intimacy, giving and receiving affection and love, having a place in a group or family); *esteem* (self respect or worth, esteem of others, confidence, competence, mastery, dignity, recognition, attention, appreciation); and *self-actualization* (self-fulfillment, being true

to one's own nature, or making the most of one's potential). Two basic cognitive needs are included in Maslow's hierarchy: the desire to *know and understand* and the desire to be surrounded by beauty (*aesthetic*). Maslow has ordered the need categories on a hierarchy where satisfaction of the lowest level (physiological) needs must occur before the higher level needs emerge (safety, love, esteem, etc. in that order). Deprivation at one level motivates behavior and requires satisfaction to some degree before the next (higher) level emerges.

As proposed by Erickson et al. (1983), the stage of trust development, from which hope is the virtue and drive the strength, is dependent upon satisfaction of the basic needs. In infancy this is accomplished within the mother-infant relationship. If the mother/caregiver is able to satisfy the infant's needs (especially physiological, safety/security, and love/belonging) from the infant's perspective, the outcome will be a "...sense of trust with a pervading attitude of hope and a drive for the future." (Erickson et al., 1983)

The second MRM proposition links object relationships and the satisfaction of human needs. Object attachment (as to the mother in infancy) is a vehicle for meeting basic needs. Attachment results when an object repeatedly meets basic needs. "The degree to which needs are satisfied by object attachment depends on the availability of those objects and the degree to which they provide comfort and security as opposed to anxiety and threat" (Erickson et al. 1983, p. 90). Secure attachment to the caregiver results in the child's perception of the world as trustworthy and facilitates trust in the

self. Basic need deficits occur with object loss, necessitating new attachments for need satisfaction. Objects of importance vary across the life span and may be concrete, abstract or symbolic. Identities, roles, relationships, places, thoughts, and ideals are examples of significant objects of attachment for adults (Erickson et al.).

Proposition three in MRM theory states that the individual's ability to mobilize coping resources is directly associated with need satisfaction. Individuals confronted with stressors, such as the diagnosis of significant illness, may experience numerous basic need deficits. Thus the individual will be in need of assistance to cope with illness. This suggests the role of nurse in this experience with either direct intervention as caregiver or indirect as facilitator of need satisfaction through individually significant objects of attachment. The proposed theoretical model, Development and Renewal of Hope, formulated from MRM propositions, is illustrated in Figure 1.

Modeling and Role Modeling theory has provided support for selection of the conceptual area and methodology for this proposed research. The phenomenon of hope as a personal nursing concern dates back some thirty years to this author's early practice in critical care units. It was observed that some gravely ill patients gave up hope, fell into despair, rapidly declined and often died. Other patients remained hopeful, maintained a fighting spirit and often survived, in spite of dire circumstances. The question of how this happened, what made the difference in hopeful and hopeless responses, was partially answered during doctoral study of the theory of Modeling and Role Modeling.

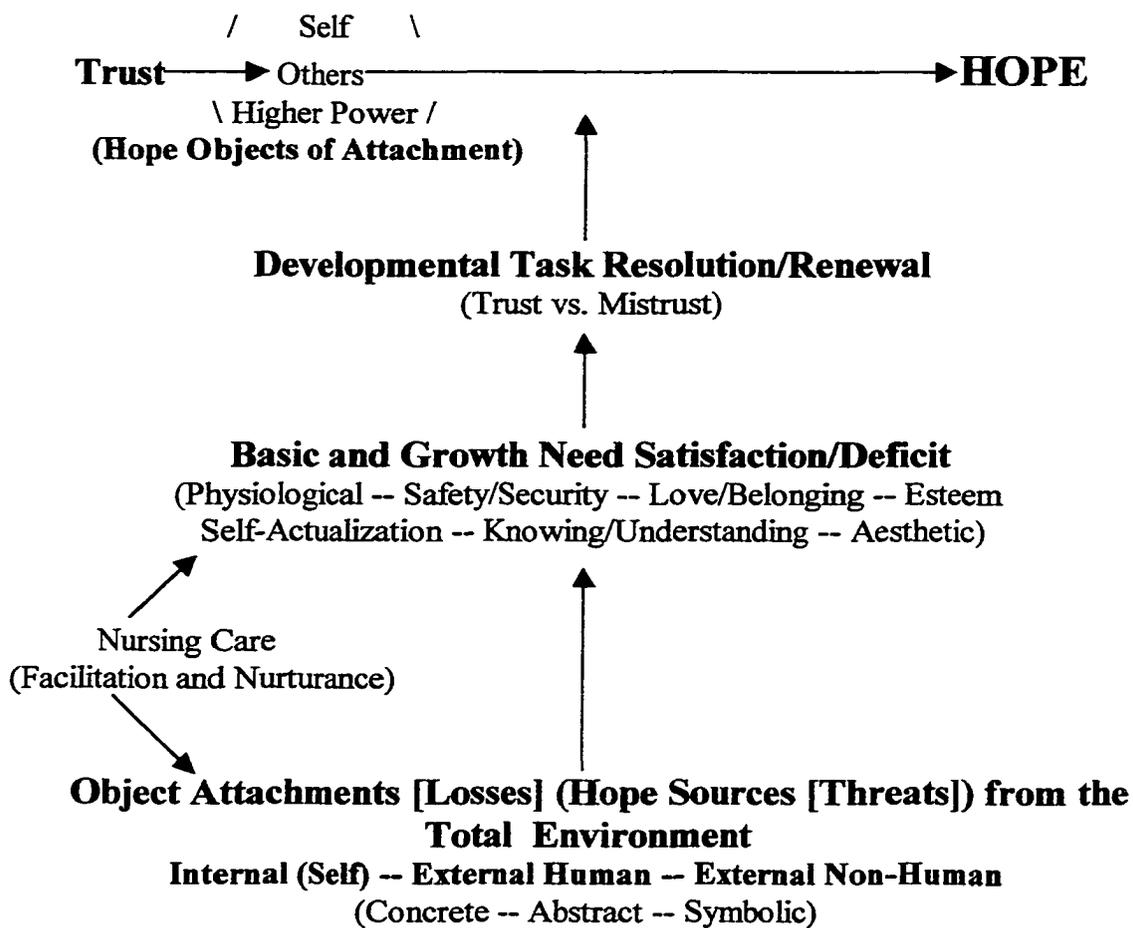


Figure 1. Tipton's Model of Development and Renewal of Hope, based on the theoretical views of Erickson et al., (1983).

As a practice theory, Modeling and Role Modeling provides guidelines to assist the practicing nurse with problems such as how to encourage and facilitate hope in patients. Considering the theorized relationship between hope and trust and the stated inherence of hope in positive orientation, some preliminary answers are found. Looking within the lists of suggested nursing interventions for the first and second aims ("building trust" and "promoting positive orientation"), the nurse finds some suggestions and examples. The authors admit they have not provided all the answers and urge nurses to think creatively, adding to the list from their own nursing experience. This research study was designed with this urging from Modeling and Role Modeling theorists in mind. This study was designed to gather data from a formalized inquiry of individual perceptions of how hope emerges, is sustained, or lost during illness and to shed further evidence upon the problem of promoting hope during illness.

More specifically, this study asks, what do persons living with cancer perceive to be the impact of factors from the internal, external, human, and non-human domains of environment on their hoping processes? A naturalistic study from the client's perspective was deemed most appropriate to discover the answers. Findings from this inquiry will serve to expand and support knowledge of hope described in MRM theory and the nursing literature. A key concept from Modeling and Role Modeling theory relevant to the proposed research questions and methodology is "client's model of the world." A special aspect of "client's model of the world" related to health is "self

care knowledge." Self care knowledge is that part of the client's model of the world related to self understanding of health processes -- that is, what has made him/her sick, less effective, or lacking growth; and likewise, what will make him/her well, more effective, or able to grow. Failure of clinicians to incorporate this knowledge into the plan of care may result in failure of the plan (Erickson, 1990).

Erickson et al. (1983) assert that all life events must be viewed from an individual's own perspective. Although humans have many perceptions in common, each is slightly different and nurses must avoid jumping to conclusions. One person's difficulty may be another's challenge. "The way an individual perceives life, events, people, situations, the way an individual communicates, thinks, feels, acts, and reacts--all of these factors comprise the *individual's model of his or her world*" (p. 84). An individual perceives the environment from a unique perspective based on past experience, past learning, and state of life.

"Using the *client's model of the world* as a base for interventions is central to our work" (Erickson et al., 1983, p. xv). Nurses practicing from this perspective "start with whatever concerns the person most," rather than imposing provider concerns on the patient (p. 34). The client is regarded as a unique, worthwhile, important individual and is considered the expert about himself or herself. The client always knows, at some level, what has made him or her ill or functioning less effectively, and knows what will help him or her to become well or to function more effectively.

The act of modeling, then is the process the nurse uses as she develops an image and understanding of the client's world -- an image and understanding developed within the client's framework *and from the client's perspective*. *Modeling* contains the art and science of nursing. That is, the *art of modeling* is the development of a mirror image of the situation from the client's perspective. It requires communication skills basic to nursing. These skills will help the nurse put one foot into a world foreign to herself. The *science of modeling* is the scientific aggregation of the data collected about the *client's model* (p. 95).

Two of the other major concepts of Modeling and Role-Modeling, critical to the activities of nursing are "nurturance" and "facilitation." The nurse who nurtures and facilitates seeks first to know, understand, and appreciate the value and significance of the client's model. Nursing care (nurturance and facilitation) is provided within the context of an ongoing interpersonal relationship aimed at assisting the client toward holistic health, *within his/her model of the world*.

It follows from the above discussion, that prerequisite to designing nursing interventions to facilitate and mobilize hope as a client resource, the nurse would start by asking the client for his or her personal perspectives ("model" or "self care knowledge") regarding hope. This special self care knowledge, known only to the person, will help the nurse to understand and plan appropriate interventions to preserve and build hope resources. Without this knowledge, the nurse may inadvertently plan inappropriate or possibly harmful interventions (Erickson, 1990).

This research study sought to explore and describe multiple individual perspectives on the hoping process, anticipating that similarities and differences would be uncovered. It is hoped that data analysis and interpretation, merging these multiple

perspectives on hope, will communicate expanded understanding and knowledge about the hoping process as influenced by the total environment.

Research Questions

The following research questions were developed to guide this study:

- (1) From the patient's perspective, what factors from the internal environment (self) impact the hoping process positively (sources of hope) and negatively (threats to hope)?
- (2) From the patient's perspective, what interactions in the external human environment (other persons) impact the hoping process positively (sources of hope) and negatively (threats to hope)?
- (3) From the patient's perspective, what factors from the external non-human environment impact the hoping process positively (sources of hope) and negatively (threats to hope)?
- (4) How do patients perceive that the identified personal sources of hope facilitate hopefulness in their life situations?
- (5) What do patients identify as primary, secondary, and tertiary sources of hope within each environmental domain and overall?
- (6) What is the perceived level of hope in each individual participant?

Definitions

For the purposes of this study, the following theoretical definitions have been developed:

Hope -- Both a noun and a verb, hope is something people have and something they do. (Noun): A fundamental human attitude or essential psychosocial resource, a positive expectation about the future, imparting an energized state of living in the present and toward the future. (Verb): To view the future with positive anticipation, enabling one to project oneself into that future and transcend present difficulty. The level of hope was measured by asking the study participants to rate their current perceived level of hopefulness on a scale of one to ten, with one being "little or no hope" and ten being "filled with hope".

Hopelessness -- The state wherein an individual has no expectation of good or success, the state of despair (Merriam-Webster, 1993). The definition of the North American Nursing Diagnosis Association (NANDA) adds "a sustained subjective emotional state in which an individual sees no alternatives or personal choices available to solve problems or to achieve what is desired and cannot mobilize energy on own behalf to establish goals" (Carpenito, 1997, p.463).

Hoping Process -- The ongoing interplay of cognitive, emotional, or behavioral activities and events by which an individual gains, maintains, or loses hope in an ebb and flow manner, impacted by multiple environmental factors. For the purposes of this study, the hoping process was explored by interview of subjects concerning specific hope-influencing factors from the internal environment (self), external human environment (other persons), and external non-human environment (all other factors) that impacted their hoping processes.

Hope-Influencing Factors -- Anything about self, other persons, or the non-human environment that was perceived by study participants as influencing their feelings of hopefulness either positively or negatively. Factors that influenced hopefulness positively were known also as **sources of hope** and factors that influenced hopefulness negatively were known also as **threats to hope**. Hope-influencing factors were measured by interviewing study participants concerning their perceptions of sources and threats to hope from the total environment. Perceptions of how the factors influenced hopefulness were also sought. Participants were asked to rank their primary, secondary, and tertiary sources of hope within each environmental domain and overall.

Total Environment -- All that is within, surrounding and/or interacting with a person; influencing life, growth, development, need satisfaction, perceptions of hope, and the hoping process. In this study, the concept of environment was not measured per se but provided an organizing framework for classifying perceived hope-influencing factors, both positive (sources) and negative (threats), arising from the environment. Environment was further defined as:

Internal Environment -- The inner world of the self, including personal characteristics, thoughts, feelings, images, sensations, resources and behaviors. Hamachek's (1992) conceptualization of self supports this definition. "As a central aspect of our existence, the self houses our total subjective and intrapersonal world; it is the distinctive center of our experience and

significance. It includes, among other things, our basic system of beliefs, attitudes, and values. The self is what constitutes our inner world as distinguished from the outer world consisting of all other people and things.” (p. 4)

External Environment -- The world outside of self. Merriam-Webster's (1993) definition of environment supports this definition, “...the circumstances, objects, or conditions by which one is surrounded...the complex of physical, chemical, and biotic factors that act upon an organism ... and ultimately determine its form and survival ... the aggregate of social and cultural conditions that influence the life of an individual...” (p. 388).

For the purposes of this study, the external environment was further divided into the human and non-human environments:

Human Environment -- All other living persons surrounding an individual, including, but not limited to family, friends, and health care professionals and workers.

Non-Human Environment -- Other living things (plant or animal), inanimate objects, places, essences or entities (concrete or abstract, physical or metaphysical) surrounding an individual.

Internal environment was the first domain of the total environment to be explored for hope-influencing factors in the interview with study informants. This was followed

by exploration of the **external human** and the **external non-human environments** for hope-influencing factors perceived by study informants.

Need Satisfaction -- The state wherein human needs, as conceptualized by Maslow (1987), are gratified. The vehicle for need satisfaction is theorized to be object attachment.

Object Attachment -- Devotion to or desire for contact or proximity with a person, thing, purpose, or ideal. Objects are concrete, abstract, or symbolic, individually significant, and vary across the life span.

Nurse -- A health care professional, caregiver and healer, designated by the legal title "Registered Nurse".

Behavior -- The conduct, actions, or attitude of an individual, verbal or non-verbal, perceived by another; including but not limited to speaking, listening, touching, teaching, visiting, availability, visibility, and presence.

Patient / Client -- A person diagnosed and living with cancer who is considered a legitimate member of the health care team, always having some control over decisions regarding own health care. In this study the patient/client (participant) interacted with one or more nurses in at least one health care setting other than home.

Setting -- The place, institutional or home, where nurses interact with patients for the purpose of providing care and healing; as hospital, clinic, extended care facility, hospice, or home.

Model of the world -- The unique way in which an individual perceives life, events, people and situations; the way an individual communicates, thinks, feels, and reacts; understanding of which is prerequisite to providing holistic care (Erickson et al., 1983).

Health -- A state of physical, mental, and spiritual well-being, not merely the absence of disease or infirmity, a state or equilibrium within the various subsystems of an holistic person (Erickson et al., 1983).

Assumptions

For the purposes of this study, the following assumptions are held:

- (1) Human persons are holistic beings, with unified dimensions of body, mind, and spirit, wherein the whole is greater than the sum of the parts.
- (2) Human dimensions of body-mind-spirit, unified and whole, are interconnected and capable of influencing each other.
- (3) Each person is unique, perceiving and deriving meaning from the world in a special way, though similarities and differences can be identified among persons.
- (4) Health is a dynamic state of well-being, defined by each person individually.
- (5) Each individual is the primary source of information about his or her health needs and well-being.
- (6) Persons are part of, influenced by, and always interacting in some way with their environment.

- (7) Persons are in a continual process of growth and development from birth to death.
- (8) Nursing care and healing activities are capable of positively impacting the health of patients.
- (9) Hope is a positive life force, an enduring attitude, and valuable resource necessary for healthy living in the present and providing drive for the future.
- (10) Participants interviewed in this research study will be honest in presenting their multiple realities.

Limitations

Since generalizability, replicability, and control are not part of the methodological design of research in the naturalistic inductive paradigm, lack of these qualities is not a limitation. The investigator's frame of reference, ideology, and biases may influence qualitative research and need to be examined before collecting data. This has been done in this chapter by explication of the researcher's theoretical orientation. Personal bias was avoided in the analysis and interpretation of data by utilizing two auditors (nurse researchers with experience in qualitative study) to review the audit trail tracking the process of classification of interview data into categories and themes.

Summary

Chapter I has introduced this naturalistic study in nursing that aimed to discover how patients gain and maintain or lose hope while living with a diagnosis of

cancer. Given the current health care environment and nature of difficulties encountered by ill persons, hope is identified as being especially important to life and health. Background and significance have been provided from the perspective of nurses and other health care professionals. Factors from the environment, internal and external, human and non-human, were the focus of investigation as they impacted the individual persons' hoping processes. Research has been found to be insufficient in determining nursing strategies to inspire and sustain hope in ill persons and in understanding the impact of the non-human environment on hope. Findings from this study will add to the knowledge base of nursing science. It is also hoped that health personnel from all backgrounds will become sensitized to the importance of promoting hope in persons living with cancer, and informed as to how their behavior impacts that hoping process. The nursing practice theory and paradigm, Modeling and Role-Modeling, provided the philosophical foundation, theoretical orientation, and methodological guidance for this study.

"As nurses, we embrace the notion of caring. We believe that our role is to facilitate health across the life span through caring actions." (Erickson, 1996, p. vii) Learning more about the nature and facilitation of the hoping processes of persons living with cancer serves to further Erickson's challenge to nurses to "help individuals achieve high levels of well-being irrespective of their physical state" (p. vii).

CHAPTER II

REVIEW OF LITERATURE

Throughout the years, the concept of hope has been studied by nurses, psychologists, physicians, and theologians. In this chapter, historical as well as current perspectives on hope are examined to establish the concept as pervasive and important to human health, the holistic well-being of body, mind and spirit. Following the overview of multidisciplinary hope literature, the nursing research literature related to the questions investigated in this study will be reviewed.

Multidisciplinary Perspectives on Hope

For at least two thousand years, the concept of hope has been of concern to humanity as evidenced by innumerable references to it in the Judeo-Christian Bible. In the nineteenth century, Florence Nightingale discussed the "chattering hopes and advices" of visitors as they impacted the mental well-being of her patients and offered hints as to appropriate topics of conversation with the sick (Nightingale, 1969). One has only to glance through the shelves of a local bookstore to note many popular works on the subject (Brown, 1996; Brownlow, 1993; Geiman, 1994; Graham, 1991; Swindoll, 1996). Turning on the television finds programs on major networks such as a C.B.S. prime time presentation, "The Power of Hope" (Graham, 1996). Health care professionals are invited to learn about hope from a theological perspective in educational programs such as, "Nurturing Hope: The Significance of Future Stories

for Assessment and Intervention", (Lester, 1996). Hope is a fundamental concern of all humanity, both lay and professional.

The word "hope," both a noun and a verb, is something one has, an "expectation of fulfillment or success" and something one does "to desire with expectation of obtainment" (Merriam-Webster, 1993, p. 558). Hope is commonly mentioned in everyday conversations as well as in professional nursing discussions. In many types of difficult situations, colloquial wisdom is communicated in phrases such as "have hope", "hope for the best", and "never give up hope". The caution not to convey "false hope" is sometimes heard in professional discussions about ill persons. This is probably related to a fear of promoting denial, deemed by many as an ineffective coping mechanism. However, as pointed out by Robinson (1993), "denial can be an adaptive response which helps the patient cope with the experience of having a life-threatening illness" (p.102). She reviews three case studies in which denial enabled effective functioning, energy conservation, and optimism in the face of serious illness. "Denial makes room for hope" (Hafen et al., 1992, p. 459). Denial becomes maladaptive when the person refuses to recognize illness and does not take appropriate self-care measures.

Cousins (1989) discussed the importance of "real hope" as a way of "putting the human spirit to work" (p. 66). "Informed denial, on the other hand -- the kind that allows for hope, the kind that actually inspires hope -- can promote health and healing" (Hafen et al., 1992, p. 461). "Informed, hopeful deniers" had better health, were less

anxious, and less depressed, as determined by interviews before and after cardiac surgery (Crawford, 1987).

A nursing scholar and cancer patient, Hall (1990), has also contested the notion of hope as denial, citing personal experiences and those of eleven men who were in stage two (asymptomatic) human immunodeficiency virus (HIV) disease. Hall (1990) asserts that evidence from her study refutes the interpretation of hope as denial. She questions the purpose of "labeling hopeful behavior by the terminally ill and dying as denial, while not similarly labeling hope among those not dying (or undiagnosed, since we are all dying)" as denial (p. 181). In describing the perceptions of her informants, she states one of the most defeating aspects of patient contacts with nurses and physicians was the implication that "there are times when hope is inappropriate" (p. 180). Hall described the process of trying to maintain hope after a terminal diagnosis as individual and lonely, without support from the health care system.

Participants gave many examples of actions of nurses and other professional caretakers that eroded hope and increased fear... Hope is deemed a form of denial or false reality instead of a universal need of humans, when it is held by persons whom medicine has decreed shall die... Several of the informants were convinced that physicians and nurses created self-fulfilling prophecies that had caused loss of hope and an early death for many of their friends (p.183).

Hall's (1990) negative perception of caregivers "robbing persons of their hope" supports the need for an investigation into the impact of health caregiver behavior on patients' hope. It is necessary to discover just how this occurs and if this perception represents a pattern. Unknowingly or otherwise dampening patients' hopeful

outlooks, nurses need to know, "just how are we doing as facilitators of hope?" All persons, regardless of diagnosis, deserve the opportunity to strive forward in search of a meaningful future. Physicians and nurses alike would do well to consider an excerpt from Lancet, 1922, written by Sir Clifford Allbutt:

A successful physician once told me that he never left a house without giving a favourable prognosis; a counsel which had perhaps colour of worldly wisdom about it; but this far he was right -- that we cannot foresee what benediction words of hope may bestow. I have told a story elsewhere of one who asked his doctor what boon he supposed to be most desired of him by patients. Was it diagnosis, or medicines, or skill, or kindly counsel? No! None of these was the most precious. What the patient yearned for, the remedy to put the most heart into him, was Hope. (Allbutt, p. 15)

If "hope is something all people need until they take their last breath" (Hall, 1990), where and when does hope begin in the life of a human being? According to developmental theorist Erik Erikson (1963, 1982) the roots of hope are found in the earliest human relationship, a secure mother-infant bond, and resolution of the "trust vs. mistrust" dilemma. With consistency and quality of parent-infant interactions, a basic sense of trust and hope is acquired, forming a foundation for all of later psychosocial development. Erikson believed that the degree to which the infant comes to trust himself, other people, and the world in general is dependent upon the care received in the early months. Hope and drive for the future emerge and permeate the entire life cycle.

Recognizing the importance of trust to hope, it is interesting to point out that Merriam-Webster (1993) lists trust as a synonym of hope. Therapeutic nurse-patient

relationships form on a basis of trust and should enhance the emergence of hope. The essence of nursing involves close encounters, intimate caring connections, capable of nurturing hope. The expansion of workloads and technologic responsibilities of nurses coupled with shorter hospital stays necessitate deliberative attention to the nurse-patient relationship, its quality and consistency, to ensure that concerns of the human spirit, such as hope, not be overlooked. Most nurse researchers who have studied hope have illuminated this “relational or affiliative” aspect of hope inspiration in their conceptual definitions and hope-fostering strategies (Dufault & Martocchio, 1985, Miller, 1992). It is recognized that the human environmental impact on the patient's hoping process is critical, including relationships with caregivers and family.

The significance of hopefulness to overall mental health is evident in the descriptions and rewards of good mental health in publications from the Hogg Foundation at The University of Texas at Austin (1992). The mentally healthy individual is characterized as one who can bear up under the floods of life. Two characteristics that help define mental health are, (1) acceptance of what cannot be changed, helping one to achieve a positive outlook, and (2) recognition of what matters, helping one maintain an upbeat approach. In listing the rewards of good mental health, hope is an obvious component:

The chief reward is the ability to face life with a sense of optimism, with the strength to meet disappointment and to recognize its transient nature... The greatest reward is that of waking up with a sense of anticipation of the coming day and of appreciation for having work to do, people to love, and hope for a good life (p. 7).

Martin E. P. Seligman (1975/1992,1990), psychologist and professor, has spent the last quarter of a century wrestling with questions about the relationship of hope and health. In his early work, Helplessness: On Development, Depression, and Death (1975/1992), he explains his theory of "learned helplessness". Animals repeatedly exposed to situations in which they had no control over noxious stimuli eventually "gave up", quit responding and sometimes died. This feeling of helplessness, complete lack of control to change a situation may lead to hopelessness. When all measures of control in a human's life are seemingly taken away, as in the Nazi concentration camp experience described by Dr. Victor E. Frankl (1959), or in the numerous devastating illnesses, injuries, or losses that may befall fragile human lives, "the last of the human freedoms--to choose one's attitude in any given set of circumstances" remains (p. 104). Control of one's thoughts, images, and fantasies is retained even in total paralysis or complete isolation. The door is thus open to the attitude of hope in the human spirit, even in the most difficult situations!

In Seligman's later work, Learned Optimism (1990), he proposes explanatory style as the reason for helplessness. "Learned helplessness is the giving-up reaction, the quitting response that follows from the belief that whatever you do doesn't matter. Explanatory style is the manner in which you habitually explain to yourself why events happen. It is the great modulator of learned helplessness" (p. 15). Seligman believes that finding temporary and specific causes of misfortune is the "art of hope", by means of preventing helplessness.

Many common features of helplessness and depression were identified by Seligman (1975). One important characteristic of depression is hopelessness, probably the most accurate predictor of suicide (Seligman, 1990). "Potential suicides strongly believe that their present misery is going to last forever and pervade all that they do, and that only death will end their suffering" (p. 126). Two dimensions of explanatory style, permanence and pervasiveness, are what lead to helplessness. "Finding permanent and universal causes for misfortune is the practice of despair" (p. 148). The old adage "this too will pass" is wiser than probably thought in preventing hopelessness and despair. In the words of Frankl (1959),

The prisoner who had lost faith in the future -- his future -- was doomed. With his loss of belief in the future, he also lost his spiritual hold; he let himself decline and became subject to mental and physical decay... Usually this happened quite suddenly... We all feared for this moment... He just lay there, hardly moving... He simply gave up. (pp. 117-118)

Preventing hopelessness is important for nurses who practice in any setting, but especially for those who care for patients experiencing depression (Campbell, 1987; Bruss, 1988). Any circumstance in which loss of control and helplessness are found, is a risk condition for loss of hope. Hopelessness, the antithesis of hopefulness, is a recognized diagnosis of the North American Nursing Diagnosis Association (NANDA). It is defined as "a sustained subjective emotional state in which an individual sees no alternatives or personal choices available to solve problems or to achieve what is desired and cannot mobilize energy on own behalf to establish goals" (Carpenito, 1997, p. 463). Whether a person is in fact ever completely hopeless, or

without even a spark of hope, is open for debate. However, the person with little or none is definitely at risk for physical, mental, or spiritual distress and even death.

The apparent relationship between mental state, including hopelessness, and illness or death was further illuminated by Engel (1968). He described a disturbed psychological state that commonly precedes illness as the "giving up-given up complex". Characteristics of this complex include feelings of helplessness and hopelessness, loss of gratifying relationships and roles, disrupted sense of continuity of time, and reactivation of memories from previous periods of giving up.

Before the field of psychoneuroimmunology was popular, Victor Frankl (1959) described mind-body relationships from observation of concentration camp deaths.

Those who know how close the connection is between the state of mind of a man -- his courage and hope, or lack of them -- and the state of immunity of his body will understand that the sudden loss of hope and courage can have a deadly effect. The ultimate cause of my friend's death was that the expected liberation did not come and he was severely disappointed. This suddenly lowered his body's resistance against the latent typhus infection. His faith in the future and his will to live had become paralyzed and his body fell victim to illness... (p. 120).

Florence Nightingale, a century before, described the mind-body connection in relation to the effects of beauty and colorful flowers in promoting a more rapid recovery. "People say the effect is only on the mind. It is no such thing. The effect is on the body, too. Little as we know about the way in which we are affected by form, by colour, and light, we do know this, that they have an actual physical effect" (p. 59). Dufault and Martocchio (1985) included certain physical aspects of the environment,

or "beauties of creation", non-human living things (pets, wild animals, birds, plants, and trees) in the "affiliative dimension" of hope describing them as "hope objects" of attachment (p. 386). Another nursing author, Brown (1989), describes an aesthetically pleasing environment as a factor facilitating the ability to hope. She suggests a few interventions to positively alter the environment of the hoping person, but fails to cite any research evidence to support her recommendations.

Several earlier nursing textbooks were reviewed before finding one that even mentioned the concept of hope. A 1954 text, The Art and Science of Nursing, by Rothweiler, White, and Geitgey states, "hope deferred maketh the heart sick" (p. 583). The authors point out the special need for hope in the "chronic patient", who after extended illness can become bored, morose, discouraged, and depressed. "Hopes grow dim as the weeks and months go by without any apparent improvement" (p. 583). They also mention a "hyper exaggerated condition of optimism" seen in some patients. No further description is found, only that this state is preferred over the despondent state of the chronic patient. It sounds similar to the modern state of denial. Mind-body connections are described. Although it was unknown as to how the mind and body influenced each other, it was a strongly held belief that the relationship existed. "The action of the mind and body sometimes moves in a vicious circle; diseased states producing definite mental conditions, and the mental states directly interfering with normal functioning of body organs. It is difficult for the nurse always to discriminate between these two influences" (p. 582-583).

Rothweiler et al. (1954) further described a state wherein the patient had lost much of his "fighting power" and manifested an "indifferent attitude," sounding much like the "giving up" phenomenon. Nurses are urged to apply any therapy to "activate the mind and physiological processes." Mental therapy is also described to include teaching and humoring. "The chronic patient should be taught that the mind may hasten or retard recovery" (p. 584). The chronic patient must be humored, "they must be given a spirit of optimism and a sense of security; a realization that they are being well taken care of and never neglected" (p. 585). "The consolations of religion, the development of a beautiful faith in spiritual values are most needed by these patients" (p. 583). "Right thinking" is stressed as a key need of the patient with chronic illness more so than any other type of patient except psychiatric.

Seligman (1990) explains the physiology of the psychological state-immune system relationship believed to account for increased physical illness among the depressed, bereaved, and pessimistic. Loss, failure, defeat, or other "bad events" make a person feel helpless. People with a pessimistic explanatory style become depressed. Depression produces catecholamine depletion and increases endorphin secretion, which can lower the immune response. Pathogens, always present, can become active producing disease. He expresses high hopes that psychotherapy to change explanatory style from pessimistic to optimistic will be effective in treating and preventing disease.

Hafen et al. (1992) add to the psychoneuroimmunology discussion that a positive attitude fosters resistance to infections, allergies, auto-immunities, and even

cancer, through a hypothalamus-antibody link. Positive emotions, thoughts, beliefs, and fantasies can boost antibody levels. "The end result does indeed depend on whether you see the glass as half full or half empty" (p. 475).

Hope has been repeatedly related to physical and mental well-being. However, the holistic philosophy of nursing also includes the spiritual dimension, which can be viewed as an energizing, unifying force, based in part on a belief in a power greater than self (Haase, Britt, Coward, Leidy, & Penn, 1992; Miller, 1992). While it is recognized that spirituality is more than religion, hope has been evident in the writings of religious leaders and theologians (Soeken & Carson, 1987). "Hope is central to an active religious faith and sustaining it is an essential function of pastoral care, even when hope is attached to a reality beyond death" (Vandecreek, Nye, & Herth, 1994). Erikson's basic sense of trust, developed in early life, forms a "touchstone for the actuality of a given religion" (Schuster & Ashburn, 1980, p. 190). Affiliation or faith in a higher power (God) results in a sense of security about the future. "Although faith could not be sustained without hope, the basis of hope is faith" (Miller, 1992, p. 413).

Spiritual beliefs were identified by Miller (1989) as supporting hope and enabling patients to transcend suffering, feeling they were being helped by God. One theologian has expressed the source of Hope in the Christian tradition as the character of "God-Who-Is-Love", a God who is trustworthy and calls us into an open-ended future (Lester, 1996). Another theologian has described hope as a "source of strength and courage to face life's harshest trials" (Swindoll, 1996, p. xi). He points out the

significance of loss of hope in noting that many a suicide note has contained the word "hopeless." Swindoll goes on to say of hope, "it is something as important to us as water is to a fish, as vital as electricity is to a light bulb, as essential as air is to a jumbo jet. Hope is that basic to life... Take away our hope, and the world is reduced to something between depression and despair" (p. 3).

Potential guidelines for promoting hope and preventing hopelessness have begun to evolve from nursing studies, with research findings considered "preliminary" by some reviewers and researchers (Farran et al., 1995). Although these authors state that such evidence is limited, they have proposed a framework, designated by the acronym HOPE, to be used as a guide for assessing hope and for intervening with persons at risk for hopelessness. The elements of the framework incorporate four central attributes of hope based on earlier work with older adults (Farran, Wilken, & Popovich, 1992). In the HOPE acronym (Farran et al., 1995), the "H" stands for health, a component of the *experiential process* and involves determining the relationship of hope/hopelessness status to current health status. Authors suggest assessing level of hope on a 1 to 10 scale, "with 1 meaning *no hope* and 10 meaning *filled with hope*" (p. 102). "Other", represented by "O" in the acronym, signifies the *relational process* of hope. Assessing and promoting relationships with significant others is recommended. "Purpose", the "P", represents one's purpose in life or *spiritual/transcendent process*. Here it is important to determine if a person's hope is based on belief in a Higher Power or other customs and practices. The "E" stands for

"engaging process", described as a *rational thought process* involving various cognitive strategies, goal setting, imaging, remembering, and humor. Although cleverly represented by the HOPE acronym, this framework is loosely related and incomplete as a guide to inspire and sustain hope. It fails to account for the impact of the total environment on the individual hoping process.

Miller (1989) interviewed sixty patients recovering from critical illness about what sustained them when giving up was a possibility. Findings from this study were used to develop an instrument to measure hope (Miller & Powers, 1988) and to design the following strategies to inspire and maintain hope: cognitive, determinism, philosophy and world view, spiritual, relationships with caregivers, family bonds, sense of being in control, goal accomplishment, humor, relaxation, and distraction (Miller, 1992). Given the level of abstraction and lack of specific guidelines, implementation of these strategies by nurses is not entirely clear from the report.

In addition to the Miller Hope Scale (Miller & Powers, 1988), other nurse researchers have developed instruments that attempt to measure the concept (Herth, 1991; Herth, 1992; Nowotny, 1989). Review of these tools reveals similarities and differences. Some items measure level of hopefulness and others indicate the presence of specific sources of hope. No instrument captures all possible sources from the total environment.

It is interesting to note the wide variety of patient diagnostic groups in which nurses have studied hope. Hinds and Martin (1989) explored the hoping process in

adolescents with cancer. Anderson, Maloney, and Redland (1993) identified nursing behaviors that influenced hope from interviews with burn-injured patients. Raleigh (1992) explored sources of hope with patients having cancer or chronic illness. Carson, Soeken, Shanty, and Terry (1990) studied hope and spiritual well-being in men with AIDS or who were HIV positive. Herth (1990b, 1993a) identified hope-fostering and hindering categories in two studies, one with terminally-ill adults and one with chronically-ill elderly. Miller (1989) interviewed patients recovering from critical illness and delineated strategies for inspiring hope in this group. A theory-based nursing intervention study with homeless veterans was conducted by Tollet and Thomas (1995). Byrne, Woodside, Landeen, Kirkpatrick, Bernardo, and Pawlick (1994) studied hope in staff caregivers of individuals with schizophrenia. These studies will be more fully outlined in the section of this chapter devoted to nursing research on hope in relation to the present research questions.

With the significance and pervasiveness of hope established within the writings of a multidisciplinary community of scholars and practitioners, further accounting of nursing research will be provided.

Nursing Research on Hope

Having selected the environmental perspective from which to explore the hoping process, review of the nursing research literature will be organized in a like manner. Hope-influencing factors from within the self (internal environment), from interaction with other persons (external human environment), and from all other

sources (external non-human environment) will be described as identified in previous nursing research. Definitions of these environment domains are found in Chapter I.

Hope and the Internal Environment

The first research question guiding this study sought to discover positive and negative factors from the internal environment, or the self, as they impact an individual's hoping process.

Hope and aspects of the internal environment have been studied in a variety of quantitative and qualitative investigations. Correlational studies of hope with other characteristics and resources are fairly common. One of the most frequently measured internal variables is self-esteem. Self-esteem, the personal valuation of self, has been linked to hope in several descriptive studies. Foote et al. (1990) found a statistically significant relationship between hope and self-esteem in a convenience sample of forty persons with multiple sclerosis. The correlation between hope and self-esteem was 0.7415 ($p < .001$). Piazza et al. (1991) looked at the relationship between hope and self-esteem in seventy-seven persons with spinal cord injury. In this group, the correlation of hope and self-esteem was found to be 0.908 ($p < .001$). The variable self-esteem was found to be the best predictor of hope when multiple regression analysis was performed. Subjects with higher levels of education (range being fourth grade to doctoral level) also had higher levels of hope, with education found to be a significant predictor of hope.

Christman (1990) looked at relationships among hope, uncertainty, symptom severity and psychosocial adjustment in sixty-eight persons undergoing radiation therapy for cancer. Greater feelings of uncertainty, decreased feelings of hope and increased symptom severity were found to be associated with more psychosocial adjustment problems in this study. Adjustment problems were measured by the Psychosocial Adjustment to Illness Scale, a forty-six item self-report scale designed to measure psychological and social adjustment to illness in seven domains (health care orientation, vocational environment, domestic environment, sexual relationships, family relationships, social environment, and emotional distress). Findings suggest that interventions to decrease uncertainty, enhance hope, and control symptoms (e.g. pain, nausea, fatigue) may lead to improved adjustment in persons with cancer.

Vandercreek, Nye and Herth (1994) measured levels of hopefulness, self-esteem and depression in well and ill persons and families, hospitalized and community-based. No significant difference in hopefulness scores was found among the groups. However, level of hope was found to be positively correlated with self-esteem ($r = .66, p < .001$) and negatively correlated with depression ($r = -.51, p < .001$). Frequent attendance at worship services and increased education were associated with higher hope.

In a study of one hundred fifty-two well adults, Coward (1996) found self-transcendence to be strongly correlated with hope, self-esteem, purpose in life, and emotional well-being. Coward has defined self-transcendence as "the capacity to reach

out beyond self boundaries to achieve broadened perspectives and behaviors that help one discover or make meaning of experience" (p. 116). This suggests that hope, like self-transcendence, comes from within but reaches beyond the inner world. Coward asserts that her study "supports the promotion of perspectives and activities that expand self-boundaries inwardly, outwardly, and temporally" (p. 121).

The relationship of hope and spiritual well-being, an internal variable, has been studied by several researchers. In a convenience sample of one hundred seventy-five women with breast cancer, hope was positively correlated with spiritual well-being (Mickley, Soeken, and Belcher, 1992). The Spiritual Well-Being Scale (Ellison, 1983) is divided into the subscales Existential Well-Being (focused on life purpose and satisfaction) and Religious Well-Being (focused on relationship with God). Existential Well-Being was found to be the strongest correlate of hope ($r = .732, p < .001$) in this group. Results of multiple regression analysis found that Existential Well-Being, the primary predictor, explained 53.6% of the variance in hope.

Carson et al. (1990) investigated the relationship between hope and spiritual well-being in sixty-five adult male patients who were either serum positive for the human immunodeficiency virus or who had been diagnosed with AIDS or AIDS Related Complex. Hope correlated significantly with Spiritual Well-Being and with both subscales, Existential and Religious. The subscale, Existential Well-Being, showed the strongest predictive value for hope.

In their study of fifty women with breast cancer, Mickley and Soeken (1993), found significant positive correlations between hope and Spiritual Well-Being, as well as with both of the subscales, Existential and Religious. Religiousness, both intrinsic (motivation to live out one's faith) and extrinsic (motivation to achieve goals through religion), was tested for correlation with hope. Only intrinsic religiousness showed a significant positive relationship with hope in one of the subgroups (Anglo). The researchers suggest further investigation of specific religious beliefs as facilitators of hope and spiritual well-being.

Fehring, Miller, and Shaw (1997) found consistent positive correlations among hope, spiritual well-being, intrinsic religiosity, and other positive mood states. In the sample, one hundred elderly people with cancer, significantly higher levels of hope and positive mood states were found in those with high levels of intrinsic religiosity and spiritual well-being. The authors recommend further investigation of the meaning and experience of hope, religiosity and spirituality in persons coping with chronic illness. Longitudinal studies on the nature of religion, religious practices and spiritual well-being are also recommended.

Herth (1989) investigated the relationship between level of hope and level of coping and other variables in one hundred twenty adults undergoing chemotherapy for cancer in three settings (hospital, outpatient, and home). One intra-personal variable was found to be significantly related to hope – religious conviction. Patients indicating a strong religious faith had higher levels of hope and coping responses than those

reporting weak faith or none. Hope and coping were also linked in Herth's (1990a) study of seventy-five recently widowed elderly. Significant positive correlations were found between hope and the use of confrontative, optimistic, palliative, supportant, and self-reliant coping styles. In bereaved spouses, "a significant positive relationship was found between the level of grief resolution and the level of hope" (p. 114), but no correlation coefficient or level of significance were reported by this author.

Hinds and Martin (1988) interviewed fifty-eight adolescents with cancer to discover the process through which they achieve hope. Using a grounded theory approach, they identified four steps in the overall process, which they termed "self-sustaining." Cognitive discomfort, distraction, cognitive comfort, and personal competence were the four sequential parts of the overall self-sustaining process of achieving hopefulness. In this group, the origins of hope were obviously felt to be within the resources of self, or the internal environment.

In a study of the process by which cancer patients search for meaning in their lives, hope was identified as a major theme from interviews with thirty persons (O'Conner, Wicker, and Geronimo, 1990). Internal resources were described by participants as supportive of hope. These included trust in the cancer treatments, faith in the doctors, positive expectations, and personal knowledge, wisdom, and strength. Respondents described renewing their faith in God, praying for strength to endure threats, and receiving a sense of peace and hope as a result of their religious faith.

God was described by seventy-four percent of respondents as always having an effect on their lives regardless of regular church attendance.

In a descriptive cross-sectional study, Herth (1990b) used methodological triangulation (semi-structured interviews and self report instruments) to explore the meaning of hope, influence of personal characteristics, and sources and threats to hope in thirty terminally ill adults. Sources within the self included categories of attainable aims (100%); spiritual base (93%); personal attributes -- determination, courage, and serenity (92%); uplifting memories (90%); and affirmation of worth (82%).

In her 1993a study, Herth used the same design as in her 1990b study with a convenience sample of sixty older adults in community and institutional settings. Three additional internal "self" variables, perceived energy level, perceived health status, and perceived functional ability were measured, with only energy level found to influence hope. Those individuals reporting severe fatigue had significantly lower levels of hope than those reporting high energy to moderate fatigue levels. This finding suggests the need for energy in order to hope. Interview data identifying threats to hope validated this finding with high fatigue reported to lower hope. Impaired cognition and uncontrolled pain and suffering were also identified as threats to hope in responses to the interview. Additional sources of hope reported by participants included interconnectedness with self, purposeful activities, sense of humor, focusing on anticipated events or the "eternal future," spiritual beliefs and practices (praying, Bible reading, listening to spiritual music, attending church), and

cognitive strategies (positive self-talk, optimizing, envisioning hopeful images, and thinking of favorite quotations). Hope was described by participants as an active process arising from within and outside the self. All participants relied on more than one strategy, depending on the situation.

In a similar longitudinal study, Herth (1993b) interviewed and measured hope and other background variables on three occasions in twenty-five family caregivers of terminally ill family members. Six hope-fostering categories (sustaining relationships, cognitive reframing, time refocusing, attainable expectations, spiritual beliefs, and uplifting energy) and three hope-hindering categories (isolation, concurrent losses, and poorly controlled symptom management) were identified based on the interview data. Some differences from a previous study by Herth (1990a) include the strategy “time refocusing” or changing to a shorter-term perspective on the future (living one day at a time to one hour or one moment). Personal beliefs in a power greater than self or in a natural order of the universe were identified as sources of hope by ninety-two percent of participants. Caregiver fatigue, poor health, decreased sleep, and concurrent losses were associated with decreased hope. Level of hope, as measured by the Herth Hope Index, increased from time one to time two and was unchanged at time three.

Ballard, Green, McCaa, and Logsdon (1997) compared levels of hope in twenty patients newly diagnosed with cancer and eighteen patients with recurrent cancer. No difference in hope was found in the two groups. However, patients with recurrent cancer reported drawing hope from faith, while those patients newly

diagnosed relied on their treatment and health care professionals as sources of hope. The researchers recommend further study of the meaning of faith for individual clients.

Hope and the External Human Environment

The influence of the external human environment (other persons) on the hoping process is the focus of the second research question. Other human beings as sources of hope have been reported in almost every research study reviewed thus far in addition to the internal self-factors outlined in the previous section. Several studies will be mentioned again briefly pointing out these interpersonal aspects of hope inspiration. Some reports of negative person-to-person interactions, or threats to hope, are also reported in the literature.

In a cross-sectional survey of fifty-five patients with cancer, Stoner and Keampfer (1985) found decreased levels of hope in those who recalled interactions with physicians where a prognosis for life expectancy was given. Hope was highest in those who had no recollection of receiving life expectancy information from their physicians. These results call into question the practice of communicating an expected survival time to persons with life-threatening illness.

Miller (1989) described several hope inspiring strategies from her previously mentioned study of patients surviving a critical illness. Those sixty individuals, interviewed after transfer from the critical care unit also identified several threats to hope involving other persons. Negative attitudes in health care workers and no one to

care about them threatened hope. Internal (self) threats included negative self-talk and physical deterioration.

Social support has frequently been linked to hope as it was in two previously reported studies with chronically ill individuals (Foote et al., 1990, Piazza et al., 1991). Social support, generally considered to be emotional support and material aid by other persons, was positively and significantly correlated with hope in both of these descriptive studies ($r = .6848, p < .001$ and $r = .891, p < .001$, respectively). Results suggest that nursing strategies that encourage positive support from family and friends may help to facilitate hopefulness in patients.

In Herth's (1990a) study of hope in elderly widows and widowers, the importance of hope during bereavement was revealed. The frequency of visits by family and friends was positively ($p < .05$) related to level of hope and level of grief resolution. Level of hope was decreased in persons who had experienced more than one concurrent loss. Loss of multiple significant persons intensifies the threat to hopefulness during bereavement.

In two separate studies, Herth (1990b, 1993b) found similar results regarding the importance of supportive human relationships to hope maintenance in two groups (terminally-ill adults and family caregivers). "Interpersonal connectedness" and "sustaining relationships" were the labels given to these hope-fostering categories. The importance of other persons was consistently emphasized by all participants. In the caregiver group, the most frequently identified sources of hope were family,

friends, health care professionals and God (or higher being). These supportive persons fostered hope through their presence, listening, availability, caring, and encouragement. Nurses who helped caregivers prioritize activities to conserve energy and listened to the expression of feelings facilitated hope. A sense of isolation (perceived separation from significant others and/or Higher Power) was identified as hindering hope. The terminally ill adults emphasized shared meaningful relationships including touch, affirmation, and radiation of hope as well as the behaviors previously described by caregivers. Most participants felt loss of hope when others withdrew emotionally while remaining physically present.

Hospital nurses who attended to various therapeutic tubes and technologies attached to a patient while ignoring the person threatened hope in a terminally-ill group (Herth, 1990b). Nurses who communicated frustration and hopelessness during episodes of patients' uncontrolled pain led to hopelessness. Loneliness and isolation hindered hope in these patients. Degrading and belittling comments and non-caring responses from caregivers impaired the ability to sustain hope. This category was labeled "devaluation of personhood." Nurses who remained present during crises, listened to feelings, shared stories, demonstrated caring, and affirmed worth enhanced hope.

Sixty elderly residents in community and institutional settings (Herth, 1993a) described hopelessness in others (loved ones, friends, and health care professionals) as "catching." The expressions on faces of doctors and nurses sometimes communicated

hopelessness. When a roommate “gave up,” one participant reported feeling hopeless. Involvement in purposeful activities, as being available to or actively caring for others reportedly increased hope in this group. Professionals who demonstrated caring toward a person became a source of hope when significant others were unavailable.

In the study by O'Connor et al. (1990), thirty persons recently diagnosed with cancer described significant things in their lives they wanted to live for -- trips, events, and most importantly, other people. Just thinking about family members helped one participant maintain hope. Ballard et al. (1997) also interviewed recently diagnosed cancer patients (n=20) and found they relied on other persons, especially nurses and physicians as primary sources of hope.

Raleigh (1992) interviewed ninety patients with cancer or chronic illness to identify and explore sources of hope. Most frequently reported sources supporting hopefulness were family, religious beliefs, and friends in that order. Self was the fourth most frequent source of hope followed by professionals. Working, keeping busy, sleeping, and eating were also mentioned as supporting hope. Visiting, listening to, talking to, cheering up, and physically helping patients were methods by which other persons supported hope in this group.

Anderson, Maloney, and Redland (1993) interviewed nine severely burned male patients to explore factors affecting feelings of hope, especially the influence of nursing actions. All patients identified professional caregivers rather than a significant family member as having the most influence on their levels of hope. Nurturance,

competence, and trust in caregivers were major influences. Caregivers became significant others for patients during times of critical burn injury. Decreased feelings of hope occurred with rough treatment, feeling powerless, and inadequate pain relief.

In a qualitative study of fifteen psychiatric nurses, Byrne et al. (1994) explored staff's conception of hope in working with schizophrenic persons. The importance of trusting human relationships and positive expectations is evident in their conclusions:

The relationship seems to be the catalyst that allows hope to develop exponentially. The 'sense of the possible' expands when two individuals in a trusting relationship can work together... An environment that provides cues that confirm the feasibility of maintaining hope seems essential for individuals with a mental illness. (p. 33-34)

Cutcliffe (1995) used grounded theory to examine how nurses (number of informants not given) inspire and instill hope in terminally ill patients with Human Immunodeficiency Virus. Data analysis resulted in an integrated theory of hope inspiration comprised of four core variables--reflection in action (self awareness and reflection by the nurse), affirmation of worth (communicating value and unconditional acceptance of the patient), creation of a partnership (negotiating care with the patient), and nursing the totality of the person (holistic care).

Tollett and Thomas (1995) reported a theory-based nursing intervention study to instill hope in forty homeless veterans. Hope, self-esteem, self-efficacy, and depression were measured before and after a group therapy intervention. The Miller Hope Scale, Rosenberg Self-Esteem Scale, General Self-Efficacy Scale, and Beck Depression Inventory were used to measure the study variables. The themes of the

nursing intervention included reality surveillance (identifying strengths, assets, and a vision for the future) and defining and refining goals (developing an individual action plan). Treatment and control groups differed significantly in level of hope at posttest using analysis of covariance procedures ($F= 8.93, p < .006$). Within the treatment group there were significant differences in levels of hope, self-esteem, and depression between pretest and posttest using paired t tests. Significant limitations of this study were small sample size ($N=40$) and the lack of accounting for medication treatment with antidepressants in fifty percent of the subjects. This study provides an example of the external human environment (a group therapy intervention) influencing hope and other internal variables in a positive direction.

Additional insight into the influence of health care professionals on patients' levels of hope has been provided by Koopmeiners et al. (1997). Using a descriptive, qualitative design they explored whether health care professionals influence level of hope and if so how. The sample of thirty-two men and women with cancer were interviewed in their hospital rooms. Health care professionals were found to influence hope both positively and negatively. Being present, giving information and demonstrating caring behaviors facilitated hope. Giving information in a disrespectful or insensitive manner was perceived as threatening hope. Providing information in a compassionate, honest, and positive manner was recommended to support hope.

Hope and the Non-Human Environment

The third research question deals with the impact of the external non-human environment on the hoping process. As defined in Chapter I, this includes a variety of places and things. Little has been reported in the nursing research literature about the influence of factors from this environmental domain on hope.

A few studies were found which looked at the relationship of hope and setting of care. Herth (1989) surveyed one hundred twenty adults undergoing chemotherapy in three settings (inpatient, outpatient, and home). Analysis of variance revealed that mean hope scores of persons receiving chemotherapy in either inpatient or outpatient settings were significantly ($p < .05$) higher than those in the home setting. The author states that this finding may be attributable to particular characteristics of the specific settings such as a hopeful attitude in professionals, presence of adequate interdisciplinary support, or a homelike environment in both inpatient and outpatient settings. Recommendations for further research include an examination of the relationship of these characteristics within settings to level of hope.

Hope, coping, concurrent losses, and grief resolution were measured in seventy-five recently (within twelve to eighteen months) widowed elderly (Herth, 1990a). Three settings in which the spouses had died were included with twenty-five widow(er)s in each group. ANOVA procedures were used to determine whether level of hope differed according to type of setting in which terminal care and death occurred. A statistically significant ($p < .001$) difference was found between settings

on level of hope. Mean scores on hope were significantly higher for widow(er)s whose spouses had died in a hospice setting than those whose spouses had died in a hospital or nursing home. After stepwise multiple regression, two variables, hope and setting, were found to account for eighty-three percent of the variance in grief resolution. Persons whose spouses died in hospice settings had better grief resolution and higher hope for several possible reasons -- longer time for anticipatory grieving, more contact with health care professionals due to extended illness, and participation in formalized bereavement support programs in hospice settings.

Perceptions of hope were influenced by place of residence in Herth's (1993a) study of sixty older adults living in community and institutional settings. Overall levels of hope were found to be high except in residents of long-term care facilities who were also experiencing high fatigue. During the interview phase regarding sources of hope, participants mentioned one or more factors from the non-human environment that supported their hope. These included music, literature, a hand-stitched doll, afghan, pets, nature, prized art, apple blossoms in springtime, and beautiful flowers. Activities such as volunteering, publishing a newsletter and writing letters facilitated hope. One ninety-six-year-old participant defined hope by the following quotation (author unknown). "Hope is like the sun, which as we journey towards it, casts a shadow on our burden behind us" (p. 154).

O'Connor et al. (1990) interviewed persons with cancer who identified a few additional sources--cancer treatments, trips, and events, the last two involving human

elements as well as special places. The family caregivers in Herth's (1993b) study added special meals, posting positive notes, planting a garden, and watching the sunset to the list of hope sources. Having adequate income was associated with higher hope in the study by Ballard et al. (1990) of patients with cancer.

Summary

In Chapter II, relevant literature from several disciplines has been reviewed to integrate nursing concern with the concept of hope into a multidisciplinary perspective. The significance of hope to holistic health has been emphasized and validated from the literature. Nursing research investigating sources and threats to hope has been reviewed and grouped according to the environmental domains conceptualized for this study -- internal (self), external human (other persons), and external non-human. These studies provide some guidance to nurses seeking to promote hopefulness and prevent hopelessness in clients. However, little research has been undertaken to examine factors from the non-human external environment as sources or threats to hope. The present study will expand knowledge of the overall hoping process by looking at the total environmental impact on hope.

CHAPTER III

METHODOLOGY

The stated purpose and research questions of this study were descriptive and exploratory in nature, with a focus on individual cancer patient's perceptions of hope while living with cancer. With this in mind, the researcher selected the naturalistic inductive paradigm and qualitative methods as the most appropriate design choice for this inquiry. This chapter will describe the design with philosophical underpinnings, population and sampling techniques, procedures and protection of human subjects, data generation, data analysis and qualities for establishing trustworthiness.

Design

Designers and planners of research should “think carefully about the consistency between design and research questions” (Newman & Benz, 1998, p. xi). The “fit” between the research questions, proposed research method, Modeling and Role Modeling (MRM) theory/paradigm for nursing practice, and the assumptions of naturalistic inductive inquiry according to Lincoln and Guba (1985) were examined for congruency. “The assumptions of the given paradigm, the research method, the investigator's theoretical perspective, and the research questions must all be consistent with each other” (Talbot, 1995).

The naturalistic inductive paradigm is derived from a tradition that assumes that facts and principles are embedded in social, cultural, and historical contexts. Truth is seen as dynamic and derived from human interaction in natural settings.

Researchers in this tradition are concerned with understanding human behavior from the person's frame of reference, by hearing the voices of those living the particular phenomenon under investigation. Qualitative data gathering methods are employed, including primarily interviewing, observing, and interpreting subjective materials. Emphasis is placed on understanding one or more persons' holistic and dynamic realities in context. Predicting, controlling, and generalizing from large samples are not research objectives, but discovering themes and patterns from single or multiple case studies are used to gain understanding of phenomena (Burns & Grove, 1999; Denzin & Lincoln, 1998; Polit, Beck, & Hungler, 2001; Polit & Hungler, 1997; Streubert & Carpenter, 1999; Talbot, 1995; Woods & Catanzaro, 1988).

Boyd (1993) has developed a general definition of qualitative research that summarizes the salient points about this methodology.

A definition of qualitative research may be stated, then, as involving broadly stated questions about human experiences and realities, studied through sustained contact with persons in their natural environments, and producing rich, descriptive data that help us to understand those persons' experiences. The emphasis is on achieving understanding that will, in turn, open up new options for action and new perspectives that can change people's worlds. (p. 69-70)

According to Lincoln and Guba (1985), naturalistic inquiry is based on the following assumptions: (1) There are multiple constructed realities that can only be studied holistically. (2) The researcher and participant interact inseparably influencing one another. (3) Knowledge gained is bound by time and context, making generalization in the traditional sense impossible. (4) The process of mutual

simultaneous shaping makes determination of cause and effect impossible. (5) Inquiry is value bound, with meaningful results coming only when value congruence is exhibited among inquirer values, paradigm, problem, theory, methods and context.

Implications for actual research operations are numerous and follow logically from the assumptions. The natural setting for inquiry is essential to capture the holistic meaning of informants in context. Qualitative methods and the adaptable human instrument are essential to make meaning of constantly changing and unpredictable interactions. Purposive sampling and inductive data analysis are indicated to uncover the full array of multiple realities. Grounded theory emerging from the data is preferred to a priori theory generation due to the dynamic nature of mutual shaping. The research design (termed "emergent") cannot be totally preplanned and inflexible in the context of multiple dynamic realities and unpredictable interactions. The meanings, interpretations, and outcomes are negotiated between researcher and respondent. Application of particularized findings is tentative and applicable only to empirically similar contexts. Special criteria of rigor (trustworthiness) are necessary, including credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985).

The nursing practice theory and paradigm, Modeling and Role-Modeling (Erickson et al., 1983), provides a philosophic base consistent with the naturalistic inductive worldview. In unfolding their theory and paradigm, Erickson and colleagues (1983) integrate the abstract with the concrete, providing real patient stories as

illustration and enrichment. Philosophically, Modeling and Role-Modeling is consistent with the naturalistic inductive paradigm. Both seek to understand unique individuals, from their models of the world (frames of reference), in their particular environments (cultures), and with their past experiences (histories). The values inherent in both are congruent: holism, each person is a unified whole (body/mind/spirit), unconditional acceptance (each person is important and worthwhile), self-care knowledge (each person is the expert about self), and lifetime growth and development (each person's reality is dynamic). Understanding a person's world is the goal rather than generalizing, predicting, controlling, or manipulating.

Nursing practice involves an interactive interpersonal process between nurse and client. Modeling and Role Modeling theory describes "...the nursing process predominantly as an on ongoing, interactive, interpersonal relationship..." (p.105). The naturalistic inductive paradigm assumes the researcher and participant interact inseparably (Lincoln & Guba, 1985).

Gathering data using qualitative methods in the naturalistic inductive tradition is generally considered to be from the "emic" viewpoint, that of an insider. Gathering data from a Modeling and Role-Modeling perspective is also emic, with the nurse stepping into the client's world in the context of a nurse-client relationship. Modeling the client's world is consistent with the emic viewpoint of qualitative research methods. Nursing in the MRM tradition is done with the client, not to the client.

Research in the naturalistic inductive tradition is done with the informant, not on the informant (subject).

One of the ethical principles of nursing is beneficence -- to do good, clearly evident in the MRM concept of "nurturance." This is consistent with an expectation of naturalistic inductive inquiry using qualitative methods -- the informant as well as the nurse will be changed for the better in the process of research. The focused listening and centered presence of the nurse researcher, coupled with the informant's feeling of being understood bring about positive change for the informant. This research process is similar to nurturance in the MRM theory and demonstrates adherence to the ethical principle of beneficence. To use terminology of the nursing process, the first step of data gathering or "assessment" is a potentially beneficial intervention, as is modeling in MRM theory. The therapeutic value again is in the nurse's listening and communicating to the client the feeling of being understood. Both the nurse (as practitioner or as researcher) and the person (as client or as informant) experience benefits in the processes of inquiry (modeling/nurturance vs. data gathering/research). In both practice and research the nurse attempts to understand a person in context from his frame of reference.

The many points of congruency between nursing practice, MRM theory, and naturalistic inquiry support the contention of this author and others (Munhall & Boyd, 1993) that naturalistic inquiry using qualitative methods is "doing what comes naturally" for a nurse as researcher.

Population and Sample

The target population for this inquiry was composed of those persons who were experiencing or recovering from cancer. The shared illness experience of cancer provided a common or similar frame of reference for the study group members. The illness experience of cancer was felt by the researcher to be one in which a person's sense of hopefulness could be challenged. The diagnosis of a significant cancer generally threatens one's anticipated longevity. Cancer may further challenge the resources of a person in day-to-day living, especially while undergoing potentially debilitating treatments such as chemotherapy, radiation, and surgery. Having a strong sense of hopefulness is believed to be important in living with and managing the problems and treatments associated with cancer. Having a minor type of skin cancer was not felt to be sufficiently challenging, and this became the only diagnosis-related exclusion factor.

No particular type of cancer was targeted. The study group included persons with ovarian, testicular, breast, bone, lymphatic, leukemia, and colon cancers. All had undergone or were undergoing a variety of treatments, including surgery, chemotherapy, radiation therapy, and alternative therapies such as herbs and color analysis. The broad nature of specifications for the cancer experience was designed to incorporate the full range of those persons for whom the hoping process would be relevant and evident, that is to uncover multiple realities (Lincoln & Guba, 1985).

Glaser and Strauss (1967) described this process as “maximum variation sampling” and believed it would make the resulting theory more useful.

Criteria for inclusion in the study consisted of the following:

- (1) English-speaking, consenting adult over 18 years of age,
- (2) Living with a cancer diagnosis (other than a minor skin cancer) for at least six months,
- (3) Received care in at least one health care setting other than home, where has interacted with one or more nurses, during or since the time of diagnosis with cancer,
- (4) Expresses recall and willingness to talk about personal illness and feelings of hope experienced since diagnosis with cancer,
- (5) Physiologically stable, alert, oriented and comfortable.

Qualitative research experts assert that informants are to be deliberately sought who have particular knowledge and experience with the research topic (Merriam, 1998; Morse, 1991, 1994; Streubert & Carpenter, 1999; Talbot, 1995). Rather than representativeness, "the qualitative principle of *appropriateness*...selecting informants who are best able to meet the informational needs of the study" is the guiding principle in qualitative sampling (Morse, 1991). Purposive, theoretical, or judgmental sampling of this type allows the researcher to "hand-pick" participants who best represent the phenomenon or topic of study (Talbot, 1995). "The researcher

makes a judgment regarding the type of subject needed to provide the most useful information about the phenomenon being studied" (Talbot, p. 255).

Principles of appropriateness and adequacy, rather than randomness and representativeness are applied to sample selection in qualitative inquiry. The researcher hoped to gain the participation of "good" informants who were articulate, reflective, and willing to share with the interviewer. Good informants have life experience with the phenomenon, are willing to examine their responses to it, and share their inner feelings with the researcher (Morse, 1991, 1994; Streubert & Carpenter, 1999). An element of researcher judgment and intuition enters into determining suitability of particular nominated or volunteer participants, e.g. the nature of the person's illness experience as sufficiently challenging and the person's awareness and openness in expressing feelings and sharing experiences. "In qualitative research, in order to ensure that the sample meets the criteria for appropriateness and adequacy, the *researcher must have control over the composition or the sample*" (Morse, 1991, p. 135). This is achieved by "primary selection," with the researcher deciding who is to be interviewed and, after the initial contact, who is to be interviewed further "secondary selection" (Morse, 1991; 1994). Each of the first fifteen participants contacted met the study criteria and was judged to be motivated and willing to share openly about their cancer experiences and feelings of hopefulness. A few were so eager that they began to tell significant information on the telephone and were asked to wait until the appointment time.

Recruitment of potential informants was by solicitation of volunteers or by nominations from persons familiar with the focus of the study, e.g. participating informants or professional colleagues of the researcher. "Nominated, network, or snowball sampling is a common method of obtaining a qualitative sample" (Morse, 1991, pp. 129-130). "The major criticism of volunteer, purposeful, and nominated samples is that the samples are 'biased' by virtue of the selection process (either self-selection or researcher-selection)" (Morse, 1991, p. 138). However, it must be recalled that this happens "by design" to gain the participation of knowledgeable, reflective, and experienced persons who are willing and able to share their stories and feelings with the researcher. In qualitative studies, "bias is used positively as a tool to facilitate the research" (p.138).

The first two volunteers were obtained from a cancer support group meeting in a large metropolitan medical center in north Texas. After being invited by the facilitator, the researcher briefly explained the nature of the study to the group members at a regular weekly meeting. After speaking to the group and answering questions, a cover/information letter about the study was handed to each member. A copy of this cover/information letter is found in Appendix B. Those persons who wished to volunteer for the study were instructed to telephone the researcher. The purpose for this was to confirm their interest, to discuss the study further, and to explain their participation in the interview process. According to Lincoln & Guba (1985), interaction between investigator and potential informant is needed during the

recruitment process, without which purposeful sampling cannot be achieved. A thoughtful researcher is needed to identify the purpose of the inquiry and to match informants to that purpose. In addition, meaningful research is not possible without the full understanding and cooperation of the participants.

After recruiting the first two participants from a cancer support group, the remainder of the sample consisted of individuals living in five different central Texas cities and surrounding rural areas. These participants were recruited by professional colleague referrals or from study participant referrals. The referring person, nurse or participant, made initial contact with the potential participants and gained permission for them to be contacted by the researcher. During this telephone call, the researcher introduced herself and gave the name of the referring person. A brief explanation of the study was given and the potential participant was asked for a mailing address. A cover/information letter more completely explaining the study was mailed. After reading this letter, potential participants were instructed to call the researcher to confirm their interest in being interviewed. At that time, appointments were made for them to be interviewed in a private, convenient location of their choice. Five of the participants chose to be interviewed in an office at their workplace, six selected their homes, and four requested to be interviewed at the researcher's office, which was close to and more private than their workplace.

The matter of sample size is generally determined by the achievement of redundancy or saturation, that is, when no new information is being obtained (Lincoln

& Guba, 1985; Merriam, 1998; Polit & Hungler, 1997; Streubert & Carpenter, 1999; Talbot, 1995). Lincoln and Guba (1985), recommend that twelve informants or cases are usually sufficient to exhaust most available information. Miles and Huberman (1994) emphasize, "sampling must be *theoretically* driven – whether the theory is prespecified or emerges as you go" (p.29). The conceptual question and not concern for "representativeness" drives sample selection. The number of cases to sample cannot be answered on statistical grounds. With complex research questions, "a study with more than fifteen cases or so can become unwieldy" (Miles & Huberman, p. 30).

Polit, Beck, and Hungler (2001), have observed, "there are no firmly established criteria or rules for sample size in qualitative research" (p. 248). Sample size is determined by the purpose of the study, informational needs, and quality of the informants. "A guiding principle in sampling is *data saturation* (*i.e.*, sampling to the point at which no new information is obtained and redundancy is achieved)" (p. 248). With sufficient depth of interviewing and a fairly homogeneous sample, a study group with fewer than ten cases may be sufficient (Polit & Hungler, 1995). The sample size needed for this study was initially estimated at fifteen to twenty participants. Recruiting new informants concluded when fifteen had been interviewed, each between one and two hours. During the last few interviews, it was felt by the researcher that redundant themes were being heard with variations occurring only in the specific examples. After transcription and review of interview data, follow up telephone conversations were obtained from several informants to validate and clarify

some of their responses. Handwritten notes were made of these conversations and were recorded on each informant's interview guide or within the transcription.

This study relied most heavily on interview data from face-to-face conversations with participants. During the interviews, respondents were asked to answer multiple questions to elicit data for each of the six research questions. In the course of questioning and answering, some participants shared poems, cards, letters, literature, photographs, art, journal writings, and other objects they perceived to be supportive of their hope. The quality, variety, and depth of data obtained further led the researcher to stop the sampling process after fifteen gracious, interesting, and informative persons had been interviewed.

The sample of fifteen persons living with a diagnosis of cancer was interviewed between April 1999 and January 2000. The sample included five men and ten women between thirty-three and seventy-five years of age and who had been living with a diagnosis of cancer for seven months to twenty-two years. A summary of sample characteristics is found in Table I.

Procedures

In keeping with MRM theory and naturalistic inductive tradition, the patient or informant is considered to be the expert about himself or herself, and is given the opportunity to express willingness and interest in being a part of the study. Understanding the focus of the research and expectations of informants is requisite to this. Therefore, during the initial contacts, the researcher explained to each potential

Table I. Sample Characteristics

<u>Number/ Pseudonym</u>	<u>Gender</u>	<u>Age</u>	<u>Marital Status</u> (Children)	<u>Years of Education</u>	<u>Employment, Occupation</u>	<u>Type of Cancer, Years since Diagnosis</u>	<u>*Level of Hope</u>
#1 Emily	F	53	Divorced (1)	12	Retired, Technician	Ovarian, 8.5	7-8
#2 Angie	F	47	Single (0)	18	Part-time, Communications	Ovarian, 1.8	8
#3 Marcia	F	48	Married (2)	14	Full-time, Library Tech.	Breast, 1.6	9
#4 Paul	M	51	Married (2)	18	Full-time, Artist/Teacher	Lymphoma and Melanoma, 22	10
#5 Maggy	F	46	Married (2)	12	Full-time, Admin. Assist.	Breast, 0.6	10+
#6 Sheila	F	51	Married (2)	18	Full-time, Teacher	Leukemia, 9.8	8-10
#7 Holly	F	52	Married (3)	13	Full-time, Secretary	Colon, 1.2	9-10
#8 Bert	M	40	Married (3)	14	Full-time, Land Surveyor	Liposarcoma, 4	9.5
#9 Walter	M	75	Married (3)	23	Retired, Physician	Leukemia, 5	8
#10 Deana	F	75	Married (3)	13	Retired, Pastor's Wife	Breast, 4.8	10
#11 Karl	M	51	Married (4)	23	Part-time, Physician	Salivary gland, 1.3	10
#12 Louis	M	39	Married (2)	14	Full-time, Land Surveyor	Testicular, 2.7	10
#13 Robin	F	55	Widowed (2)	16	Retired, Research Assist.	Breast, 12.6	10
#14 Pam	F	60	Married (3)	18	Homemaker	Breast, 4.2	10
#15 Audrey	F	33	Married (2)	16	Full-time, Regist. Nurse	Breast, 3	10

Mean Age in Years=51.7; Range=33-75 years

Mean Years of Education=16.1; Range=12-23 years

Mean Years Since Diagnosis=5.5; Range=0.6-22 years

*Mean Level of Hope=9.37; Range=(7-8) to 10. This score was the rating given by participants for "current perceived level of hope" on a scale of 1 to 10, with "1" being "little or none" and "10" being "filled with hope." (Answer to Research Question #6)

informant the purpose of the study -- to examine perceptions of positive and negative factors which impact his or her hoping process during life with a cancer diagnosis. They were told that the expectation of their part in the interview process was to talk about their personal experiences with cancer and to discuss their feelings of hope while living with this diagnosis. They were told that they could cancel or stop participation at any time before or after beginning the interview.

Confidentiality of participant data was ensured by several procedures. Each participant was asked to select a fictitious name to be used for identification purposes in the study. No participant felt that this was necessary, and no one wished to be called by an alternative name during the interview. The researcher did assign fictitious names to each interview tape and had the transcriber reference each participant by this name. The master list of participants, their phone numbers, and assigned fictitious names was kept in a secure location in the researcher's home. Privacy was ensured during the interview by conducting each in a private office or in the participant's home. Only persons involved in the research process were allowed access to the tapes, including the supervising professor, committee members, auditors, and transcriber.

There were believed to be no significant risks involved in study participation, other than possibly minor psychological discomfort in discussing negative influences or times of decreased hopefulness. The researcher, master's prepared in psychiatric-mental health nursing, made herself available to participants by phone should they have any concerns or thoughts after the interview. This option was explained in the

cover/information letter that all participants had been given and was reviewed verbally at the conclusion of the interview (see Appendix B). No one called with any negative afterthoughts. However, the researcher did receive additional positive stories, a speech given to cancer survivors by one participant, and several hopeful scriptures. These were received via e-mail and regular mail from four different participants. These data are included in the interview book with the transcription of each participant's interview. Several informants have subsequently expressed positive feelings about their participation in the interview experience and have inquired about progress of the overall research study. A few have expressed interest in reading the final dissertation.

Data Generation

The parallel nature of qualitative research methods and MRM practice is obvious in relation to interviewing, the primary data gathering tool. Interactive, interpersonal relationships are inherent in qualitative methods and nursing practice. Person-centered, nonjudgmental, trust-building behavior is needed from the nurse/investigator to facilitate effective interviewing and sharing of information. The patient/informant is considered to be the expert about him/herself, possessing unique self-care knowledge. Active listening with centered presence is essential behavior of both professional nurses and qualitative investigators. "Nurse researchers have clinical interviewing skills, for example, that transfer nicely in research interviews, and they

may find that gaining access to informants is relatively easy, based on the general public's perceptions of nurses" (Boyd, 1993, p. 88).

The human being is the primary instrument and interviewing is the primary mode of data collection in qualitative research (Glaser & Strauss, 1967; Lincoln & Guba, 1985; May, 1991; Merriam, 1998; Munhall & Boyd, 1993; Talbot, 1995). The "human as instrument" has several advantages as the primary tool for data gathering in qualitative studies (Lincoln & Guba, 1985). The human is capable of understanding multiple realities, evaluating differential interactions, and perceiving nuances in meaning. Although imperfect, the human instrument is "infinitely adaptable" to change and unpredictability, making it especially suitable to a variety of interview and observational situations. The human instrument is able to focus on a target (research objective), remain on a trajectory toward it, yet follow and find the target through a variety of differing pathways and time periods. The human instrument is able to understand the participant holistically, process data immediately, and give feedback (summarize, clarify, and amplify) as necessary. "The multipurpose human can collect information about multiple factors -- and at multiple levels -- simultaneously" (Lincoln & Guba, 1985, p. 193).

A semi-structured interview guide (see Appendix A) was developed with open-ended questions and specific prompts (determined from review of literature). This tool was designed to ensure that similar information would be elicited from all participants. Semi-structured interviewing techniques have the advantage of acquiring

desired data yet allowing for some flexibility in researcher-participant conversation. “The interview schedule (list of questions) or interview guide is created to direct the interview on a path consistent with the purpose” (Newman & Benz, 1998, p.67).

The Interview Guide (Appendix A) was divided into three sections. Part I included introduction of the researcher and a brief review of the overall study purpose. Background and demographic information was obtained about the informant’s life profile (age, marital status, children, education, occupation, income adequacy, religious preference) and cancer experience (type of cancer, length of time since diagnosis, therapies received, health insurance, care environments, and concurrent losses). This format helped to establish rapport with the informant and gave the researcher a brief overview of their cancer experience. In Part II, informants were asked to rate their current level of hopefulness on a scale from “one to ten” with one being “little or none” and ten being “the most hopeful they could imagine,” as suggested by Farran et al. (1995). All participants then easily selected a number from one to ten, reflecting their current perceived level of hopefulness. Each was then asked to describe a time since having cancer when their hope was as low as they could remember and what had helped them to regain a state of hopefulness. They were also asked to describe a time when their hope was as high as they could remember. This part of the interview was designed to establish a range of hope fluctuation in their lives preparatory to considering specific positive and negative hope-influencing factors. In the analysis, data from this section were included with other positive and negative

hope-influencing factors provided by the participants. In Part III, open-ended questions were developed asking for participants to describe personal hope-influencing factors from the three domains of environment as defined in this study. These questions are found in the Interview Guide, a copy of which is found in Appendix A.

A list of specific cues had been developed from the findings of previous research studies reviewed in Chapter II. Authors of previous studies had reported a variety of specific sources and threats to hope. These had been compiled and grouped into environmental domains, as defined in this study, to provide the additional prompts intended for use after the open-ended questions had been asked. However, after a pilot interview and the first few actual interviews, it became clear that these were not needed and seemed awkward and unnatural after the spontaneous reflections and rich data obtained from the open-ended type of questioning. After the third interview, the specific cues were dropped altogether.

The responses to the open-ended questions provided incidents, experiences, and examples of factors from the three domains (self, other persons, and external environment) as they impacted the individual participant's sense of hopefulness. Specific questions were framed "on-the-spot" to encourage participants to explore various aspects in greater depth. Responses often explained how the particular factor influenced hope (especially for other persons as sources of hope), so specific "how" questions were not consistently asked.

After exhausting their thoughts on sources and threats to hope in each domain, participants were asked to rank by importance their primary, secondary, and tertiary sources of hope within each domain and overall. The researcher kept written notes about each informant's expressed sources of hope, which were reviewed before asking for the rankings. Many times, participants added additional data before or during ranking that was included with positive factors. One person refused to rank the various persons in her life because they were all equally important and she did not want to place one above the others. One was uncomfortable with this question because she felt guilty ranking her best friend higher than her husband, but did comply with the request. Others said that ranking was difficult because the importance of various sources fluctuated with time and circumstances. Therefore, data were initially incomplete for a few rankings. During follow-up telephone calls, rankings were completed for most. In the case of one participant, family stated said she was too ill to talk. Results of the rankings are found in the Chapter IV.

At the conclusion of the interview, all informants were thanked verbally for their participation, and again later by means of a personal written thank-you note. Each expressed a willingness to be called back by the researcher if clarification was needed regarding any of their responses. This was needed for only four interviews and was done over the telephone. The participants were encouraged to contact the researcher if needed for concerns or afterthoughts.

The interview was initially estimated to take approximately one hour. Depending upon the insight, awareness, and particular experiences of each respondent, most interviews were a little over one hour, with the maximum being two hours. Respondents were asked periodically if they were fatigued or needed a break. No one ever expressed fatigue, and all declined the need for a break. All interviews were accomplished within one appointment time.

Interviews were audio taped and the service of a transcriber was secured. The informants had given implicit permission for this by reading the cover/information letter and calling back for the appointment. Before beginning, they were again reminded that the interview would be audio taped, to which all agreed. The tape recorder was always positioned between or as close as possible to the researcher and the participant. Only a few words were inaudible and a few brief periods of data loss occurred when the researcher failed to turn over the tape exactly when side one was completed. Notes kept by the researcher helped to avoid loss of data.

In addition to their verbal descriptions about hope-influencing factors, some participants shared journal writings, plants, jewelry, photographs, needlepoint, scriptures, a written speech, e-mailed stories, and genealogical work during or after the interview. Observations about these were recorded in the researcher's notes written on the Interview Guide during and after the actual conversation with the informant. In qualitative inquiry, words (field notes or transcribed interviews) are the most common forms of data. However, other innovative sources of data, as listed

above, may be included if they contribute to understanding and presenting the human experience under study (Boyd, 1993; Highley & Ferentz, 1988; Talbot, 1995). Unique sources of data are appropriate and desirable when they contribute to the following outcome. “The end product, the findings, represent the researcher's best effort to organize and present an accurate picture of what has been learned by going to the people in their natural settings and being with them for a time in order to gain as much insight as possible about their lives.” (Boyd, 1993, p. 75)

Data Analysis

The procedure for analyzing the data generated in this study is best described as inductive, systematic, and creative. The outcome (findings) represents the researcher's unique interpretation of the meanings that emerged from (were grounded in) the data. Analysis of data revealed a myriad of hope-sustaining sources and potential hope-draining threats that were categorized into themes and sub-themes. Findings were synthesized to describe the hoping process of persons living with cancer as impacted by factors from the three domains of environment. The theory proposed in Chapter I, entitled “Development and Renewal of Hope” (Figure 1.) was supported by the data. In addition, a new theory emerged from the data, “Hope Emergence and Growth” (Figure 2.) and is described in Chapter V. With this knowledge, it is hoped that nurses will more fully understand patients' hoping processes while living with cancer and more effectively plan interventions to facilitate hopeful attitudes in their patients.

The process of analyzing research data is a critical thinking activity analogous to a phase in the nursing process also known as "analysis of data." After collecting and validating data from multiple sources (assessment), the database is searched for relevant cues (data bits) and relationships (cue clusters) hypothesized to represent problem statements (nursing diagnoses) or wellness areas (strengths). The database is reviewed and more data collected as needed until the final interpretation is synthesized. The nursing process is an inductive analytic process with which all nurses are familiar, giving further support to the author's contention that research in the naturalistic inductive paradigm is "doing what comes naturally for nurses." Modeling and Role Modeling perspectives on this process are clearly described in Chapter Ten of Erickson et al. (1983), "How Does One Aggregate, Analyze, and Synthesize Data?" (p. 148-168). Synthesizing clinical data into pre-specified nursing diagnoses admittedly represents divergence from the intent of naturalistic inductive research, where findings emerge from the data without predetermined categories.

The process of inductive data analysis implemented in this study is related to the guidelines specified by Lincoln and Guba (1985), Miles and Huberman (1994), and Hutchinson (1993). During the data collection phase, researcher and informant interacted to mutually create the data. During analysis, the individual raw units of information, the realities "constructed" by the informants, were "deconstructed" then "reconstructed" into meaningful wholes. Lincoln and Guba term this analytic process "data induction" and Miles and Huberman call it "data reduction." Lincoln and Guba

note the similarity of inductive data analysis to content analysis, and further describe two essential sub processes, "unitizing" and "categorizing". Unitizing is a process of breaking the data into the smallest possible units of meaning.

In the present study, these individual units of data (participant quotes) were given preliminary theme names as the researcher read through the transcriptions. After several readings, the initial labels were grouped and regrouped as theme categories were reorganized, collapsed, and relabeled. Categorizing involves a "constant comparative process" of organizing the unitized data into groupings. Each of the units within a theme category must exhibit related meaning. Properties were described which served as inclusion-exclusion criteria for continued categorizing. These consisted of notes in the margins of interview transcriptions. Lists of categories and key words were created, reviewed, and recreated on several tablets of paper. Individual data units were highlighted in the text with colored markers according to the research questions. Stick-on tabs, color-coded by research question, were labeled with theme category names and placed along the right hand margin of each page to facilitate locating similar data units within context.

There were more initial categories than were ultimately finalized, due to collapsing some categories and eliminating a few with little supportive evidence, such as one theme, "sense of humor," having only two participant examples. Most theme categories finally developed were supported with evidence from half or more of all participants. A few categories were supported by six or seven of the fifteen

participants. Categories were named in a manner that attempted to capture the "essence" of the properties. Once the theme categories were finalized, the computer clipboard was used to gather related data bits into files named by theme category for each of the first three research questions. From these files of participant quotes taken from interview transcriptions, the text of findings was written and further interpreted.

In data analysis for grounded theory, as relationships among categories begin to emerge, ultimately a "theory" or explanation of the relationships is described. Lincoln and Guba (1985) describe the discovery of theory as emerging from or "grounded in the data" in the same manner as the originators of grounded theory methodology (Glaser & Strauss, 1967). Since the introduction of grounded theory methodology some thirty years ago, guidelines and procedures have evolved, including the use of a priori theory (Strauss & Corbin, 1994). As in the present research study, existing theories "appropriate to the area of investigation... may be *elaborated* and modified as incoming data are meticulously played against them" (p. 273). This process of rigorous comparison of data to the theoretical model presented in Chapter I (Figure 1.) was employed in the process of data analysis. Data obtained in answer to research questions one, two, and three described a variety of hope objects of attachment/loss (concrete, abstract, or symbolic) from the total environment (internal, external human, and external non-human). Data obtained in answer to research question four described need satisfactions or need deficits depending upon whether the participant was describing how a specific source of hope or a specific threat to hope

influenced them. The data for question four, how the source/threat influences the hoping process, was usually embedded in the responses participants gave to research questions one, two, and three, rather than from a separate interview question.

The importance of data analysis as a creative process has been emphasized by many qualitative research authorities (Denzin & Lincoln, 1998; Lincoln & Guba, 1985; Morse, 1991; Munhall & Boyd, 1993; Talbot, 1995). In fact, creative ability, the ability to be perceptive and think abstractly, has been described as the most important quality of qualitative researchers (Morse, 1991). The task of composing order out of the mass of information accumulated during data generation, requires persistent pondering, searching, and interpreting. Given the nature of "human as instrument," each being unique with its own constructed reality, value system, and model of the world; there is never one precise interpretation of qualitative data. The human instrument begins to create meaning (interpret data) during the initial data gathering phase of the research process. The overwhelming task of creating order out of massive amounts of data, as described above, was fully experienced by the researcher in the data analysis process of this study.

Hutchinson (1993) has described the data analysis procedures in grounded theory as both systematic and intense. Beginning with the first interview, the researcher simultaneously collects, codes, and analyzes data. Coding has been described as Level I, Level II, and Level III. Level I coding (analogous to unitizing) breaks data into small pieces. In relation to the proposed theoretical model of this

study, these are the specific perceived hope-influencing factors (sources or threats) grouped by the three environmental domains. Level II coding involves finding patterns or groupings of Level I data (theme categorizing). Level III codes or theoretical constructs conceptualize the relationships among the categories. An overall construct integrating the elements of the theory is illuminated and holds the entire grounded theory together. In this study, this is analogous to the proposed theoretical model in Chapter I (Figure 1.), which was validated by the study. An additional theory emerged from the data (Figure 2.) and is presented in Chapter V.

Incident descriptions and explanations of hope sources/threats illustrated the hoping process and environmental impact in a full, rich, detailed manner, termed "thick descriptions" by Lincoln and Guba (1985). Data for research questions one, two, and three (hope-influencing factors from the three domains of environment) are presented in the manner described by Sandelowski (2000) as accurate, comprehensive, and "close to the data." Details are important to capture the individual's point of view (Denzin & Lincoln, 1998). "The voices and interpretations of those under study are key to understanding the phenomenon of interest" (Polit, Beck, & Hungler, 2001, p. 12).

The process of data analysis began tentatively with the initial interview (documented as notes on the Interview Guide). This continued with each subsequent interview. The initial categories were reviewed, reorganized, and renamed with higher levels of abstraction. Interviewing stopped when redundancy or saturation of data was

achieved. Final analysis was not completed until all interviews had been read and reread. After studying all informants' interview data, a composite picture or overall description was developed (theme categories and processes), recognizing that no individual was a mirror reflection of the end result, but similarities and differences existed. It must be recalled that naturalistic designs are "emergent," allowing for flexibility in the evolving inquiry --"the design must therefore be 'played by ear'; it must unfold, cascade, roll, and emerge" (Lincoln & Guba, 1985, p. 209).

Trustworthiness

The quality of scientific rigor, or trustworthiness, is judged differently in the naturalistic and conventional paradigms (Burns & Grove, 1993; Lincoln & Guba, 1985; Polit & Hungler, 1997; Sandelowski, 1986; Talbot, 1995). "The goal of rigor in qualitative research is to accurately represent study participants' experiences" (Streubert & Carpenter, 1999, p.28). The conventional criteria of internal validity, external validity, reliability, and objectivity do not fit well with naturalistic epistemology. In evaluating naturalistic studies for rigor, Talbot (1995) and Polit and Hungler (1997) assert that the most widely accepted criteria among all researchers are those set forth by Lincoln and Guba (1985). The following four qualities -- credibility, transferability, dependability, and confirmability -- were used in this study to establish trustworthiness (Lincoln and Guba, 1985).

In establishing credibility, or truthvalue of the findings, the researcher first needs to demonstrate "prolonged engagement," or the investment of sufficient time in

the research setting. The planned in-depth interviews, building of trust, eliciting the background illness data as a context for hope, triangulating data sources (interview, observation, object interpretation), and validating findings with participants all have contributed to obtaining credible results. The skill of the researcher as interviewer, the human instrument, is important in gathering credible data. Prior to conducting this study, the researcher, master's prepared in psychiatric-mental health nursing, has spent some thirty years practicing and teaching therapeutic communication and interviewing skills in a variety of contexts. Peer debriefing was conducted to explore aspects of the inquiry with two colleagues who have experience in naturalistic research. Negative case analysis was attempted during interviewing by seeking a broad range of positive and negative factors influencing the hoping process in the variety of personal illness experiences. "Member checking," as described by Lincoln and Guba (1985, p. 314), was done to validate accuracy of the findings with participants. Findings were validated with participants during the interview by clarifying responses when needed and summarizing hope-influencing factors prior to requests for ranking. Follow-up telephone conversations helped to further clarify and validate some data after the transcriptions were read.

Transferability refers to the extent to which the findings can be applied to other contexts. The rich thick descriptions of the hope-sustaining and hope-draining factors and incidents, from the three environmental domains, as experienced by persons with cancer, facilitate the reader's judgment about the fittingness of findings to other

contexts. Client groups with other types of chronic illnesses of a life-threatening nature (e. g. lupus, stroke, coronary artery disease, amyotrophic lateralizing sclerosis) are possible groups for crossover applications. According to Lincoln and Guba (1985), "if there is to be transferability, the burden of proof lies less with the original investigator than with the person seeking to make the application elsewhere" (p.298). Anyone seeking to make a transfer must determine contextual similarity. "The expectation for determining whether the findings fit or are transferable rests with potential users of the findings and not with the researchers" (Streubert & Carpenter, 1999).

Dependability, strongly related to credibility, is best evaluated by the consistency or auditability of research processes. If other researchers can follow the decision-making process of the investigator and arrive at similar conclusions, the study is consistent and auditable. A documented "audit trail," explicitly describing the procedures followed in gathering and analyzing data were used to evaluate this quality by the supervising professor and auditors. An interview guide was used to ensure that participants are asked for the same information. Audio-taping, field notes, and validating transcriptions with tapes ensured accuracy of data. Participants were telephoned to validate or clarify data, with notes made of these conversations.

Confirmability refers to the degree to which the findings are grounded in the data, coming from the informants and not the biases and perspectives of the researcher. Two auditors were asked to trace a sample of findings back to the raw

data and determine if the interpretation was logical, as well as to review the entire structure of data analysis, utilizing the audit trail described above. Personal notes of the researcher; all raw data, unitized and categorized; as well as analytic notes and methodological notes were made available for review by the auditors.

Summary

This chapter has provided an overview and justification for the choice of methodology employed in this naturalistic inductive inquiry using qualitative methods. The parallel nature of nursing practice, Modeling and Role Modeling theory, and naturalistic inquiry according to Lincoln and Guba (1985) has been demonstrated, supporting the choice of a qualitative design for this nursing inquiry. The implementation of this method in the current study has been described, including procedures for protection of human subjects, sampling, data generation, data analysis, and measures of trustworthiness. In brief, the present study was conducted with an inductive approach utilizing primarily semi-structured interviewing. Participants were asked for brief personal profile data and a general background description of their personal illness (type of cancer, length of time since diagnosis, types of therapy, and settings of care). Data elicited consisted of detailed descriptions of situations, events, interactions, feelings and thoughts illuminating the impact, positive and negative, of factors from the internal (self) and external (human and non-human) environments on the individual's sense of hopefulness. These data were audio taped and transcribed. After the analysis of data, involving extensive review and re-review of participant

transcripts, theme categories were developed for grouping the positive hope-influencing factors. Patterns and themes that emerged from participant data were compared to the theoretical model in Chapter I to determine its usefulness in explaining the process of hope development and renewal. Further theory development (elaboration) progressed beyond this initially proposed model and resulted in an additional theory that emerged from the data, to be presented in Chapter V. Procedures for establishing trustworthiness have been described. Throughout this chapter, attempt has been made to adhere to the philosophic principles and axioms of the naturalistic inductive paradigm and to demonstrate congruence with the philosophic base of Modeling and Role Modeling theory and the nursing profession.

CHAPTER IV

FINDINGS AND INTERPRETATIONS OF DATA

Fifteen persons living with a diagnosis of cancer were interviewed to determine their current perceived levels of hopefulness, positive and negative factors that influenced their sense of hopefulness from each of three environmental domains, and rankings of the positive factors by importance. Participant perceptions of how the identified positive and negative factors influenced their hoping processes were elicited directly or often imbedded in the description of the factor itself. Ranking sources (positive factors) of hope by importance (first, second, and third) was the most difficult question for them, especially when asked to rank the significant persons in their lives. The importance of various factors fluctuated with time and circumstances.

All informants were volunteers who willingly participated in the study with candor and enthusiasm. The responses of participants were both surprising and inspirational to the researcher. All quite openly shared the story of their cancer experience and many seemed eager to begin telling this story to the researcher prior to beginning the actual interview. They often began to share significant data unsolicited on the telephone during the recruitment process. The depth and richness of data gathered were exciting and of better quality than anticipated by the researcher. It was the honor and privilege of the researcher to hear and document participant stories and interpret and merge them into the findings of this study. Detailed descriptions and many verbatim quotations of participant responses are provided so the reader will

experience the power and clarity with which they recounted their experiences and stories of hoping in life with cancer. In naturalistic inquiry, “the voices and interpretations of those under study are key to understanding the phenomenon of interest” (Polit et al., 2001, p. 12-13). The researcher’s analysis, organization of data into themes and categories, is presented with discussion and interpretation immediately before each aggregation of participant responses.

The prepared guide used during the interview process is found in Appendix A. During the actual interviews, participants did not always choose to describe their hope-influencing factors and experiences in the preplanned order (self, other humans, external environment). A few jumped between the broad categories of environment or got off course and had to be gently drawn back. This did not seem to matter, as data units could be separated and regrouped by the researcher during the analysis. If the participant chose to discuss one area before another, or to go back and forth between areas, this was allowed by the researcher. Only periodic cueing was found to be necessary to cover positive and negative hope-influencing factors (sources and threats) in all three environmental domains. In therapeutic relationships with clients, the process of moving with the client during the interview is called pacing (Welch and Gonzalez, 1999). Lincoln and Guba (1985) described analogous and advantageous characteristics of the human as research instrument – responsiveness and adaptability.

The material discussed in Chapter IV is organized according to the research questions that guided this study. Data will be presented in order of these questions

with illustrations of relevant participant contributions to the findings of each. Related findings from the literature are integrated into the introductory discussion of each section. A listing of theme categories developed from the large amount of data obtained for positive self-factors (the internal environment) is presented below. The number of negative factors (threats to hope) identified by participants was much smaller than the number of positive factors for each environmental domain. Participant illustrations of negative factors were merged into separate sections by research question and immediately follow the positive factors. A theme of “loss” was found to be common to all examples of negative hope-influencing factors.

Data and interpretations for positive and negative factors from the internal environment (research question one) will be presented first, followed by the external human environment (research question two) and the external non-human environment (research question three). Findings and interpretations concerning the process of hoping (research question four), rankings of factors by importance (research question five), and levels of hopefulness (research question six) will conclude this chapter.

Positive Hope-Influencing Factors from the Internal Environment (Self)

The first research question formulated to guide this study focused on individual or “self-factors” influencing the hoping process. As noted in Chapter I, the research question was stated as follows, “From the patient's perspective, what factors from the internal environment (self) impact the hoping process positively (sources of hope) and negatively (threats to hope)? The internal environment was defined as “the

intrapersonal and subjective inner world of the self, including personal characteristics, beliefs, values, thoughts, images, feelings, sensations, actions, and behaviors. In the “self” portion of the interview (see Appendix A), informants were asked, “What comes to mind as something about yourself that helps you to be hopeful?” They were cued to think of things such as personal characteristics, qualities, beliefs, thoughts, and activities that helped them to be hopeful. After exploring the positive factors (sources of hope), they were asked to think of anything about themselves that threatened or took away from their hopefulness. The results include theme categories representing various self-strategies or aspects of self (the internal environment) that influenced hopefulness positively. Negative self-factors, or threats to hope, from the internal environment, linked by a common theme of loss, follow the discussion of positive factors.

After analysis of the interview data, four broad theme categories with three to five subcategories under each emerged from the data for positive hope-influencing factors from the internal environment. These included: Personal Characteristics (Positive Outlook, Determined Fighting Spirit, Strength, Gratitude, Needed by and Helpful to Others), Uplifting Thoughts (Future Orientation, Short-Term Time Perspective, Comparative Thinking, Remembering Positive Role Models, Creative Imagining), Sustaining Beliefs (Faith, Prayer, Sacred Writings and Rituals), and Self Care (Educating Self, Work and Career, Self Protection and Maintenance, Self Restoration, Feeling Good/Asymptomatic).

Personal Characteristics

The first broad theme category is composed of self-identified personal characteristics perceived by participants as helpful in sustaining their sense of hopefulness. These include Positive Outlook, Determined Fighting Spirit, Strength, Gratitude, and Needed by and Helpful to Others. Each of these themes is presented with appropriate illustrations of data supporting each categorization and references to similar findings from the literature. Self esteem has been positively correlated with hope in several previous studies (Foote et al., 1990; Piazza et al., 1991; Vandercreek, Nye, and Herth; 1994; and Coward, 1996). Although self-esteem was not measured in this study, the ability to identify personal character strengths for research question one requires some degree of ability to see oneself in a positive light, or self-esteem.

Positive Outlook

Fourteen of the fifteen participants contributed to the data composing this theme. Keeping a positive outlook or attitude was felt to be an important factor in maintaining hopefulness by a majority of participants. Expecting good outcomes, looking for positive aspects of difficult situations, and replacing negative thoughts with positive ones are self-strategies found in this category. Some participants did not mention positive attitude per se, but displayed it through the examples of positive expectations and thoughts about cancer and their future. Expressing confidence in the future is considered equivalent to a positive outlook. Some participants admitted that keeping a positive attitude was sometimes difficult if not impossible, but these

episodes were temporary. Two participants talked of purposefully interrupting negative thoughts and replacing them with positive. This cognitive strategy is similar to one described by Hinds and Martin (1988) in their study of adolescents with cancer. They developed a category titled “cognitive discomfort,” having two sub-themes, “thought stopping” and “thought reflection” (p. 337). “Positive expectations” were linked to hoping in a study of thirty persons with cancer (O’Conner, Wicker, and Geronimo, 1990). In her 1993a study of hope, Herth interviewed sixty older adults in community and institutional settings who reported two cognitive strategies, “positive self talk” and “optimizing,” as sources of hope. Seligman (1990) in his book, Learned Optimism, asserts that optimism is a learned skill.

Learned optimism is not a rediscovery of the “power of positive thinking.” The skills of optimism do not emerge from the pink Sunday-school world of happy events... What is crucial is what you think when you fail, using the power of “non-negative thinking.” Changing the destructive things you say to yourself when you experience the setbacks that life deals all of us is the central skill of optimism (p. 15).

Emily stated that she never really thinks about how hopeful she is. However, she believes attitude has a lot to do with cancer survival. After having been told she had six months to a year to live (eight years ago), she has tried to find good in every day that she has survived since that time.

I think your attitude has a lot to do with it... I don’t know how to explain that... Because I never really think about how hopeful I am... I just kind of take every day as a gift. So I wake up every morning, and it’s a good day, even if you don’t feel terrific, it’s a good day to be alive. When they’ve told you “six months to a year,” and here it is... Look at all the time I’ve lived!

Emily used the word “positive” several times to describe the attitude she tries to maintain. “Ignorance is bliss” is a familiar saying that comes close to describing her attitude after the initial surgery and bone marrow transplant. “I had been through so much... I was just real positive. I just thought it was like any other kind of surgery -- you just have it taken out, and you have your treatment, and you get on with your life. And I never dreamed it would come back. I was ignorant, but it was good because I had fifteen months thinking I was going [to be okay].”

In spite of her lack of optimism about achieving a cure, Emily remains hopeful about research helping her to gain more time. “I don’t really think that this cancer thing is going to go away, but, you know, they keep coming up with things, and I’ve lived eight and a half years. Who’s to say I can’t live another eight years.”

“My overall exuberance” was a characteristic given by Angie as something that influences her hoping process positively. “The way I approach things with a lot of energy and really, initially, a lot of optimism” are what she says help her to be hopeful. There was hesitancy about her mention of a positive attitude, as if this is something not consistently maintained. “So my energy and exuberance, and usually positive attitude, usually, I think, helps.”

Being positive is a valued characteristic that Marcia tries to maintain in herself and to teach her children. She tries not to have negative thoughts. “I don’t allow negative thoughts. I try to be real positive, and that’s the way I’ve brought up my kids. You’ve got to think positive if you want positive things to happen in your life.

And that's pretty much the way I am." During the past year of diagnosis and treatment for breast cancer, Marcia developed a strategy for controlling negative thoughts. "If I allowed a negative thought to come into my mind, I would -- If I couldn't think of something positive -- I would go pick up my Bible and just open it and look... I've probably always been a Bible reader, but I think last year I probably read it more."

Going to appointments at her treatment center did not have positive associations for Marcia. She countered this by reminding herself that she had had her surgery, chemotherapy, and radiation therapy there and as a result was "doing great." She purposely focused on the positive as she drove to the treatment center. "I'm going to think positive about this, that way I won't dread the trip over there. And so now when I go to [the treatment center], I don't dread it... I think a lot of the way I see things -- it's in your head. If I think I'm going to not like a place, I try to see why I'm not going to like it and look for the good points."

Twenty-two years ago his doctors did not give Paul much hope about beating his cancer. Paul has never agreed with them and has always expressed confidence about his future. "I always felt like something would happen right." He has had multiple rounds of chemotherapy for several different types of cancer and is still in treatment. If God has a direction for his life, then Paul is not about to try to "out think" that situation. "Sure, I'm always hopeful, but... that may not be the direction God is... like He may not want me to go much more." Even thinking that he may not

live much longer, Paul is still hopeful. "I'm always pretty positive about things." After rating himself a "ten" on the one to ten hope scale, Paul reflected about his attitude.

My attitude has always been that, 'I'll get through this, and I'll go back to work.' And I never thought I'd need anything else, even though the thought and the dialogue with the doctor is always encroaching on your thought process. I really cannot explain exactly why, but I still felt like something was going to happen right, or I would last longer than they expected me to, which has already happened more than once.

Maggy has expressed a hopeful, confident attitude since her diagnosis with breast cancer seven months ago. "There's hope in every day... I had every assurance that everything was going to be okay." After the initial diagnosis she said, "Okay, whatever has to be done, we'll take care of it, and we'll get it done." Maggy went on to say, "I've kept that kind of attitude through the whole thing... I knew that everything was going to be okay, or at least that I could handle whatever." Rarely does Maggy's mind wander into a negative realm. "I don't think like that."

Holly tries to display a positive image and attitude mostly for her family. When listening to her, one has the impression that she has often felt worse than she actually admitted during her past fourteen-month struggle with metastatic colon cancer. On the day of her interview she did look wonderful. As will be seen in later examples, Holly and her family members regularly try to interrupt negative thoughts.

There is no cure for the type of cancer Bert has battled for five years. The only available treatment is to have repeated surgeries to remove the large liposarcomas that grow in his abdomen. He does not dwell on that, but displays a confident, optimistic

attitude about his ability to undergo and recover from any additional surgery he might need. "I've walked away from five [surgeries]. I can walk away from five more."

Deana subscribes to many of the philosophical principles of Al-Anon, a program she describes as "very positive." She has received much support from her Al-Anon sponsor in dealing with breast cancer and maintaining hopefulness. She explains the positive nature of Al-Anon in the following paragraph.

Well, Al-Anon is a very positive program. To begin with, you really do not look on the negative side of anything in Al-Anon. You look forward to today and forget yesterday, and you look forward to tomorrow, and you do not project. That is the one really good thing in Al-Anon... You do not figure out what is going to happen. You do not figure out what bad things are going to happen to you, or even what things of any sort are going to happen to you... You do not plan on anything happening. You just plan on doing it one day at a time... living the rest of your life for a better time.

Karl sees himself as "sort of a Pollyanna" who usually has a positive outlook about the future. He believes that this attitude may be a defense mechanism that helps to give him some comfort. He obviously is not freed from worry by his efforts to think positively in his current situation. He is undergoing experimental chemotherapy for metastatic cancer. "I think being sort of a Pollyanna about things -- I always figure things are going to work out, and I will be successful. And I did not really dwell too much on anything less than that... So I guess that may be a defense mechanism, true or untrue, that seems to sustain me or give me some comfort."

During his diagnosis and treatment for testicular cancer, Louis had a positive attitude, a confidence about his future. He always felt that, "Everything would be all

right one way or the other... Things were going to be okay for my family, and that whatever happened everything would still be okay.” Prior to having cancer, he saw himself as very healthy, semi-athletic, and a hard worker who could provide for his family as long as he was healthy. Finding that he was a survivor and could endure the hardships of the treatment has made him a “better person” in his estimation. “I am a survivor... I have a good outlook.”

Robin always looks for the positive, even in painful, disappointing, or even devastating situations. “I truly believe that good things can come out of bad... No matter how bad the situation is there is something there to hold on to -- there is something positive. We might not wish that it had gone that way, but I know that I cannot change it, and so I deal with it.”

Pam believes that positive thinking is important to maintain hope and can influence one’s body. Her concept of God includes the belief that He wants humans to be whole and has provided many means of achieving wholeness, including positive thinking.

I think God wants us to be whole, and I think that there are many, many ways that he has provided. He has provided doctors, medicines, natural herbs, natural things in the environment... I would even go so far as to say positive thinking... I think positive thinking certainly helps. I think we are spirit, soul, and body... three separate entities. They all function as a unit of wholeness, so one affects the other. If your thinking is off, your body can be very off.

While listening to participants discuss efforts to keep a positive outlook or attitude, the researcher considered the possibility that they were using the term

synonymously with hope. Hope was defined in Chapter I of this study as a “positive expectation about the future.” Participants were not given a definition of hope nor were they asked for one. They were merely requested to rate their current feelings of hopefulness on a one to ten scale and to think of and discuss positive and negative factors (sources and threats) influencing their perceptions of hope.

Determined Fighting Spirit

Thirteen of fifteen participants mentioned something about fighting or displaying courage, stubbornness, or determination in battling cancer. Having a strong will to live is also a characteristic included in this theme category. Marcia said it all in one sentence, “You’ve got to keep fighting.” Angie told the poignant story of a favorite nurse calling her a “brave little warrior.” Many illustrations of this determined fighting spirit follow. No previous nursing research studies were found which linked hope to a fighting spirit, stubbornness, or strong will. “Determination” and “courage” were sources of hope identified in Herth’s 1990b study of thirty terminally ill adults. Hafen et al. (1992) discussed the role of a fighting spirit in protecting health. “People with a fighting spirit fully accept the diagnosis, adopt an optimistic attitude filled with faith, seek information about how to help themselves, and are determined to fight the disease. Their attitude is, ‘I won’t let cancer beat me! I’m trying everything to get better’” (p. 535).

Besides being “a fighter,” Emily sees herself as “determined, stubborn, and strong-willed.” She believes that she will never be cured of cancer and will fight it for

the remainder of her life. “I think it’s something I’m gonna fight for the rest of my life... I’m a realist, and I know what I’m dealing with... But I don’t think I’m anywhere near dying. I don’t know how to explain it. I don’t fear death. I am at complete peace, so I really don’t dwell on it that much.” Emily describes a confidence and a courageous attitude about dealing with life in general. “I’m definitely not one to just throw up my hands and say, ‘I can’t deal with this.’ I can deal with whatever comes along, because what choice do you have?” Besides not fearing death, she is not afraid of many other things. “I really don’t have a lot of fears.”

Angie describes herself by other people’s assessments. “People say I’m very bull-headed and stubborn, and if I want to do something badly enough, I get it done. So, in that way, my stubbornness is kind of a positive.” When asked if she considered herself a fighter, she said, “Sometimes... It depends on how I physically feel.” Angie told the following story, involving one of her favorite hospital nurses. Soon after her initial surgery, she developed a bowel obstruction and was readmitted to the hospital. Having just had her first chemotherapy treatment, her hair had begun to fall out. Angie had asked her sister to shave her hair, before it totally fell out. The nurse came into her room and found the sister with horse clippers and clumps of curly auburn hair falling onto the hospital bed. All the nurse said in observation was, “brave little warrior.” Angie had remembered the phrase, as it implied to her that this would be a battle against the cancer, and she was just beginning to fight it.

When asked about sources of hope from within himself, Paul reflected, “I think my desire to live. I feel motivated to go... to keep going.” Paul’s doctor often asks him questions like, “How could you get through this?” He just tells him, “It’s because I want to live a little longer. It’s just that simple.” Paul attributes his strong will to live, in part, to his artistic aspirations. “I’ve got paintings to paint.”

Being brave herself and promoting courage in others is important to Maggy. “You have to be brave.” She often talks with other cancer patients and their daughters trying to give them encouragement. Maggy also sees herself as being stubborn and having a strong will. “I do have a very strong self-will, my will to keep going on... There’s too much life to live.” During the interview, Maggy mentioned her stubbornness trait at least five times.

My husband tells everybody it’s the German in me, you know, stubborn, stubborn! ... We joke about my stubbornness, my German stubbornness. We joke about that, but that is a trait that I attribute to helping me get to where I am today, because I was never in a position to go to college. I’m the second oldest of ten children... Basically, I helped raise them... So I’m a survivor... As far as I’ve gotten in my life, it’s because I’ve worked real hard to get there... I am a compassionate person, but I think, overall, and my family would say this to the end... They’d say, “She’s just stubborn.”

For Sheila, it was always clear that she wanted to be treated with the best of whatever therapy was available to fight her cancer. In a follow-up telephone call, she said, “The patient has two choices, to live and do all you can to make it possible, or to do nothing and die.” Like Maggy, it was her “stubbornness” that stood out as the most important source of hope from within herself.

I wanted to try whatever was available... As long as we were doing something... I was not going to let this thing beat me. If there was anything I could do to make this treatment work better, I was going to do it, and I was going to find out everything I could find out... good, bad, or purple! It didn't really matter. I was going to find out what the current research said, what the current options were, what was out there

Bravely facing her uncertain future, Holly is no longer afraid of dying, but feels comfortable about it. "It's not threatening because I feel like I am not that afraid of death. I used to be, but I am not anymore. I am comfortable with it one way or the other. Whichever way I go, I know it is going to be okay." Holly believes that when she feels good and looks happy then her family is happy and knows that she is fighting. "I feel good about myself, and if I feel good about myself and look happy, then my family is happy because they don't think that there is anything bothering me. So then they know that I'm fighting, and they don't think I have cancer at that point either." Holly's perceptions of fighting seem to be more of a front she puts on for her family's benefit than a genuine determined fighting spirit.

Deana wanted to have the optional chemotherapy after her mastectomy because, "I wanted to live as long as possible without fear of returning cancer." She read a passage from her journal, demonstrating her determination to live, "I will do everything I am supposed to do... because I want to live as long as I can, and I want to do what I can right now to ward it off."

Karl quoted a line from the movie Shawshank Redemption that occurs to him "pretty regularly." This is when the star, Morgan Freeman says, "You either need to

get busy living, or get busy dying.” It helps Karl to remind himself on a regular basis, “Do what it takes to live. Don’t be going in the other direction.”

Robin did not describe herself as brave or courageous, but as someone who “refused to live in fear” as her mother had done. “I think from early on I was determined that I was not going to live my life like that.” Robin described her mother as “afraid of everything.” Robin’s strong faith and confidence in herself and her God helped her gain this attitude. “I had the strong faith that whatever came, my spirit and my soul, with the help of God, would get me through it. You know, even if it was going to be painful, maybe it would hurt, maybe it was disappointing, even devastating, like losing [her husband]... I refuse to live in fear.”

Robin says that people worry about her living alone out in the country. People worry about her being alone at her needlework studio at night. “I do not worry about those things. That is where I need to be. That is what I need to be doing. And if adversity comes along, I will deal with it at the time. I do not take unnecessary risks though. I keep the doors locked and things like that!”

Pam remembered a scripture passage that helped her to feel more hopeful after diagnosis. Like several other participants, she felt she faced a decision of choosing life over death. “I felt it was the Holy Spirit telling me, giving me some scriptures... ‘Choose this day. You have before you set life and death. I hope you choose life.’ And then I began to calm down and get more peaceful.” Later in the interview she returned to this passage again. “This scripture kept coming to me and, again, it is in

the Psalms.” After Pam made the decision -- choosing life over death -- she prayed for guidance that God would show her what to do. “After I made that choice, I said, ‘God, I want to live. I choose life, and I choose you. Now, show me what to do.’”

Some of Audrey’s most important sources of hope came from within herself. She became angry and determined not to let cancer interrupt her plans for the future. “I had a four-year-old and a newborn at home. I was not going let it get between me and what I wanted to do. It made me mad.” When asked at the conclusion of her interview what she thought was her most important source of hope overall, Audrey responded, “I think the fighter part. I do think the fighter part.” This fighter spirit emerged very early after she was diagnosed with breast cancer at the age of thirty.

The lowest moment was the day that I came in [after learning of the diagnosis], and I just cried in her [daughter’s] room, and then I got very mad. I was about to start my last semester of nursing school. I had just had a baby. I had all this stuff going on, and I had planned on doing the screenings and stuff when I turned thirty. Well, I was pregnant, so I could not start mammograms... So, then I started taking it like it kind of beat me to the punch, and that was when I got mad. It became personal then, kind of like me-against-it type thing. I took it more as a fight-type thing.

Audrey was determined and resistant to accepting advice or help at times during her battle. Although she did not describe herself as stubborn, she sounds as persistent and determined as Angie, Maggy, and Sheila. The nursing school dean and some of her instructors tried to get Audrey to drop out of school. “I guess looking back, it may have been more of their protectiveness or something. But, at the time, I was taking it as, ‘You cannot handle this.’ That bothered me because I thought if I

think I can do this, and I want to try this, why are you sitting there telling me, “No, don’t?” She realized it would be difficult and a lot to handle, but her determination was strong. “I wanted to try.” After surgery she returned to school, but Audrey resisted help from her peers with carrying her heavy book bag up a flight of stairs.

We would always kind of meet out in the front and go up to class... Coming up the steps, I am just huffing and puffing, and they’d say, “Let me carry your books now.” And this went on for a couple of weeks, and finally, they just had to take it from me. From then on, it was a little bit easier. But I did not want any help at first. I think it was more like, “I am going to do this.”

Clearly, participants link a fighting spirit, the courage to deal with whatever comes along, and a determination to “beat it” with facilitating the hoping process. Choosing to live is prerequisite to beginning the fight. Confidence in their own abilities and the motivation to do everything necessary to fight cancer are a part of this theme. Soldiers throughout time have fought with like courage and determination to win their battles.

Strength

Nine of the fifteen participants mentioned the importance of some type of strength -- physical, mental, emotional, spiritual or strength of will. Going into treatment (chemotherapy or surgery) with a reserve of strength helped them to endure these difficulties. Regaining physical strength after debilitating treatments was a milestone for many and was associated with increased hopefulness. In a previous study, thirty persons with cancer “prayed for strength to endure threats” and identified “strength” as an internal resource supportive of their hope (O’Conner et al., 1990).

Emily recognizes that she is a strong person emotionally. She attributes this to heritage and the fact that her mother had a similar asset. “I say I’ve come from good stock because my mother was a real strong person emotionally.” Her oncologist has also told her that she’s a strong person emotionally – “the strongest patient emotionally that he’s ever dealt with.”

I know when I was in the hospital initially diagnosed, I didn’t cry or anything. You know, I was just in there and going with the flow. And he [her doctor] asked my girlfriend -- she’d come to the hospital every day to see me -- and he asked her out in the hall, “Is Emily really doing okay, or is she just putting on a show for us?”

Describing herself as “strong-willed,” Emily believes she can deal with whatever happens. “I think I’m pretty strong-willed and I think I’m a fighter. I’m definitely not one to just throw up my hands and say, ‘I can’t deal with this.’ I can deal with what ever comes along, because what choice do you have?” The only experience she had difficulty dealing with was a bone marrow transplant, during which she became seriously ill, uncomfortable, and debilitated. Regaining her strength was a milestone in recovery after the transplant. “I finally got my strength back.”

For Angie, good physical feelings are the greatest source of hope she identifies from within herself. Physical strength and absence of symptoms such as fatigue or exhaustion constitute overall strength. “The greatest source of hope from within myself is how I physically feel. If I don’t feel physically good, my hope just plummets. If I feel physically strong, and I’m not having symptoms and all that, then I feel very strong.”

During a follow-up telephone call with Paul, he talked of needing to strengthen his mind and body during episodes of cancer reoccurrence and chemotherapy. “I strengthen my mind and body by building fences and working in my studio.” He is an artist and teacher who has been dealing with cancer for over twenty years. Due to the limitations of chemotherapy he must stay out of public places and does this “strengthening” work at home.

Maggy talked of her strong self-will and stubbornness, traits that she equates with her survivorship. These traits have helped her to achieve in life and to deal with cancer. When she underwent chemotherapy, she remained strong enough to drive herself to and from the treatments. Ordinarily, patients are asked to have a driver. “I drove myself. You know, and that’s just the way it goes. I just take myself, but that’s the way I am. I can do this, you know, I am strong enough. I can do this... I am just a very strong personality... I do have a very strong self-will.”

Walter discovered his seventy-five year-old-body had more strength than he thought it did. He had initially declined treatment for leukemia, due to the poor response and side effects he believed a person his age would experience. This pessimism was the result of his years of practice in internal medicine, from which he is now retired. He talked enthusiastically and almost with amazement about his body’s positive response to treatments for recurring abscesses that developed after he was diagnosed with leukemia.

I recovered from that. The drainage quit; I went back and had them look at it, and he looked all around and everything was going great for me. My count got back to a good count... back where it was at baseline. The encouraging news to me was that when I had this severe infection my white count did raise, go up to combat the infection, and the platelet count even went up, so my body could respond to stress for some reason.

He was happy, relieved, and surprised to quickly recover his strength, especially for driving a golf ball, after surgery for an abscess. "Interestingly enough, I did recover my strength very rapidly after that. I was amazed at how fast I did recover, within a few months. And I was able to hit a golf ball about as far as I ever did."

Physical fitness was a strength trait that helped Karl, a physician in his early fifties, survive his initial surgery and later simultaneous administration of chemotherapy and radiation therapy. "The first surgery -- I had to have a tracheostomy. They left the "trach" in for about a week, and I did not sleep for five days and nights because I could not breathe, and I think my stamina and my fitness/exercise got me through that... I was just walking the floors at night in the hospital." Later, he recognized the importance of mental and spiritual strength in addition to the physical. He felt that his spiritual strength was especially challenged by his illness.

I was physically fit, and that helped a lot because I realized, and I should have written this in the journal I was keeping. That there may come a time when you will need every bit of mental, spiritual, and physical strength that you have to get through something. I felt like mine was a certain test in spiritual strength. I was pushing the envelope.

Louis and Bert, both around forty, value their physical strength, athleticism and continued ability to participate in sports and various recreational activities in spite of having cancer. Bert is able to water ski avidly with his family after “walking away from five difficult surgeries.” Louis, who has always enjoyed sports and sees himself as “real healthy and semi-athletic,” proved to himself through the cancer experience that he really “could endure hardships.”

Robin has experienced two major challenges to her endurance in the past few years. She underwent cancer surgery and treatment at the same time as her husband. He did not survive his illness and she did. Her friends and family see her as a strong person. “I guess people see me as strong because you just keep on going.”

Strength is a characteristic that facilitates the ability of participants to endure the challenges of living with cancer and to project themselves actively forward into the future – to live on in spite of difficulties and losses. Strength is of benefit to a fighter or a warrior, whether the war is on a battlefield, in a hospital room, or in one’s mind.

Gratitude

More than half of participants, eight of the fifteen, viewed themselves as lucky or blessed in spite of having cancer. They did not fail to recognize difficulties, but their general outlook was one of gratitude and appreciation for the positive aspects of their lives. Some perceived overall benefits from having experienced cancer. No previous nursing studies were found that identified gratitude, feeling lucky, or being blessed as sources of hope. The work of Maslow (1987) supports this category in his

observation of self-actualizing people as having “fresh appreciation... the wonderful capacity to appreciate again and again, freshly and naively, the basic goods of life” (p. 136). In his words, “life could be vastly improved if we could count our blessings as self-actualizing people can and do, and if we could retain their constant sense of good fortune and gratitude for it” (p. 137).

Emily, in her fifties, has had ovarian cancer for over eight years, spending little more than one year in a remission. She has outlived all prognostications regarding her expected length of life, is not sure when she’ll die, and isn’t fearful about it. Emily is grateful for every day that she is alive, considering each day a “gift” and a “good day” even if she doesn’t feel good. “All my days are good, even the bad ones are good.” She enumerates what she can do rather than what she cannot do or has lost. Divorced, with a grown son, and living alone with her dog and cat, Emily counts her blessings, especially friends. “I see how blessed I am to have friends.”

If I became bedridden two months from now, I don’t have a complaint because I’ve had eight and a half good years. I’m not saying it’s been easy, but they’ve been good years. I have always been able to go out, and take care of myself, and take care of my house. And, you know, I think I’m fairly active. I go and do whatever I want to do... I’m really more content with my life right now than I’ve ever been... I don’t really think that this cancer thing is going to go away, but, you know, they keep coming up with things, and I’ve lived eight and a half years. Who’s to say I can’t live another eight years.

With people all over central Texas and the world praying for her, Maggy feels extremely blessed. She has family members in Indonesia praying. “I have people in Oregon praying. It’s amazing... even the housekeepers have told me that they’ve

shared my name with the prayer chain of their churches... It's amazing, the prayer support that I've been able to get. I don't know why I'm so blessed, but I am... I feel it, you know, I really do." Maggy also believes that she has learned a great deal from her cancer experience. She no longer worries, is grateful for every day; and, like Emily, considers each day a gift. "I have learned what's important. I have learned to be grateful for every day... I go through every day and look at it as a blessing... it's another gift."

During the course of his interview, Bert made at least five references to being lucky or having it good in his life. He feels lucky for having his wife and four children. "My wife... and my four children... they just mean the world to me... I have had a few little curves in life... It has helped me to open my eyes to what I truly have and how blessed I am. Like I am the luckiest person to be alive." Surviving five extensive abdominal surgeries has left Bert with a sense of gratitude. "I do believe that I am the luckiest person in the world because I have been able to go through five fairly difficult surgeries, and I have walked away from each one of them. And I can still water ski. I can still run. I can still exercise. I can still do whatever." A visit to the children's ward at a large cancer center opened his eyes. "In the back of my mind somewhere, I thought I was lucky, and I thought I was fortunate, but seeing what I saw... it really opened my eyes... I am the luckiest person alive." He feels fortunate for having had wonderful loving parents.

I have always said this, "I am the luckiest person in the world," and people just look at me and say, "Yeah, right." But I am... My parents were very... They are wonderful people -- lots of love and care. So I have had it good all of my life, and that is why I intend to share that wealth with my family, not money wise.

Deana made an entry in her journal during her recovery from breast cancer surgery. "My blood pressure is 179/61. Weight is 154 pounds. I have lost a few pounds. I am heavier than I have ever been at any time in my life. I am still filled with much gratitude for so many blessings." Recognizing that things could be better, Deana did not forget her blessings. When asked to think of people who had threatened her sense of hopefulness, she responded, "Maybe there have been, but they never relayed the message to me, and I am grateful for that. You learn to go through a lot of gratitudes, and I am grateful for small favors. I am grateful."

After talking about the tremendous amount of support he had received in the time since diagnosis, Walter expressed the following with a quiet sincerity, "As you can see, I have had such great love since being diagnosed with leukemia and I had written myself off. I am so grateful for everything. The other thing is I do not get angry at anything. There is nothing worth getting angry over to me anymore. That is just something that has disappeared."

Karl and his wife have experienced and improved marital relationship since he developed cancer. Having been married for thirty years and lacking a sense of anything new, cancer has drawn them closer and been a blessing. Each has felt encouraged by the other's response to the difficult situation.

We have actually felt that this illness was a blessing... because neither of us wanted to go back to the way we were ... After thirty years of marriage there is not a lot left new to it. But this illness has really drawn us close. She has seen the way I have gone through it, and it has been an encouragement to her. And I have seen all that she was trying to do and does for me, and that was an encouragement to me.

Louis went through a troublesome depression after surgery and chemotherapy. He had a difficult time bouncing back and returning to full force at work. Learning that he could “endure hardship” made him a better person. “Then when I lost my health, that caused me some depression... I think the treatment and all that in the long run maybe, probably, made me a better person... I am a survivor, and the little bumps in the road do not really bother me so much... I have a good outlook.”

Pam’s experience with cancer has been one with little of the suffering or pain that she has witnessed in one of her close friends with cancer. For this relative comfort she feels “very grateful.” She also feels blessed by the tremendous support she’s received from her church family.

Having an attitude of gratitude, a feeling of being lucky or blessed, fosters positive feelings, complementing and supporting hopefulness. Those who voiced this attitude did not ignore or deny their difficulties, but looked beyond adversity to their “gratitudes,” the blessings in their lives. The ability to do this helped them to stay hopeful by countering the losses with gains, the negatives with positives.

Needed by and Helpful to Others

Feeling needed by and being helpful to others was linked to hope by twelve of the fifteen participants. Children and spouses were frequently mentioned as those who needed them. These significant family members as well as pets and other cancer patients provided some with reasons to live and not die. It was very common for participants to want to “give back” and help those in similar cancer situations. Many expressed a desire to give hope to others with cancer through their own personal survival stories. This did not happen immediately, but took time in order that they deal with their own experiences before helping others. Having the ability to empathize is required to perceive another’s needs. Some felt needed by and helped persons with other types of needs unrelated to cancer. Some participants helped others through various church and volunteer activities in their communities. Most admit that helping is a circle of benefit -- it helps both the helper and the recipient. Participation in this research project was often accompanied by the statement, “I hope this helps someone.”

No previous studies were found which linked hopefulness to feeling needed or being helpful to others. However, this attribute is implied in the concept of self-transcendence, “the capacity to reach out beyond self boundaries,” linked to hope in at least one nursing study (Coward, 1996, p. 116). Frankl (1984) discussed this characteristic, terming it “the self-transcendence of human existence” (p. 115).

By declaring that man is responsible and must actualize the potential meaning of his life, I wish to stress that the true meaning of life is to be discovered in the world rather than within man or his own psyche, as though it were a closed system... Being human always points, and is directed, to something, or someone, other than oneself – be it a meaning to fulfill or another human being to encounter. The more one forgets himself – by giving himself to a cause to serve or another person to love – the more human he is and the more he actualizes himself (p. 115).

Another of Maslow's (1987) qualities of self-actualizing people supports this category, a trait termed "human kinship... a deep feeling of identification, sympathy, and affection for human beings in general." Because of this feeling of kinship, "self-actualizing people have a genuine desire to help the human race" (p. 138).

The need to be there for another person (her teenage son) gave Emily a reason to keep living. Emily does much to help others – visiting shut-ins for her church, seeing new cancer patients at the medical center, and visiting nursing home residents. Although she takes good care of herself, she thinks it is helpful not to focus too much on self. She expresses empathy for those who are alone, do not drive and cannot leave their homes. Her sense of humor was evident in the following story about praying to see her son graduate from high school.

When I first got sick, I prayed that I would see my son graduate because he was fifteen, and he didn't have a relationship with his father. And I felt like I couldn't die. I mean... It just wasn't in the plan... There's no way I could die because my son needed me, and I laugh now and say, "maybe the Lord thought I meant college," because he [her son] went to school for three years and then dropped out, and he's probably never going to go back to college.

Emily has always been grateful for the fact that she has been able to drive, get out, and do things with friends during her eight years of living with ovarian cancer.

Her empathy for those who are not so lucky motivates her to help improve their situations. Emily seems to have asked herself the same question she projects to the following nursing home resident.

I talk a lot on the phone to other cancer patients. I visit Angie and people in church. I do a lot of things... If you think things are bad, you can get out there and find people that have things so much worse than you do. So if I have a pity party I go down to [the medical center]... Or, I see someone who is ninety-six years old in a nursing home, and her mind is still good, and she's thinking, "Why am I here left on this earth?"... I take my ex-mother-in-law to the grocery store all the time. I take her to the doctor, and, you know, she doesn't even ask her kids to do that. But, you know, she's eighty-six and she just feels comfortable asking me because she knows I'm willing to do it. And it's not that I'm such a good person, it's just that, you know, I've been without transportation. I know what it's like.

When asked to think some more about how doing things for others helped her to be hopeful, Emily replied, "I think it's just that I don't focus on me... I'm not a self-centered... you know, the world doesn't revolve around Emily." Her ability to empathize is again evident. "Because there are people that don't have anyone, you know, they're out there, and they don't drive, and they're housebound. And so I think it helps if you look around and see other peoples' problems instead of focusing on 'oh poor me -- I have this problem.'"

Being needed by her pets gives Angie a reason to keep living. They need her for their survival and in return provide much love and affection to Angie, their caregiver. Besides receiving their love, she likes feeling responsible for them. Riding her horses provides energy, enjoyment and exercise. Angie frequently walks out into her horse pasture just to hug and kiss her two horses and foal.

They [her dogs, cats, and horses] depend on me, and they love me, and I like being responsible for taking care of them... They're a reason for me to continue going because I care about them, and I don't want anything to happen to them... I have to be strong and well to take care of them. Plus, you have to have some kind of energy to get up and ride a horse.

Helping other women with ovarian cancer is important to Angie. She frequently shares her experiences in her support group. She has spoken more formally about communicating with one's physician to a large group of ovarian cancer survivors at a national retreat in Montana. "Giving back" is something she hopes to continue as long as her health allows.

I feel much better when I am helping other people in their recovery or management of having cancer -- either talking to people at my support group or talking to a group as a whole. If I can give back something, or give them something to help them deal with their disease, I feel very good about that... Either giving them hints on how to talk to their doctor, or what to do with the nurses, or how to manage the chemo, or what kind of an attitude, what frame of mind to be in -- those are all things that I've learned from having it myself.

Angie has a goal of helping other ovarian cancer patients in the political arena by speaking on behalf of a national coalition. She is a communications professional who coaches television anchors all over the country and has taught public speaking for ten years in a large metropolitan area community college.

I really believe that I could be a powerful voice for the N.O.C.C., which is the National Ovarian Cancer Coalition, and it doesn't get enough media exposure because most of the women that are diagnosed with ovarian cancer die right away. It's unlike breast cancer in that there's a higher survival rate [with breast cancer.] So there are a lot of people out there advocating funds, and they just get a lot more research because they're a louder voice... So, I, if I survive, want to be a loud voice for the N.O.C.C. and do seminars, or public appearances, or whatever representing the N.O.C.C. at conferences

Maggy tries to be aware of opportunities to help other women who have breast cancer or their daughters. “Like I was talking about some of the mothers and the daughters that are here... I am trying to be aware of the opportunities that come to me to share my faith, my hope, and my experiences with others.” She sees herself as a good listener who always looks for ways to help. “I’m a good listener. I like to listen to other people to see if I can help them. And I have done that through this whole thing. I use what I’ve been through as a tool to help others.” Her occupation as an administrative assistant frequently brings Maggy into contact with the daughters of women “that are going through breast cancer and going through the treatments.” She always wears colorful hats to cover her bald head and feels this makes her easily recognizable as a cancer patient undergoing chemotherapy. “I am able to minister to the daughters because I can say there is hope, and you have to keep that hope alive. You have to keep hope alive.”

Maggy never “makes light of a bad situation” but tries to help others see how to deal with it “in a way that has been an encouragement (so I’m told) to other people.” She realizes that her role a helper is of benefit to herself as well as to those she helps. “It all comes back to me, because it helps me. If I can encourage, these people are encouraging me. So it’s a circle, it’s a circle.”

Although she feels needed by her husband and children, Sheila knows that if she were to die they would be okay. Her children are now grown and don’t need her as much as they used to. Her feelings about her husband are a little different. “I

wouldn't want to leave my husband here by himself, but if that's got to be... That's part of what I was thinking even when I was going through treatment. It's like, I've done what I think I needed to do so far, and if this is it, then somebody will take care of him, and I'll be in a better place."

While going through treatment for her leukemia, Sheila was often part of a research study. She was never certain the research would actually help her, but knew it could help a lot of other people. "I was always part of a protocol somewhere along the line, and when things got dark, it was like, 'Oh well, even if this doesn't work, somebody's going to learn something, and maybe it will keep my kids from having to worry about it, or the next generation, or the next twenty years, or whatever.'" Being in research studies felt consistent with her life's career, teaching. "I am a show and tell if nothing else. I am an audiovisual. I am part of a study, and if anybody else has to go through this, maybe they will have learned something from what I am going through... Even if it doesn't work for me, then they'll know what not to do."

The social services department or the nurses at her local hospital often call upon Sheila to visit new patients. She believes that it helps other patients to see someone who has been "where they are and is still walking around." Sheila considers herself "a success story." Anytime she is asked to visit another patient she goes. "You put the lipstick on and you make sure your hair is combed, and you go in and say, 'Yea, you can get through this.' I mean I don't offer a diagnosis. I don't do

anything medical... It's just, 'This is what happened to me, and if you need to talk to somebody, give me a call.'”

Sheila sent the researcher a copy of a speech she had given at a conference for cancer caregivers. She always attends the conferences for survivors sponsored by a large south Texas cancer center. About these annual conferences, she makes the following observations:

You put a thousand cancer survivors in a hotel ballroom with a speaker, a motivational speaker – it's just an amazing thing! The speaker this year was Steve Allen... Dave Trivechy was the speaker one year. He was the one who had bone cancer, the major league pitcher. He threw a ball and on national TV you heard his arm break. George Foreman was the speaker one year... All kinds of really amazing people... all survivors!

Bert hopes to someday return the favors, prayers, and thoughts that have been given to him during the past five years with five major abdominal surgeries for recurrent liposarcomas. “I want to return the favors... and the prayers... and all the thoughts and hopes that everybody has given me over the last five years and even further back... those are very critical to me.”

Bert has intense feelings of needing and being needed by his family. “Not only do I need them, but they need me -- it is a two-way street -- I need them too.” Of his wife and four children, Bert says, “My family is still depending on me, and that is a major hold that I have.” This motivation “gets him going” everyday and is something he “does not want to lose.”

My family is still depending on me, and that is a major hold that I have... I just feel like if I am not here, that things will not run the way they should be run,

and that is probably a terrible statement, a terrible thing to say. [Name of his wife] is probably the most capable and strongest person whom I have known, and somewhat level headed. But I just feel like, you know, God gave her to me. He gave us four children, and my job is to take care of them, bottom line... That is a major motivator for me. It is that I either need or want to think that my family needs me. So as long as I think that... there is nothing that is going to keep me down!

Walter, in his seventies, is retired from medicine and spends a significant amount of time doing volunteer work, but not in the area of cancer. "We [he and his wife] work with the Open Arms church... It takes care of nothing but street people basically, and we get involved in collecting diapers and baby formulas, and mostly help take care of their children who come in." He and his wife "really keep them going with a lot of supplies... They had two hundred for Thanksgiving dinner, so we purchased five turkeys. And you have to keep up the grocery shopping."

Deana, also in her seventies, is a retired minister's wife. She has always been active in volunteer work, and started an Al-Anon group at her church a few years ago. This was related to experiences with one of her children who abused alcohol and drugs prior to his death five years ago. Her Al-Anon sponsor, living in another community, has been her main hope supportive person in dealing with cancer. Deana now takes care of her invalid husband, who has been bedfast at home for the past year. Once during her interview she had to stop and go check on him.

Karl was an active surgeon before developing metastatic cancer in his neck and bones. Since his diagnosis, over a year ago, going in to work and seeing patients has been a major hope supportive activity. As a member of a helping profession, he helps

himself through helping others.

Louis feels needed by his wife and two young children. Just before getting cancer, he had purchased a large amount of life insurance. Having planned ahead and obtained the life insurance gave him a sense that he had helped them and they would be okay if he did not survive.

Not to be morbid, but when I was sick, we had just not long before that incorporated the business. And I had added quite a bit of life insurance because I had a lot more obligations here at the business and wanted my family to be taken care of if I got run over by a train or something. I never really imagined getting a disease. But I did have some hope that, you know, God never came to me and said, "Hey, you are going to be fine." But I always felt like things were going to be okay for my family, and that whatever happened everything would still be okay... I just would not want to check out and leave a bunch of debt for them to deal with.

Besides being needed by his wife and young children, Louis felt needed by his business and his business partner, who also has cancer. "My business, knowing that we had a pretty good thing going over here, and that it was waiting on me... I mean, you know, they were not sitting around waiting on me, but there would be something for me to do, and there was a mission here for me to occupy." The surveying business is usually most busy in the spring and summer. With spring coming on and from the communication he had with his partner, Louis realized that there were lots of things needing to be done. This, and the fact that his partner would need surgery again and be out of the office, motivated Louis to get back to work when he was feeling depressed. "So, even though in my first month or two back, I felt depressed because I

just did not have the zip. I really wanted to be back, and when I got back, I did not feel like I could do anything, but the hope part was that ‘Hey, I need to get back.’”

Robin could not die because she was needed by her two children and her husband who also had cancer. “Of course, you think of family first, the children, you want to show them that there is a way to deal with things that can get you through.” The fact that her children were not grown yet, the “job was not finished yet,” gave her hope. “They were in school. They were in activities that I knew I always wanted to be part of. The two things I always wanted to be in life were a wife and a mother, and... being able to participate with them and all their activities... I definitely did not want that to be all over. The job was not finished!”

Pam felt needed by her pregnant daughter in Colorado who was due to deliver shortly after Pam’s breast cancer surgery.

In January, one of the reasons that I elected to have the mastectomy as opposed to the lumpectomy was all concerned with the fact that my daughter, my oldest daughter, was going to have a second child... She was having it in the home again, and the first one -- it all went real well, except that she has such big babies that when they delivered the placenta -- she is all placenta, and she hemorrhages, and it was so scary. I just simply felt that I had to be there, I really did. And so that was the primary reason that I chose to have the mastectomy and reconstruction, because if I had had the lumpectomy, I would be back here having radiation and could not be there.

Pam always talks with new cancer patients whenever she is asked to do so. She tries to encourage them and give them hope. This is not entirely pleasant for her because she tends to relive her own experiences. “There are just so many people, and you kind of re-live it with them whenever you talk to them, except that it is nice to be

able to give them hope... I am always available if anybody wants me to, and I will certainly be encouraging about it because that is what I think God wants us to be.”

Audrey had just had a baby when diagnosed with breast cancer. She also had a husband and four-year-old at home. It just “wasn’t in the plan” for her to be sick or worse to die. Her husband became angry about her cancer diagnosis and she said, “I was concerned about him.” Three years later, at the time of her interview, Audrey had become a Registered Nurse who worked with oncology patients. “Some of the doctors have even asked for me to talk to people, not as a nurse but as a person.” She says it helps her as well them to talk about her experiences as a patient.

The ability to reach out and help others evolves after the participant has dealt with their own situations. The support that they had received seemed to precipitate a desire to give back. The feeling of being needed to care for significant others, including pets and other patients, can become a major anchor on hope and the will to live on into the future.

Uplifting Thoughts

The second broad theme category that emerged from the data is titled “Uplifting Thoughts.” Participants consistently described certain thought patterns that helped them to be hopeful. This category is composed of five subcategories entitled Future Orientation, Short-Term Time Perspective, Comparative Thinking, Remembering Positive Role Models, and Creative Imagining. The five sub-themes are

described with appropriate illustrations of participant data and related research supporting each categorization.

Future Orientation

This theme covers thoughts about activities (trips, weddings, graduations) planned for the future and goals the person may have (building a business, starting a career, finishing a degree). Thinking of these upcoming goals, activities and events helped participants to stay hopeful. Thoughts of these seem to beckon the person forward into the future. These become reasons to live and reasons to avoid death. All fifteen participants talked about the future and contributed to this theme. Herth (1990b) found “attainable aims” a source of hope in all terminally ill participants. “Focusing on anticipated events” was identified as a source of hope in a study of sixty older adults living in community and institutional settings (Herth, 1993a).

Emily had several goals and activities she looked forward to seeing happen. One goal, already accomplished, was recalled from when she first became ill. She prayed to see her son graduate from high school, a goal he did accomplish. The other goal also involved her son and his future.

Well, the only goal I really have now is... I think everything in my life would be complete if my son had a wonderful woman in his life. I mean he wouldn't have to be married. He could be, that would be a good thing. But I'm not saying that I want him to be married because I'm ready for him to be married, because I don't think he's emotionally ready. He's twenty-three, but... he didn't start dating, he's very young, so I don't think he's really ready. But I would just like for him to have someone who adored him. That's what all mother's want, you know, you want your kids to have somebody that loves

them, respects them... It's not a goal for me, it's a goal for him, but it's something that would affect my life.

Emily thought about one upcoming event that was planned with her friend Angie. They were both looking forward to traveling to Montana in a few months for a national ovarian cancer survivors' retreat. In Emily's words, "Angie and I are going together...it should be a blast!" Angie was also looking forward to this event.

Without calling them goals, Angie listed several things she wanted "to live for." These included the new dream home she was building in the country, outside the large metropolitan area where she was living at the time. There were several places she wanted to visit before dying – Hawaii, Alaska, and Australia.

The things that I have to live for which are my new compound... my home in the country. There are some places I'd like to go before I die, which would be... I've never been to Hawaii. I've never been to Alaska. I've never been to Australia. I'd like to go to Australia. Australia's really the only country abroad that I'd like to go to because they're very health conscious, and I think the people would be interesting.

Angie had recently become aware of a political coalition, which advocates for increased funding of ovarian cancer research. Having a career in the field of media and communications, she feels she could be an effective speaker for that group. "If I survive, I want to be a loud voice for the N.O.C.C. [National Ovarian Cancer Coalition] and do seminars, or public appearances, or whatever representing the N.O.C.C. at conferences."

After listening to the examples above, the researcher said, "You've been telling me some things that you want to do in the future. So thinking about those things, is

that a source of hope? Angie replied, "Extreme source... goals." She went on to say that she didn't ever really sit down and make a list of her goals. But she always had them in her mind.

Goals... I wouldn't say that I was a real specific sit down and these are my goals and I'm gonna accomplish them... But I've always had goals in my mind that I wanted to do, and I've usually accomplished them. It may have taken me awhile, but usually, if I set a goal, and people say I'm very bull-headed and stubborn... If I want to do something badly enough, I get it done.

At the end of her interview, the researcher asked Angie if there was "anything else that you can think of about hope, that you could say?" Her last thought on hope was a goal that sounded more like a very remote dream. Never having been married, she thought the possibility of finding a husband might still happen.

I have kind of a funny one that I don't talk about a whole lot, but I would still like to think that someday I might meet someone and have a nice relationship -- a partner in life -- and I haven't done that yet, but I've not really put myself in a position to do that. But I'm certainly building a big enough house that if that happens it would be nice. But I don't have to have that; it's just kind of a little "probably won't happen" goal.

Marcia said explicitly that "thinking about the future" was a source of hope for her. At the time she was diagnosed with cancer, she was engaged to be married. Two days after she found out she had cancer, Marcia and her fiancé went to the cancer center to meet people and see educational videos. She remembers him saying to her, "We're going to get through this; we're going to get married and live to be old people." The time when her hope was as high as she could remember was after her

radiation therapy and four months before her intended marriage date. She did get married and was a happy newlywed at the time of her interview.

Focusing on his creative work helped Paul, an artist, to stay hopeful and able to tolerate the down times of chemotherapy. His mind was always thinking of images and future creations. "I've got paintings to paint!" He had a little "fire" of creativity he had to keep burning. "I had to still keep that little fire going because I knew that if this ever slowed down, I didn't want to have to start everything all over again... dealing with creativity... that's just all I know."

Maggy always plans ahead and thinks about the future. She does this to prepare for anticipated events and for the unforeseen. She shops frequently for hats and shoes, and even buying things she has "nothing to wear with" at the time. "I have these real pink shoes I have nothing to wear with, yet!"

I have my way that I see things, and I see things ahead. I think about not only what's happening now; but, okay, if we take this situation, let's take it to this step and see if this should happen, what do we need to do to prepare to be there? Or if this happened, what can we do? I think ahead and, therefore, I prepare ahead.

Sheila is cautiously optimistic about the future. At times she is troubled with graft versus host disease from her bone marrow transplant. She is teaching full-time and going to graduate school. "I am hopeful that I am going to finish my own degree... scared, but hopeful." When going through cancer treatment, Sheila was always part of a research study. She was never sure it would help her get well, but hoped it would help her children or the next generation. "Even if it doesn't work for

me, then they'll know what not to do... It could help somebody else." Sheila and several other participants expressed the hope that participation in this dissertation research study would help other people.

Holly had been thinking about her death, planning her funeral, and anticipating her family's grief. She did not say that this helped her feel hopeful, but denied these musings as a threat to her hope. She is not afraid of death and feels "it will be okay" whichever way she goes. The entire conversation surrounding this is included as follows:

Holly: Well there are times that I have thought that I may die, but I have not been that sick to let my mind go into that part. But I have even visualized my own funeral. I know what I'm going to wear. I have already told my family, I said, "If I die, I want you to put this on me."

Researcher: So you have told this to your family?

Holly: Yea. My husband knows the music that I want and everything, and I told him, I said, "If the Lord takes me, I don't want y'all to be sad because He needs me more than y'all do." I said, "I know that is hard to understand," and that is what I have always told them... "If I lost one of y'all, it would hurt too." I said, "But the Lord knows that I have lost my mother to brain cancer, and my grandparents, and you can see a person suffer so long, and then you're begging for Him to take them, and I don't want that."

Researcher: Planning your funeral and getting ready, is that something that helps you feel hopeful, or is that more of a threat?

Holly: It's not threatening because I feel like I am not that afraid of death. I used to be, but I am not anymore. I am comfortable with it one way or the other; whichever way I go, I know it is going to be okay.

A trip that Bert looks forward to every year is "going to the Colorado River with all of my family and our friends." This tradition "is getting better every year... It is a pretty important thing in my life."

Knowing that it means so much to so many, that it is really an important event. It, by far, outshines... pheasant hunting every year, but that is just a bunch of guys... which is fun, but it is not like it is... watching children catch fish... Every year it is getting better because there is something new happening. I guess I have never really sat down and thought about how important it is for me to go on this... we get so much enjoyment, and I learn so much. Every year, we say, we need to do this three times a year.

Walter and his wife look forward to trips with friends and members of their church, "Like next week, we are going to go down and see the lights of Fredericksburg." They especially enjoyed a large gospel choir that sang in Ft. Worth, Texas and hope they come within driving distance so they can go again. Walter's enthusiasm and enjoyment for this choir is evident in his description. "There must be sixty-five or seventy of them, a huge number of people who sing old southern gospel music, and they have all gotten together and formed a group that they call the Hour, and they sing all of these old gospel songs with some instrumental music and all, and I just go crazy over it."

Two years ago, when Deana and her daughter-in-law were out under a tree, they had a conversation about the future and Deana's assumed demise. The daughter-in-law said, "Oh, I don't know where we are going to go on holidays." Deana queried, "Are you speaking in the future? Are you speaking of my demise?" Her daughter-in-law said, "Yes." Deana replied, "Well, give me twenty years and then we'll talk about that." She laughed. Deana admitted to feeling hopeful whenever she is with her three-year-old grandson. She intends to see him graduate from college. "Well, I feel hopeful when I am with my three-year-old grandchild. I want to see him

graduate from college, and that could be awhile, but I will be here.”

Karl admits to being “sort of a Pollyanna about things.” He generally expects the future to work out positively for him.

I always figure things are going to work out, and I will be successful, and I do not really dwell too much on anything less than that. So I have been telling myself, for the most part, that this is a bad year, a bad two years, and we will get past it and then things will settle down and will be easy, fun, or light again and I will not be worried everyday.

Karl elaborated about spells of anxiety he experienced when unsure how long he had to live. During this time, he spent sleepless nights and walked around like a zombie. “It might last a few weeks sometimes before we got a plan together and knew what was going on and were not so anxious in anticipating what the news was going to be.” Getting a plan together helped him to feel better about the future.

Louis planned for the future in a way that made him feel more hopeful about his family’s future. He had obtained life insurance to protect his family just before getting cancer. This gave him peace of mind that they would be financially secure if anything happened to him. His family gave him something to live for and a desire to see his children grow up. “When I was ill and felt like it, I would eat supper at the supper table. We would always pray before we ate, and my kids would pray that Daddy would get well. And you find yourself crying while you are trying to eat supper, and I felt like I wanted to see them grow up and that I had a lot of things to live for.”

Louis looked forward to receiving get well cards and messages from a lady he didn't even know, who worked at his sister's church. When ill at home from chemotherapy, the prospect of receiving a card motivated him to walk out to his mailbox in hopes of finding one. "But that was a big boost for me just to go to the mailbox. I would walk everyday. Our mailbox is a long way from our house, and I would walk up there and would pretty much know when I was going to be getting a card."

Louis and his partner, Bert, were in the process of building a business when both developed cancer in their late thirties. Knowing he had this goal and a "mission" to accomplish helped get him to get out of a depression and back to work after he finished treatment.

I would say, being mister selfish business man, that my business, knowing that we had a pretty good thing going over here, and that it was waiting on me. I mean, you know, they were not sitting around waiting on me, but there would be something for me to do, and there was a mission here for me to occupy. So, our work is usually most busy in the spring and summer, and with spring coming and the communication I had with Bert was that there were lots of things coming in to be done. So, even though in my first month or two back, I felt depressed because I just did not have the zip. I really wanted to be back, and when I got back, I did not feel like I could do anything, but the hope part was that "Hey, I need to get back."

Robin had two things she always wanted to be in life – "a wife and a mother." When she developed cancer, these goals were incomplete. There were activities at her children's school she hoped to be a part of. "The job was not finished yet." It was important for Robin to be able "to participate with them and all their activities." She

“definitely did not want that to be over.” Her husband had cancer at the same time she did. She spoke most lovingly of his support of her. He is no longer alive to testify to all that she meant to him during his battle with cancer.

A scripture kept coming to Pam that she believed foretold her future – “that I was not going to die, but that I would be ‘living to declare the works of God’... And that stayed with me the whole time.” That was “probably the most helpful thing” increasing her hopefulness after the frightening diagnosis of cancer. After undergoing surgery she looked forward to a Christmas trip to visit her daughter and family. “Although the doctor was not so sure I should go... to Colorado Springs for Christmas, and the beauty of the snow and having my grandchildren all around me... that was very positive. I was looking forward to it as a time of recovering.”

When Audrey was diagnosed with cancer, she had an infant and a four-year-old at home. She was about to enter her last semester of nursing school, and was determined not to let cancer become an obstacle to achieving her goals. It helped Audrey to feel “normal” to continue with her regular schedule and plans for graduation.

I had my final semester... I found the lump the day before my critical care exam and, given the family history, I pretty well knew at that point. I did the exam... I had the biopsy. Then I had an excisional biopsy like on December nineteenth and said, “Okay, school starts back in January, and I can have surgery here, that gives me four weeks of recovery.” I had my calendar. I still have this thing. I had all the times listed out. I had assignments for the year. I had surgery on December 27. I had the drains and everything for a couple of weeks... Even when I had the drains, I had a wind suit and stuff, and I stuck them inside and went to the mall. I took it as something else I had to do. It was something else I put on my calendar that I had to do, and I guess I just wanted to be normal. I just went about my same stuff and started school back

at the end of January and had some healing and stuff to do. I did not get chemotherapy until the end of February. That was when the hair started falling out and that kind of stuff. It was like, “put it between reading Chapters 10 through 12 and getting blood drawn.” ... It was not going to get between me and what I wanted to do. It made me mad!

Having plans, activities, and goals to think about and work toward is clearly supportive of hope in this group. Looking forward to upcoming joys and milestones for self or family helped support hope and motivate participants to move forward into the future.

Short Term Time Perspective

Thinking more short term and less long term became a new thought pattern for several (six of fifteen) participants. Living “one day at a time” is a commonly heard axiom that takes on key meaning to those with cancer. Getting through a day sometimes becomes an effort to put one foot in front of the other, hour-by-hour, or moment-by-moment. Compressing or narrowing the future makes hoping easier in some difficult situations. A similar strategy was identified in Herth’s 1993b study of family caregivers of terminally ill. This category was described as “time refocusing,” or changing to a shorter term perspective on the future. In Seligman’s (1990) work on learned optimism, “finding temporary and specific causes for misfortune is the art of hope” (p.49). Suffering can be more easily endured when considered temporary.

Emily changed her perspective on time shortly after being diagnosed. Things were done “now” and not put off until later. She often wondered if she was doing some of her favorite things for the last time.

I remember when I was first diagnosed. Vegas was one of my very favorite places to go. I just love Vegas, and I would go and I'd say, "I wonder if this is the last time I'm gonna go?" Or Christmas time would come around, and I'd think, you know, "I may not be around this time next year," and after awhile, I'm thinking, you know, I have to do this.

Eight years later, at the time of her interview, Emily is still battling cancer. She had a reoccurrence six years ago. Her thinking is still short term, but she no longer speculates about the "last time" when doing things.

The last time I went to Vegas, that never crossed my mind. But there were a lot of times that I would focus on the short-term, you know, like "What am I going to do six months from now rather than six years from now." You do change, it's not like you don't have long-term goals, but you don't put a whole lot of emphasis on long-term. You work more for six months... I don't know that I plan two years from now.

Angie tries to remind herself "not to worry about the future and to enjoy today." She admits to the worth and the difficulty of "living one day at a time... good to do but sometimes hard." Angie was diagnosed twenty-two months before her interview and has been in continuous chemotherapy without achieving a remission. Sometimes her days are a matter of "just putting one foot in front of the other."

Paul has been dealing with various cancers and chemotherapies for twenty-two years. His time perspective has changed and he fully understands what "day-to-day" and "one day at a time" mean. He no longer thinks "too far ahead." As a result, "everything seems to be a little clearer."

You know... it's just a day-to-day deal. That was one thing that really was troubling. I had always thought out ahead too far. And I'd always... my mind, of course, that's the way my mind works, is to try to think maybe too far ahead. And now I don't think that far ahead, and it doesn't bother me. I

think maybe, I'm really fully understanding what day-to-day means... One day at a time definitely is something that has become more evident, and the definition of that is much more clear. Everything seems to be a little clearer for some reason or another.

Three other participants had changed their perspectives on time, similar to those above. Like Emily and Paul, Louis admits that cancer has given him a different perspective on things, "looking at things in the short-term versus the long-term." Deana tries to live her life by the Al-Anon philosophy. "You just plan on doing it one day at a time... living the rest of your life one day at a time."

Karl chooses to look at his difficulties as temporary, holding on to the idea that the past year of struggles with cancer was just a "bad year" and he would get past it. Karl, like Angie, "learned daily how to put one foot in front of the other." He often took things one "hour at a time" rather than one day at a time.

And I guess I have always been a patient, low-profile-type person. So I think that through the procedures, the chemotherapy, and the radiation... I just learned daily how to put one foot in front of the other and take it not just a day at a time, but an hour at a time. I think if I would have been a type A personality and involved in that or an anxious, impatient person, I do not know if I would have gotten through it. Some people do not get through it... I just had a lot of help.

The hope-influencing effect of this short term, one day at a time living seems to lie in removing worry for the future or thoughts of dying when that is not imminent. Enjoying the day becomes a pleasant end in itself, freeing one's self from worry about tomorrow. For some, just getting through the day seems more bearable than thinking

that suffering may continue indefinitely. Not putting important things off shows that the possibility decreased longevity has not been forgotten.

Comparative Thinking

This theme covers the cognitive efforts to compare one's present state or situation to a less favorable past or present state or situation. Comparisons were made relative to oneself and to other persons with cancer or other unfortunate circumstances. It seems that this strategy would be of only temporary benefit to remaining hopeful. Subjects for comparison must be available and less fortunate for this relative positivism to work. Hinds and Martin (1988) induced a similar theme in their grounded theory study of adolescents with cancer. They named this self-initiated strategy, "It could always be worse," defining it as "favorably comparing their situations with other possible health outcomes or situations of others" (p.337). Adolescents stated that the strategy had to be self initiated and did not work for them if suggested by another. A therapeutic factor identified by Yalom (1995), termed "universality," describes the recognition that one's problems are not unique and other people have problems also, sometimes more severe. Nine of the fifteen informants described thought patterns reflecting this category.

Emily uses comparative thinking to feel better about how she is doing relative to herself at other times and relative to other persons. Nothing has ever been as bad as the bone marrow transplant. Since that experience, all days are good by comparison. She visits elderly shut-ins, nursing home residents, and newly diagnosed ovarian

cancer patients, all of which help her to feel lucky about where she is today. Being around other people who don't have cancer helps take the focus off of herself and her own problems.

All my days are good, even the bad ones are good... because I can remember the bone marrow transplant and, you know, I used to just pray to die it was so awful... I just didn't think I could stand it because you're just so sick and so weak. It was just such a horrible experience that anything from that is up. I think you have to remember the bad to appreciate the good... I think most of my days are good. You know, if you think things are bad, you can get out there and find people that have things so much worse than you do. So if I have a pity party, I go down to [the medical center], or I see someone who is ninety-six years old in a nursing home, and her mind is still good, and she's thinking, "Why am I here left on this earth?" There are people that don't have anyone... that don't drive anymore... they're housebound... I think it helps if you look around and see other peoples' problems instead of focusing on "Oh poor me - I have this problem." I think being around other people that don't necessarily have cancer, but people who are lonely [helps].

Maggy compares how she feels today to where she was a year ago and feels a sense of accomplishment for what she's learned. "Even now, getting back into, into the rat race, you know, of the work. I keep thinking, 'This is where you were last year; we don't need to go back there. We need to learn.' I have learned what's important."

Sheila, a leukemia survivor, felt better about her lack of therapeutic choices, not having to make difficult decisions, compared to those persons with breast cancer.

I always emphasize with the breast cancer people, the survivors, when we go to [the cancer center] for these annual workshops and conferences. I don't know what I would do if they said to me, "Now you decide." The decision was basically either we try this, or see ya... we don't do anything, and you're going to die. And so I never had to decide, "Well, okay, do I want a lumpectomy or a radical mastectomy, or do I want both breasts or just one." I

never had to make those kinds of decisions... I can't imagine making those decisions.

Holly compares her probability of dying from cancer to dying suddenly of a "coronary." She admits to times of thinking, "Well, I have got cancer. That's a life-threatening disease, but... I could come to work, have a coronary, and die right there." Her mother died of brain cancer and she has colon cancer. Holly denies comparing herself to her mother, however, comparisons are made in spite of her assertion to the contrary. In some ways she feels better off than her mother, and in other respects similar.

Well, hers was a different kind. I don't really compare mine with my mother. Now, if it was in my head, I would, because hers had feelers. But now my colon cancer is a mass. But I had two positive lymph nodes, so that, to me, is almost like feelers, but they did get those out.... It has metastasized to the liver, so I know that there are feelers like in my body. But it's not to a main artery, like in her brain, so that messed her up. Mine... eventually, it may mess my body up.

Holly also compares her experiences with chemotherapy to those of other people she knows. She tolerated her treatments fairly well with minimal side effects, so her comparisons were favorable.

Well, like I said, at night, there were times that I would throw up. Of course, I had pills to take to keep me from doing that, and sometimes they worked and sometimes they did not, but I did okay. I feel like I did okay compared to what some people go through. Oh, I've seen people just turn colors, lose their hair, and everything, but I've seen them pull through it too.

Bert noticed other people with cancer and thought, "they have all the hope in the world, and they have serious health problems, serious health problems." Although

he said he would never do it, Bert went up to the children's ward at a large south Texas cancer center. "I went to the children's ward, and that opened up my eyes like nothing has ever opened my eyes." When he was hospitalized for twenty-three days and "unable to produce a daily function," he thought, "Big deal, you will be out of here in a few weeks or a few days, your body will come around... There are people who cannot produce a daily function."

After spending a very difficult period of receiving chemotherapy and radiation simultaneously, Karl said he would consider surgery rather than do that again. He called this dreaded combination a "silent enemy," but admitted his troubles were not the worst he had ever heard.

What I am talking about is not the worst thing that I hear... I hear other people have more of a problem and feel worse, and get sicker. So I kept telling myself, "Don't complain, it could be a lot worse," and I would get through it that way. I would see others and hear about others who just were not able to tolerate it.

Louis thought he had problems, but knew they could have been worse. His perspective was changed when he noticed a young child with cancer receiving chemotherapy at the same time he was. Similarly, Emily had noticed "a nineteen-year-old kid" who had a bone marrow transplant at the same time she did. "He died without ever having a chance to live." Louis spoke of his comparative thinking.

Everybody has got problems, and your problems are not the biggest problems in the world. They are big to you, but there are other people who are, you know... I would be in there getting chemotherapy feeling bad and feel like throwing up, or I threw up four times today, and thinking, "Man, poor me," and then you see a five year old with an I.V. sticking out of them, and they're

trying to play with an action figure. Their chances of living to ten years old may not be very good. And you have gotten to do and see a lot of things, and you are feeling sorry for yourself. It gives you a different perspective.

Pam had come home the morning of her interview “having been with my maid, my dear, dearest friend who is dying of abdominal cancer that has metastasized.” She had observed her friend in “terrible pain” and did not understand why she was suffering so much. Pam is grateful in comparison for not having suffered with her cancer. “I felt so helpless because all I could do was be there and pray for her, which I was happy to do, but it is a distressing thing... Anyway, it made me very grateful to know that I had not, my suffering was very minimal.”

Audrey, a Registered Nurse, worked in the field of oncology at the time of her interview. She had been diagnosed with breast cancer three years earlier while still a nursing student. Working with cancer patients every day, she compared her type of cancer with others, arriving at a hopeful perspective. “I mean cancer is awful, but people are seeing more people doing their treatments and their therapy and getting on with it. And not all cancer is the same... I mean breast cancer is not the same as pancreatic or something.”

Audrey’s mother, like Holly’s, had been diagnosed with cancer prior to her daughter. Holly’s mother did not survive her brain cancer. Audrey’s mother had survived many years after breast cancer. Audrey also has an aunt with the same diagnosis, still living. She compared herself favorably to her mother, calling her mother “a source of hope.”

My mom and I have talked a lot. She had surgery, and she had chemo, and I was like a senior in high school when that happened to her. And I remember being so involved in band, and cheerleading, and basketball. I did not really concentrate that much on what she was going through. She is a source of hope because she had nodes that were involved, and I did not, but she has done well.

Comparative thinking as a hopeful thought pattern was described by nearly two-thirds of the participants. Clearly it is a manner of looking at one's situation relative to another's or to one's own at a different time. In order for this to work favorably, the participant must be aware of someone less fortunate than self and/or must have shown personal improvement from the past. Otherwise, one's comparison might result in an unfavorable relative assessment.

Remembering Positive Role Models

Thinking of other people as role models who demonstrated desirable attitudes or behavior in dealing with adversity helped many (six of fifteen) participants stay hopeful. These role models were family members, friends, coworkers, nurses, and even the author of a book. A similar theme was induced in Hinds and Martin's 1988 study of adolescents with cancer. They termed this "Knowledge of Survivors," defined as "the extent to which adolescents seek information about other adolescents with similar health situations and who outlive the illness" (p. 338). "Imitative behavior" is a therapeutic factor identified by Yalom (1995), where persons model themselves after positive behaviors in others.

Angie thinks of her sister whenever faced with a difficult situation. “Whenever I feel helpless, I ask myself, ‘How would my sister deal with this.’” Angie also looked to her good friend Emily as a model for dealing with ovarian cancer in a positive way. Emily had visited her in the hospital when Angie was first diagnosed and they developed a close friendship. Angie described her friend very enthusiastically.

She is a nine-year survivor. She is always very hopeful. She accepts the cards that have been dealt to her, and she lives each day as fully as she possibly can. She says eventually the cancer will kill her, but she’s going to enjoy the time that she has. And they gave her six months to live. And she’s lived nine years, so that’s a powerful [emphatically] example. She never is down in the dumps really, unless she is physically feeling bad. She always has a positive attitude, and she is a fighter.

Three persons in Marcia’s life have influenced her sense of hopefulness positively – her mother, her maternal grandmother, and her maternal great grandmother. Her maternal great grandmother “lived up until she was ninety-two.” She was a “very positive go getter... and she was a prayer.” Praying is a behavior that has always been in her mother’s family. “That’s where I got it.”

The researcher asked Marcia to elaborate a little bit more about how her mother and her grandmother’s influence helped her to stay hopeful. Marcia replied, “Seeing what they’ve gone through in their lives, the way they’ve handled loss, and how they’ve been able to carry on with a very positive attitude regardless of what happened in their lives. You know, we’re not guaranteed anything, but we can make the most of what we have.” Marcia’s grandmother could “say a little word” that

would help her feel more hopeful. She gave the following example of her grandmother's future-oriented perspective. To Marcia, this example portrays hope.

It's just her way. I can call her on the phone, and before we get off the phone, I'll realize before I hang up, there she did it. She put that little word in there or a little sentence. And she's now eighty-seven. And I called her Sunday, and she said she and my grandfather had decided – here they'd made it to their sixty-eighth wedding anniversary, but they were going to shoot for their seventy-fifth. And she said, you know, "We just pray that God lets us be healthy enough so that we can see those days." To me, that's hope!

Marcia read a book that was especially meaningful to her. She spoke highly of the author, also a cancer patient. "Oh, this woman – it's wonderful she's written this book." When she heard the author had died, she remembered going to the restroom at work and crying. Then she thought, "That's life, but look what she contributed."

She wrote this book, and she gave me hope. She's given all these other people hope that read this book, and she died, but she had every kind of cancer that you can think of, but her book was so encouraging – how you've got to be positive, and you can't let yourself think that this is the end. You've got to keep fighting.

Sheila's role model of faith is her mother. This "amazing woman" has a lot to do with who Sheila has become as a person. "She's an amazing woman, and I think that has a lot to do with who I am. I am certain it does, and she has an amazing faith." Sheila mentioned that her father was developing Alzheimer's disease and this was becoming difficult for her mother. She expressed the hope that her mother's faith not be "shaken by this" and that she not "act depressed." It was as if she didn't want to see anything less than an idealized picture of her amazing role model. Allowing her mother to express negative feelings will be important in facing this challenge together.

Holly's coworkers have served as role models for handling losses. She has observed several coworkers who have lost loved ones. "And I have seen them cope with it, and I know what they have gone through, and it helps me." She appreciates the fact that they always tell her that she looks good and don't act like she's dying.

It lifts me up to think that they are not looking at me as Holly, "You're not going to be with us very long, or you are dying." I have never seen that in any of them... They always say positive things – that I look good. "You know, you don't even look like you're sick." So, I just say, "Thank you!" You know, and I just go about my day.

Bert's role models serve as examples for a future role he hopes to fulfill. He has carefully observed the behavior of his friends and a favorite deacon from his church when they have visited him during five hospitalizations and surgeries. He hopes someday to be "half as good as they" are at offering support. "I wish I could be a person who comes and sits by peoples' side and knows all the right things to say." In his eyes, these people are "saints." He aspires to have "like a small percentage of their ability because they are amazing people... the cream of the crop." Someday Bert wants to return the "prayers, thoughts, favors, and hopes" that have been given to him by these role models.

Audrey was a senior nursing student when going through chemotherapy after her diagnosis with breast cancer. Given this situation, it is not hard to understand why she paid special attention to the attitude of the nurses in the treatment room. "The nurses in the treatment room were great... They kept focusing on the future stuff, and that helped... They helped me. They were very future-oriented and very positive."

Several desirable characteristics observed in the role models were described by participants. These consisted of being hopeful, positive, future-oriented, empathetic, faithful, accepting, and encouraging. Coping well with loss or adversity and demonstrating a fighting spirit were also valued characteristics in role models. Role models gave participants examples of attitudes and behaviors to think about and after which to pattern their own responses to having cancer. Role models facilitate a learning process for dealing with adversity and inspiration for sagging spirits.

Creative Imagining

Participants engaged their creativity and imagination in support of hopefulness in several ways. Some practiced purposeful imagery to mentally attack the cancer in their bodies. Others utilized their creative talents in unique hope supportive ways. Nine of the fifteen described some type of creative activity as supporting hopefulness. Adolescents with cancer described a similar imaging strategy termed “looking forward to normalcy,” in which they visualized themselves as recovered and healthy (Hinds and Martin, 1988). “Envisioning hopeful images” was a strategy enhancing hopefulness identified in Herth’s 1993a study of older adults. Creativity is a “universal characteristic” of all self actualizing people observed by Maslow (1987). “There is no exception. Each one shows in one way or another a special kind of creativeness or originality or inventiveness” (p. 142).

Angie practices purposeful imagery while soaking in her bathtub, surrounded by lighted candles. She visualizes “a bright white light” going through her body from

head to toe knocking out cancer cells. This is more meaningful than the “Pac-man chewing up cancer cells” image that was suggested by a nurse. A naturally creative person, Angie had started a new job two years before developing cancer. She coaches television news anchors all over the country using her own unique, original methods. Her creative talents are currently being used to decorate her new dream home, in a manner she describes as “very different, very bright, very cheerful, very me.”

Paul is also a very creative person, who works as an artist and teacher. He clearly links creativity and healing. At the time of the interview, he was working on sculptures, but he also does paintings and other media. He talked about different images continually going through his head inspiring his art. Creativity is something that has developed over his lifetime. “I’m always trying to sharpen my skills and broaden the horizon of my creativity, so to speak.” He described “a river of creativity flowing through him” that was so full, he could only select a few pieces to work on.

The river of creativity that flows through me, so to speak, is so full that I choose a piece. I pick a piece out of the river, and I know there are some that are going to get by, but so be it. I will just have to take what I can and do with what I can, even though I see some of those floating around. There is just not enough time in life.

Paul described a profound connection between his healing and his creativity. He felt that “if the creativity part of my being was dammed up, or slowed down, or stopped, then the healing process just would slow down or stop... So I feel like there is a big connection between the creativity and the healing.”

I don't think there is anything that can stop me from healing as much as I can heal, at this point, because the creativity is so deeply entrenched. The thought process took a lifetime to get to a point where I feel like it is coming out of me so fast now... There is no negative thought process about that... It's coming out so fast now that the creativity is incredibly prolific. I don't have any fear about it... Sometimes it is like chopping through a jungle with a machete, sometimes it is floating calmly downstream...

Maggy's creative activities include decorating her multiple hats with a variety of sprayed on colors and coordinating bands. At the time of her interview, she had no hair due to chemotherapy and was known as the "hat lady" at work. She used a type of imagery at work when she became tired and needed a break. "If I felt tired, I would just rest and maybe daydream – take a 'mini vacation' in my mind. And I do that a lot of the time."

Sheila has creative abilities helpful to self as well as others. She has written about her cancer experiences and made speeches to large groups of patients at the south Texas cancer center where she attends annual workshops. She shared a speech that she wrote in 1993 for an American Cancer Society presentation entitled "Spirituality and Healing: Perspectives for Caregivers." An excerpt from her address is included here because it is about hope.

Spirituality is HOPE, not DESPAIR. The diagnosis of cancer was for too long reason for despair. So little hope could be offered. As you all know so well, there is a tremendous hope for nearly all cancer patients. And for those with a spiritual outlook, there is always hope in accepting God's will, even if it seems harsh. The patient who does not see himself or herself as a survivor from the very moment of diagnosis is denied the gift of HOPE.

Visualizing Christmas lights and angels outside on the hospital grounds became a pleasant reverie for Sheila when hospitalized during the Christmas season.

I kept getting put in [the hospital] for pneumonia at Christmas time when all the lights and all of those angels are outside the front door. They became something that I could think about. I couldn't see them, except if you went down the hall you could see them... But I saw them as I went in.

Holly's greatest source of hope was her "confidence in the Lord," something that keeps her going. This faith has roots in an earlier life experience of seeing the Spirit. "I just felt like the Lord was going to take care of me... because at one time in my life I have seen the Spirit, and I have confidence that he is watching over me." Holly did not elaborate about the details of this experience.

As a young adult, Robin had an experience similar to Holly's. She saw the image of God in a chapel while praying alone after a devastating experience. The memory of this vision supports her faith in God today as her major source of hope. Creative activities in which she regularly engages include playing the piano and stitching. "Of course, I stitch. I like to do needlework. That helps... That satisfies the creativity in me, I guess. I have always said that whatever talent I have, God put it in my fingers... playing the piano, or stitching."

Although a lot of people do not believe her, Deana is sometimes comforted by the perception that she can see an image of her son who died five years earlier. A book about life after death supports her notions about this. "I read Embraced by the Light... A lot of people said, "I don't believe it." It was about life after death... Well,

a lot of people have not believed it, but I like to believe that I can see him [son who died] standing there.” When asked if that image was helpful, she replied, “Yes. It was wonderful. It is all right if they did not want to believe it. I am not going to argue with them... I do not have any point to argue with that... It is like anything else, your own personal feelings.”

Writing in her journal is a creative activity that helps Deana to feel hopeful. “I think anytime you get your thoughts on paper it is helpful.” She read several entries from this journal during the interview, mainly about her feelings and reactions at the time of diagnosis and during treatment. The following excerpt is the first entry she read from her journal.

Monday and Tuesday – removal of fluid by aspirating – 60 cc on Monday, 55 cc on Tuesday, and 35 cc on Friday, and I still feel lousy. On Monday the 30th, I was getting cabin fever, so we went to [nearby city]. It is now Tuesday, I am having blood work in the hospital. I am waiting to see GYN for a Pap smear. I am feeling a little better today. I have no energy level. My non-breast is not a problem; in fact, I was stunned when I looked at it. It is just gone with a big scar across it. I thought it would be caved in and awful looking, but it is not. I feel a little better today – this is January 31st. I am at [the hospital]... My blood pressure is 179/61. Weight is 154 pounds. I have lost a few pounds. I am heavier than I have ever been at any time in my life. I am still filled with much gratitude for so many blessings. I will know on February 1 whether or not I will have chemotherapy or not. I want to live as long as possible without fear of returning cancer. I will do everything I am supposed to do.

Audrey and Karl, both health care professionals, have special images they visualize that are supportive of hope. Karl sometimes visualizes his body’s cancer cells being chewed up by his natural killer cells and white blood cells, similar to the Pac-

man image used by some cancer patients. Similar to Angie, Audrey imagines a white light sparking throughout her body and coming out purple. She created this image herself. “I had heard about people before who would imagine... Pac-man eating up the little cells.” Her healing image is much more colorful and innovative.

Another thing I used to do back when I was going through treatment, I would take a long bath, and I even did it in bed, or wherever – visualize stuff. People think that is all weird stuff, but I would see like this white light come in at the top of my head. And you know when things like spark? This light would go through my body, and when it would reach certain points, like it would spark. Like in the chest area, it was getting all the cancer. Like if there was anything in the lungs, it would spark a little there. Anything in my pelvis – it would spark a little there. It would do this all the way through and then come out my toes as this purple light.

The benefits and powers of creativity and imagery were many for this group – to fight cancer, to heal, to escape for pleasant mental mini vacations, and to connect to one’s God or loved ones now dead. Creative expression through music, art, writing, speaking, designing hats, or stitching needlepoint became means of self-expression and sometimes self understanding supportive of hope for these participants.

Sustaining Beliefs

The third broad theme category, Sustaining Beliefs, is composed of the many references participants made to a higher power, their religion, and spirituality. All fifteen expressed a belief in or made reference to God. The subcategories under Sustaining Beliefs are Faith, Prayer, and Sacred Writings and Rituals. These are powerful sources of hope, with eleven of fifteen ranking faith, prayer, or scriptures among their top three most important sources of hope overall.

There are many references linking hope and spirituality in the nursing research literature. Scores for the Spiritual Well-Being Scale (Ellison, 1983), an instrument measuring religious and existential well-being, have frequently been positively correlated with scores on hope scales (Carson et al., 1990; Mickley, Soeken, and Belcher, 1992; Mickley and Soeken, 1993; Fehring, Miller, and Shaw, 1997). One category of hope sources induced from data in Herth's (1990b) study of terminally ill adults was "Spiritual Base," found in ninety-three percent of participants. Using the same design with sixty older adults in community and institutional settings yielded a similar category, "Spiritual Beliefs and Practices" (Herth, 1993a).

Faith

Faith was almost exclusively expressed to be in God. One participant mentioned trusting physicians and nurses in addition to God. Synonyms of faith are trust and confidence (Devlin, 1987). Almost half (seven of fifteen) of the participants rated faith in God most highly in importance as a source of hope, both for the internal environment and overall. Besides gaining hope, outcomes of having faith included acceptance, peace, strength, and courage. Having faith in God increases morale, provides direction to life, and confidence that a higher power is in control and things will be okay no matter what. God is an entity with whom participants communicated via prayer. Eleven of the fifteen participants contributed data to this theme.

In Hind's and Martin's (1988) study of adolescents with cancer, a similar sub-theme under "Distraction," was identified as "God Will Take Care of Me," defined as

“the extent to which the adolescents remind themselves that a Greater Being exists and makes correct decisions about life” (p. 338). Patients indicating a “strong religious faith” had higher levels of hope and coping in Herth’s (1989) study of one hundred twenty adults undergoing chemotherapy. In a study of the process by which cancer patients search for meaning in life, respondents who renewed their faith in God and prayed for strength to endure threats received a sense of peace and hope (O’Conner et al., 1990).

When questioned about sources of hope in her life, Emily did not hesitate in saying, “I think my faith is the number one thing. I have a tremendous amount of faith, and I think the Lord’s in control of my life, and He will take me when it’s time but not a day before.” She expressed peace and no fear about death. She talked at length about prayer and religious activities covered in subsequent sections.

Paul, who has lived for twenty-two years battling a variety of cancers, shared an interesting perspective on faith as “spiritual” and hope as “human.” He expressed acceptance of God’s direction for his life, even if that included death.

To me, hope is more on the human side, and faith is more on the spiritual side. You have to watch what you’re hoping for, so to speak, because you may put yourself in a situation of creative myths that don’t really pan out. So I’m kind of allowing the hope side of it to be directed by the faith side, because I figure, you know, being a somewhat religious person, that if God has a direction for me then it is not for me to try to out think that situation. Sure, I’m always hopeful. But, you know, that may not be the direction God is... Like He may not want me to go much more.

When asked to tell about the most important thing that helps her to be hopeful, Maggy replied, "My faith in Jesus Christ is my most, is the most important because He is the one I turned to immediately... He's the one that gave me the strength to get through this... I couldn't get along like I have if I didn't have Him in my life." She had to "turn it over" to God in order to get over the shock of the "C" word. "It wasn't in my hands... And like I said, it took me a day and a half, and then I said, 'Okay... I can't do this. I can't do this,' and we turned it over to the Lord... He's done it all, and He's given me the strength to go on, and joke and cut up, and be my happy-go-lucky self." Her faith in God helped her to stay calm when facing her surgeries. "Calm and just matter of fact. I had every assurance that everything was going to be okay. I had no reservations, even though I got tired of waiting to go into surgery, and even when I came out. There's a peace, there's a real calming peace, and I've not been anxious." She discussed prayer at length as a means of communication with God.

Later in the interview when asked to rank the importance of sources of hope within herself, Maggy returned to her faith again with enthusiasm. Her faith is the number one hope-influencing factor in "self" as a category and overall in her life.

Absolutely... My faith in Jesus Christ. He is the healer... He can take care of things. He is the great physician. He can make decisions... I have every confidence that He is taking care of things and has done it. He is the one that keeps me calm... There's hope in every day... but honestly, my faith has been my strong point; from the get-go, it has been what has pulled me through this... Because there are times, even when you have family and friends and

other people around, it's that communication between me and the Lord, where he says, "Okay, it's okay," and then you feel it. You feel a real peace.

Sheila's faith helps her deal with the possibility of cancer reoccurring or of developing something else. Her faith makes the prospect of death easier to accept and the afterlife become "a better place."

I do not anticipate a recurrence, but that is still something that no matter how far out you are, every time you have an annual check-up, it's like "what if?"... I have a lot of acquaintances and people at [a large cancer center] who have developed something completely different than what they started with and have succumbed to it... The other half of that is, I think, my faith says, "Well, okay, so I die"... My kids are ready. They're on their own. Their lives are good. I've done what I can. From now on, they have to take care of it. I wouldn't want to leave my husband here by himself, but if that's got to be, that's part of what I was thinking even when I was going through treatment. It's like, I've done what I think I needed to do so far, and if this is it, then somebody will take care of him, and I'll be in a better place.

Sheila credited her mother, "an amazing woman," with having a lot to do with who she is as a person of faith. "She has an amazing faith, and I am sure that has something to do with who I am." Faith in God was the most common, but not the exclusive topic of participant discussions of faith. Sheila was the only participant who also spoke explicitly about having trust in her doctors and nurses. Trust is a synonym of faith. "There is a certain level of trust that you have the best doctors, and that they do know what they are doing, and the best nurses who are trained to take care of what is wrong with you and keep you safe."

Holly used the word "confidence," another synonym of faith, to describe her relationship with God. "I just feel like that day in the hospital when the doctor told me

that I had less than a year to live. I didn't feel like I had less than a year. I just felt like the Lord was going to take care of me, because at one time in my life I have seen the Spirit, and I have confidence that He is watching over me." She believes that "the Lord has a plan for everybody."

Walter gave up thoughts of living very long after his cancer diagnosis. He started going to church regularly and developed confidence in the minister and in Christian literature. "I had a lot of confidence in the minister, and so faith kept me going to a large extent, morale wise." Over the past couple of years his faith has "markedly increased" and greatly helped him to stay hopeful. When asked to say more about how his faith helped him to be hopeful, he replied as follows. "Well, it gives me a little bit of confidence in the Christian literature. To be truthful... anytime I have ever talked to a minister they have said, 'Well you are an agnostic.' Well, probably I was, but I have come around quite a bit since then. I think the faith has made me feel better." While explaining his faith to the researcher, Walter told the story of a friend's cancer that he felt illustrated divine intervention and reliance on faith.

Some things have occurred that I should probably tell you about. There is a member of our church, for example, who was perfectly normal and who went in for a routine physical and had a diagnosis, the bottom line was inoperable cancer of the lung. You know, just go to [the local hospital] and get some treatment and prepare for the worst, which was almost identical to what I went through... So she called me. She knew about me. She said, "Could I have that doctor who takes care of you?"... I said, "I will talk to him about it."... Well, he got his staff to call her at home... And he arranged to have this person seen right away... But the bottom line is that she has a malignancy, but it is a very slow-growing one that she can live with, like I have, almost for years maybe. Well, you see her now, and she was depressed before. You almost

have to calm her down. You almost feel like some things happen that must have a divine intervention. You'll never be able to prove it. You just have to have that faith, and that is where I stand with it.

Karl's faith has been helpful in supporting his hope, but has not protected him from all fears as it has in some of the other participants. Even though "I thought I had a lot of faith, I was surprised to see how frightened I was... When you are face to face with death, you do not want to go, and you want to stay around a lot longer." In thinking about the life-threatening nature of cancer, "believing in life after death has been an immense help."

Even though Louis feels, "I am not really as good of a Christian person as I should be," he does have faith. His faith gives him "a lot of hope," and more so than hope, he says a "confidence that everything will be all right one way or the other."

The first thing that came to Robin's mind when asked about sources of hope since her cancer diagnosis was faith. "My faith in God has always been a sustaining factor. I truly believe that He upholds me through all adversity and it is proven, it is proven that He has been there. This has been since I was a teenager, not just since the cancer. This has been kind of basic in my life." Throughout her life, through many types of adversity, her faith has been strong. Her faith is "just me... the basic daily life." At the end of Robin's interview, when asked about her greatest overall source of hope, her immediate response was, "my faith in God."

I had the strong faith that whatever came, my spirit and my soul, with the help of God, would get me through it... even if it was going to be painful maybe, maybe it hurt, maybe it was disappointing, even devastating, like losing [her

husband]. But I refuse to live in fear, and so I think that is something about me. I think because of that I... and I truly believe that good things can come out of bad, and again that is proven over and over... That no matter how bad the situation is, there is something there to hold on to – there is something positive. We might not wish that it had gone that way, but I know that I cannot change it, and so I deal with it.

Although never describing her beliefs as “faith,” Pam’s trust in God was evident throughout her interview. Initially very threatened by the prospect of cancer and surgery, Pam believed she had help from “the Holy Spirit,” putting hopeful thoughts and scriptures in her mind. One of the most important things that helped Pam stay hopeful was her concept of a good God, who created humans to be healthy.

I really believe it was the thoughts that went through my mind, and I believe that was the Holy Spirit reminding me of some of the scriptures... “I set before you this day, life and death, but I wish that you would choose life,” and after I made that choice, and I said, “God, I want to live. I choose life, and I choose you. Now, show me what to do.” ... I think probably the most important thing is my belief in the goodness of God. I believe God is a good God. I believe he created us to be healthy. I think our bodies as a whole, our immune systems, and that, have a wonderful, built-in healing method.

When asked to rank by importance the top three sources of hope from within herself, Pam had difficulty. First she said “scripture,” then shared the following thoughts.

I think it all kind of fits together. Prayer and the fact that God answers prayer, and the Holy Spirit is active in our lives, speaking to us and putting thoughts in our minds, bringing all things to our memories, such as different scriptures, plus I do not believe that anything is coincidence... Even though it may seem accidental or a coincidence, I believe that if you belong to God, and you have asked Jesus into your life to be your Lord and Savior, and have committed your life to Him, then nothing is coincidental... His hand is in it. That is a very encouraging thing.

Audrey never used the word “faith” per se during her interview. However, she said her most important source of hope since diagnosis with cancer was God. With mild amusement, she confessed her belief that “God talks to me through the radio.” She remembered different times throughout diagnosis and treatment, when she would think and feel things. Being a young wife, mother of an infant and a toddler, and a nursing student, she thought, “How am I going to do this?” While listening to the radio, “Things came on... that would be like, ‘Yes, you can.’” She would pray about concerns. “Then I have the radio on, and I can just switch it at a certain time, and there is a song that will come on that will be like an answer.”

Examples and testimonials regarding faith (trust or confidence) as a source of hope were given by the majority of participants. God was the most frequently mentioned object of faith; but doctors and nurses, a minister, and the Christian literature were also mentioned. “Faith in God” was ranked very high in importance as a source of hope – the single most important source overall for seven of the fifteen participants.

Prayer

All participants spoke of prayer as a source of hope. Some mentioned only their personal prayers, and others mentioned the prayers of other persons offered on their behalf. Many spoke of both personal and intercessory prayer as positive hope-influencing factors. Many different benefits of prayer were elucidated by participants. The examples of intercessory prayer, involving actions of other persons, might also

apply to results for the second research question. For coherence of participant perspectives on prayer, these data are presented together with personal self-initiated prayer. Dividing participant perspectives on prayer was felt to fragment the holistic view of this key hope-influencing strategy.

“Spiritual Base” was a category developed in Herth’s (1990b) study of terminally ill adults. “Praying and enlisting the prayers of others” were two specific practices identified by participants, one of whom said “prayers lift me up when I need comfort” (p. 1255). Larry Dossey, a physician and author of Healing Words (1993), reviewed many research studies on the benefits of prayer and has personally observed many patients “improve dramatically following prayer” (p. 9). Hafen et al. (1992) reviewed research on prayer pointing to benefits such as feeling better, relaxation, and healing – “...prayer, as an expression of spirituality, can work in concert with medical treatment to bring about physiological changes and recoveries” (p. 387).

Emily does do “a lot of prayer” and has “really long talks with God.” She feels that she has as direct a connection to God as anyone else, lay or clergy. She does not necessarily need anyone “praying over her.” She prays for other persons beside herself. Emily believes that God answers her prayers, but not always in the manner she wishes.

I just have really long talks with God, and I just feel like he answers my prayers. He may not answer them the way I want them to be answered, but I know that he hears every prayer that I say... whether it’s for me, my son, Angie, or anybody else. You know... I don’t think anybody has a more direct line than I do... There are people that think other people can pray over you

and all this, and I don't believe that. I believe that my line...God hears my prayers just as well as he hears a minister's prayers, or anybody else's.

Angie also prays herself, but, more importantly, she appreciates the prayers of others on her behalf. The chaplain who has visited her on numerous occasions in the hospital says "wonderful prayers" whenever Angie is hospitalized. Angie is aware of at least two churches in different communities whose members pray for her. Her neighbors, friends, and family members pray regularly for her health. Angie says little "mantras" which help her to feel less anxious during frightening times. "I do pray and I have little mantras when I'm feeling really bad or anxious. You go through periods where you get really anxious about what's going to happen to you, so there are little prayers, mantras that you say over and over to yourself." These consist of repeating the same phrase, such as "I'm at peace, God is in control," while in a meditative state.

"I pray a lot" was one response from Marcia, when questioned about sources of hope from within herself. "I think just the fact that I've prayed so much of my adult life... I'm sitting here today, and I've been through so much adversity with the divorce and then, on top of all that, with the cancer. I just believe in prayer." Her mother and grandmother set examples of "praying persons" for her.

Paul did not mention prayer during his initial interview, although he did talk about faith and accepting God's direction for his life. During a follow-up telephone conversation, he said, "Prayer and meditation are very much a part of my faith. Prayer is something I do all the time!"

Maggy, whose number one overall source of hope is her “faith in Jesus Christ,” prays “everyday, almost all day” for herself and others. “He is the one that keeps me calm.” She prays more often during times of adversity, as during her cancer experience. “I probably talk to Him a whole lot more. We always do when trouble comes along. I have talked a lot to Him... I’m trying to learn to listen to Him.” She is comforted by the prayers of “people all over the state” and “all over the world.”

I have my brother and his wife over in Indonesia... I have people in Oregon praying. It’s amazing... even the housekeepers have told me that they’ve shared my name with the prayer chain of their churches... It’s amazing, the prayer support that I’ve been able to get... I don’t know why I’m so blessed, but I am, I feel it; you know, I really do... I pray everyday... almost all day... It may not be for me that I pray. Something may happen, and I’ll just, I shoot these little quickie prayers up. But, yes, we talk to each other on the way to work. We talk to each other on the way home. We talk to each other... Well, He listens to me, let’s put it that way. I try to do some listening, but I do a lot of talking too, but I know that He’s the one... [tearfully]... He’s the one that gave me the strength to get through this.

Praying with her mother in the hospital was a regular practice for Sheila. Whenever she was hospitalized for leukemia, pneumonia, or the bone marrow transplant, her mother came from another state and stayed with her. She “was there everyday in my hospital room... and praying with me was part of it.” Her mother was Sheila’s role model of “amazing faith.”

Holly developed colon cancer a few years after her mother died of brain cancer. Holly declared, “I pray a lot.” Praying and talking to her deceased mother is something that helps Holly to be hopeful and gives her reassurance. “I talk to her. I pray to her, and I keep pictures around. And then I feel her talking to me saying, ‘It’s

going to be okay... you're going to be okay.” In her prayers she tells the Lord, “My place is with you and serving you.”

When asked by the researcher to tell about the first thing that came to mind as a source of hope, Bert's thought was of prayer. Especially during hospitalization, prayer is a "place to go... to be close to God." He believes he owes his life to healing prayers. "I truly believe that I would not be here today without the healing prayers that I have had."

Prayer is not something that you do whenever you are in the hospital. It is something that you do everyday. But it seems like when you are in the hospital, and there is nobody else there – it is a place to go. It is a place for me. I can visit very frequently during that time... During a normal day, like today, I may pray twice as opposed to being in a hospital bed, and the complications and things like that, and it is really getting you down... People are coming in with encouragement and prayer, and that is probably number one, to be close to God and to understand... what He is doing in my life... That is the first thing that comes to my mind.

Churches in several central Texas cities keep Walter on their "prayer lists." Of this prayer support, he reflected, "Well, that is the most I can hope for. I have good friends who are praying for me and maybe it can be of help." He recalled one incident of suffering a severe abscess in his neck that had to be drained surgically. On the way to surgery, he recalled the pain being so unbearable that he prayed to die in surgery to end his suffering. Walter did not die and gained relief through the surgery, for which he was exceedingly grateful.

I can remember this so well... When I was going down the hallway to the operating room, I knew I was going to go to sleep. I was already beginning to feel it, and [wife] was with me. I took off my wedding ring because my fingers

had gotten... I had lost so much weight that I was afraid it would drop off... I was praying to myself, "I hope I don't ever wake up. I don't want to go through this any more."

Deana talked during her interview of learning the prayers of Al-Anon while going through her cancer treatment. Two were especially meaningful and she read them from the journal she had kept at the time. The purposes of these prayers were to "improve our conscious contact with God as we understand Him... and for knowledge of His will for us and the power to carry that out." Of humans in general, she said, "We tend to follow our own likes. We want to do it like we want to do it."

Third-step prayer: To God I open myself to Thee to deal with me and to do with me as Thou wilt. Release me of the bondage of self that I may better do Thy will. Take away my difficulties that I may openly bear witness to those I would have of Thy power, Thy love, and Thy way of life. May I do Thy will in all things. Fourth-step prayer: God is my creator. I am now willing to choose good over bad. I pray that you now remove from me every single defect of character which stands in the way of my usefulness to you. Grant me strength as I go out from here to do your duty. Amen.

Karl prays consistently every day to remain hopeful. He admits to praying more at this time of facing a life-threatening illness. Saying the daily Rosary brings comfort and peace when he feels frightened, anxious and depressed. The prayers of other people around the country lift him up in a "sea of prayer."

Well, everything goes hand in hand, but I suspect that the thing that I do consistently and daily, several times a day, to remain hopeful is prayer. Your prayer life expands rapidly when you are faced with your own mortality. The prayers that I say, even though they are my own made up prayers, have become the same day after day and night after night. I try to pray for other things and other people, and then toward the end try to sneak in a good word for myself... It is interesting how the daily Rosary has been a source of comfort even at very frightening, anxious, depressed times. I could easily gain

some peace and comfort through that approach. And I have to say that the prayers of my family and friends... like the priest told me, it sounded like I was in a "sea of prayer." Not just this town or this state but churches and other denominations in other states have learned through the grapevine and have been praying. So, I have to feel bolstered by those things. Of course, every week at mass we pray for the sick, and I am still on that prayer list.

Louis said that during cancer treatment, "I did pray a lot and my faith gave me a lot of hope." God never came to Louis and said, "Hey, you are going to be fine," but he always felt like things were going to be okay for his family, and that "whatever happened everything would still be okay." He acquired a special friend at another church, referred to as the "note card lady," who assured him that her church was praying for him. Feeling somewhat neglected by his church, this lady's weekly notes and intercessory prayers helped him a great deal. His two small children prayed for his health at mealtime.

"Faith in God" was the first thing Robin thought of as a source of hope in her life. Prayer, daily devotionals, and regular church attendance have been "basics in her life" since before she had cancer. She told the story of praying alone in a chapel after what she described as a "devastating experience," that happened when she was a young adult. While kneeling at the altar in prayer, she believed she saw the image of God, and received His reassurance that she would be okay. The memory of this appearance and assurance has stayed with her for more than thirty years.

Prayer brings Pam hope, encouragement, and answers. She belongs to a prayer group that meets every Monday morning. During her cancer diagnosis and

treatment, she “prayed all the time.” One thing she prayed for initially was that she would have a miracle healing and avoid surgery. “I did hold out for awhile... that I would have a miracle healing and not have to have the surgery.” A few “strange things” happened that made her feel that she “was really going to have to go through the surgery.” A believer in miracles, she did not understand “why I did not have a miracle, but I guess that is the sovereignty of God.” She began to prepare for surgery, but continued to pray that her tumor would dissolve and go away. Amazingly, it had decreased in size by the time of surgery.

What I needed to do was prepare, plus I wanted to have some time for praying... so that maybe it would dissolve and go away. It dissolved some, which was amazing to the doctors, but it did not go away... Originally... six different doctors agreed that it was between 4.5 and 5 centimeters. But, actually, when they took it out, they were amazed. It was only 3, ... which was an amazing thing, and they had no explanation for it. I did, but they did not. Whether they thought I was crazy or not, I do not know, but they were very kind, very nice.

Pam believes that God answers her prayers. Prayers answered resulted in her feeling calm and not fearful going into surgery. “That was one of the things I did ask the Lord before I went, that He would give them [caregivers] guiding wisdom that they would speak to me the things that I needed to hear and nothing else.” She believed that was why she never heard anything fearful from her caregivers before surgery. Two physicians prayed with her. The radiologist “asked me if I would like prayer, and he prayed with me, and then my primary physician, who is a good friend, prayed with me. I felt very, very good about that.”

Pam felt “really poorly” for several months after surgery. “I did not know why I felt so bad... this went on too long.” Around March, she “bowed her face before the Lord” and prayed to discover what was missing and what she needed to do about it. “Almost instantly, the very same afternoon,” she found, through a friend, a tape about the body needing vitamins and supplemental minerals. “I began, for the first time in my life, to take vitamins. I began to take supplemental minerals, and I went around looking for specific nutrition books.” She began to feel much better and has continued the vitamin and mineral supplements that started as a result of prayer.

When Audrey prays about things, she often receives the answer while listening to her radio. She and her husband joke about “God speaking to her through the radio.” However, this positive factor was among the top three in her ranking of sources of hope by importance.

I can pray about things...Then I have the radio on, and then I can just switch it at a certain time, and there is a song that will come on that will be like an answer. My husband thinks I am crazy, but that is my way that I do things. And I can remember different times throughout my diagnosis and chemo and stuff, thinking things and feeling things and thinking, “How am I going to do this?” And having things come on the radio that would be like, “Yes, you can.”

Prayer was a means for participants to communicate with, feel connected to, and achieve closeness with God. Through prayer, participants gained strength, relaxation, comfort, peace, direction, and knowledge. Healing prayers increased longevity, shrunk tumors, and brought serenity to troubled spirits. Receiving reassurance from God that “everything would be okay one way or the other” sounds

very much like an open door for hope. Clearly, prayer is something consistently linked to hope by those dealing with adversity such as cancer. All fifteen participants in this study relied upon this self-strategy to help themselves stay hopeful.

Sacred Writings and Rituals

Religious writings and rituals is a theme comprised of church membership and attendance, singing hymns, devotionals, church outreach activities, taking communion, seeking confession and reconciliation, and reading and/or remembering sacred writings and scriptures. Prayer might have been included here, but due to its size, was placed in a separate theme category. Nine of fifteen participants contributed to this theme category. “Listening to spiritual music... participating in religious activities... and visiting members and leaders of their spiritual community” (p. 1255) were hope supportive practices identified by Herth (1990b). Frequent attendance at worship services was associated with higher hope scores in a study by Vandercreek et al. (1994). Seventy-four percent of participants in the study by O’Conner et al. (1990) said God was always influencing their lives regardless of church attendance. Spiritual beliefs and practices (praying, Bible reading, listening to spiritual music, thinking of favorite quotations, and attending church) were described as sources of hope by Herth (1993a) in a study of sixty older adults in community and institutional settings.

There were five different religious preferences given by participants in the demographic data section. Of these, there were six Methodists, four Baptists, three Catholics, one Lutheran, and one Bible church member. Twelve stated they were

members of a particular church group and three denied church membership. Regarding attendance, eleven claimed “regular,” three said “irregular,” and one said “none... oh, twice a year.”

Emily attends church every week, visits “shut-ins” for her church, and prays frequently. She quoted part of the Bible during her interview when talking about God’s control of her mortality. “The Lord’s in control of my life, and He will take me when it’s time, but not a day before. Whether it’s the cancer, a heart attack, or a truck hitting me, you know... the Bible says it, ‘your days are numbered,’ and so we don’t know.” For over six years, she has been in continuous treatment for advanced ovarian cancer and states, “I don’t fear death.”

Marcia referred to a Bible verse she had learned which helped her to gain hope and strength for enduring cancer treatment. She quoted Philippians 4:13, “I can do all things through Him that strengthens me.” She expressed the need to think positively in order to have positive things to happen in her life. “I don’t allow negative thoughts.” However, when a negative thought did occur, one strategy she used was Bible reading. “I read the Bible a lot last year. I’ve probably always been a Bible reader, but I think last year I probably read it more. If I thought, if I allowed a negative thought to come into my mind, I would – if I couldn’t think of something positive – I would go pick up my Bible and just open it and look.”

Later on the day of her interview, Maggy sent a follow-up e-mail message to the researcher. The purpose was to provide two meaningful scriptures, helpful in lifting her spirits and renewing her strength. The e-mail message is as follows:

I did forget to give you the two scriptures that have been and continue to be an inspiration to me. Sometimes at night when I couldn't sleep I would repeat over and over in my mind, "I can do all things through Christ who strengthens me." The other verse is Isaiah 40:31, "But they that wait upon the Lord shall renew their strength; they shall mount up with wings as eagles; they shall run, and not be weary; and they shall walk and not faint." When I do feel down a little, I repeat these verses and my strength is new again. Thank you for coming over and allowing me to share my experiences with you. I do hope what I said will be of help to others.

Holly always plays religious music tapes in her car while going to and from work. She usually sings along with the music. "The Old Rugged Cross" was one example she gave. Holly remembers scriptures such as "I can do everything and anything with the help of Jesus." Thinking of this gives her confidence in dealing with cancer. "I always say 'I can do this with His help,' and I repeat that frequently."

"Going to mass... being in church" was emphasized by Bert as something that helps him to feel hopeful.

Going to mass... this is the individual time... What I want to do with my time is give it to God... This is God's time to reach you in His house, and you need to give Him your undivided attention. So, I guess, when I am at mass, taking part in it on an individual basis... it is time to be at peace with myself and try to concentrate... To me, what I have been through and what I have seen, you have to do it... you have to... You have to be a little bit selfish and take the time. I do not think that it is selfish, but in a way it is. I want my own time.

Bert shared much about being in church with his wife and children. He wouldn't go without them, but four young children often interfere with his ability to

focus and concentrate. After listening to his many thoughts about being in church, the researcher concluded, “You feel hopeful in mass?” Bert’s immediate reply was, “Exactly... one hundred percent.”

During the early months following his cancer diagnosis, Walter “had taken up going to church every week.” In his mind he had “given up as far as any significant length of living” and church became “very helpful” to him. He joined a Bible study group because “I had a lot of doubts about religion.” Discussions in this group helped by allowing him to voice his doubts and hear other people’s opinions. Walter and his wife became more active in volunteer outreach activities through their church. “We are involved in a lot of extracurricular church activities... and we work with the Open Arms Church... It takes care of nothing but street people basically, and we get involved in collecting diapers and baby formulas, and mostly help take care of their children who come in... We do a great deal for them.” Walter stated that he no longer read books or journals about medicine (from which he is retired), but talked excitedly about several books he had read about Bible characters.

Just recently, I read a book on Joseph. I read a book on David... It is supposed to be direct quotations of Jesus... It is done by a bunch of theologians at the University Hospital and, much to my amazement, only fifteen to twenty percent are absolutely certain that this is a direct quotation... The red-letter edition, they thought, was most accurate with the quotations by a guy named Thomas, not the doubting Thomas... who is supposed to be a brother of Jesus... My son brought me a book for my birthday, and I have read everything about Thomas now.

During the anxious, uncertain time before his first cancer surgery, Karl went to visit the young priest at his church. He hoped to achieve a maximum “state of grace” through the traditional comforting rituals of his Catholic faith. He said to the priest, “I am looking at fifteen to twenty hours of surgery and do not know what is going to happen. I do not really want to go into it in any less a state of grace than I can.” To achieve this end, Karl was interested in “confession, reconciliation, and communion” before his surgery.

After his cancer was diagnosed, Karl was unable to work. He was confined to home during chemotherapy and radiation treatment. During this time, he read voraciously, “primarily inspirational books.” He could not concentrate on any type of literature other than “books that were written about how to cope, how to make God more a part of your daily life, and how to gain hope and peace, and even joy during trying times.”

Staying active in her church, attending regularly, and praying have been important religious activities in Robin’s life since before she was diagnosed with cancer. All of these habits, plus “daily devotionals” and just “being in church” help her to remain hopeful.

During the first twenty minutes after finding out she had cancer, Pam thought of scriptures about choosing life over death.

For about twenty minutes until I finally just stopped my own sniffing and crying... I felt it was the Holy Spirit telling me, giving me some scriptures on... Well, “choose this day you have before you set life and death. I hope

you choose life,” and then I began to calm down and get more peaceful... This scripture kept coming to me... it is in the Psalms. I will have to look it up, but it is, “that I would not die, but I would live and declare the works of God,” and that stayed with me the whole time.

When asked by the researcher to think of her most important source of hope, Pam replied, “I think the scriptures.” She did not elaborate, merely stating, “I think what the scripture has to say about who we are in Christ Jesus and what God desires for us is the most hopeful and helpful of all.” Her second most important source was “the comfort one feels in prayer, peace of mind and comfort.” Third was participating in communion, a ritual that has increased in frequency since she developed cancer. This activity helps her to feel cleansed and whole.

And I did not mention taking communion, but I think taking communion is a wonderful opportunity too. I call it “getting cleaned up and getting rid of the toxic poisons in your mind and in your spirit,” and I think that affects your body too. And I think it is also a wonderful opportunity after you do that then to reach out and receive the wholeness that Christ came to bring us. So I would say communion. That increased ever since I have had cancer, I have increased my participation in communion.

Besides hope itself, other helpful outcomes from religious practices, rituals and writings were inspiration, confidence, grace, peace, joy, strength, cleansing, and comfort. For some participants, these faith-based activities had been lifelong habits and for others, cancer was the precipitating factor in their emergence.

Self Care

The fourth and final theme category of positive hope-influencing factors from the internal environment is broadly referred to as Self Care. Five subcategories were

identified from participant data. These included Educating Self, Work and Career, Self Protection and Maintenance, Self Restoration, and Feeling Good/Asymptomatic. Although many involve interaction with the external environment (human or non-human), the motivation and impetus for engaging in these comes from within the self. “Self Care” is a major concept in the nursing theory Modeling and Role Modeling (Erickson et al., 1983) that has provided theoretical orientation and methodological guidance for this study. Data supporting this broad theme validate the MRM concept known as “Self Care: Knowledge, Resources, and Action” defined by Erickson et al. (1983) as follows:

At some level a person knows what has made him or her sick, lessened his or her effectiveness, or interfered with his or her growth. The person also knows what will make him or her well, optimize his or her effectiveness or fulfillment (given circumstances), or promote his or her growth. We call this *self-care knowledge*. *Self-care resources* are two-fold, internal and external. *Self-care action* is the development and utilization of self-care knowledge and self-care resources. Through self-care action the individual mobilizes internal resources and acquires additional resources that will help the individual gain, maintain, and promote an optimal level of holistic health (p. 48).

Participants demonstrated self care in a variety of ways, some very unique and some shared by others. Outcomes of self-care behaviors were increased knowledge, basic need satisfactions (comfort, security, activity, relaxation), joy, fun, and energy. Purpose and self-actualization were often achieved through self-care activities.

Educating Self

Eleven of the fifteen participants discussed some type of learning as a positive hope-influencing factor. Most accomplished this by solitary reading, but some learned

in support groups and by asking questions of their health care providers. Reading was the most commonly mentioned method of learning. Other benefits of reading are also included here, such as distraction. For a few, the Internet was informative. Books written by authors with cancer were especially popular and supportive of hope. Seeing how authors with cancer dealt with adversity helped many. Self-understanding was gained when participants identified with authors. Power, control, and increased involvement in the treatment process were common benefits of increased knowledge. Nutrition was a frequently mentioned topic of information seeking. Many learned how to cope with cancer more effectively. Increased interest in studying religion was evident among several participants, especially the two physicians. Besides increased hope, benefits of this avenue of inquiry included inspiration, peace and learning life lessons. Some learned what was really important in life through their cancer experience.

Previous nursing research on hope (Piazza et al., 1991) found higher levels of education were associated with higher levels of hope. Education was found to be a significant predictor of hope. "Personal knowledge and wisdom" were described as supportive of hope in the study of cancer patients' search for meaning in life by O'Conner et al. (1990). According to Maslow (1987), it is not necessarily formal education that teaches great lessons, all of life is education. In the "Afterward" to Motivation and Personality, Cox (1987) has written of Maslow's perspectives on education and the transformative power of illness:

For Maslow, learning was in some way relevant to all of the human needs. Learning involves not merely the acquisition of data and facts, but the holistic reintegration of the individual, continually producing changes in self-image, feeling, behavior, and relationship to the environment. He viewed education as occurring during the entire span of life, and not confined to the classroom... Illness is potentially transformative because it can cause a sudden shift in values, an awakening. Many people have begun to take responsibility for their own wellness. Self help books on diet, nutrition, exercise and stress reduction have become best sellers (p. 253, 259).

Emily did not discuss learning at length, but has read “a lot of books about cancer.” The context of her statement was a discussion of losses (death, divorce, ending relationships) that often precede the onset of cancer. Her doctor had asked what happened to her in the year before onset of her cancer. Emily had lost a significant relationship with a man she had hoped to spend the rest of her life with. She has since read about this link between loss and cancer in several books.

Angie does not learn as much by reading as she does by asking questions. She expresses the opinion that all cancer patients do not want to know all the details as she now does. There was an earlier time when initially diagnosed that Angie rejected all books, pamphlets, and written instructions, depending upon caregivers to verbally communicate essential information. This validates well-known nursing principles that methods of learning and timing of instruction are important variables in client learning. Clients will not learn until they are ready. Angie now considers herself somewhat of an expert about ovarian cancer. She and Emily both ask many questions of their oncology physicians, the office nurses, and chemotherapy nurses.

I guess my own communication skills make me feel like I have some control because I'm not afraid to ask questions. I'm more of a cancer patient that wants to know. Many of them don't want to know... Well, I have an innate curiosity, so I want to know. I want to know what it looks like, how far it's gone. I just want to know specifics... I've learned a lot about ovarian cancer. I get a monthly newsletter called "Conversations." I have collected quite a little library of books and booklets. People in my support group get a lot of information off the Internet. I get a lot by word-of-mouth at support group.

Marcia, a library technician, has read several types of books in the past year since being diagnosed with breast cancer. One book in particular gave her hope and grief when she learned of the author's death. Attachment to an author and her book can facilitate the hoping process.

I read quite a bit last year. There's one book that someone gave me, and I read... and I found out in April that this woman had died, and so I went to the restroom... and I remember crying... but then I thought, "look what she contributed." She wrote this book, and she gave me hope. She's given all these other people hope that read this book, and she died, but she had every kind of cancer that you can think of. Her book was so encouraging... how you've got to be positive, and you can't let yourself think that this is the end. You've got to keep fighting...

Sometimes Marcia found herself reading three different types of books at the same time. Other participants expressed difficulty concentrating on fiction books, but for Marcia, they were a distraction and helped her get outside of herself when she needed to do that.

I read, not only the Bible, but a lot of different kinds of books. There were times when I just read a fiction book just to get myself out of me, not think about me. Before last year, I would start a book, and I would finish it before I started another one. Last year, I noticed that I might be reading three books at one time. I might have a fiction book over here. I might have a religious book over here, and I might have a cancer book over here... I was reading them all at once, and I think it was the way I might be feeling.

Maggy did not talk about reading or studying about cancer, but reflected upon a different kind of learning that had happened for her in the past year since developing cancer. Mainly, she has learned what is important in life, not to worry and to be grateful for every day.

I keep thinking, "This is where you were last year; we don't need to go back there. We need to learn." I have learned what's important. I have learned to be grateful for everyday. I have learned not to worry. I used to be the biggest worrier. Now, if I cannot fix it and worrying is not going to help it, I'm not going to worry about it because I don't need to have that extra burden. I have learned a whole lot, and I'm sorry that it took this to get my attention, but I have learned just a whole lot through that.

For Sheila, "Information is power!" Over the past ten years of dealing with leukemia, bone marrow transplant, and graft versus host disease (G.V.H.), she has read many books about cancer and coping with adversity. Being informed has helped her in decision-making about her treatments. Reading the galley proofs for one book, written by a physician with cancer, was a "privilege" for her. Sheila has recognized herself in some books, and feels that learning about herself is an added benefit of reading, in addition to the power factor.

Information is power and that was an important part of what I was dealing with... Wendy Harphan has a book, Life After Cancer, which is excellent. I had the privilege of reading the galley proofs from that at one point, and she asked me to read through it. She was one of the first ones to talk about fatigue as a legitimate post-cancer reality, not just in your head... There is something physiological going on... She is a doctor herself... She contracted cancer and went through all of this... So I did a lot of reading, a lot! I still do a lot of reading... I have got one book that I picked up three weeks ago called the Survivor Personality and another one, called the Adversity Quotient [about] how you handle adversity.

The tenacity in her voice was obvious when Sheila described her quest for information. With persistence, she asked her physician for articles to read and studied about all the proposed and possible treatments. Sheila was determined “to be part of it and to know as much as I could know about what the options were.”

I was not going to let this thing beat me. If there was anything I could do to make this treatment work better, I was going to do it. And I was going to find out everything I could find out, good, bad, or purple! It didn't really matter. I was going to find out what the current research said, what the current options were, what was out there. There were times when we were looking at treatment for the G.V.H. One treatment for G.V.H. was thalidomide. I mean, since obviously I was not in a position to be having any more children, that didn't frighten me, but the fact that I knew what that was, I thought, “Oh, okay, well, here is something that is being used as an immunosuppressant... as a treatment for G.V.H. I didn't go that way because they had the Prograph available. So I became part of the study for that. But, I didn't go into it unaware.

Sheila talked about the characteristics of educated patients she believes will emerge in the next millennium. She currently reads a “network newsletter” that has described the “wired patient” of the next millennium.

Health care is going to have to deal with patients who have found out as much as they can... It may be a challenge to get people to calm down... At the conference last month, there were people saying, “Well what about dah-dah, dah-dah, dah-dah? I'm dying anyway. I want to try it. Don't waste it on some rabbit. Give me that shot, whatever it is, and let's see.” And so they were trying to say, “No, that's not how research is done. That's not how we can do that.” You could feel the frustration. There's a possible treatment out there... I never had that frustration because we were trying what we knew to be currently the best shot.

Walter had recently retired from practicing medicine when he developed a leukemia type of cancer. His response was to summon the librarian's assistance in

obtaining articles from medical journals about his diagnosis. He learned through reading these that there were no other reported cases exactly like his. For Walter, this information did not bring power, comfort, or hope. Since he was feeling relatively well, he declined treatment due to his knowledge of the poor response to chemotherapy in elderly persons with this type of leukemia. His doctors agreed that was one alternative.

I got the librarian to get me... about twenty some odd cases at that time, and I read each one of them carefully... None of them fit my case. The peripheral blood in all of these others was more immature than mine, and it was more obvious of a myelodysplastic syndrome that was beginning to develop immature forms. My neutrophils were not immature, except maybe some in the bone marrow.

After that, Walter started going to church, talking with the minister, and discussing faith with other church members. At the time of his interview he said, "I do not read medicine." Instead he reads about religious characters. "Just recently, I read a book on Joseph. I read a book on David, and I got interested in a red-letter edition of a book from the library that is supposed to be direct quotations of Jesus... And I have read everything about Thomas."

Deana loves to read. A major supporter, her Al-Anon sponsor, frequently sends her books. She mentioned reading books about cancer and books for entertainment such as mysteries. "I love to read... I will read almost anything... I have almost finished reading Love, Medicine, and Miracles by Bernie Siegel. That was related to the breast cancer. It is very well written." She says she does not have

much time to read, as she cares for an invalid husband. "I have not had a lot of time to read. When [her husband] was in the hospital in [another city] for three and a half weeks, "I read eight books, and I have read one short one since then." As previously mentioned, after her son died (just before she developed cancer), Deana read Embraced by the Light (Eadie, 1992). This book, about the author's near death experience and the afterlife, still gives Deana comfort in dealing with that loss.

Karl "read voraciously this last year," primarily books about religion and coping. He could not concentrate on anything other than books that taught him a life lesson or were reassuring. Like Walter, all of his medical knowledge did not comfort his troubled spirit and he turned to religion and inspirational writings.

My wife and I would be sitting there just staring in the dark or reading. I read primarily inspirational books... books that were written about how to cope, how to make God more a part of your daily life, and how to gain hope and peace, and even joy during trying times. I was, interestingly enough, pretty well turned off by everything on television and movies, and the novels that people gave me. I just could not sit there and absorb, but something that taught me a life lesson or was reassuring... Every two or three days I would get through another book or find another one. I guess I was probably given maybe twenty or thirty, or maybe forty books, and I would always kind of be reading through one and hoping that another one would show up so I could go from one to the other. I think a lot of it was distraction, it kind of got me focused and onto a track that was reassuring and comforting per se.

Louis read mostly books about cancer and nutrition, several by one particular physician. As a result of reading about nutrition, his diet became eighty percent vegetarian. His parents sent him encouraging newspaper stories about people with

the same type of cancer, testicular. He read from web sites on the Internet, especially one sponsored by Lance Armstrong.

The books that I read were dieting books and books on cancer-causing food... There is a Dr. Wehl (I think is his name). Anyway, he writes about diet and how it relates to cancer, and he is an MD, kind of a little bit off the wall type of guy... just a little bit of an alternative medicine type of guy. We got several of his books just to see what he had to say... During my chemo and stuff, I was, I would say, about eighty percent vegetarian or something like that. I guess I eat hardly zero red meat – maybe ten percent of my diet is red meat. I primarily eat fish and vegetables and chicken.

Books about cancer, coping and nutrition were helpful to Pam. She did “lots of reading,” finding that “very, very helpful.” Friends and some people she “barely knew” brought her books that were helpful.

[A friend] who had had breast cancer dropped by ten or twelve cancer books, and they were all different. Some were about healing... One was a Bernie Siegel book... They just were all encompassing of all different aspects. They were all very helpful... A lady whom I barely knew, she sent me a book, I Can Cope, and that was very good. What made it nice was it was actually her book, so it was underlined and things from when she had gone through this, so that was helpful.

Pam became particularly interested in nutrition when she was at a low point in her hoping process, unable to bounce back after her cancer surgery. Pam went looking for specific nutrition books. First, she tried the hospital where she had had her surgery but found nothing. “I could not believe it.” Next, she went to a health food store and almost left empty-handed. Intuition called her back into the store. As a result of her discovery, she began taking vitamin and mineral supplements. Soon she was feeling “wonderful.”

I looked around, and I saw this little booklet on... Well, it had to do with nutrition. And I left, and I got in the car, and it was like that just stayed with me, "Go back and get that book." It was only \$3.95. It was by a woman nutritionist. She had a whole bunch of degrees. Anyway, I read that and saw that there were some things that I could be taking, and I started taking colloidal minerals and vitamins, heavy in vitamin C and vitamin E, and other vitamins, and it was not three or four days, I started feeling wonderful, and I have been taking them ever since.

Audrey, like Sheila, described "information as power." She was a senior nursing student at the time of her diagnosis and information made her "feel better." She looked up the short and long-term effects of her chemotherapeutic agents. She wanted to know her blood counts and what everything meant. She felt this need to know was a "control-type issue." Being involved in how her cancer would be handled, investigating it, and learning about it was helpful to Audrey. "I felt like I had more of a handle on it that way. I did not just want it happening around me without knowing what was going on."

I was up here wanting to know my counts, plus I had to have them for school... I was finding out, "What does this mean?" Okay, my count says this, "What does that mean?"... I know that is a lot a control-type issue, but that was how I could handle it. I would read about it. I would look up what this meant for this situation and find out about the different chemotherapy drugs. "Well, if this can happen now, what is going to happen in ten years?" Information made me feel better, information and, I guess, being more involved in how it was going to be handled.

Educating self provided knowledge, inspiration, improved coping, and assistance with treatment decision making. Besides increased hope, many participants experienced greater feelings of self-understanding, control, power, peace, and encouragement as a result of reading or learning.

Work and Career

Of the fifteen participants, four were retired, three owned their own businesses, seven were employees, and one had never worked outside the home, but engaged in many volunteer activities. Working as an employee in a meaningful occupation or working for one's self in a personal business brought many participants a sense of purpose, accomplishment, and a reason to live. For others, working helped distract them and get their mind off of their problems. Volunteer work kept one informant as busy as employment. For most participants, working was a necessity to gain income for supporting themselves and/or their families. However, the participant's self-described benefits go much farther and deeper, including actualization of their purpose in life, a mission to accomplish, and healing effects for their health problems. Eleven of fifteen participants contributed data to this theme category. No previous studies looked at hope and work or career per se. However, purpose in life and having purposeful activities have been linked to hope. Sixty older adults in a study by Herth (1993a) identified a hope fostering strategy entitled "Purposeful Activities," that provided meaning and purpose in their lives. Coward (1996) found a significant positive correlation between hope and purpose in life in one hundred fifty-two healthy adults in her study, "Self-Transcendence and Correlates in a Healthy Population."

At the time of her interview, Emily had retired from employment as a telephone company technician. However, her life was full with involvement in volunteer work for church and visiting newly diagnosed patients. After her diagnosis

eight years ago, Emily went back to work almost immediately once she achieved a remission. Her “boss was a doll” and she felt good after getting over her initial anxiety about performing a very technical job again. Her remission lasted little more than a year, after which she retired. She has been in almost continuous chemotherapy for the past six years trying to keep her advanced ovarian cancer under control.

Angie does not consider her self retired, although there have been periods in the past two years of chemotherapy that she has been unable to work. She is a self-employed talent coach for television stations all over the country. When asked to describe what she does, Angie said, “I work with people in communications.” She has developed her own unique style of coaching news anchors in their camera presence and communication skills. Since becoming ill, her clients have traveled to her home for coaching services. Some of her news directors and anchors have asked her to write a book so her material will not be lost. Angie’s career is extremely important to her and gives her a reason to live and helps her to feel normal.

Oh, my career is very important to me. That gives me a reason to live because I believe that’s what God put me on earth for to begin with – to use my talent and skill in communication to help people. I get a great deal of satisfaction from coaching people, then seeing them improve and implement the things that I gave them... They often go on and get better jobs and really accomplish a lot in their own careers... I won’t give that [career] up at all, and my family’s all telling me that I shouldn’t do it... that I don’t need to work... but it’s very important to me... That’s normalcy to me – working – I feel normal.

After recovering from surgery for breast cancer, Marcia went back to her job as a library technician. She continued to work while receiving several weeks of

chemotherapy. She often felt so sick she considered quitting her job, but never did. During a couple of bad times, she called the social worker at the clinic where she had been treated seeking counsel about quitting. Even though she felt very ill at times, Marcia said that it helped her to come to work.

At first I would feel so fatigued. I would feel so bad. I would be so emotional. I would feel so nauseated. I would go into the break room, and I would call her [the social worker] and say, "Should I quit my job?" She said, "Just be patient with yourself. You've had all these drugs put into you. You've got to give your body time." I'd go into the back and sit there awhile.

Paul connects his "desire to live" and his "healing" with his personal creative artistry and his interactions with students in the classroom. These two things "definitely" help him to be more hopeful. He felt that if the creativity part of his being was ever "dammed up, or slowed down, or stopped, then the healing process just would slow down or stop." He had to "keep that little fire going" because he knew that if it ever slowed down he "didn't want to have to start everything all over again." He kept his mind on "dealing with creativity." One of Paul's final thoughts was a future-oriented career goal, "I've got paintings to paint."

I think my desire to live... is all very much a part of the tapestry of my personal work in creativity and the interaction in the classroom – these are probably the two biggest things that have helped me... I was thinking about the next thing I was going to do in a creative sense to keep my mind occupied... I always felt like those were healing things. I don't think there is anything that can stop me from healing as much as I can heal, at this point, because the creativity is so deeply entrenched, and the thought process it took a lifetime to get to... is coming out of me so fast now that there is no negative thought process about that... The creativity is incredibly prolific... So I feel like there is a big connection between the creativity and the healing.

At the time of the interview Paul was working on sculptures, just one of his many artistic media. His manner of speaking in describing his work was captivating to the researcher. "Right now I'm involved in ceramic sculpture, and it's based on primitive art... on a wide range of cultures and primitivism. And I've come up with this kind of conglomerate. I'm calling it primitive rococo which is overdone primitivism, and that's just the way my mind is working." Paul has difficulty staying in one artistic medium, so he may work on several at once. He keeps books of his many creative ideas, choosing to work on only a few. "There's just not enough time in life."

During her surgery and chemotherapy, Maggy took very little time off from her work as an administrative assistant. "I never really took time off. I had so many people say, 'Well are you back at work yet?' I said, 'I never quit!' And, they said, 'What?' I said, 'Why stay home when you need to be out?'" She said if she had been "real sick" she would have taken more time at home. "But a headache, you can get over in a day." She would have her chemotherapy on Thursdays. "You miss work the next day, and you have two days to get your system built up, and you go back to work on Monday. There's too much going on. I don't have time to miss this. I don't want to miss it." Later in the interview, after talking about sources of hope from the external environment, Maggy said it was her "work environment" that was most important to her. "I am here more than anywhere else."

Sheila has worked as an English teacher in high school and college. She is currently an English professor and doctoral student. The beginning of school gives her

something to look forward to. “I like the fall of the year. I am a born teacher. I love the fall. I love the fact that the kids are back in school. That it’s a new beginning. It is more a new year to me than January is... That is when the champagne needs to fly... Happy New Year is the beginning of a new school year.” Her identity as “teacher” was so important, she used it in a hopeful way when she was the sickest.

One time, when I was the sickest at [a local hospital], before I went down to [a large cancer center], in that time frame when I was undergoing the second part of the second round of chemo, I came and sat in my office on the third floor of [a university building] just to convince myself I was still a teacher. I was not a cancer patient. I was still a teacher. And I came and sat in my office and cried. Then we went back [to the hospital]. That really meant something to me... That was a very hopeful thing to sit in my office.

Getting out of the house, going to work, and keeping her regular routines helps Holly to stay hopeful. Otherwise she would sit around and think about her problems. “Don’t sit around because the more you sit around you’re going to think about your problems... Just get out... Do things... Keep your regular routines. Don’t stop doing things. I mean your life has not stopped.” She does not jump up everyday energetic and ready to go. Sometimes it takes some effort. Holly reflected back upon the morning of the day of her interview. “Because like this morning I thought, ‘Oh, do I have to go to work? I just feel kind of yuck.’ And I said, ‘Lord, get me out of bed.’” Her family often cautions her about not overdoing herself at work. Her family members say, “Don’t overdo it... You’re going to overwork yourself. You’re going to get tired.” Holly replies, “As long as I feel good, I’m going

to do it.” Obviously, going to work is extremely important to Holly who is currently undergoing experimental chemotherapy for metastatic colon cancer.

For Bert, his work is something he loves and is a way of supporting his wife and four young children. He and Louis are business partners in a land surveying company that they started. Besides an income, Bert gains a sense of peace from his outdoor work environment. He feels fortunate not to have lost any of his mental capacity to perform his job because of his diagnosis and five surgeries.

I am a registered land surveyor, and I love being outside. I used to survey in areas around the state of Texas where there is not a lot of activity... I love being out in southwest Texas... in the hills around Big Bend... We used to do a lot of surveying out there. To me, that is as peaceful as it gets... I still have the knowledge to be able to understand my job responsibilities... I am very fortunate.

For Karl, getting back to work as a physician was very important after diagnosis and treatment with radiation and chemotherapy. It was like going to a comfortable home, since his workplace and treatment center were the same institution. Being at work was something normal and familiar to him and a distraction that made the time go faster. He looked forward to getting back to work and facing the day.

Getting back to work... It was a month after the first surgery and ten days after the second surgery that I came back to work. And it was, at a minimum, a distraction and, at a maximum, being home or something normal and things I was used to. Everyone at the hospital and clinic [his workplace and treatment center] was so good to me and so gracious. I looked forward to getting back and coming to work and facing the day... The time goes by faster.

Louis and Bert, aged thirty-nine and forty, share similar life challenges. Together they started a business and soon after became cancer patients. They have

two very different types of cancer, liposarcoma and testicular. Louis spoke of trading places with Bert as patient and being “the man in charge.”

My business partner, Bert, also a cancer patient, fortunately was not ill during my illness. And, when I got well or through with my treatment, he became ill again... We run a professional business that requires a license to operate. We are both licensed surveyors. He was going to be out of commission, and I had to kind of pull myself together so that I could be the man in charge, whether I felt like it or not. So it kind of helped me to get back up off feeling sorry and down about myself... That made me feel hopeful that I could get over this.

Going back to work was a necessity for Louis because of Bert’s illness. In addition, returning to work helped Louis get over a real depression from surgery, chemotherapy, and several weeks of inactivity at home. His business was both a mission and something he cared about. He had worked to build it, it was becoming larger, and more work was coming in due to the coming spring season.

I would say, being mister selfish businessman, that my business... knowing that we had a pretty good thing going over here, and that it was waiting on me... I mean, you know, they were not sitting around waiting on me, but there would be something for me to do, and there was a mission here for me to occupy. So, our work is usually most busy in the spring and summer, and with spring coming... The communication I had with Bert was that there were lots of things coming in to be done. So, even though in my first month or two back, I felt depressed because I just did not have the zip... I really wanted to be back. And when I got back, I did not feel like I could do anything, but the hope part was that “Hey, I need to get back.”

Audrey was not employed, but was a senior nursing student when she developed breast cancer. She seemed almost driven to finish nursing school and not let cancer interrupt her life trajectory. Those who tried to encourage her to drop out

were perceived as thinking she couldn't handle things. Continuing with her regular schedule made her feel normal.

I guess I just wanted to be normal. I just went about my same stuff and started school back at the end of January and had some healing and stuff to do. I did not get chemotherapy until the end of February. That was when the hair started falling out and that kind of stuff. It was like, put it between reading chapters ten through twelve, and getting blood drawn... The Dean and a couple of the other instructors wanted me to drop out... I guess, looking back, it may have been more of their protectiveness or something. But, at the time, I was taking it as, 'You cannot handle this.'

From the examples given, one can see that working provided participants much more than a livelihood. Being back at work represented normalcy and familiarity, a mission and an identity, and for some it brought about healing. Many linked being able to work directly to feeling hopeful.

Self Protection and Maintenance

Every participant contributed examples to the theme category of self-protection and maintenance. Caring for, protecting, and maintaining one's self helped participants to feel more hopeful. Examples of specific behaviors are many and varied, including traditional health practices (nutrition, exercise, rest) and personally fulfilling activities done to achieve relaxation. Several have learned to listen to their bodies, set priorities, pace themselves, and streamline their lives. A few participants protected themselves by avoiding unpleasant persons or situations. In her study of family caregivers of terminally ill, Herth (1993b) induced a category, "Uplifting Energy," in which caregivers described the nurse helping them "to prioritize and decide what was

essential and what could be let go” and “learning to balance available energy” (p. 6). Nurses assisted subjects in the above example, but the informants in the current study reported self-maintenance activities initiated on their own.

Emily regularly interacts with other women living with ovarian cancer, many of whom do not live very long after diagnosis. She visits newly diagnosed patients in the hospital at the request of her doctor and his nurses. Her picture and cancer story hang on the wall across from the elevator on the gynecologic oncology nursing unit at a large metropolitan medical center, where she started a support group for ovarian cancer patients. Having battled her own cancer for eight years, she meets many patients who become friends, such as Angie, a fellow participant in this study. Another friend in their support group had recently died at the time of the Emily’s interview. When asked about recent losses in her life, Emily responded, “Lots and lots, because, you see, I meet a lot of patients. I told Angie, you know, you cannot get too attached. We have lost three out of our support group, and we have only been together for a year.” Emily protects herself from these frequent losses by not becoming too attached. However the bonds between Emily and Angie, a two-year survivor, are strong. Emily has helped Angie learn to take care of and pace herself during chemotherapy.

I think most of my days are good. Even when I feel a little fatigued, I just lay around. It’s not the end of the world, you know. I’ve told Angie that you need to pace yourself, and if you feel tired, go to bed. Don’t think you have to be up doing errands. Those things will wait... I have learned to be better to

myself. If I don't feel good... I take care of Emily. That's become the number one priority of mine.

Angie looks to Emily as her role model in living with ovarian cancer. She has tried to take better care of herself, think more rationally than emotionally, and not do everything at once. "I try to take one step at a time... When I'm overwhelmed I just try to put one foot in front of the other." Having a mother whom she perceives as "negative," Angie now chooses "to be around positive people," such as Emily to better care for herself and her emotions.

Marcia felt down every time she visited her oncologist. She believed it was her doctor's tendency to discuss only statistics, and her lack of ability as a "people person." Marcia preferred to see the radiation oncologist and told him so. He replied, "You're the patient, you can pick the doctor you want to see." Marcia said, "Well, I would much rather see you." She took care of herself by changing doctors. Since then, "He's been my follow-up doctor."

Overall, Paul has tried to streamline his thoughts, simplify things, and prioritize his life. This has helped him to remain calm, not waste time, and not get "dragged down," emotionally, mentally, or spiritually.

I guess you would say streamlining my thought process into what I feel like my priorities should be instead of wasting my time on things that would either drag me down emotionally, or mentally, or spiritually, and try to focus on keeping it as simple as possible because it is already complicated... I felt like I needed to simplify that... It just seems like going over these priorities of what I should be dealing with and how I should be dealing with it in more of a calm fashion has really sort of taken place, but I had to start that while I was in the worst part of the process physically and mentally.

Paul sees the importance of “everyday things like cooking, talking to your sons, dealing with the relationship with your wife and family as a whole... working on your house, planting flowers, all of those little things.” He has also tried to listen more to his body and mind taking time to rest, lay down, or daydream. “What I’ve been trying to do is listen to that a little bit more. And, if I decide that I need to rest, to me, that’s just my body saying, ‘Okay, you’ve got to lay down. You’ve got to rest.’” A professional artist, Paul’s mind is always working, thinking of his next creative inspiration. Rest also includes his mind. “I just look at it as taking a deep breath and mentally daydreaming, and I don’t feel guilty about resting.”

Maggy, like Paul, takes “mini-vacations in her mind” at work when needing a break. As happened for Angie, self care for Maggy involved avoiding people who decreased her hopefulness. Following her husband’s preaching job took Maggy to different country churches every Sunday. She experienced a negative group who told “horror stories” at a time when she could not handle that. She became selective in where she went.

My one experience which was right after my first chemo, or just before my first chemo... I think it was the Sunday before I was getting my first chemo. I went to church with [her husband], and he was preaching at one of our country churches. And I know the older people meant well, but they all had to tell me their horror stories, you know, and it bothered me, to the point that I could not eat. You know, if it bothers me enough that I can’t eat, it’s pretty bad... But, after that, I just told [her husband] I said, “Maybe I need to just back off and not be around some of these people.” I was selective in where I went.

Sheila discussed her need to read and learn all about her disease process (leukemia) and the treatment options. She adamantly wished to be included in the decision-making process and to become “a partner with her physician.”

Dr. [name of physician] was amazing... He was a little bit stoic when we first started, but... we developed a real relationship. He did not want me to be reading a lot of stuff, and that’s not how I work, and so I was asking him... “Okay, tell me about this bone marrow thing... Get me an article. I want to see what it says.” And he was hesitant in giving it to me until I finally said, “I want to see that. I don’t care if you think the odds are not all that great. I need to know what they are. I need to know how this works. I need to make it happen.”... He finally said, “Okay, you’re in charge here. You’re calling these things.”

Holly took care of herself by enjoying the everyday things and being with people. “Cleaning house... I love to cook... I guess it is just cooking, or just getting out and going to the mall, and just seeing people.” An important weekly activity is going to church with her family.

Bert also takes time to attend mass every week with his family (wife and four children). This time is extremely important to him in his hoping process. He stated that in mass he feels “one hundred percent” hopeful. It is his individual time to concentrate, focus, and be at peace.

This is the individual time. This is my time... What I want to do with my time is give it to God... I would not go without my family... I want my family to be with me, but it is my time to focus, and to concentrate... It is time to be at peace with myself and try to concentrate... To me, what I have been through and what I have seen, you have to do it... You have to be a little bit selfish and take the time. I do not think that it is selfish, but in a way it is. I want my own time.

Walter spoke about doing several things for himself – growing vegetables (when his wife wanted flowers), taking trips, cutting wood, playing bridge, and playing golf. No longer interested in reading about medicine, his new interest had become religion. He went to church weekly, attended Bible study groups, and read voraciously about various religious figures.

Writing letters or keeping her journal became important self-care behaviors for Deana, helping to “get her feelings out.” Reading from her journal, she said, “I do not know how to start. I do not know what to say. I only know I need to get my feelings out. My journal is the only way to do that. Although I have missed many months of writing, I have expressed my feelings in a letter to my Al-Alon sponsor.”

Choosing to have chemotherapy was a means of achieving increased longevity and peace of mind. Again, Deana read from her journal, “I want the chemotherapy because I want to live as long as I can, and I want to do what I can right now to ward it off, so I would not have to worry about it.” She went on to say, “That was my feeling, you know, that I would not have to worry about it, and I have never been sorry about the chemotherapy, and I have always said if I have to have chemotherapy again, then I will do it. I will never wear a wig again. I will paint a happy face and have a baldhead.” Another thing she will not do again is leave on a trip with something like cancer surgery pending.

There is something that I would not do... I was diagnosed before Christmas and we were to go to California for about eight or nine days, and I was coming back for my surgery. I would not do that again... I would cancel the trip. I

was worried, and I thought, “Well, this will spoil the trip.” This is the only time that we could go. I would not do that again... It is not being selfish... It put kind of a cloud on my trip, and I mean it. I did not want to disturb anybody, and I would not do it again.

Deana loves to cook and be outdoors. “I believe I would just die if I couldn’t get up and cook.” She cooks “big meals” and listed the foods in the hearty meal she had cooked at noon the day of the interview, making the researcher hungry. Deana loves being outdoors. “I love to go sit in the swing by myself.” While outside, she will pick up pecans, sit in the sun, listen to the birds, read a book, just look around at nature. In spite of providing many self-care examples Deana felt she could take even better care of herself. “I do not take as good of care of myself as I should.”

Performing daily care rituals – “routine things I do like the oral care that I have to go through as a ritual a couple of times a day, the medication and supplements that I go through certain times” – helps Karl to feel hopeful. More importantly, being able to continue his work as a physician lifts his spirits. His employer allows him to pace himself at work, working when he feels well enough. Everyone at his workplace, from the top on down, has told him, “Do whatever you want to do. If you don’t want to work, that is fine. Get well.” He has not had any worries about his job. “That was a real relief, and I could take off when I was too sick and get back any time I wanted, and the people in the clinic, the secretaries and appointment clerks, never complained a bit.”

Louis read about nutrition and cancer, changing his diet to “about eighty percent vegetarian.” He now eats only about ten percent red meat. “I primarily eat fish and vegetables and chicken.” He worked on his home in the country trying to make it more “user friendly.” Some things had been difficult for him while in a weakened state from chemotherapy, such as opening the gate and garage door and feeding the cows. Thinking about the projects gave him something to plan on while ill.

I saw a lot of things that I wanted to get worked on, so when I did get well, we got electric gate openers and an electric garage door opener. I was trying to think of things to accomplish that were things that I did not think were such inconveniences when I was in full health capacity, but when I got weakened, then all of a sudden those little things became huge, and I said, “We have got to get this fixed,” so I had some projects planned, and I kind of pointed to that... At that time, we had cows, we had like ten, and one was a bull, like an 1800-pound bull. We fed square bales as opposed to the big round bales, and I had to learn to drive a tractor and all that stuff... Well, anyway, in the heart of winter, they needed hay all the time, and they got kind of obnoxious. She [his wife] felt uncomfortable being around them to go give them hay, and they about knocked her over getting to it, and so... I guess during my down time, she made me promise that we would get rid of them... We got rid of them and bought sheep, so that was kind of something to be planning on.

Louis told a poignant story about self-care and his own intuition regarding his body. His local oncologist saw spots in his lungs on a follow-up chest x-ray and told Louis it was a reoccurrence of his testicular cancer. He recommended additional chemotherapy. Louis had been feeling very well and, for some reason, he didn't believe that the cancer had returned in his lungs. He was also very reluctant to undergo chemotherapy again because it had been very hard on him the first time. On the website sponsored by Lance Armstrong, the world-renowned cyclist with testicular

cancer, Louis had noticed that a side effect of his particular chemotherapy could be fibrosis in the lungs. He took the initiative to get a second opinion from Lance's doctor in another state. This doctor agreed that he did not need more chemotherapy. Louis believed that if he had not studied about his disease on the Internet and gone for the second opinion, he would have died from the unneeded chemotherapy.

Robin talked about various activities she does for relaxation. Sometimes she plays the piano in the middle of the night when unable to sleep. "I play the piano a lot... It is very relaxing; of course, being here alone... You know, even in the middle of the night, if I cannot sleep, I get up and come in and play the piano." These "just for me" activities also include stitching and swimming. She finds hope in "the basics of daily life." After her cancer surgery, Robin remembers spending "lots of time in the bedroom in the recliner," a place where she could relax and heal.

Sometimes it was difficult to lie in bed because of the mastectomy. I spent lots of time in the recliner, and it just was comfortable... It is where I did my healing. Even when people came, they would visit me in the bedroom. We had the two recliners in there, so it was easy to have visitors in there. I can remember a number of people. That is where I was comfortable. That is where I could relax and heal.

Pam is trying to change her lifestyle which she finds to be "real hard" after living "fifty some years in a certain pattern." Things she feels the need to change include not doing too much, increasing her rest and sleep, decreasing stress, exercising, and improving nutrition. She started taking supplemental vitamins and minerals after surgery and has continued with positive results.

When diagnosed with cancer, Audrey desperately wished to continue nursing school and graduate as planned. Against the advice of teachers and family members, she graduated on time without missing any classes. Continuing her regular schedule made her feel normal. Cancer made her angry and she was determined to accomplish her goals.

It was something else I put on my calendar that I had to do, and I guess I just wanted to be normal. I just went about my same stuff and started school back at the end of January and had some healing and stuff to do. I did not get chemotherapy until the end of February... That was when the hair started falling out and that kind of stuff. It was like... put it between reading chapters ten through twelve and getting blood drawn... And like I said, I had a four-year-old and a newborn at home. It was not going to get between me and what I wanted to do. It made me mad!

For the “peace of mind,” Audrey underwent a prophylactic mastectomy in spite of an oncologist’s negative descriptions of possible appearance outcomes. “My cancer was on the right side, and I had the prophylactic done on the left just as a precautionary thing... The data says the lumpectomy is just as good as the mastectomy as far as reoccurrence if you get radiation with the lumpectomy... But it is the peace of mind that that breast tissue is gone.” Additional self-care practices mentioned by Audrey include getting regular checkups with blood counts and taking vitamins and mineral supplements.

All participants described at least one type of self-care protection or maintenance behavior that helped them to feel more hopeful. Some altered relationships, especially with their physicians. Several admitted to having learned to

slow down and pace themselves, rest more, or improve nutrition since developing cancer. As a “wake up call,” cancer served as a motivator for many positive lifestyle changes in participants.

Self Restoration

The examples in the self restoration theme category are self-initiated, self-fulfilling activities chosen by participants for leisure time or play. They are related to self-protection and maintenance, but go farther to create fun and enjoyment at a higher level. Many of these joyful pursuits involve the interaction of participants with the external environment. Some are solitary activities and others involve other persons. Many activities are physical, recreational, and energizing; while others are quiet and relaxing but equally pleasurable. All bring joy, fun, and entertainment. Each unique participant has decided what is personally meaningful in their individual lives, outside of working and their careers. The continued ability to participate in these activities in spite of cancer facilitates the hoping process. All fifteen participants contributed data to this theme category.

The category entitled, “Do Something,” part of the overall theme, “Distraction,” is a comparable finding in Hind’s and Martin’s (1988) study of adolescents with cancer. All adolescents used this strategy, defined as “the degree to which adolescents make themselves keep busy with a physical activity, alone or with others, to occupy time and thoughts and provide mental relief” (p. 337). Another trait observed by Maslow (1987) in self-actualizing people was “fun and gaiety... easily

compared to the games of children and puppies... cheerful, humorous and playful... basically an enjoyment and a delight” (p. 154).

Emily is retired from employment due to her cancer, but each of her days is a “good day” and a fun day. Unless she is feeling ill from chemotherapy, she is out doing a variety of things.

I just have fun every day... I do something... I go to the Arboretum and see all the beautiful flowers. I piddle in my yard in the summer, and plant flowers, and mow, and I read a lot. I like to go to the movies. I am always going out to dinner with friends. I talk a lot on the phone to other cancer patients. I visit Angie and people in church.

Angie enjoys swimming, horseback riding, and walking. Some of her joyful activities also give her “a lot of hope and reason to keep going.” Feeling well physically is the major source of hope for Angie, so some of these activities take on added importance.

I do get to swim at my brother’s. It’s a good source of activity. It helps my joints. It makes me feel powerful. I am very coordinated in the water... My horse trailer reminds me that pretty soon I will be able to load my horses up and go and participate in the horse activities that I really enjoy... like parades, the trail rides, the supper rides, and different activities... That gives me a lot of hope and reason to keep going... Getting up and walking around on my property, going in the tack room, giving the horses their feed, walking out to the pasture to hug and kiss on them... just physically making the muscles and joints move – that makes me feel better.

Marcia loves quiet relaxing activities at home – reading, listening to music, sitting in her swing, and watching her plants grow. “It was really relaxing [after chemotherapy] just to go home and just turn on the music and just sit there and relax.” Sometimes she sat in her living room just looking at her plants. “I love my plants...

My plants were number one because some of my plants I started as little, and now they're really huge. I can remember sitting in my living room thinking how things can just grow... They can start out so small and can just change the way they look and everything in a matter of years."

I read quite a bit last year... I read the Bible a lot last year. I read, not only the Bible, but a lot of different kinds of books. There were times when I read a fiction book just to get myself out of me... not to think about me. Before last year, I would start a book, and I would finish it before I started another one. Last year, I noticed that I might be reading three books at one time. I might have a fiction book over here... I might have a religious book over here, and I might have a cancer book over here... I was reading them all at once, and I think it was the way I might be feeling.

Paul enjoys planting flowers in his leisure time at home. He has a flower garden, herbs and fences. A professional artist and teacher, growing flowers is seen as another extension of his creativity. On an even more personal level, things that grow become another part of his family.

Even though some people would say, "Well, that's just planting flowers." To me, that's just another extension of your creativity... I have flowers. I have herbs. I have fences... Especially on things that grow, like trees or whatever... To me, that is just another child, another friend, another part of the family... If I had a choice, like, if I'd rather plant flowers than paint paintings, I like painting. That's going to be a very tough choice. I like painting, but if I have no paint or canvas and I have flowers... It's the same thing to me.

Being out among people is a favorite activity for Maggy. She is one who loves her work environment, where she has almost constant human contact. Only if she is tired, will she stay home and engage in solitary activities. "I love getting out... If I have the energy to get out and to be around people, I just go wandering through the

stores... If I'm tired, I stay home... But, other than that... As far as alone time, I love to color in my coloring books. That is the best therapy. That has helped me... I also do needlework... I look at my craft books.”

Sheila loves to sing and is a choir director outside of her work as an English teacher. Listening to her music tapes helped to bring her out of a psychotic drug reaction during her bone marrow transplant. She has less leisure time than usual right now due to attending graduate school working toward her doctoral degree.

Holly, like Maggy, enjoys “just getting out and going to the mall, and seeing people.” Her daughters usually go with her, but she admits, “I have gone by myself.” At home she actually enjoys cleaning house with her daughters’ help. “I used to do yard work, but I do not go out as much because of the sun.” Holly loves to cook, but this has mostly been taken over by her husband since her cancer diagnosis.

Bert told about several leisure-time activities that are really important to him – coaching his daughter’s soccer team, going on an annual family camping trip to the Colorado River, and water skiing at his local lake every summer. “We are avid, very, very avid water skiers... We ski on an average, from spring to fall, on average, probably three days a week... We did an enormous amount of water skiing this year... We traded in the old boat and got a different boat.” As with the other family activities Bert loves, he is especially gratified to watch his children, “out behind the boat riding on a tube or whatever they are doing... grinning ear to ear.”

When asked about activities that help his mind and spirits, Walter discussed golf, bridge, gardening, cutting wood, and church activities. “My aunt had played duplicate bridge beforehand, but I had not, so I took it up when I retired... I just jumped into hot water. I checked out basic bridge books and read those, and we discussed it between us... We still have lots of problems with it. Bridge is a very complicated game.” Walter doesn’t buy his firewood. “I go out into the country and cut my own wood.” This is of concern to his family due to his age, illness, and the use of a chainsaw alone in the country. “Most people would go into orbit to hear that I am out there by myself, but I am very cautious and do not take any chances.” He loves to get out in his yard and “garden a little bit.” He grows pansies for his wife and vegetables for himself.

At the time of the interview, Walter and his wife were “involved in a lot of extracurricular church activities.” They work with a church that “takes care of nothing but street people basically... We get involved in collecting diapers and baby formulas, and mostly help take care of their children who come in.” They had recently purchased five turkeys to feed two hundred for a Thanksgiving dinner. “Well, we do a great deal for them.” Walter no longer reads about medicine since his retirement and illness, but prefers reading about Christianity and various religious figures. “And another thing – we are into genealogy.” Retirement and cancer do not seem to have slowed Walter down at all.

Deana enjoys writing, sometimes in her journal, but more often in letters to

friends. “I like to write. I like writing about what our lives are – what we do. And some friends my age say, ‘Well, you lead such an interesting life,’ and I just die laughing when I get their letters back because that is great if they think so.” Deana and her husband are “kind of at a crossroads right now for the most part” due to his invalid status. “I just try to make the letters interesting. The last time I had a letter from my friend, and I had had the stroke, she said, ‘Well, if you would learn to act your age, you would be better off.’”

Besides being able to keep in touch with all of her friends, writing helps Deana to get her feelings out. This is mostly through journaling her cancer experiences. She read many entries from this journal during her interview. “I think that anytime you get your thoughts on paper it is helpful... I have always written. My mother was a writer, and my grandmother was a writer.”

Although writing is her first love, Deana is also a reader. “I love to read. I have not had a lot of time to read... I will read almost anything. I like mysteries.” She also loves to cook. “I believe I would just die if I couldn’t get up and cook. I cook big meals... I had roast and potatoes, carrots, black-eyed peas, and cornbread for lunch.” When not reading, writing, or cooking, Deana likes to sit in the swing and just look around at nature, enjoy the sun, or listen to the birds. She likes to pick up pecans when outdoors. Deana likes growing green plants, especially the two that belonged to her deceased son. “I like living plants. I like to see them grow. I like for them to do well. I always get a little upset when they die. [Pointing out her

window]... The two ferns that are out there are special to me. The one that is hanging was one of [her son's]." Growing those two plants gives her hope.

During his interview, Karl did not go into depth about participation in leisure activities. He did mention going snow skiing in Colorado with his family, walking outside his home, checking his gardens, attending a family reunion, and spending time with a new grandbaby.

Prior to getting cancer, Louis had always perceived himself as athletic and healthy. "I was always real healthy and semi-athletic and enjoyed being outdoors and doing all those kinds of things – hunting, fishing, sports, golf, and tennis, and then when you think you might not can do those things, it is kind of a downer." He affirmed the researcher's query about whether participating in these activities helps keep his spirits up. At the time of his interview he was working on his home in the country, complete with a donkey, twenty chickens, and sheep. He has "had to learn to drive a tractor and all that stuff."

For enjoyment, Robin plays the piano, sometimes in the middle of the night, when she cannot sleep. Stitching and needlework "satisfies the creativity in me... I have always said that whatever talent I have, God put it in my fingers, playing the piano, or stitching." She likes to walk or sit outside her home in the country. When she was recovering from surgery in the late spring and summer, she swam in her pool. That helped her arms and shoulders get back into full range of motion. "Some of the older ladies from church would come out and swim with me. It was a hoot. You

know, and I had these expanders in, so I was way out to here [motions to her chest]. It was funny.”

Pam loves reading, classical music “mostly in the majors,” and decorating her home. Her home was especially beautiful and comforting during the Christmas season when she had her cancer surgery four years ago. It was equally beautiful, with plants and flowers, the morning of her interview, a few days before Christmas.

Audrey, a busy mother, wife, and Registered Nurse, has little leisure time. She especially likes to listen to the radio and sometimes feels God speaks to her through the radio, at times when she has thought or prayed about something. She and her family live in the country. “I like to go outside. Whether it is being in the back yard in the swing, or just on the front porch.”

Activities special to each participant clearly provide a variety of benefits – emotional release, enjoyment, entertainment, exercise, and escape from the ordinary. Without them life could become dull, boring and possibly devoid of hope.

Feeling Good/Asymptomatic

Feeling good consists of being free of physical symptoms such as pain, weakness, nausea; but also includes not having unpleasant psychological symptoms such as anxiety, depression, or low self-esteem. Participants often mentioned strategies they used to help themselves feel better, such as walking, creating, shopping, or taking medication or vitamins and minerals. “Feeling good” is a theme that was

very important to several participants and the most important source of hope to one. Most of the informants (eight of fifteen) contributed data to this theme category.

Many studies have linked hope or its loss to severity and control of physical symptoms. Christman (1990) found decreased feelings of hope and increased symptom severity to be associated with more psychosocial adjustment problems. Findings of this study suggest that interventions to enhance hope and control symptoms (pain, nausea, and fatigue) may lead to improved adjustment in persons with cancer. In a study by Herth (1993a), “perceived energy level” was found to influence hope. Threats to hope included high fatigue, impaired cognition, uncontrolled pain and suffering. “Poorly controlled symptom management” was identified as a hope hindering category by Herth (1993b). “Caregiver fatigue” and “decreased sleep” were associated with decreased hope in the same study. The needs discussed in his category are part of Maslow’s most basic level, physiological needs, deprivation of which Erickson et al. (1983) note “can very often lead to the initiation or aggravation of physical or mental distress and illness” (p. 56).

The most important factor that influences Angie’s sense of hopefulness, is how she physically feels. “If I don’t feel physically good, everything else goes to pot.” When feeling “really good physically” she may not believe that she has cancer. The troubling symptoms she mentioned included joint pain and stiffness, abdominal pain, neuropathy, nausea, vomiting, diarrhea, fatigue, and exhaustion.

The greatest source of hope from within myself is how I physically feel. If I don't feel physically good, my hope just plummets. If I feel physically strong, and I'm not having symptoms and all that, then I feel very strong. Sometimes I don't even believe that I have cancer when I feel really good physically. So that's the greatest source to me... how I physically feel.

Angie is able to manage her symptoms to some extent with medication. Exercise helps her joint pain and stiffness unless extreme fatigue prevents it. At times, such as during chemotherapy, the symptoms are not controllable and she just has to endure them along with her decreased hopefulness.

Emily's perception of feeling good was having energy. She acknowledged feeling more hopeful when she feels energetic. The day following chemotherapy was especially wonderful, even though she realized it was probably drug-induced. "The day after chemo was my good, good day, because the day after chemo I feel tremendous, just wonderful! That Decadron kicks in and, you know, it's kind of like taking speed... it gives you a kind of a false sense of feeling terrific. I guess that's why they give it to you."

Going back to work was frightening to Emily. However, the reaction of her supervisor, her improved physical appearance, and increased strength seemed to account for "feeling good" at that time. "I went back to work, and my boss was a doll, and I thought the cancer thing was behind me. My hair came back. You know, I had enough hair when I went back to work, I didn't have to wear a cap or anything. I had real short hair, but it was cute, and I felt good. I finally got my strength back."

Paul has had cancer and chemotherapy for many years. He forgot what feeling good was until he began to regain it. At one point he had been on chemotherapy for a period of four years. His creativity kept his mind occupied during that time and he was unaware of the “weight of everything” that had been on him.

If they put a chain of chemotherapy on you, over a period of time, say four years or something, and after that four-year period, you start feeling better... I had the strangest feeling. I had forgotten what feeling good was about, and I didn't know I had lost that feeling until after it was back... Until I started getting, “Wow, this is great,” and I didn't fully understand the weight of everything because I wasn't really thinking about that. I was thinking about the next thing I was going to do in a creative sense to keep my mind occupied.

Getting out, “just to go wandering through the stores,” is something that helps Maggy feel good, if she has “the energy to get out and to be around people.” She has several new pairs of shoes to show as evidence from her “feel good” outings. “One of the things that I know my husband would say right now about me is that I'd go shopping and buy something. I've bought more new shoes since we started chemo, because it makes me feel good... Now, I've got these real pink shoes with nothing to wear yet... But those things make me feel good!

At the time of her interview, Holly was feeling especially well and as hopeful as she could ever remember. Even though she was about to go to another regional cancer center for experimental chemotherapy, she had no pain and felt like she didn't have cancer. “I can tell you that right now I do not feel like I have cancer. I do not hurt... and, if you do not hurt, you feel well, so I just feel like something is working in my body.” One wonders if renewed hope of another possible cure or her obvious

acceptance about her plight and possible death is lifting her spirits. Holly died one year after her interview.

Walter's pain was so severe at one point that he prayed not to wake up after surgery because he did not want to endure the pain any longer. Luckily, surgery drained the painful abscess in his neck and his pain was relieved.

But the minute he [his doctor] got that abscess drained and I got back to my room, my pain went away. I couldn't believe it, so all that pain was due to... and he said the infection had gone out and caused a periostitis of the mastoid and clear back into my cervical vertebrae. So that is why I was having such horrible pain. Once he got that thing drained and washed out good... Oh boy, he did a fantastic job! I had no desire for anybody to give me a narcotic. If I thought they were, I would have run them off because my pain was gone.

After listening to this story, the researcher said, "Your pain was gone. So how was your hope then?" Walter replied, "Oh, much improved, much improved. The pain was gone." The link between pain and loss of hope and relief of pain and rise in hope seems clear in several participants.

Karl was very explicit about the influence of physical symptoms on his attitude and hopefulness. Being able to "sleep well at night" and "having a good appetite," influenced his ability "to get up and get about my business each day." Physical pain, weakness, fatigue, and nausea get him "down."

What I notice is that when I am having physical pain or weakness, fatigue, or even nausea, then that tends to work on getting me down, and even though there is no change in prognosis, when I feel good, I get my energy and appetite back and do not have pain. That has a strong effect on my attitude and my hopefulness.

Pam felt “very poorly” for several months after her cancer surgery, having to “fight depression.” She prayed that God would help her to discover the reason. As a result of answers to prayer she started taking vitamin and mineral supplements and reading nutrition books. “I started taking colloidal minerals and vitamins, heavy in vitamin C and vitamin E, and other vitamins. And it was not three or four days, I started feeling wonderful, and I have been taking them ever since.”

The symptoms described in the preceding data are unpleasant in and of themselves, often interfering with desired life activities. However, the link to hopefulness makes relief doubly important. Participants have many self-strategies for feeling better, but there are many obvious areas where nursing intervention could influence these physical and emotional states and assist the client to feel better. When relief is not possible, the participant’s capacity to endure is tested. The relationship of physical pain, fatigue, and other symptoms to hopefulness may have been more obvious to other nurses than it was to the researcher, prior to collecting these data.

Negative Hope-Influencing Factors from the Internal Environment

Data from this study are primarily focused on positive hope-influencing factors. However, all participants were asked about and did discuss hope threatening or draining factors to some extent. There were insufficient data to categorize by sub-themes other than environmental domain and the overriding theme of loss. Nearly all examples involve loss or threats of loss – from basic need satisfactions to anticipated longevity, from loss clear thinking to loss of one’s mind to psychosis. Loss of

significant others by death or breakup of a relationship has been mentioned by a few participants as a possible contributing factor to the development of cancer. Grieving and concurrent losses have been linked to loss of hope in previous studies (Herth, 1989; Herth, 1993b). Previous research findings on the relationship of symptoms and hope were cited in the preceding category, Feeling Good/Asymptomatic.

Participant illustrations of negative hope-influencing factors are grouped by self, other humans, and the non-human environment, and will follow each section of positive hope-influencing factors. The following section provides examples of negative hope-influencing factors (threats to hope) that fall into the realm of “self” or the internal environment. Ten of fifteen participants provided examples for this category.

During the bone marrow transplant, Emily described feeling very ill and wanting to die. This was the worst thing she had ever been through. “You’re thinking, ‘I’m really sick, I’ve got this rash all over my body, I don’t think I could feel any worse, I’ve got blisters under my arms and in my vagina and my rectum and I’m bleeding... I’m just so, so sick’... I felt so down... Maybe I’m not going to make it.”

The negative story continued as Emily described her feelings of isolation and weakness during the bone marrow transplant. “I was isolated... I only got out of my room twice in six weeks.” She lost muscle tone in her previously toned legs. “I could hardly walk when I got out of there... That’s a long time of laying down.” Although describing herself as a person with few fears ordinarily, the experience of bone marrow

transplant was very frightening. During that time she experienced feelings of uncertainty, physical deterioration, and impaired thinking. At least three times during the interview, Emily said she always tries to think positively about the future. However, she admitted to engaging in negative self-talk during the bone marrow transplant experience.

During the bone marrow transplant and recovery, Emily was away from work for about eight months. When finally going back to work, Emily felt frightened, weak, and unsure of her ability to do the technical job she held.

I went back to work, and I was really scared to go back to work. But my doctor said, You have no evidence of disease, you have to go back to work.” And I’m thinking, “But I’m still so weak.” And high-dose chemo affects your brain. I don’t care what anybody says – so if I go off on a tangent, just pull me back – chemo does affect your brain... You don’t have a cut-off valve at your neck that says chemo don’t go. It goes to your brain, and it does affect you. It affects your memory, your spelling, everything... When I went back to work, I was scared because my job was technical, and I had to do schematics and troubleshoot equipment. It was very technical, and I was afraid I couldn’t do it... Anyway, I went back to work.

The reoccurrence of cancer was a threat to Emily’s newly regained strength and hope. This setback happened about a year after she had recovered from the bone marrow transplant and returned to work. “I thought my life was back on track... Everything was behind me... I was just out there in ‘la la’ land.” She remembers the day she discovered the lump in her neck. “I was in a seminar, a retirement seminar, and I was feeling my neck, and I found a pea-sized node... I’ve never had one here... That’s weird!” The reoccurrence was harder on Emily than the initial diagnosis,

“because I had been through so much.” Since that time, six years ago, she has not been cancer free, undergoing almost continuous chemotherapy of many varieties.

Angie recalled two times since her diagnosis in which her sense of hopefulness had been very low. The first was during the period after the initial diagnosis and recently when she moved to a new home. She had a few weeks to get this huge task accomplished became totally exhausted in the process. “I was physically and mentally exhausted, and I had abused my prescription medicine and... I thought I was going to die.” During her recent exhaustion and drug withdrawal, Angie was told by her family to go to the hospital, but she refused. “I stayed at my sister’s and rested until I was able to come out of it.” Being at her “second home” was a more hopeful option than hospitalization at that time. Emily did not consider the hospital a hopeful place due to the number of painful things that had happened to her while hospitalized – “bowel obstructions, bags draining, ileostomy, needles... to me you get worse in the hospital.”

Similar to Emily’s experience of physical discomfort during the bone marrow transplant, Angie links her physical feelings to loss of hope. “The greatest source of hope from within myself is how I physically feel... If I don’t feel physically good, everything else goes to pot.” The worst feelings were “exhaustion... fatigue, because I have a tendency to do more than I should...neuropathy in my feet... they hurt... I’m very, very stiff in the morning... I have a lot of joint pain.” All of these are “directly related to the chemotherapy.”

Maggy's low point, like many others, was right after finding out she had cancer, "probably the day I got the diagnosis... March 8th... when the doctor told me."

She describes how she overcame the initial shock.

I worked through the shock and I got over it... once I got over the initial shock (that took about a day and a half)... And I'm one of those that I have to pull back, retreat, pull myself together. And then by the Wednesday after I found out on Monday, it was, 'Okay, whatever has to be done, we'll take care of it, and we'll get it done.'

Maggy described a decreasing hope perception, loss of personhood, and unpleasant side effects of chemotherapy. Chemotherapy caused her to "get dormant for a while... sometimes you feel like you're not a person... you feel like you're a pin cushion." When treatments are over, "you start getting your energy back, you start becoming a person again... all of a sudden when you're finished, you spring into life."

Sometimes when reading a story about someone who died of cancer or an article about cancer in general, Maggy feels a loss of hope. "I was reading an article in the paper last night where there are some cancers that they are getting a hold of, but breast cancer has gone on the rise. Well, that's alarming, and you have to work with it. You can't let yourself be alarmed."

Maggy admitted to few negative thoughts. When feeling tired at work, she occasionally daydreams, takes "mini vacations" in her mind. She reported that, during these episodes, her mind sometimes wanders into the negative realm. "But if I felt tired, I would just rest and maybe daydream. Take a mini vacation in my mind, and I do that a lot of the time. My thoughts may wander... but they never wander, maybe

once or twice... would I wander to a negative realm. I don't think like that."

Sheila's point of lowest hope was during her bone marrow transplant experience. She had a psychotic reaction to the combination of morphine and acyclovir, and described frightening hallucinations and suicidal ideations. Looking back on the psychotic episode was hard for Sheila because it was so "awful" and hard to imagine. After the experience, it took her a long time to be able to talk about it.

When I was psychotic from the reaction of the morphine and stuff, it seemed logical to me at that point that I should die... That if my being alive was causing pain for somebody else, then I didn't need to be there, and that was really strange. That whole thing was, because what I was hallucinating was, you know, that breathing thing that they give you, that you have to blow, blow, blow, and make the thing go up and down... If I couldn't make that work, then they were killing people. That was my hallucination, and I was seeing a video on the wall that was not there... Then you go back into the hospital with pneumonia, and they give you one of those things again. There's nothing you can say, "You don't understand what this thing says to me, or what this thing does to me... the connections I made to this thing." That was pretty... really scary... I mean suicide seemed like an option. I didn't know how I was going to do it... It just seemed to me that I felt like it... Which is probably why they had me in a straight jacket.

Sheila also discussed the debilitating fatigue of cancer patients. She describes the fatigue as "genuine... not just in your head." The fatigue is so severe that "it can really knock you flat." Another discomfort she mentioned was the hospital bed, necessitating "chiropractic work" after discharge.

Holly's lowest hope was during her initial chemotherapy when she felt very ill, vomited at night, and thought she was not going to make it. "The first time between September and December 1998, I was taking chemo that would make me sick. In the

middle of the night, I would throw up and everything, and I just felt like... This is it. I'm not gonna last."

Walter told several stories of decreased hopefulness, the lowest during his diagnostic phase. He is a retired physician who specialized in internal medicine. His medical knowledge did not contribute to hopefulness. He initially declined any therapy because he did not feel too bad and feared a poor response in a person his age. Rather, he chose to read medical literature on his diagnosis. Church, confidence in the minister, and faith kept him going during this down time.

So the question was, "Should I have therapy?"... That was my low point. I have dealt with enough leukemia of this acute type, especially acute myelomonocytic type. It does not respond worth a hoot in older people, and they are sick as a dog. I felt pretty good... So I said 'I would just like to look into it more and could you get your librarian to get me some literature on this?'... She found about twenty some odd cases at that time, and I read each one of them carefully, and none of them fit my case. I still felt pretty good, and I said, 'I would like to just be followed... Right now, I do not want any treatment.' And they agreed that is one alternative... because you have to go into the hospital for about six weeks for intense chemotherapy that requires constant blood counts and blood transfusions. And you are sick and almost have to be isolated to keep from getting infections, and on and on and on... If I was not going to respond, I didn't want to do that... Basically, I had given up as far as any significant length of living. And, now in the meantime, I had taken up going to church every week, and I did get some satisfaction from that... I had a lot of confidence in the minister, and so faith kept me going to a large extent, morale wise.

Walter told another story of decreased hopefulness after radiation therapy when he experienced excruciating pain from a mass, "big as a hen egg," in his neck. The presence of uncontrolled pain drained his hope to the point that he was contemplating suicide.

I never had such excruciating pain. It got up into my mastoid and the back of my neck. I had oral narcotics and hydrocortisone, but it would not relieve the pain at all, and this is where I was really getting low. And I thought, if I have to go through this, I would rather just kiss it off. But I am not going to holler for Dr. Kevorkian. But you know... if he had dropped by, he might have gotten an invitation to talk to me.

When his neck began to drain, Walter self diagnosed the mass as an abscess and requested a surgeon. On the way to the operating room, his hope was so low that he began to pray not to wake up from the anesthesia.

They discussed with me what they were going to do, to put me to sleep. I can remember this so well. When I was going down the hallway to the operating room, I knew I was going to go to sleep... I can tell you this, I was praying to myself, 'I hope I don't ever wake up. I don't want to go through this any more.' So, that was a low point if you want to call it that. Then I woke up in the Intensive Care Unit during that night... moaning and groaning, and I thought I was in Dante's hell, almost. Then they gave me enough medicine, sedation, that it caused me to have urinary incontinence. And they had given me a lot of I.V. fluids during all of this. It took them about three or four hours to work on my neck to get it drained... I was so embarrassed... I just had an overflow of urine. I managed that, but it took forever to get this neck healed over, like months, and I can say that I have never gotten my strength back after that radiation.

Karl, who had rated himself as "nine" on the one to ten hope scale, reflected about the time when his hope was as low as he could remember. This was just a few months ago, when he found out that his cancer had metastasized to his spine and pelvis. The discouraging news and side effects of chemotherapy and radiation dropped his hope to a "two" on the scale. He stated, "I was sick physically and mentally."

I think what comes to mind was a few months ago when I learned that this was not metastasis to my hip, but there were multiple metastases to my spine and pelvis. Once they started with the chemo and radiation again, the physical and

mental challenge was its greatest, and on that scale, I probably got down to two.

Receiving simultaneous treatments with chemotherapy and radiation was especially “tough” for Karl. He said he would almost consider another surgery before going through a month or six weeks of chemotherapy and radiation at the same time. “That is sort of a silent enemy.”

The presence of physical symptoms – discomforts such as pain, weakness, nausea, insomnia, and fatigue – is something that decreases hopefulness in Karl, regardless of his current prognosis. He mentioned another distressing symptom, even more critical to survival that occurred in the Intensive Care Unit after his initial surgery. “I had to have a tracheostomy. They left the ‘trach’ in for about a week, and I did not sleep for five days and nights because I could not breathe... I would not lie down because I could not breathe.”

What I notice is that when I’m having physical pain or weakness, fatigue, or even nausea, then that tends to work on getting me down, even though there is no change in prognosis. When I feel good, when I get my energy and appetite back and do not have pain, then that has a strong effect on my attitude and my hopefulness.

Karl was surprised to see how frightened he was even though, he thought he had a lot of faith. “When you are face to face with death, you do not want to go, and you want to stay around a lot longer.” He admitted to periods when he felt “worried” every day.

That comes in spells, because over the last year I have had times when it looked like I had beaten this thing and was going to win, and I could sleep well

at night, had a good appetite, and was ready to get up and get about my business each day. And then there were times when I really did not know. My wife really did not know how long I had or what was going to happen. And those were sleepless nights, and I think the mental and physical strain both had me pretty ripped. I could get to work, and I could get to the table, and take a walk outside, but it was like I was walking on thin ice and really had to put a front on to get a smile out and be animated. I was like a zombie walking around, you know, at those times.

Watching the news, movies, and reading novels were not hopeful activities for Karl, during the first few months after his diagnosis. He preferred reading inspirational books, “books that were written about how to cope, how to make God more a part of your daily life, and how to gain hope and peace, and even joy during trying times.” Something that taught him a life lesson or was reassuring was needed during these difficult months.

I was, interestingly enough, pretty well turned off by everything on television and movies, and the novels that people gave me... I just could not sit there and absorb... I started seeing the news sometimes, and I could not even watch the news about the school shootings and the Kosovo refugees, and all the atrocities that go on, and even the storms that were killing people and destroying lives – that was something that I just could not handle.

Louis identified “my last cycle of chemotherapy” as his lowest period of his hope. He started into it in a vulnerable state. “I did not really think I could handle it, a lot of I.V.’s, an I.V. every day, and I was just beat down.” Reflecting further, he recalled his diagnostic phase, when he began to question whether he could provide for his family in the future and wondered what he would lose in the course of this illness.

When I became diagnosed with cancer, that kind of set me back wondering how I could be a provider and how things could work out, because I have always felt like if you have health, you can make a go in America, you know, at

anything... Then when I lost my health, that caused me some depression... I was always real healthy and semi-athletic and enjoyed being outdoors and doing all those kinds of things – hunting, fishing, sports, golf and tennis – then when you think you might not can do those things, it is kind of a downer.

Loss of control, loss of self worth, being out of touch and feeling unneeded troubled Louis as he finished his chemotherapy and thought about returning to work. He felt “lost” and “really down.” Encouragement from his business partner, also a cancer patient, helped pull him out of the slump. When his partner became ill, he “had to pull himself together” and get back to work to be “the man in charge.”

At the end of my chemotherapy, March 31, 1998, I had always been in control of this particular business here (a company I started), and I had been away from it for three months. I did not work or do anything involving the business for three months because I just did not feel like it, and my white blood cell count was too low to be around people. So I was totally out of control for three months, and then realized, when I was done with my treatment, that I was going to be back in the workplace. And I felt unneeded because, obviously, they were doing okay without me, and I really was not hitting on all cylinders, so it was not like I was a great contributor when I came back. And I did not know all the stuff that had been going on for three months, so I was kind of lost, and I really got down. Feeling like I was not worthwhile, and that was kind of sad for me. It made me feel sad because I could not snap out of it. I just felt like I was not doing anybody any good. I did not feel good at home, so I was not doing much there, and I was not doing much here.

Louis had memories from childhood that influenced his hopefulness negatively. His uncle had experienced cancer and he remembered his parents talking about it in the kitchen. Louis’s impression of persons with cancer and chemotherapy was that they were close to dying.

Nobody really knows what to think about chemotherapy unless they are involved with it. But your typical, my generation’s typical experience was that, just for me, I had an uncle who had cancer, in the sixties and seventies. When

you would see somebody with cancer, basically chemo was just the next thing before they died. And generally, when you are ten years old or whatever, I was ten in 1970, and chemotherapy just seemed like something they were practicing with because almost everybody I can remember never... I can remember hearing my parents in the kitchen saying, 'Well, he has got cancer. You know he is going to die.' Even though people would try to say, 'Hey, we're praying for you,' I always felt like, for the most part, people thought you were a goner. That was the feeling I got, that it is not curable. It is just prolongable. That is what I felt like.

After talking about Lance Armstrong's web site on the Internet as a "hopeful thing," he recalled another web site, the "Testicular Cancer" web site that had some very discouraging personal stories of what happened to individuals after getting cancer.

A lot of those were very depressing... I would read those thinking initially, 'Hey, here is something, this is going to be pretty helpful.' Then you read it, and here is a guy who has had chemo... He has had surgery... He has had to sell his house, and he was basically writing a story... to warn others of how bad things were... Somebody on chemo... he vomited and vomited until he thought he could not vomit any more... You are just like, I don't even want to read this... There were some very helpful ones that may have said, 'I have been cancer free for two years now,' or 'I went through this.' Seemed like, at the time, there were less hopeful ones and more kind of depressive-type stories.

Pam had a tendency to blame herself for getting cancer in the first place – for not eating right, not exercising, being overweight, and having too much stress. She had some "nagging" doubts about one of her treatment decisions, not to have chemotherapy after her mastectomy. She said she had to "fight depression" for a long time after her diagnosis and surgery. These feelings, guilt and self doubt, were recalled as threats to hopefulness. Pam sounded very depressed for a long time after her cancer diagnosis and surgery. She was unable to do one of her favorite activities,

reading, because her mind was unable to focus. Her impaired thinking was “depressing” to her and she had to watch television as an alternative to reading. “I love to read, but I could not read. I guess it was the anesthesia. My mind would not focus. I had a real hard time with that. That was depressing. That was the most depressing thing – that I could not think real well, I could not focus. So I watched TV.”

Audrey recalled her time of lowest hope as being “the day I had the biopsy.” She and her husband had just had a baby daughter in October and her biopsy was in December. She was about to start her last semester of nursing school. Audrey recalled the day of the biopsy, “coming home and going into the baby’s room and just crying.” She felt that cancer had come unfairly and unexpectedly into her life. “I had just had a baby. I had all this stuff going on, and I had planned on doing the screenings and stuff when I turned thirty. Well, I was pregnant, so I could not start mammograms. So, then I started taking it like it kind of beat me to the punch, and that was when I got mad.”

Based on the findings of this study, it appears that negative hope-influencing factors revolved around feelings of real or threatened loss. For the internal environment examples included loss of longevity, loss of control, loss of self-esteem, loss of future plans or goals, loss of comfort, loss of clear thinking, loss of energy or vitality, and loss of ability to perform desired activities. Losses interfere with an individual’s hoping process requiring time, energy, and usually assistance to overcome.

There are many obvious implications for nursing intervention to assist persons with negative factors from the internal environment by meeting basic human needs.

As the focus shifts to the external environment in the next part of this chapter, the self is not removed, but remains integral to interactions and interpretations the participants make of their external environment.

Positive Hope-Influencing Factors from the External Human Environment

Hope-influencing factors from the external environment come from the world outside the self, all that surrounds an individual, both human and non-human. This section covers analysis and interpretations of data obtained in answer to research questions two, found in Chapter I: “From the patient’s perspective, what interactions in the external human environment (other persons) impact the hoping process positively (sources of hope) and negatively (threats to hope)?” For research question two, participants were asked to think of and tell about interactions with persons in their lives who influenced their hopefulness positively (sources of hope) or negatively (threats to hope).

It is again recognized that all perceptions of the external environment are filtered through and influenced by the self (internal environment). It is further noted that perceptions of human beings and their surroundings are often difficult to truly separate. For instance, perceptions of a home are often influenced by perceptions the occupants living there. Perceptions of a hospital or a chemotherapy department are often influenced by perceptions of the health caregivers working there. Past memories

and experiences in certain environments come forward to influence present perceptions, e.g. childhood experiences. All realms of the total environment interact to influence each other.

The impact of other human beings as sources of hope has been widely reported in nursing literature on hope. Many nurse authors and researchers who have studied hope have illuminated human “relational or affiliative” aspects of hope inspiration (Dufault & Martocchio, 1985, Miller, 1992). It has been consistently recognized that the human environmental impact on a patient’s hoping process is critical. Farran et al. (1995) described a HOPE acronym. “Other”, represented by “O” in the acronym, signifies the *relational process* of hope. Authors recommend assessing and promoting relationships with significant others to promote hopefulness. Miller (1989) linked social support, generally considered to be emotional support and material aid by other persons, with hope. Both social support and self-esteem have been positively correlated with hope in studies of patients with multiple sclerosis (Foote et al., 1990) and spinal cord injuries (Piazza et al., 1991). “Social Support is necessary for an individual to acquire the personal resources and material aid and promote continuing human development. The person can obtain emotional support, help and reassurance through social support networks” (Foote et al., p. 156). Results suggest that nursing strategies encouraging support from other humans will help facilitate the hoping process in patients.

In two separate studies, Herth (1990b, 1993b) found similar results regarding the importance of supportive human relationships to hope maintenance in two groups (terminally-ill adults and family caregivers). “Interpersonal connectedness” and “sustaining relationships” were the labels given to these hope-fostering categories. In the study by O’Connor et al. (1990), thirty persons recently diagnosed with cancer, described significant things in their lives they wanted to live for – trips, events, and most importantly, other people. Just thinking about family members helped one participant maintain hope.

Ballard et al. (1997) also interviewed recently diagnosed cancer patients (n=20) and found they relied on other persons, especially nurses and physicians as primary sources of hope. Raleigh (1992) interviewed ninety patients with cancer or chronic illness to identify and explore sources of hope. Among the three most frequently reported sources supporting hopefulness were family and friends. Visiting, listening to, talking to, cheering up, and physically helping patients were methods by which other persons supported hope in this group.

All fifteen participants in this study discussed positive and negative interactions with other human beings that influenced their hoping processes while living with cancer. The specific questions for this domain are listed in the Interview Guide found in Appendix A. The initial broad question asked participants to think about who (other persons) in their lives served as sources of hope for them. Participants consistently mentioned their relationships to significant persons in their discussions of

hope-influencing interactions. Hope-supportive interactions were described as occurring in many types of human relationships. Family members – spouses, siblings, parents, grandparents, children, grandchildren – provided many types of invaluable support to the persons with cancer. During the diagnostic process, outpatient care, hospitalizations, and home care, the supportive actions of family members were crucial to well-being and hopefulness. Friends, employers, coworkers, members of faith communities, and support group members were frequently mentioned for their gifts and services, which also aided the hoping process. Members of the healthcare professions, usually doctors and nurses, were frequently identified as positive hope-influencing factors.

The results of the analysis of data for this section will be presented according to relational groupings, with examples of the myriad types of hope-supportive interactions described by the participants. Theme categories that emerged from participant data for all relational groupings except health care providers include the following: encouragement (positive expectations, boosting spirits, supporting self-esteem, empathizing, accepting), companionship (presence, closeness, togetherness), love (affection, caring), gifts (food, books, blood, bone marrow, services), communications (cards, calls, visits, e-mails, talks, listening), and role modeling (hope, faith, strength, peace). Special theme categories were developed for interactions with health care providers. These will be presented before the participant data for that relational group.

As the illustrations of participant data are presented, the reader will frequently notice the presence of more than one theme in a participant vignette or excerpt. It was judged by the researcher to be most appropriate to present each participant's perceptions of hope-influencing interactions with other humans intact, by relational groupings, rather than fragmenting their stories into the individual themes. The themes induced were each supported by fewer participants than the self-strategies, further supporting the decision to present these data by relational groupings. Overall, the volume of data obtained for hope-influencing factors from the external human environment was less than for the internal environment.

The negative hope-influencing persons and interactions will be presented following discussion of the positives. Given that there were fewer negative than positive factors reported for the human environment, the negatives are presented together and not divided into relational groupings. Again the theme of loss pervades the threats to hope in this environmental domain.

Participants in this study describe as follows their positive perceptions of the influence of other persons on their hoping processes.

Spouses

Spouses of participants were frequently mentioned sources of hope for participants. Of the fifteen persons interviewed, eleven were married one was engaged, one was single and never married, one was divorced, and one was widowed. Eight of the married participants described their spouse as a source of hope during the

cancer experience. The one who was engaged also mentioned her fiancé as a positive factor and the one who was widowed discussed at length the support of her spouse who had died of cancer himself. There were many ways in which participants perceived their spouses as supporting hopefulness.

Marcia, who was engaged at the time of diagnosis, but has been married since then, described positive interactions with her fiancé. These are exemplified by his presence, encouragement, and support her sagging self-esteem. In her final evaluation, “He was a big source of hope!”

He went with me... Two days after I found out I had cancer, they sent me over to the cancer center. I met all these people, and I saw all the videos, and he was with me. At one point he cried, and that was the last time I ever saw him cry. From then on, he said, “We’re going to get through this. We’re going to get married and live to be old people.” And there were very many times when I felt depressed, when I lost my hair, and he would say, “You’re beautiful. It will grow back.” So, you know, he was a big [emphatically] source of hope.

Maggie also was comforted by her husband’s presence during the initial shock phase of the diagnosis. “He stayed with me all the time, he did not leave my side.”

Paul named “my wife” as the one person who was most helpful in supporting his hope.

She is probably as close as you can get to the ups and downs, and seeing me at my lowest points, and my highest points, and all the points in between. Her strength, she is a very loving person. She is a very giving person. That has been good for me because I can see how much she is giving, and it makes me see how little I am giving.

Sheila’s thoughts of her spouse were of not wanting to leave him alone if she were to die. If that was her fate, she felt that, “Somebody will take care of him.”

Even though her husband “doesn’t do hospitals well”, both he and her mother stayed with her at the hospital in another city during her bone marrow transplant. The bone marrow transplant was a particularly frightening experience for her, complicated by psychosis from a drug reaction. During this difficult time, their presence was felt by her even though they couldn’t be in the room with her, “I knew my Mom and husband were there.” She could count on her husband to reassure her when she needed to hear it, reminding her of their partnership, “We’re going to get through this – together. We’re going to get through this.”

Holly’s described her spouse as “sick,” having had two slight strokes, high blood pressure, and back problems. In spite of these limitations, he has done all the cooking since she was diagnosed. “He takes care of everything. He cooks every evening now that I don’t.”

Bert feels hopeful when he looks at his wife, whom he considers “the most capable and strongest person” he knows. He is further supported by “her willingness to accept the way that I am, her strong background and beliefs, and her ability to be just together when all of this is going on.”

Karl described support from his wife and benefits to his marriage in the process of dealing with cancer. “My wife was there every step of the way and really put her life totally on hold to rearrange everything around me and what I needed.” Their “love and intimacy was rekindled.” This illness “has really drawn us close” after thirty years of marriage, and “not a lot left new to it.” If he was awake and could not sleep at

three o'clock in the morning she would sit up and say, "Let's talk if we need to talk." He felt that his wife "actually suffered mentally and spiritually along with me when times were rough."

Robin described the response of her husband to her breast cancer diagnosis and care. "He was extremely supportive and caring." She attributed his positive response to the fact that he, as a child, had been through breast cancer and difficult cobalt treatments with his mother. "She survived many years after that, so I think he had a hopefulness too." Her husband was a very "positive person" and "could not have been more loving and supportive through it all." He had cancer at the same time as Robin, but did not survive his.

Walter, in his seventies, talked of going to a variety of church and volunteer activities with his wife during the time since retirement and becoming ill with cancer. Together they have been on bus trips with other retired persons and worked together on family genealogy. "Mainly I tag along after [wife]... I found out that I have a good wife to live my life with." His wife, who listened to part of the interview, admitted, "I keep him busy."

Parents and Grandparents

Marcia attributed her ability to stay hopeful and keep a positive attitude to her heritage and the example set by her mother, grandmother, and great-grandmother.

That grandmother's mother lived until she was ninety-two... She was a very positive go-getter... And she was a pray-er, and so it's just been in my family, my mom's family. That's where I got it... Seeing what they've gone through

in their lives, the way they've handled loss, and how they've been able to carry on with a very positive attitude regardless of what happened in their lives... you know, we're not guaranteed anything, but we can make the most of what we have.

Regular telephone conversations with her eighty-seven year old grandmother bring hopefulness and encouragement for Marcia. Interactions with her grandmother exemplify hope for Marcia.

I can call her on the phone, and before we get off the phone, I'll realize before I hang up, there she did it, she put that little word in there or a little sentence... I called her Sunday, and she said she and my grandfather had decided... here they'd made it to their sixty-eighth wedding anniversary, but they were going to shoot for their seventy-fifth... And she said, you know, "We just pray that God lets us be healthy enough so that we can see those days." To me, that's hope.

When asked specifically how her mother helped her stay hopeful, Marcia discussed her encouragement and presence during difficult times.

She's an encourager, and when I went through my cancer treatment, she came down a lot and was with me... She knew that I was going to be able to handle all of it, and that I was going to come through this... She spent a lot of time with us... Every time I had a chemo treatment, she would come and stay with us a couple of days afterward because I would get extremely sick.

Sheila spoke of her mother as "there through the whole thing," traveling from another state and staying for several months. During the long weeks in the hospital, her mother "never left" and spent time reading to her and praying with her. Sheila described her mother as "an amazing woman...with an amazing faith...and I am sure that has a lot to do with who I am". Besides her presence and prayers, Sheila's mother, like Marcia's, served as a role model for her daughter.

Audrey was a member of the second generation to experience breast cancer after both her mother and her aunt had gone through the experience many years earlier. “My Mother is big into Reach to Recovery. She goes and visits people... My Mom and I have talked a lot... She is a source of hope because she had nodes that were involved and I did not, but she has done well.”

Bert’s respect and praise for his parents was often repeated in his interview. “I look at my parents and I think, if I can only be half as good as my parents... I would leave this earth a happy person. Their care and their hopefulness plays a major role... They are wonderful people... lots of love and care.”

Louis received aid and encouragement from his elderly father during his all day outpatient chemotherapy treatments. His father would come to the hospital, bring him lunch, and talk to him.

During treatment, he would bring me my lunch because if you are on an all day treatment, they do not bring you your lunch, so you rely on family or someone to bring it. And my Dad would usually come up there and bring me some soup or something light that I could eat without getting sick, and he would talk to me, and that was kind of encouraging.

Louis’s mother and father were described as “pretty thorough newspaper readers.” They would watch for and point out stories, like an article about the mayor of Austin, Texas, also a testicular cancer survivor. “During my illness, there was some story on him, and he had been cancer free for nine years, so that was positive to hear of a true-to-life survival story.”

Siblings

When asked to tell about the first thing that came to her mind as a hope-influencing factor, Angie talked about her sister as someone who serves as a role model, “I try to pattern my behavior after her... taking better care of myself, thinking more rationally, and taking one step at a time.” During the time that she was undergoing chemotherapy, Angie lived with her sister’s family receiving care such as specially prepared meals and companionship. “I don’t have to be alone there because her family is there, and my niece... I just don’t feel isolated.”

Three other participants also mentioned sisters as hope-supportive persons. Sheila talked with pride about her younger sister who was a “near perfect match” as a bone marrow donor. It was “a very special part of what was going on” to have her sister as her marrow donor.

Emily admitted to not being particularly close to her oldest sister before cancer, and finding a new closeness and love in this relationship after her diagnosis.

I tell people, I think I felt more loved when I had cancer than I ever have in my life because... even my own sister. She and I were not real, real close. There was so much age difference... She just said, “I knew I loved you, but I just didn’t know how much I loved you until you got cancer.” I mean, she and I are so close now, and I don’t know that we ever would have had that. I don’t know, I was the baby, and she thought mother was partial to me, and she had her six kids... Her kids are my age or older. My sister is like twenty-one years older than me.

Audrey, who was diagnosed with cancer while trying to finish nursing school, described the encouragement and aid of her younger sister and the role reversal that happened in their relationship.

My sister, I think, got mad at me because she wanted me to take more care of myself. Like I said, I was doing all this stuff, and she was one of the ones too who said, "Well, why don't you just wait and do this?" She is my younger sister... She was always the one who was a little bit of a troublemaker, and I was the big sister and would take care of things. And so, I think, she was more afraid of losing me, me dying, so she wanted me to "forget all this other stuff and take care of yourself." At the time, my sister had moved back home for a few months. She was coming up to help with [Audrey's infant daughter]. My sister has always been the kind who was terribly afraid of babies... but she came. She stayed with us. She would help with [daughter]. She had to hold [daughter] when she got her first immunizations because I had had surgery and could not hold her, so the way I looked at her changed too... because I had been taking care of her... I saw her differently.

Later in the interview, Audrey mentioned her own cancer experience having a positive influence on her sister's health care practices. "She's a lot more into doing her mammograms now."

Karl stated that his "sisters and brothers did as much as they could with the distance involved." They had come to visit and wanted to help all they could. He felt that the experience of cancer had brought his entire family closer. Since he has developed cancer, Karl's extended family has "had a couple of reunions so we all could get together and have a little fun."

Children and Grandchildren

Children of all ages were frequently described as positive hope-influencing factors. Bert, the father of four children under the age of fourteen, admitted, "My

children just have to look at me and that gives me all the hope in the world, and I just have to look at them... They are great therapy!”

Deana waited until after Christmas to tell her children about the diagnosis. Her oldest son responded, “Well, Mother, it’s not like you’re dying!” Deana realized the truth in this and said, “You’re right, it’s not.” Looking back on this, she said, “That was a source of hope right there!”

Audrey believed that not all parents might elect to tell their young children about a parent’s cancer diagnosis. She did tell her four-year old son about her cancer and chemotherapy, with positive results.

My son... he was real cool about it. He was four when all this happened, and I remember when I had to tell him about when my hair was going to fall out. He had had some steroids for something, and the doctor told him, “Okay, you might feel a little bit hungry over the next couple of days while you are taking these.” So I told him, “You remember when the doctor told you that when you take this medicine, you might get a little bit hungry from it,” and he said, “yea.” “Well, the medicine mommy has got to take will make her hair fall out.” He said, “Oh, but it will come back?” I said, “Yea, it will come back.” He said, “Well, then, that is okay.” He was four, and I know some people do not want to tell their kids, but kids know what is going on. When something is going on in the house, they know, and I did not want to tell him everything was fine because what if mommy is sick, he would want to know.

Audrey’s son also gave her his special Batman toy to take with her and help her during the chemotherapy treatments. Audrey admitted to carrying that little Batman toy around in her purse for some time during and after her chemotherapy. Its power, significance and symbolism were an important source of hope for her. “He had given me his Batman to go with me to chemo, and he was big into Batman at the time.

He said, "Here, you can take this with you. Can you play with it while you're there?" I remember thinking, "Okay, Batman is like chemo, then I guess Two-face is like the cancer cells".

Marcia's teenage daughter was one of the top three persons most important in helping her to stay hopeful. Besides cooking for her, Marcia's daughter was described as "always there when I came home from a treatment, any kind of a treatment, or home from work."

Sheila's teenagers decorated her hospital room with cards and posters and tried to be cheerful even though she knew the times were difficult for them. Her teenage daughter came to understand her mother's symptoms very well, and better than most other family members. "There is a certain understanding of what 'really, really sick' is and what 'not quite so sick' is, and how you can deal with it." It was comfort for her to know that her daughter understood this, could remain calm, and would know what to do.

Holly's four daughters and two granddaughters are "all around to visit me." They've always been a "close knit family." Her daughters help her clean, go shopping with her, talk to her when she feels down, laugh and cut up with her, and rub her feet. Holly says, "They just really pamper me." With the closeness and love comes the realization, "We're so close that it's gonna hurt when any of us pass because there is so much love."

Louis was very touched by the support he received from his immediate family, especially his young children, during the time that he received chemotherapy and was often at home feeling ill.

You will probably think this is corny, but, with my kids, my little boy, he was at that age where he liked to see karate guys and stuff, and he wanted to do karate, and we would watch Walker Texas Ranger. And the reruns would come on at seven o'clock... I would come home from my treatment, and they would eat. Then [my wife] would usually bring some soup on a TV tray to my bed. And then they would come up, and we would watch Ranger... Anyway, I kind of looked forward to that. It was like my daily highlight, and I did not really think of it until you just asked me, but that was a big highlight... I would say the encouragement by my own immediate family, my wife and my children... When I was ill and felt like it, I would eat supper at the supper table. We would always pray before we ate, and my kids would pray that Daddy would get well. And you find yourself crying while you are trying to eat supper, and I felt like I wanted to see them grow up and that I had a lot of things to live for.

Louis, like Bert, just had to look at his children to feel encouraged, "Just seeing them gave me encouragement to want to live and take care of them."

The participants who had grandchildren – Sheila, Holly, Walter, Deana, Karl, and Pam – all mentioned their young grandchildren with warmth, pride, and joy at various points in the interviews. Sheila, grandmother of two, was her daughter's labor coach and helped with the birth of her second granddaughter. "That was a major thrill, a joy. I never should have seen either one of them. That is the only time I saw my husband break down. The first time I held our first grandbaby, and he looked and said, "You're not supposed to be here, and he just collapsed."

Deana stated, “Well I feel hopeful when I am with my three-year-old grandson. I want to see him graduate from college, and that could be a while, but I will be here.”

Walter almost puffed up when he said, “I have one grandchild that is just the apple of my eye who is so brilliant it is almost unreal. He is number one percent nationwide in his scholastic scoring for Hispanics.” He went on to tell that this young man had a presidential recommendation to the Air Force Academy and how he has “really enjoyed seeing him come through high school and getting what he wants.” This has occurred in the past few years, beginning when Walter was “first sick.” Desires to see one’s progeny grow and develop definitely seem to enhance hopefulness.

Friends

Emily expressed with amazement the amount of support she received from friends she didn’t even know she had before being diagnosed with cancer.

I had a lot of support... You just don’t know how many friends you have I think until you go through something like this. I had to have transfusions. There were so many people from work. I called a friend of mine and said I need some donors and thirty minutes later he called... I needed seven and he had fourteen. People just really were supportive in every way.

During her bone marrow transplant Emily described having “lots of company” every day and receiving much love and many prayers. “I was surrounded by people that loved me. I got cards every day and people were praying for me all the time.” These benefits were so important to her that she never refused company even though there were many times when she didn’t feel like having company.

Angie talked at length about “my good friend Emily, a nine year cancer survivor,” and fellow participant in this study. For Angie, Emily represents an example of hope, acceptance, and living on in spite of having cancer.

She’s always very hopeful, accepts the cards dealt to her, and lives each day as fully as possible. She says the cancer will eventually kill her but she’s going to enjoy the time she has. They gave her six months to live and she’s lived nine years. So that’s a powerful [loudly] example... She never is down in the dumps really... She has a positive attitude and she is a fighter.

Paul described feeling that his friends were behind him and helped him to feel energized and motivated to keep going when they are together.

I see my friends in a different way. I think that they are behind me is the main thing, and that really helps – the energy of that. And I believe that it sounds kind of crazy, but, you know, it’s one of these kinds of deals where I don’t have any physical evidence to prove it, but I feel that when people get together there is something going on. I feel energized. I feel motivated to go on... you know...to keep going.

Friends as a source of hope mean a great deal to Bert, who has had numerous hospitalizations for removal of reoccurring tumors. Of his friends and healing he states, “We are very close... If you have ever had five surgeries... you get a lot of attention... The amount of attention that you get, it is wonderful. It helps the body heal. It helps the mind heal.” He mentioned having received many “beautiful gifts.” The hope that he has received from them “was not from the gifts, but from the individuals who brought them.”

Karl and Pam both received helpful books about coping with cancer as gifts from friends. For Karl these were frequent and welcome gifts. “I guess I was

probably given maybe twenty or thirty, or maybe forty books, and I would always kind of be reading through one and hoping that another one would show up so I could go from one to the other. Karl was very clear on how his friends had helped him to stay hopeful during the past fifteen months of continuous cancer treatment.

I get calls everyday, and visits everyday, and tons of cards and gifts. My friends, well, like I said before, would call everyday or would be there when I called to talk. And it was very important to me to seize or dwell on the positive things that they said. I had a friend who would say, "You're going to be all right. I know it." That really lifted my day. That was the high point of the day. And those who said, "Well, it is a terrible thing and everybody has a crisis in their life, you just have to do the best you can to get through it," that seemed not helpful to me. I could kind of tell that there were a fair number of people who just felt in their heart that it was going to be okay; whether I live or die, it was going to be okay... But it felt so good when people were encouraging and positive. Those are the kind of folks that you want to stay around and lean upon.

For an entire year, one friend gave Karl a card every week. This might be a "a funny or even a risqué card," but his friend would always "write a little note in there and a scripture." There were several friends who would call him daily "during the rough times." Some of them would come over unannounced. "It was always good and helped time go by when people would drop in and just stay for thirty minutes or an hour visiting." Karl had one friend who never spoke a discouraging word. "He believed every step of the way that either it was taken care of, or... there were things we could do to beat it, and he was just so positive all along the way that I looked forward to seeing him and talking to him."

Bert and Louis gave support to each other, both having cancer and working together as business partners. It has been fortunate that they were never ill at the same time. The need to have one of them in the office, helped to bring Louis out of a depression when Bert became ill again.

I would say basically encouragement from my business partner, Bert, and fortunately he, also a cancer patient, was not ill during my illness. And, when I got well or through with my treatment, he became ill again. And so, because we run a professional business that requires a license to operate... He was going to be out of commission, and I had to kind of pull myself together so that I could be the man in charge, whether I felt like it or not. So it kind of helped me to get back up... Bert stayed in touch with me all the time. He was encouraging.

An “electronic” friend to Louis was Lance Armstrong, the world class cycling athlete who was diagnosed with the same type of cancer. Louis became aware of Lance’s cancer story through the Internet, and a web site Lance established to inform readers about testicular cancer. Lance’s story and others on the web site were encouraging to Louis. Treatment resources were also publicized, one of which Louis utilized for a key second opinion. He traveled a lengthy distance to see Lance’s doctor in another state. This resulted in avoiding further risky chemotherapy that had been recommended by his local oncologist, chemotherapy that was ultimately found to be unnecessary. Shadows on his chest x-ray were misdiagnosed as recurrent tumor, when in reality they were areas of fibrosis from a previous chemotherapy drug.

Walter and his wife were amazed at the response of his friends. Walter’s wife gave an example. “One of these guys came with a big pot of soup he had made

special. He had gotten a new recipe and was trying it and wanted Walter to try it. And they just wanted to visit.” Walter has had many visitors and offers of help. “We were just overwhelmed with people wanting to do good... Have you ever known anybody who has gotten one hundred and eighty-five get-well cards?”

Church Leaders and Friends

One of Bert’s friends, also a deacon at his church, was especially important to him during his numerous hospital stays. Bert stated that when this deacon walks into his room, there is “a glow” and the “room lights up.” He is at “his most hopeful time spiritually” when this deacon visits.

He brings peace to me... I know that everything is fine. No matter how bad a day I am having...[name of deacon friend] can walk in that room, and I can smile, and I can cry, and when he leaves, I feel great, without question. I do not always understand it. I do not always question it, and I do not always try to read something into it. I just know that when he walks into the room how I feel... better in a matter of seconds... He can just light up a room. I am at my most hopeful time, spiritually, when he walks into the room. To me he is my saint and he always will be.

Walter, a retired physician with leukemia, professed great faith in his minister and in the prayers of friends in his church and surrounding churches.

Basically, I had given up as far as any significant length of living. And, now, in the meantime, I had taken up going to church every week, and I did get some satisfaction from that. Now, no question, I had a lot of confidence in the minister, and so faith kept me going to a large extent, morale wise. Also, I could not believe the friends I had! [emphatically] I had friends from churches all over – through my bridge – in [named three surrounding cities] and other churches here in town. They had me on prayer lists and, with that, I thought – Well, that is the most I can hope for. I have good friends who are praying for me and maybe it can be of help.

Maggy also talked of having “a lot of prayer support – a lot of prayer support, and that has been probably the biggest boost that I have had.” Her husband’s job as a minister had resulted in the word of her illness getting out through e-mail to all area churches, to various places in the United States, and “all over the world.” As a result of this widespread tremendous prayer support, Maggy stated “I knew everything was going to be okay, or at least that I could handle whatever.”

Karl was also deeply comforted and supported by the prayers of others, using a comforting analogy learned from his priest.

The prayers of my family and friends have been like – the priest told me that it sounded like I was in a “sea of prayer,” not just this town or this state, but churches and other denominations in other states have learned through the grapevine and have been praying. So, I have to feel bolstered by those things. Of course, every week at mass we pray for the sick, and I am still on that prayer list.

Karl sought the counsel of his local parish priests both before and after surgery. Interactions with them led to a sense of peace, comfort, safety, and security for him.

Well, you mentioned earlier about the people... religious people... the young priest... Before my first surgery, I went to visit with him, and I said, “I am looking at fifteen to twenty hours of surgery and do not know what is going to happen. I do not really want to go into it in any less a state of grace than I can.” And so I was interested in confession, sacrament of reconciliation, and even communion before [surgery]. Really, from that point on, I got a sense of peace and comfort when I was around this priest, and both priests I know are here in town. One time when I was strong enough to go visit – I don’t think it was a mass – I was just over there at the church... I was standing between them, and it occurred to me how comfortable or safe I felt just between those two Holy men. And, I have a relative, my aunt’s brother-in-law is a Bishop,

and he called. He wrote. He is very comforting. He has sort of been there for the family at weddings and baptisms and funerals.

Louis experienced a boost to his hopefulness from a lady he had never met but who “worked at a church with his sister.” She sent him encouraging cards once a week. He ranked his lady among his top three human sources of hope.

Once a week, I would get a card, my entire treatment time. I would get a card from her with a handwritten note, a full-page note, telling me that the church was praying for me and how they talked to my sister to check on me. And it made me feel good, and it makes me more aware... Little things like that are important. I do not do enough now... just talking about it right now brings it back to my attention... That was a big boost for me just to go to the mailbox. I would walk everyday. Our mailbox is a long way from our house, and I would walk up there and would pretty much know when I was going to be getting a card.

One of Robin’s main hope-supportive persons was her minister and family friend, described as “my best friend, we are like sisters.” At the time of her diagnosis with cancer, as well as her husband’s diagnosis with cancer, she was their local pastor. Her influence was quiet but powerful.

I remember that she was there with [husband] and me when they were about to diagnose us. She was always... she was a great support for [husband] as well as for me... I think what she did more than anything... she has this knack of knowing what to do in every situation, but she does it quietly and very... She is a little person, but she is very strong. She is not perceived as being a strong person because she is little and kind of quiet, but when a situation comes up, she is solid, a solid rock.

Robin also described support from a man she barely knew in her local church. He helped her to cope with breast cancer in a very unique way, suggested by his characterization of God.

I remember a man at the Methodist church. One day after church, he handed me his business card, and he had written on the back of it. He just handed it to me and walked off. I got home and I turned it over and looked on the back of it, and it said, "I know you will be just fine. God is with you. She will take care of you." That has always been uplifting. Just the uniqueness – that he thought it might help a woman in a difficult time to think that God could think as a woman, feel as a woman, and experience as a woman. I thought that was most unique.

Pam's "whole church family" supported her in many ways. "I was just so overwhelmed at the kindness of people with notes, calls, appearances... that I get all emotional and warm thinking about it today. It was just really, really nice." Her pastor helped her by openly discussing her cancer experience and gave her a new perspective on his pastoral care abilities.

The pastor we had at that time, I liked as a person, but I really could not stand him as a preacher, and I guess I was very negative and critical about him... He just was so nice and sweet to me. He was definitely a pastor. He gave me great pastoral support and care. [When asked how he did this, Pam explained.] He was just very open about it. He came up to the hospital with his wife, while I was in surgery, to spend some time with [her husband], and then he would call occasionally, and he would... he was just so delighted at what he considered my good news, that... you know... I was going to live. I mean, he just was very open, and that was what was important to me.

Pam appreciated her pastor's openness in comparison to some of her "charismatic friends" who did not even acknowledge her cancer. It really helped her to have someone "just talk about it" and bring it out into the open. Pam was also uplifted by the prayers of a person she did not know, but was told by friends, had been praying for her. This unknown person became someone special to Pam in supporting her hopefulness.

I still think how kind she was, you know, not knowing me at all, I appreciated that... She had never seen me before... And she was a strong prayer person, so she had great compassion for me and obviously spent some time praying for me... And so I feel a real bond to her to this day... She would be someone special.

Employers and Coworkers

Marcia admitted to receiving “a lot of hope from the people at work.” The staff of the library where she works ordered several books about cancer. A couple of books came in about women who had lived through it and were doing well. “And it’s not like they forced them on me. They would say, ‘These books have come in, would you like to look at them?’ And so, they were really hopeful too.”

Even when she felt ill from chemotherapy, it helped Marcia to come to work. One of her coworkers who also had cancer gave her more hope than anyone else through his concern and example.

He was an inspiration to me, a big one, because he was so positive. When he left [to go home to die] he’d call me and I wanted to go see him, but he said, “No.” He didn’t want me to see him like that... and he died. He probably gave me more hope than anyone on this whole campus because he told me that he got cancer like eight years before, and he was in his late seventies and still working... I still miss him. He was a super guy.

Paul, an artist and teacher feels very connected and cared for by his coworkers and students. “I have good connections with the people I work with... The people I work with now are very close friends, and I know they care for me, so I feel good about that... And I care for the students, and I think they care about me.”

Maggy, who works as an administrative assistant, spoke very highly of the support she had received from her boss and several coworkers. They displayed positive attitudes, offered encouragement and help, and shared common experiences in dealing with cancer.

At a beckoning call, they are here. I have had so many offers to do things for me. I said, "I would allow you to do these things for me if I could not do them on my own, but allow me to do them on my own. If I cannot do them, I will call you."... Otherwise, you become very dependent, and you can lose that sense of independence.

Of her immediate supervisor, Maggy commented, "I'll tell you what, [name of her supervisor] has just been a tremendous support... He's been there through thick and thin... He has encouraged me... He chewed me out when I wouldn't take a nap... He's been a real encourager." This person was ranked among her top three most important human sources of hope. Several staff members were also named and described as key sources of hope in helping Maggy to stay hopeful while dealing with cancer.

I've had tremendous support from staff members here. I'd say [named a coworker] has probably been my best booster. She has been there to boost me and to always be positive... Someone else is Marcia. I think because she has been through this. She would just tell me so much... She would encourage me... I think it brought back memories that she wanted to erase to a point, and I understand that, but she was always there because she has been there so recently... Holly as much as she could... because of what she is going through. She and I have bonded... you know, I'm her booster, and she is my booster. But she has always had an upbeat attitude, and I think, "If she can do it, by golly I can."

Maggy ranked one of these coworkers as the most important human source of

hope in her experience with cancer. This person stayed in daily contact with her, was upbeat, and made her laugh. She described this person as “exceptional” and listed many ways in which she had supported her sense of hopefulness.

She took me for some of my treatments and things... some tests that I had to have before chemo. I had to have the heart scan and stuff, and she took me for that and was always there... always supportive... You know, never a day would go by that she didn't call... She would at least call first thing in the morning, always. And she was at the hospital after my surgery. No, [named her] by far, stands out, far and above. I just hope I can be there for her if she ever has any problems.

Karl's employer allowed him to adjust his work schedule, frequently rearranging daylong appointment schedules, as needed according to how he was feeling. For this, he was very grateful because being able to work even half a day greatly boosted his hopefulness. When specifically describing his coworkers [physicians], Karl stated, “They have all been too good, too kind. They have gone out of their way to help me with whatever was needed.” Beyond the physician coworkers, he praised the entire staff of the hospital and clinic, “Everyone at work was so good to me and so gracious.”

Support Groups

Angie described her ovarian cancer support group as a positive influencing factor, ranking it among her top three “people sources” of hope. She elaborated in great detail about how they helped her by sharing common bonds, providing information, and emotional support.

Oh, I just have immediate bonds with all those women because they all have the same story you do. They're facing the same statistics that you do. And so you come together once a week and you share your experiences and your feelings and where you are in your treatment. And it's a valuable source of information because they come from other hospitals in the area, so there are different kinds of treatment. So, it's not only supportive in that it's emotionally supportive! [emphatically] It's a good place for research, to get information.

Another group that Emily described as supportive was her annual Montana retreat group, composed of women of all ages and stages of ovarian cancer. "They're mostly stage threes and fours [most severe stages]... many that had only a matter of months to live, but they were still [emphatically] extremely hopeful!"

Sheila attends annual conferences at a large cancer center in south Texas and named several famous athletes and entertainment personalities who have spoken to these groups. "You put a thousand cancer survivors in a hotel ballroom with a speaker, a motivational speaker, and it's just an amazing thing." She named a couple in their seventies who are both cancer survivors and volunteers at the treatment center. Sheila looks forward to seeing them every year at the conference.

The conferences are really great... I mean it sounds like you're all excited... Where are you going this weekend? "I'm going to a cancer conference." It doesn't sound like something that would be uplifting, but it is. There is a couple... They are in their seventies... They volunteer... They are there every year. It is just an amazing thing to have that connection.

Deana, in her seventies, and four years out from breast cancer surgery and chemotherapy, described another type of support group, not focused on cancer, but "a great source of hope" for her. This was Al-Anon, a group she had belonged to before

developing cancer. One of her sons, who died five years earlier, was an alcoholic, precipitating Deana's involvement in the group. She has kept a journal since diagnosis and read parts of it during the interview. She had made many references to Al-Anon principles, such as "living one day at a time," and to the positive nature of the program. Although her original sponsor lives in another part of the state, she keeps in frequent contact with her, receiving helpful books and frequent telephone calls from this individual. Deana believed that her ability to deal with the cancer diagnosis was in large part due to Al-Anon and to her sponsor. When initially asked for the first thing that came to her mind as a source of hope, Deana said, without hesitation, her Al-Anon sponsor.

A more informal support group, nursing school friends, was given by Audrey as one of her positive hope-influencing factors.

And I think being in nursing school... because there were about five of us that pretty much hung together. And one of them would come up with me to get blood drawn between lunch or something. One of the times I had to come up between classes for the saline injections for the implants. I let one of them come with me, and they watched. I think they were a source of hope too, because I can remember the day when I told them... and they kind of made me mad just that first day. We were sitting in the student union, and I was telling them, and they looked awful... I mean they just looked like "Oh, my God!"... And it kind of made me mad because I had gotten over the point, the despair part at that point... and I was going to finish school, and.... Then they started, "Well, if you are going to go through school... if you need help, then we are going to help you."

Karl, a practicing physician, did not belong to a formal support group. He did, however, describe a group of fellow patients he regularly observed while going for radiation or chemotherapy. Their interactions taught him a significant lesson.

I gleaned encouragement from just seeing other patients and what they were going through. For instance, in chemotherapy and radiation therapy, I have passed some of the same people each time that we are there. And they might be smiling or might be joking with the nurses or therapists, and that taught me a real lesson that you are not going to gain anything by just dragging around and being down about it.

Several informants mentioned visits from other patients with the same type of cancer as sources of hope. Emily and Angie had met and become friends as a result of their common diagnosis. Emily, a nine-year survivor and regular patient visitor, met and talked with Angie during her initial hospitalization. It helped Angie to feel more hopeful just by listening to Emily's story. They bonded immediately and started a support group for women with ovarian cancer at their medical center. Robin and Pam both mentioned patient visitors who had had breast cancer and reconstruction. These women came to their homes, offered to talk, and even to show them their breasts. Pam named two breast cancer survivors and friends who had visited her. Robin discussed at length two "dear ladies" who had made the whole experience more real.

There were two other people who were a tremendous help, and they had been through it. At that time, you would go and talk to the surgeon, and you would talk to the plastic surgeon if you were going to do reconstruction. And they sit you in a room, and you see a video of what to expect, but you do not see anything real. It is all diagrams... but these two ladies – dear, dear ladies – both came out to my house and sat and talked with me and answered all of my questions. And [named one] even showed me her breast and what it looked like to have a mastectomy and then have reconstruction. And that meant

everything in the world to me... you know... for them to come in and talk to me and say, "This is the way it happens, and this is the outcome." They both, still today, are survivors. They both had it worse than I did... They had worse diagnoses than I did.

Two participants, Marcia and Bert, had been treated at the same major cancer center in a south Texas metropolitan area. Marcia commented on the kindness and aid of volunteers who were also cancer patients. These helpful and kind persons would meet the new patients at the door and guide them through the whole system of laboratory, radiology, and appointments two or three times until the new patients felt comfortable.

Health Care Providers

Nurses and physicians in hospital and outpatient settings were frequently affirmed by participants as sources of hope. Infrequently mentioned were other types of health care workers – therapists, technicians, orderlies, and social workers. Due to the special professional nature of these relationships, special theme categories were developed from the data describing interactions with health care providers. These include competence (knowledgeable, communication skills, technological skills), caring and compassion (concern, closeness, understanding, encouragement, emotional support, comforting, special attention), and recognition and respect (knows the patient, remembers things about the patient, partners with the patient, empowers the patient, learns from the patient). Several themes may be noted in any one participant excerpt. Attempts to divide vignettes and categorize by theme resulted in very

fragmented findings. Therefore, perceptions of health care providers' hope-influencing interactions are presented intact for each participant.

Emily told in detail a story of her difficult bone marrow transplant, the time when her hope was as low as she could remember. One positive hope-influencing aspect during this time was becoming close to the nurses on the unit. "The nurse gets real close with the bone marrow patient. They spend a lot of time in your room, and we discuss other patients. Maybe they're not supposed to, I don't know, but we do." As a result, Emily came to know and feel concern for the other patients on her unit. "I'd say 'how's mister so and so down there doing,' even though I didn't know his name... I heard him throwing up last night."

Later Emily talked about the "caring and competent" nurses who worked in her oncologist's office and the chemotherapy treatment room, giving two specific examples by name. These nurses were able to "answer any question I asked." She appreciated nurses who remembered her name and things about her. "They all know me, I've been coming for so long." The nurses respected her ability and experience in dealing with cancer, frequently calling upon her to visit new ovarian cancer patients. Emily looks upon her oncologist almost as a friend. "He knows me personally and remembers little things about me." About his concern for her, she said, "I feel like he genuinely cares about me."

Angie also spoke highly of the nurses she had encountered in the doctor's office and the hospital. There was one nurse in particular in her oncologist's office

who was especially “kind, supportive, understanding, and very knowledgeable.” She mentioned three or four nurses in the chemotherapy infusion room who were supportive. “You could come in there very sick and they were very understanding about that, so I would say they were sources of hope.” After describing the hospital environment as unpleasant and a negative hope-influencing factor, Angie recalled the nurses as being “the best thing about the hospital.”

Angie recalled positively her experience with a doctor in Philadelphia to whom she had gone for a second opinion. Besides his knowledge of chemotherapy, he gave her a whole new way of thinking about cancer. “He put me on the correct chemotherapy and I was able to communicate well with him. And he was the one who told me that he didn’t think of cancer as a terminal illness. He thought of cancer as a chronic illness, which is a much more hopeful approach!”

When asked about her local physician’s office, Angie launched into a lengthy discussion of her two oncologists, the first being “negative” and the second as being helpful only after she understood his personality and communication style. She eventually learned how to “manage” him. In some detail, she described the evolution of this relationship into what sounded like a genuinely caring and trusting partnership. “I believe that he genuinely cares about me.” She told him “We are in this together” and “You need to do everything in the world to help me save my life.” She believes “He’s committed to that.”

When asked for the first thing that came to mind as a hope-influencing factor, Marcia listed several “hopeful” health care providers – a Registered Nurse, a social worker, a radiologist, and her surgeon. On the day following her initial diagnosis, “They had me watch those movies... They had me watch a video, then they’d talk to me... They kept assuring me that I was going to make it.” Of all the people in the cancer center who talked with her that day, she said, “They were just so hopeful.”

One particular Registered Nurse, who worked in Marcia’s oncologist’s office, was especially encouraging, concerned, and an “up” person.

She was always so hopeful. Matter of fact, she even called me at home after my chemo, maybe the next day and would say, “Are you doing okay? Are you feeling okay?” And she would say, “You know, it gets better. It’s gonna get better. You’ve only got three more to go. You’re going to get better. You’ve only got two. And when I went in for my last one, she made sure she saw me and said, “See, you’ve made it. It’s all over with.” She was a really up person.

Marcia described one of her physicians, the radiologist, most fondly. After finishing her course of radiology treatments, she was expressing her sadness at not being able to see him any more. His response was empowering, “You’re the patient, you can pick the doctor you want to see.” Marcia told him, “I would much rather see you,” and she switched. With the radiologist as her “follow-up doctor,” she avoided one of her threats to hope, the oncologist, who was “not a people person” and only discussed statistics.

Paul has had an ongoing battle with various types of cancer over the past twenty-two years. Paul expressed the perception that all of his nurses have been “very

positive.” He felt most strongly about his physician of the past fifteen years, described as a “great healer.”

He lets me know that, yes, there is only so much they can do, but he thinks I’m pretty tough and a lot of the healing has taken place because of my attitude. I would say that he has kept me alive, but I have kept myself alive too. [When asked, “How has he kept you alive?].… He has done everything he can do medically. Emotionally, he has… I mean we don’t hang out on weekends or anything, but he’s always behind me. He asks me questions sometimes, ‘How did that happen? How could you get through this?’ I just tell him… It’s because I want to live a little longer. It’s just that simple.

Maggy was also positive in her reflections on the hope-influencing interactions with her surgeon, her oncologist, and the physician’s assistant. They were always “supportive, encouraging, and gave needed information.” However, nurses were most highly praised for their “excellence” – hopeful attitudes, sense of humor, and ability to make a difficult situation better.

The ones that I enjoyed being around the most were the nurses in the treatment center for chemo because they were always upbeat, and, like they said, ‘This is not a place to come and end. There’s hope in this place… That’s what we’re here for.’ They were always upbeat, always made you laugh, and you felt good… you know, as good as you could in that situation. The first time was a little frightening, because I didn’t know what to expect, but I did not get sick through any of my treatments, not a bit. I had a light headache after one, but I would go home and eat and watch movies… I would say probably the ones that stand out the most are the nurses in the chemo treatment center. They’re excellent, they’re excellent!

Maggy definitely perceived the chemotherapy center as a hopeful place largely because of the nurses. She still feels connected to them several months after chemotherapy. “I will go back in there and check with them every now and then, and I do see them every now and then.”

Sheila likewise was happy with her nurses. "I wasn't isolated, I wasn't afraid. The nurses were wonderful... The nurses were great." One nurse, who cared for her for two or three years in the hospital and treatment room, would always bring her communion, a relief that "all of that was taken care of, and I didn't even have to think about it." The nurses on the cancer unit at the hospital allowed her to be herself, to feel depressed, and supported "whatever I felt like." They helped her to be more comfortable by giving special attention to her intravenous lines so she could wear her own sweatshirts and pants rather than insisting she wear the traditional hospital gown.

All of them on the sixth floor in the cancer unit... they're all amazing. If I was depressed, they would let me be depressed without pushing it to say, "You've got to feel better," ... They were supportive of whatever I felt like. It wasn't that I had to always be on display or on stage, or creating any kind of an image for them. I could be myself. One of the things that helped me, too, and this sounds silly... but I wore sweats. I didn't wear hospital gowns, and they would unhook the I.V. so I could get the sweatshirts on, or the tee shirts on, and then put them back on... I didn't have to be in that gown. And I didn't feel like I had to be under the covers every minute... I could be comfortable. My body wasn't in any kind of a normal shape.

Sheila's physician was "a little bit stoic at first" but later they "developed a real relationship." For some reason, he did not want her to be "reading a lot of stuff." She let him know "that's not how I work." She asked him for explanations and articles about her treatments. Although hesitant at first, he complied and put her "in charge."

Okay, tell me about this bone marrow thing... Get me an article. I want to see what it says, and he was hesitant in giving it to me until I finally said, 'I want to see that. I don't care if you think the odds are not all that great. I need to know what they are. I need to know how this works. I need to make it

happen.’ So, he did. He finally said, “Okay, you’re in charge here, you’re calling these things.’

Sheila described having a sense of trust that she had the best doctors who knew what they were doing and the best nurses “who are trained to take care of what is wrong with you and keep you safe.” She felt safe in the hospital and didn’t want to leave “because I knew in the hospital at least I wasn’t going to die in the middle of the night without anybody knowing it.” She was glad they were honest with her about how sick she was going to be during the bone marrow transplant.

The nurses came to know Sheila well and she came to know them. Being a career teacher, she appreciated it when they asked her questions about what was going on at their children’s school, because it “took my mind off me long enough to help somebody else.” On nights when she was “feeling lousy” and couldn’t sleep, the nurses would talk to her and even exchange jokes, making her feel more normal and less depersonalized.

I remember one night, for whatever reason, I was awake, and somebody came in and we traded Aggie jokes for about four hours. I mean, it didn’t prove anything. It didn’t change the world in any way, but it is something I remember as being, ‘Yea, I can do this. I am not some anonymous number. I am not some disease.’ So, we told jokes back and forth.

Sheila was the only person of three transplanted on the same day that survived. After surviving her bone marrow transplant, she and her husband, both Irish, “had a St. Patrick’s Day party – all of the green, all of the corned beef, all of the green beer, all of the Irish coffee.” They invited her doctors, her nurses, and her mother. About this

grateful celebration, her doctor later confessed to her mother, "I didn't know whether we'd make this or not."

Holly's physicians helped her to be hopeful by finding treatment resources and switching to new and different drugs. Her nurses in the chemotherapy department were "jolly, jolly, jolly." They "wouldn't let you get down." Although she never had a bad reaction herself, she observed the nurses caring for and "pampering" those who became ill during chemotherapy.

For Bert, whose number one source of hope was prayer, providers of this resource also included his health caregivers. "I truly believe that I would not be here today without the healing prayers that I have had, prayers from my doctors, nurses...[and others]." He expressed great confidence in his surgeon, and he's had five separate operations to remove abdominal tumors. "He's probably by far the best surgeon that I have ever seen. I do not know that I would ever want another one." The nurses on his usual hospital unit "know me now... they recognize me, and that makes me... feel very, very comfortable." Having had five major abdominal surgeries, Bert has spent much time in the hospital.

I have seen a lot of things spending that much time in the hospital, and I have seen how they react to a lot of things, and their patients truly could not survive without them. They could not survive without them. I love them to death, and there are so many that... are way over-worked, and the paperwork is amazing that they have to do, and I really feel for them. And so it kind of takes away from them being able to just be with you more often, but they are always there when I need them. I have never been there one time when I needed someone and there was not somebody there... I have had some student nurses... and

each and every one of them has been as nice, polite, and caring and seems to really want to know what is going on.

Walter, a retired physician, still feels grateful for a nurse on the oncology service who advocated to get him pain relief. His physician at the time was a just strictly a radiologist and Walter “tried to talk to him about his pain” with no results. It took the nurse talking to him to get it done. “She managed to get him to write an order for the hydrocodone which I took for a while.” During one hospitalization, he experienced incontinence and felt very embarrassed. The nurses just changed his sheets and “in and out” catheterized him as he requested. A “major rise my spirits” occurred when his doctor finally brought him news of “a clean bill of health” after three years of battling leukemia and frequent infections. He was extremely happy with his care, “I take my hat off because of the care I received.”

Deana felt the oncology nurses were wonderful. “They really were wonderful.” The nurse practitioner in the surgeon’s office was extremely helpful and reassuring.

Well, she just told me I was going to be all right, and I believe health care professionals. I think sometimes they give you the worst scenario first, which I think is wonderful. If it does not happen, then you are grateful. Some people say I wish the doctor had not told me all of that. I have never been angry at health care professionals for giving me worst. I have been angry at them... but not for giving me worst scenarios first.

Karl was very positive about all of his caregivers. He was cared for in his workplace, being a practicing physician at the time of his diagnosis. It was almost like he was being cared for by his family, with everyone described as “too kind, too good.”

He was especially touched by the actions of a particular nurse who washed and dried his feet when he was unable to reach them after his first post-operative shower.

About the care of those ladies and few gentlemen I had worked with for so many, many years... I knew they were good at what they did... but I really did not appreciate how gentle and angelic they were. Some did not mind if it took a long time to change a dressing or to get some tape off... The main thing was to help and not hurt, so it gave me a real strong, or new appreciation for what they do... While I was in the hospital, the doctors were great. They would cut me open and sew me up and come everyday for five or ten minutes. But hour after hour, day in and day out, all night long, the nurses were there providing care. So, I wish I had been nicer to them all these years.

Karl was touched by the fact that orderlies and other people he did not know in his workplace came up to him and patted him on the back and said they were praying for him and pulling for him. He wished he had been “more supportive and open than he had been all these years, because they really showed me how much it means and how you are supposed to be.”

Louis recalled two physicians who influenced his hope positively and two who influenced it negatively. His initial medical consult with the oncologist, where the first “bomb” was dropped on him, was rushed and impersonal. In contrast, his radiation oncologist was unhurried, encouraging, seemed involved with medicine, and wanted to help people. “He would take as much time as you wanted to explain what was going on, or what the treatment was going to do.” His basic outlook was positive. “He seemed to think, from his experience, a lot of his patients had been treated with radiation, survived and did well, [saying] ‘This is going to kind of make you tired, but

you will be fine'... He was encouraging.” Louis remembered him wearing a sticker that said, “God is in charge.”

When Louis experienced a reoccurrence and needed a mediastinoscopy on Christmas Eve, his thoracic surgeon, was “very professional, very comforting.” He dropped the second “bomb” on Louis in a way that was “exceptionally caring... uplifting and encouraging... He even called me at home to check on me.”

The nurses in the chemotherapy department were knowledgeable, considerate, and compassionate to Louis.

When the chemotherapy began, the first lady I dealt with in the chemo ward was the head nurse in that department... She is a saucy old thing, but she is very thorough, and she understands chemotherapy, probably much better than any of the doctors whom I have dealt with. And she makes it as comfortable as possible, considering they are putting an I.V. in the back of your hand and then giving you a couple of gallons of fluid, especially my first time. I grew up always hating needles. I still cannot take a shot without passing out.

Near the end of his interview, Louis returned to discuss more about health care providers, both doctors and nurses. He felt the nurses could give lessons to other health care providers on how to interact and empathize with patients.

I just think that, in general, the health care providers who are on the interaction end with the patients, that is, the doctors at the time of diagnosis or at the time of consult, probably need to take some lessons from the actual chemo nurses on how to really show and demonstrate true compassion, because those ladies seemed to feel your pain.

From his experience, Louis felt the doctor and nurse in the clinic environment were more “non-caring” than the ones spending a month or more with the patient

during chemotherapy. Of the chemotherapy nurses, he gave the following testimonial to their positive impact on hopefulness.

Those people seem to really involve themselves with you, with what that person is feeling. I know that nurses cannot always do that because there is a profit that has to be made and people have to come and go. But because cancer is such a stressful and shocking and major roadblock in peoples' lives, I think it needs to be handled a little more delicately than a tonsillectomy or something. I mean if you are dealing with something that has a pretty bad track record of killing people... What most people think of with cancer. It is just eventual death. You do not think of, "Oh well, you are just going to get an arm amputated, and you will be fine." That stuff just spreads. You can slow it down, but you cannot stop it. And I think the caregivers might give it a little more thought or thoughtfulness.

He wished they would spend more time explaining things and cite some hopeful examples, not just discouraging statistics.

'Hey, you know, this does kill fifty percent of the people,' or maybe not even say that... Do not even use percentages, just say... 'There is a lady or a man similar to you who is in your same age group, and he had exactly what you have and he had this treatment and that was eight years ago and he is pretty good proof that we can lick this thing.' It seemed like more often than not from the doctor's standpoint, you would just hear, 'Well, this is highly serious. I am not going to lie to you. We could lose you.' That does not exactly give you a lot of encouragement.

Of all the participants interviewed, Louis gave the most thought to the question of health care providers as sources or threats to hope. He had experienced both positive and negative physicians and had learned a great deal which he shared. His second opinion doctor in another state was the "virtuoso" of doctor-patient interactions.

And I will say that the doctor in Indiana to whom I went to see for a second opinion when I had a supposed reoccurrence... His style was kind of a

virtuoso compared to a beginning violin student or something. He was just in the right groove, and he found something that he just totally loved with practicing medicine. He had a way of making you feel like... and being able to back it up statistically, too, from all the hard work that he has done. If any way possible, he would go to the nth degree to try to solve your case or try to get you well, and that is what you want to hear. You want to hear that you can be made well. You do not want to hear that, 'More than likely there is nothing we can do,' or, 'There is a strong chance that we are not going to stop it.' I think that if you have this person who is a professional who is not whisking you out and who wants to get you well, then you want to be well. If they say, 'not much chance,' then you kind of throw down the guns. I mean, you kind of are thinking, 'Well they are the high-powered professionals, and they say I am a goner, so I guess I am.' That is the lesson I learned. But I think it would do the health care professionals more good to hear it than for me just to talk about it.

After giving his long and thoughtful evaluation of doctor-patient interactions and hope, Louis was assured by the researcher that a goal of this study was to inform health care providers of his and other patients' perceptions. At the end of his interview, he stated, "I hope this helps somebody."

Robin recalled one nurse in the plastic surgery department who taught her exercises for keeping her skin supple over the tissue expanders used in breast reconstruction. This nurse "was just terrific, she really made that a lot easier." This nurse got down on the floor with Robin and demonstrated exactly what to do. "She was just a bright, cheery, upbeat person, and I can remember several years after my care had been completed, seeing her in the hospital, and she was always inquiring... She is one I would remember."

After a suspicious mammogram, Robin's physician recommended a biopsy. Not having a palpable lump, she went ahead on a planned vacation and "blew it off for

three weeks.” It was not until her physician telephoned her at home and urged her to come back, that she “got off dead center on it.” It was a big surprise when it turned out to be malignant. “Because it was caught so early, then that is when the hope kicked in... I am forever grateful to [physician’s name] for pushing my button.”

Pam’s perceptions of her physicians were mostly positive. The offers of two of them to pray with her was a great source of hope and security. They gave her information and allowed her to choose the course of therapy. Only once when a plastic surgeon questioned her decision not to have chemotherapy, did she feel less hopeful and experienced “little nagging doubts.” In the oncologist’s office after surgery, Pam began to speculate on the cause of her cancer, blaming herself for stressors, for becoming overweight, and for not exercising or eating right. Her oncologist listened to her and helped her to feel better. “He was very, very kind and very nice and said that I was not to blame myself.. that they did not know why, but I was being too hard on myself.” Pam used “very nice” to describe her nurses in the hospital after surgery. “They were there, they were competent, and I just had a good feeling about it.” Everyone who came into her room including the residents, technicians, and housekeeping staff left her with a positive feeling.

Audrey considered the nurse clinician at the hospital “a friend.” This nurse came to know Audrey personally and would always return her calls promptly. At the conclusion of chemotherapy, the nurse clinician brought Audrey “a little plaque with balloons and everything because she knew I was going to nursing school and she kind

of knew my family and everything.” Another nurse in the chemotherapy room was encouraging to Audrey. When she came in for chemotherapy, the nurse would say, “You did fine with it, you got through the first one and did fine, and you can get through this.” By the time she finished her course of therapy, the head nurse was trying to recruit Audrey to work after graduation. It was not the prospect of a job that helped her to be hopeful, but the fact that they were focusing on the future in a positive way.

The nurses in the treatment room were great. And the one who was in charge of it kept saying, “Hey, you know, we will be having an opening about the time you are finishing.” They kept focusing on the future stuff, and that helped. “We are going to be needing someone in the chemotherapy room about August, and you should be through, if you are bored.” They helped me. They were very future oriented and very positive.

Audrey, now a Registered Nurse, feels that nurses are more “optimistic” than doctors. “Nurses too, we are honest, but we are also cheerleaders, and physicians are not always that way.” She described the evolution of her relationship with her oncologist, who was negative at first and tried to discourage her from having a mastectomy because it was so disfiguring. This physician ended up allowing Audrey to choose her type of treatment and later asking her to talk with newly diagnosed patients.

Physicians were consistently discussed as bearers of good or bad news about the course of a person’s cancer and the effectiveness of treatments. The “news” itself as well as the way in which it was reported often influenced the participants’

perceptions of hopefulness. The highest hope experience Angie could recall was after getting the news of a clear C.A.T. [Computerized Axial Tomography] scan from her doctor. “For twenty months I had been on chemotherapy solidly, so I was very relieved to find out there was something that got the tumor.” Louis was likewise most hopeful “after my first cycle of chemotherapy when they did a C.A.T. scan and everything had gone away.” The skill with which physicians inform patients of bad news is probably more important than the way in which they bring good news. The ability of both physicians and nurses to understand the patient, demonstrate caring and concern, and to know them personally was perceived as important by participants.

Negative Hope-Influencing Factors from the Human Environment

The number of negative human interactions discussed by this group of persons with cancer was less than the number of positives. Losses of various types are again found overriding the factors associated with decreased hopefulness in the human environment as they were for the internal environment.

The loss of three members of her support group within the past year was a negative hope-influencing factor for Emily. She also mentioned the recent loss (two weeks ago) of another friend to cancer and the fact that he had developed cancer one year after his son died. She discussed her belief that loss had something to do with the onset of her cancer.

I had a five and a half year relationship, and about a year before I came down with cancer, we split up the final time. And I think that had a lot to do with me getting cancer, because I was just devastated. I mean, he was the person that I

thought I would push around in a wheelchair, and it just didn't work out. It was worse than my divorce, emotionally. I mean it was just so traumatic... usually they ask you when you're diagnosed, "What happened to you in the last year?"

Emily talked at length about her bone marrow transplant as "such a horrible, horrible experience." There were eight patients on her wing and she became aware of their sufferings in addition to her own. She describes several types of physical discomforts, gasping for breath, vomiting, rashes, blisters, and bleeding. The psychological discomfort of anxiety and fear for her survival are evident.

There were eight of us on a wing. Three people died while I was there. You know about every time somebody dies because... it's not carpeted. The walls are very thin. You can hear people throwing up. You can hear people gasping for breath. There were people on respirators. You know all this... three people dying. And you're in there thinking, "I'm really sick. I've got this rash all over my body, and I don't think I could feel any worse. I've got blisters under my arms and in my vagina and in my rectum, and I'm bleeding... I'm just so, so sick, and maybe I'm not going to make it... because all these people are dying."

Emily went on to talk more about one of the three patients on the unit who died during the six weeks she was there. "A nineteen year old kid came in the day I came in, and he died the day I left. And that was so hard on me because of his age. I just thought, 'Why not me instead of him?' He's not even experienced life."

Angie described her mother as a person who has threatened her hope. The lack of helpful support from her mother was disappointing and distressing to Angie. The negative effect of the daughter's cancer on the mother's health is apparent from her description.

She has a tendency to have an overall negative attitude about anything, and so she initially was very negative and didn't understand what I was going through

[tearful]. She became very self-centered and took on all those feelings herself. It was like the cancer was happening to her. And since then she's had a lot of health problems and has kind of deteriorated.

One of Angie's oncologists was identified as a negative factor. After the initial surgery, she had given Angie little hope for the chemotherapy to work at all due to the cell type of the tumor. She predicted that the tumor behind her liver was not likely to go away. "She was proven wrong, so I dumped her. Now she probably had a relatively negative attitude because she had cancer herself."

Angie described a particular nurse in the chemotherapy infusion room who threatened her hope with poor health habits, negative attitude, inappropriate conversational topics, and weak technical skills. "If I'm going to get chemotherapy and I'm going to get a particular nurse, then that's pretty threatening." When asked what it was about the particular nurse, Angie replied, "The nurse is terrible, she smokes, she's negative, she talks about her own aches and pains, she's a terrible sticker." Angie believes she's not alone in this perception, "Everybody just dreads if they have to get her." This particular nurse makes "the whole experience terrible." Angie was very clear about the influence of this nurse on her sense of hopefulness. "So that threatens my hope when I have to deal with her."

In Angie's mind, the hospital is a very negative, threatening, unhelpful place, to be avoided if possible. Several complications happened to her while hospitalized. The thought of hospitalization brings back these painful memories.

The hospital is not a very hopeful place because you seem to get sicker in the hospital. I had an experience recently where I probably could have been hospitalized because I was exhausted and I was going through drug withdrawal, but I didn't want to go to the hospital because, to me, you get sicker in the hospital. You get weaker... You come out of there feeling worse than when you went in... All my memories of being in the hospital... I was so ill and sick and hooked up and bags draining, and it's just not a very pleasant or hopeful environment for me. Even though the nurses were the best thing about the hospital.

Marcia's hope was at its lowest point the day she talked to her doctor and he told her that she had cancer. She even remembered the exact date, January seventeenth. "I went home and for one hour my hope was as low as it has ever been, and then I had a cry, a talk with God, and from then on I have not felt that way."

When asked to think of any people who had ever threatened or caused her to feel less hopeful, Marcia quickly responded, "My father... He is on the other extreme. He's negative. He was brought up in a very negative, non-spiritual atmosphere. She reflected about her grandmother on that side of the family. "She was not hopeful. She was a very... she was depressed a lot. And I think because my dad was brought up in all that, it's still so hard for him to think positive and to think that things are going to turn out." When her father found out that she had cancer, he called a couple of times, and would be crying. He'd say, "I know things are going to be okay... I know things are going to be okay." This did not help Marcia's sense of hopefulness, because it was "like he was trying to convince himself."

Whenever Marcia had to go to the oncologist's office, and she would feel "so down... because she's not a people person." Marcia wasn't fond of this physician

because she only talked about statistics. “And I think when you’re going through something like that, you don’t want to know that sixty-four percent of women that have lymph nodes infected are going to get it again. And I think she was the only one that I really didn’t want to be around.”

Marcia did quite a bit of reading the year after she was diagnosed with cancer. She became very attached to one author who had cancer herself, wrote a book about it, and then died. “There’s one book that someone gave me, and I read... And I thought, ‘Oh, this woman – it’s wonderful she’s written this book.’” And she found out in April that this woman had died. Hearing of this loss, she went to the restroom at her workplace. “And I remember crying because I was just so... and then I thought, ‘But that’s life, but look what she contributed. She wrote this book, and she gave me hope.’”

Marcia is a person who basically thinks hope “is in your head.” She stated, “If I think I’m not going to like a place, I try to see why I’m not going to like it and look for the good points.” In spite of trying to use this strategy, there was one place about which she could never change her negative thoughts. Most of her thoughts seemed to be triggered by her observations and interpretations of the other patients receiving therapy.

The chemo room... that was the one place... I didn’t like that chemo treatment room because they have you all... everybody is sitting in there together, and... a lot of those people in there are not feeling very happy... And so here you’re sitting there, getting chemo, and you’re looking around, and everybody is looking... they don’t look very happy. They look like they don’t want to be

there, of course. And some of them look very, very sick. And I would try to read the whole time I was in there and not look around me... But that was another place that you don't feel a lot of hope.

Marcia's last thought on decreased hopefulness was related to a loss combined with a positive life change. Having recently married, she and her husband bought a home. "So I've moved over there... You know, it was really tough...[to leave her mobile home]."

And a lot of people thought I was crazy because I'd been through so much in that mobile home. And [daughter's name] and I had been there since she was six. And then last year sort of cemented the fact that it was home... It was hard to move, but I mean... I'm fine now. I'm still unpacking.

When asked about a time when his hope was as low as he could remember, Paul discussed the episodes of receiving heavy chemotherapy. Both the side effects of chemotherapy (fatigue, insomnia, hyperactivity) and the doctor's negative prognostications threatened his hopefulness. Paul was so heavily saturated with drugs for so long that he had forgotten what it felt like to be normal.

I think a lot of that had to do with the heavy load of chemicals on my body and the reactions – my hearing, my sight. I think, probably, the weight of all that, and the emotional stress of the doctor saying, 'You have five weeks to live; you've got five years to live; you've got half of that'... I think probably the lowest point was when I was totally saturated with chemicals because I was continually going into chemotherapy. And when one would get over, just as I would get over it, something else would come up, and they would give me more chemotherapy. And that put a lot of stress on the situation. The only thing that I can see that has caused that to be a little bit rough in areas is the heavy saturation of drugs – the affect on my senses... the battle with the closing side of my mind, I guess you can say. The side that is always saying, 'No way, why are you doing this? It's really not worth the trouble.' But I think a lot of that is because the type of drugs they give you affect you in so many different ways. You are tired, and you are hyperactive at the same time.

They gave me steroids, and the steroids would keep me awake for days at a time. I would catch myself in the middle of the night, doing things, you know, cutting pieces of paper into symbols or models and stuff, just to keep my mind occupied. But, see, I didn't know how saturated I was until it was basically over.

Paul admitted to some difficulty "just trying to deal with people," which is really more his problem. "I don't necessarily say that it's those peoples' problem, or they are not the problem... The problem is me trying to adjust to it. I have always found that to be kind of difficult because people, to me, are relatively complicated."

One experience just before beginning chemotherapy caused Maggy to lose some hope. The response of other people to the knowledge of a person's cancer can sometimes hinder hoping in spite of good intentions.

I went to church with [her husband] and he was preaching at one of our country churches... And I know the older people meant well, but they all had to tell me their horror stories... And it bothered me, to the point that I could not eat. You know, if it bothers me enough that I can't eat, it's pretty bad, because I have never lost my appetite... But, after that, I just told [husband], I said, 'Maybe I need to just back off and not be around some of these people.' I was selective in where I went, but then as we had the chemo, I quit going because I didn't need to be around people that much. That was, that was probably my biggest downer, that Sunday ... I guess, you know, we talked earlier about a low point, maybe that was a lower point. That was about three weeks after my diagnosis... everybody knew, and they meant well... and I took it, and I was able to handle it for the most part until we got in the car and were heading home. And I told him, I said, 'I can't handle this right now, all of their little stories,' and there were success stories, but yet some were a little negative...and it bothers you. It can get to you when you really haven't gotten into your treatment yet, and you're really trying to be positive about this. That was probably my low point... and there's nothing against the people that's just ... that's just human beings. They all want to tell you their horror stories.

Maggy has not been back to that particular church, but feels she will eventually

go back. Although she couldn't handle the situation at the time she feels able to handle it now. Maggy is a very understanding and forgiving person, recognizing that the church people didn't mean to be discouraging, they were just being human. She contrasts the "bad church" with other little churches where she received just what she needed at the time – love. "I will eventually go back when he preaches out there... I can handle it now, but then, I could not... The other little churches that I've been to have all been very supportive... They've just come up and given me their love. That's all."

Sheila, when asked about feeling a loss of hope, denied ever feeling despair. "If we're looking at despair, as the opposite of hope, I don't think I was ever at that point. I was angry a few times." This was directed at God for the suffering that she had observed in her family as they dealt with her cancer. She describes what sounds like a death wish to relieve her family's suffering.

There were times in my treatment that I was ticked off at God for doing this. Not for doing it to me, but for what everybody else was going through... what my kids were going through, what my husband was going through... I thought, 'That's not fair. They don't deserve this... why don't we just get this over with? If I'm going, let me go, and let's not drag this out and make life hard for them.'

Sheila tells more about her family's response to her cancer later in the interview. Her teenage daughter, who liked to decorate her mother's hospital rooms, wanted to put up a cat poster captioned, "Shit Happens." Sheila's husband expressed reservations about putting that one up. Sheila responded, "No, that's going up."

That's what her evaluation of her life and mine is at the moment, and that's going up. That's part of what's going on."

During another hospitalization for meningitis, Sheila was placed on a different floor, away from her usual caregivers on the oncology floor. Her overall impression of the hospital was that it was a safe, secure place and that caregivers were trustworthy. However, this was an "unnerving" experience for her because she felt she "wasn't being paid attention to, and I knew it, but I couldn't tell them that I knew it."

Holly's mother died of a brain tumor and at times during the interview she compared herself to her mother in a way that did not enhance her hope.

Well, hers was a different kind. I don't really compare mine with my mother. Now, if it was in my head, I would, because hers had feelers. But now my colon cancer is a mass, but I had two positive lymph nodes. So that, to me, is almost like feelers, but they did get those out... But it has metastasized to the liver, so I know that there are feelers like in my body, but it's not to a main artery, like in her brain, so that it messed her up. Mine... eventually, it may mess my body up.

Holly did not respond to traditional therapy and sought help from alternative therapies, including herbs and color therapy. The color therapist, who analyzed her hair, initially told her she had cancer in four body parts, a worrisome assessment.

I had my hair analyzed, and that person, who analyzed my hair, told me that I had cancer in four parts of my body – in the large intestine, the small, the liver, and the cells' metabolism... I am not for sure what the cells' metabolism is.... I don't know if that is just in my body, the cells, or what it is, or maybe my cells are very active... I don't know... anyway, that is how I got into color therapy.

Bert described his period of lowest hope after his fourth cancer surgery. He poignantly described the course of his illness over the past five years and its effect on family life and his desire to be with family and friends.

The second surgery was very major. It was ten different surgeries. They extracted a lot of my internal organs. They removed a kidney, my spleen... a lot of things. The cancer did not come back for a year and ten months. It came back, third surgery, removed it. It was not anything major, just in and out, about seven days spent in the hospital. The fourth one was twenty-three days in the hospital, and a lot of problems with coming home; having to be readmitted back into the hospital twice, going to the emergency room, and the bowels not working. I was not able to drink or eat anything. Nothing was awake... The sarcomas do not bother me. They have never bothered me. It is the down time that bothers me... being away from my family and activities... that is the tough one, and the twenty-three days in the hospital. That was a low point but, as soon as I was able to come back home... back up on the scale... When you start thinking that you might have to plan vacations and family time and stuff like that around surgeries... it is a nuisance. It is like always having to walk around that bees' nest.

Of his uncertain prognosis, Bert states, "We have seen specialists in this field, and there are no cures. What they do is resect and hope for the best. I guess the downfall of that is that there are no cures." He has been told that his sarcomas will continue to grow back. The only treatment available is repeated abdominal surgery for resection of the tumors.

Deana, a retired pastor's wife in her seventies, developed cancer one year after the death of one of her sons. Deana's time of lowest hope was also after the initial diagnosis, "when I found out that I had breast cancer... That is probably the worst news that a woman can get." Her physician's manner in breaking this news made it a little better. "But [physician's name], bless his heart, called me to tell me the day that

he discovered that I had cancer. Her doctor said, “I promise you this will not kill you,” and she said, “Well, it better not. I will come back and get you...” Then she went in to see the surgeon and had the biopsy, “I really came out very low at that point.”

Another low point for Deana came after a conversation with her cousin, a Registered Nurse. About two years after completion of her cancer surgery and chemotherapy, her cousin telephoned to check on her. All physical ailments in a person who has had cancer are not necessarily related to cancer, a fact this nurse relative must not have known.

My cousin called me about two and a half years ago, and she said, ‘Deana, how is your cancer?’ and I thought, ‘I don’t have cancer any more,’ but I said, ‘I have a recurrent urinary tract infection.’ She said, ‘Oh, your cancer is back.’ Well, that was a Friday afternoon, and she is an R.N., so that was not very good news and really disturbed me. I said, ‘I know it is not cancer because that is not where it returns.’ She said, ‘Oh, yes, it is... it returns everywhere.’ So, I was pretty low at that point. I called [a friend who is an R.N.] and she got me into the doctor sometime early Monday morning. And they had a hard time finding this. They took about forty-five x-rays, and they found that I had a kidney stone that was causing the urinary tract infection.

Some of Karl’s friends, who tried to be encouraging, really discouraged him by minimizing his experience. Characterizing his illness as a crisis like “everybody has in their lives,” was not a hopeful perspective.

Those who said, ‘Well, it’s a terrible thing and everybody has a crisis in their life. You just have to do the best you can to get through it.’ That seemed not helpful to me... I did not want to hear anything negative. I wanted to know the truth, and so no one tried to blow smoke in my eyes. But, I could kind of tell that there were a fair number of people who just felt in their heart that it was going to be okay; whether I live or die, it was going to be okay. But when folks tried to get sort of objective with it all, and in any way suggestive that it was not going to turn out for the best – it worried me a little bit. I understood

it, and I was not upset with them, but it felt so good when people were encouraging and positive. Those are the kind of folks that you want to stay around and lean upon.

Louis felt out of touch and forgotten by his “church family” when he was ill while undergoing chemotherapy. He partially excused this by saying it might have been because they lived far out in the country.

We were members of the [name of a church], and we were pretty regular there... We did not have a lot of contact during that time with church members. Like they kind of forgot about us, and so they were not really a great support group. I am not saying bad things about them, I am just saying... We live kind of far out, so it is not like we have people next door to run over. But there was not a whole lot of communication with them, and so I did not have a whole lot of church family support.

Louis’s first physician, the urology surgeon, was a negative hope-influencing factor. This physician was abrupt and took little time to talk with his patient about the diagnosis and treatment.

I had a particular doctor... an urologist, who initially made the original diagnosis at my early onset of testicular cancer. He did my testicular removal surgery and...when I returned to visit with him... He did a fabulous surgery but, on the return visit, for the consult, when he had to drop the bomb on me, that is how he did it. He basically said, “You have got cancer, and you are going to have to have treatment.” And it was not a very good bedside manner where it was a sit down and talk to you for five minutes and explain it to you. It was, “You have cancer. It is serious. It is growing fast. You have to have radiation, which might stop it. If that does not stop it, you are going to have chemo. Next patient please”...That was my initial dealing with it. You are in like shock, and it is like so matter-of-fact... That was negative.

Robin’s point of lowest hope was when her doctor recommended that both she and her husband undergo chemotherapy at the same time. She had been diagnosed with cancer a few months before he was diagnosed. The threat to her young children

and family life was great. She was very relieved when the oncologist said she did not have to get chemotherapy.

Of course all of mine was overshadowed by [her husband's] diagnosis nine months later... a really low point was in July... I had had the surgery, and that was all that was recommended at that time, and I was not even referred to Oncology. And then [her husband] was diagnosed, and he began chemotherapy treatment. When I went back for my one-year checkup, the studies had come out that even women who had no known involvement could benefit from a round of chemotherapy, so my doctor sent me then to the oncologist. This was like in July, and there was extreme anxiety because [her husband] was undergoing chemo, and it was possible that they were going to recommend that I undergo chemo. And the thought of us both undergoing chemo at the same time and its impact on the family – I was a mess. But he reviewed everything and said that the cancer was caught at such an early stage that he did not see any reason to go through that, and hope increased after that!

Robin's mother was not a role model of hopefulness for her daughter. She worried about everything, always expecting something bad to happen. Robin recognized this pattern and decided not to live her life that way. "My mother was and is today a horrific worrier. She lived her life in fear because she always worried about 'what if this bad thing happens' or 'what if that bad thing happens,' and I think from early on I was determined that I was not going to live my life like that.

Pam's most difficult period of decreased hopefulness was at the time of her initial diagnosis with breast cancer. Shortly after a mammogram, her primary care physician called her at home and told her it appeared as if she had cancer. He had scheduled her for a biopsy the next day. Her immediate reaction was to think of pain, suffering, and death. Regaining her sense of hopefulness took some time.

I cannot express the black cloud and the almost like disbelief... It was almost like a cloud that came down over me, and the first thing that I thought of was pain, suffering, and death. It was just an unbelievable, awful moment, and it lasted after I talked to him... It lasted for about twenty minutes until I finally just stopped my own sniffing and crying and it was like... Then I began to calm down and get more peaceful, but it took... it took a long time. It was not over immediately because there were just days where I had to fight depression.

Pam was distressed the day of her interview, having just that morning observed the suffering of a dear friend who was dying of cancer. After visiting her friend, she expressed helplessness and lack of ability to understand suffering.

I came home this morning having been with my maid, my dear, dearest friend who is dying of abdominal cancer that has metastasized. And she is in such terrible pain, and I do not really quite understand all that. And she is a Christian and a good woman, and a believer in prayer and healing, so I do not always understand all these things... You feel so helpless. I felt so helpless because all I could do was be there and pray for her, which I was happy to do, but it is a distressing thing. Anyway, it made me grateful to know that I had not, that my suffering was very minimal.

Pam was hurt and angry by the response of some of her charismatic friends to the fact that she had cancer. She thought they probably knew about it, and were praying for her, but they never acknowledged it, spoke of it, or showed concern openly for her health. She assumed their lack of response to her situation was because they were uncomfortable with it.

I found that I had some negative experiences from some of my charismatic friends that I, to this day, have to work at not to feel hurt or bitter about. They knew that I had cancer, and I am sure probably prayed for me, but they would never, to my face, act like there was anything wrong. They never said to me, 'How are you feeling? Are you hurt? Are you okay? I am sorry.' They acted like nothing had ever happened. And that taught me a lesson. That you really have to meet people head on and let them know that you know and that you are concerned.

Pam feels distressed whenever she hears of someone else getting breast cancer, which is about every two weeks. She fears that it is becoming rampant and is concerned for her own daughters' health. She wonders and speculates about the cause. Pam empathizes with other cancer patients and is available to talk with them. She likes to give them hope!

It is somewhat distressing to me that it seems like every couple of weeks somebody else I know or somebody has come down with breast cancer. It is just like almost rampant, and that is distressing to me because I think of my own daughters, and I think, 'Why is it so rampant? What is causing this? It has got to be the environment, it has got to be the pollutants, it has got to be what is in the foods, additives and things like that.'... It is just wild, and so that is an upsetting, distressing thing... There are just so many people, and you kind of relive it with them whenever you talk to them, except that it is nice to be able to give them hope.

Audrey, a Registered Nurse who now works with cancer patients, occasionally feels down when she identifies with a patient in similar circumstances or when one of her patients dies. In general, it helps her to work in this field and be of assistance other cancer patients.

There are times that it does bother me because I will come across somebody's record, or their situation, or something where their tumor will be the same size as mine was, or they are young, or they have similar circumstances or something, and it will kind of get to me then. When I worked on the floor, there were always people who were dying, and it bothered me more working on the floor.

When Audrey was a senior in nursing school and going through cancer treatment it bothered her that the Dean and some of her instructors wanted her to drop out. At the time, she perceived this as their lack of confidence in her, rather than what

she later thought was their protectiveness. She was determined to finish school and did so without a break.

When I was in nursing school and had been diagnosed between semesters or whatever, and I came back, and not so much my advisor because she was really good about it, but the Dean and a couple of the other instructors wanted me to drop out... I guess looking back it may have been more of their protectiveness or something. But, at the time, I was taking it as, 'You cannot handle this.' That bothered me because I thought if I think I can do this, and I want to try this, why are you sitting there telling me, 'No, don't'? Looking at it now, I think it may have been more of a protective-type thing... Take care of yourself, take care of your family type thing. But, at the time, I did not see it that way. I saw it more as they did not think I could do it... And that was a negative. And grant it, it was a lot to do, but I wanted to do it, and I wanted to try.

Working in the oncology field has given Audrey added knowledge of breast cancer and its treatment. She learns of the latest research, but has found that added knowledge does not always enhance hopefulness. Her tumor was large in comparison to many, which she knows is associated with reoccurrence and metastasis. She worries about the chemotherapy she took and the increased possibility of leukemia. Audrey concludes that knowledge is not always hopeful.

I thought, "Yea, that is big, and that is not good." But now I think that ... like I said, working with it and knowing the bigger the size, the worse it is, and the more chance of reoccurrence, the more chance of spreading. And working with it, you are forced to know it. It is not always good... Because you question more... Like now, I am thinking, 'Okay, I did all the chemo.' The research study I was on was comparing some high-doses of Adriamycin and Cytosan with standard doses.... Well... now, ten years after chemotherapy, a lot of women are coming up with leukemias and that kind of thing, and my mind goes click, 'I had the high doses, so does that mean I could start showing up with leukemia in less time?'... So knowing things...is not always good. It was at the time, because it gave me a handle on things. It let me know what was going on, but the more you know – the more you question.

Audrey's husband's initial reaction to her cancer was distressing to her because he was so angry. She was concerned and felt like she needed to support him. When they talked he would question, "Why does this have to happen to you and not someone else? ... You were always so good, you never did anything wrong." She became more "settled" with it, telling him "Okay, this is how it is, and this is what I am going to do, and this is going to be okay, and I don't know why." She got to that place where "I did not want to figure it out anymore."

Audrey's daughter was more of a threat to her sense of hopefulness than was her husband. She felt like she had given her the breast cancer gene. Both Audrey's mother and aunt had also had breast cancer. "I just feel the mother guilt. I was the mother. I had her."

The oncologist was initially a threat to Audrey's hope. "She was not optimistic, I guess, but that is the physician's role. They have to tell you... They want to make sure you know all the facts – you know what the worst scenario could be." The oncologist went over all the statistics. "I didn't want to hear about that then because I knew it was bad." She already knew it was serious because of the size of the lump. Audrey admits to hearing "the glass empty" when told she had a fifty percent chance of reoccurrence.

Audrey felt that her oncologist did not support her desires to have a mastectomy as her treatment option and to finish nursing school. Instead of having the entire breast removed, the oncologist seemed to be leaning toward lumpectomy with

radiation. Although her doctor never used these words – “it is horrible and disfiguring, and it will be grotesque, and you will never have sex again” – that is what Audrey heard in what she said. For Audrey, the mastectomy meant “peace of mind that the breast tissue was gone.” She had a mastectomy with reconstruction. The physician also tried to convince her not to finish school. “I think she kind of had to be talked into agreeing to let me finish school.” In the beginning, “I thought she was negative.” She feels better about her doctor now, three years later. This physician often asks Audrey to talk with new cancer patients.

Negative factors from the human environment involved many relational groups – family members, friends, church members, and health care providers. Real or perceived threats of loss (e.g. loss of significant persons by death or divorce; loss of companionship, respect, self-esteem, comfort, or expected support) lessened participants’ hopefulness in negative hope-influencing human interactions.

Positive Hope-Influencing Factors from the External Non-Human Environment

The final realm of environment for which data were gathered concerning hope-influencing factors was the external non-human, including all the world surrounding an individual except other persons. The external non-human environment, part of the world outside of self, was defined in Chapter I as “other living things (plant or animal), inanimate objects, places, essences or entities (concrete, abstract, physical, or metaphysical) surrounding an individual.” The following data were obtained in response to the third research question: “From the patient’s perspective, what factors

from the external non-human environment impact the hoping process positively (sources of hope) and negatively (threats to hope)?" The amount of data collected in answer to this question was smaller than that obtained for the first two research questions. It is recalled from Chapter I that this is the area for which little research has been conducted to investigate hope-influencing factors.

For research question three, participants were asked to think of and tell about aspects of the non-human environment (places, objects, things -- living or non-living, plant or animal) that influenced their hopefulness positively or negatively (see Interview Guide in Appendix A). They were also asked about environments where they had received health care. Participants were queried for both positive and negative factors from this environmental domain.

Little has been reported in the nursing research literature about the influence of factors from this environmental domain on hope. Florence Nightingale (1969) wrote of the importance of beauty and colorful flowers in promoting a more rapid recovery. Dufault and Martocchio (1985) included physical aspects of the environment, "beauties of creation", and non-human living things (pets, wild animals, birds, plants, and trees) in a dimension of hope termed "affiliative." Another nursing author, (Brown, 1989) described "aesthetically pleasing environment" as a factor facilitating hopefulness. She suggested a few interventions to positively alter the environment but failed to cite any research evidence to support her recommendations.

A few studies have examined the relationship of hope and setting of care. Herth (1989) surveyed adults undergoing chemotherapy in three settings (inpatient, outpatient, and home), finding that mean hope scores of persons receiving chemotherapy in either inpatient or outpatient settings were significantly higher than those in the home setting. Perceptions of hope were influenced by place of residence in Herth's (1993a) study of older adults living in community and institutional settings. Overall levels of hope were found to be high except in residents of long-term care facilities. During the interview phase participants mentioned a few factors from the non-human environment that supported their hope -- music, literature, a hand-stitched doll, afghan, pets, nature, prized art, apple blossoms in springtime, and beautiful flowers. The family caregivers in Herth's (1993b) study added special meals, posting positive notes, planting a garden, and watching the sunset to the list of hope sources. Having adequate income was associated with higher hope in the study by Ballard et al. (1990) of patients with cancer.

Participant perceptions of the external non-human environment in general will be presented followed by that most relevant to health care providers – perceptions of the hospital and chemotherapy room. Positive hope-influencing factors from these two health care settings have been separated from other non-human environmental influences. It is recognized that human caregivers are very much a part of the hospital and chemotherapy room milieu and it is again noted that the human and non-human environments interact with each other and with the self to create perceptions.

Theme categories developed from these data include: pleasant sensory stimuli (majestic views, sweet smells, nature, flowers, music), symbols (cross, rosary, butterfly, pictures, hats), comfort (beauty, sunshine, bathing, swinging,), safety (home, chapel, hospital, pet guardians), power (mountains, water, church, chemotherapy room), and surrogates (pets, plants, stuffed animals). It is noted that environmental aspects often demonstrate more than one theme, e.g. water – the comfort of a bath, the power of a swim, and the beauty of a lake. A symbol, such as a cross or rosary, may bring the bearer feelings power, comfort, safety, and hope. A home offers comfort and beauty, rest and relaxation, and safety and security.

Positive hope-influencing factors from the non-human environment will be presented first, followed by negative factors. As for the internal and human environments, negative factors from the non-human environment are also surrounded by the theme of loss.

When talking about the many activities and outings that helped her to be hopeful, Emily mentioned the following environmental aspects. “I like to go to the Arboretum and see all the beautiful flowers. I piddle in my yard in the summer, and plant flowers, and mow.” She expressed appreciation for the beauty of nature and the sweet smell of flowers, with these sorts of things making her “feel uplifted.” In addition to flowers and nature, her white chow dog is an important non-human “friend.” She felt that he helped her to feel more hopeful by bringing “companionship, joy, and security” to her life. He is a “one woman dog” in that, “he only likes me.”

Another hopeful place for Emily was her church. In church she feels surrounded by friends and “a little closer to God.” Emily is very active in her church, visiting shut-ins and attending regularly. Her faith is a very important self-sustaining factor, reinforced by her presence in church. During the interview, the researcher observed a small gold cross around her neck.

Angie’s first thoughts of non-human environmental sources of hope were “all my animals” – two dogs, three cats, and two horses. She went on to explain how these pets help her to stay hopeful. Her horses provide her with joyful activity and needed exercise for her painful joints. Angie’s animals are something for her to take care of, “they depend on me... I have to be strong and well to take care of them.” That motivation sounds similar to a mother’s need to care for her children. Significant inanimate objects for Angie, also related to her animals. “I have pictures and statues of my animals... I like to look at those... When I can’t have my animals there, I look at those and they remind me of my animals.” One object also associated with animals was the horse trailer parked near her home. Looking at it triggered thoughts of future fun – hope-instilling activities she planned to do when stronger. “I love to look at my horse trailer because that reminds me that pretty soon I’ll be able to load my horses up and go and participate in the horse activities that I really enjoy, like parades and trail rides and supper rides. So that gives me a lot of hope and reason to keep going.”

Other symbolic sources of hope are two pieces of jewelry, given to Angie by her family and a friend. “I do have two things that I wear around my neck.” One is a

cross, given to her by her family. "I never take it off." Another piece, called the "rings of hope" has five little gold rings on it. This was given to her by a friend with ovarian cancer at a time when Angie was struggling with a difficult decision. It had always been a dream of hers to move to the country where she could have all of her animals right at home. "She [her friend] said, 'I should follow my heart and do it.' And she has since died." Angie lives happily in her new country home, surrounded by her animal family. A small gift can have great power and significance. A friend now gone is fondly remembered.

Being in the water, bathing or swimming, was a positive factor for Angie. She wished for her own swimming pool, but was happy to swim at her brother's home. Besides hope, water brings feelings of comfort, power and coordination to Angie. She swam competitively for many childhood years.

Water is a big source of hope for me... I like to get in the tub and soak in the water. I was a good swimmer, so I feel very comfortable and powerful in the water. It would be nice if I had a swimming pool because I'd probably be in it a lot. It's also good when I get to swim at my brother's. It's a good source of activity. It helps my joints. It makes me feel powerful again. I'm very coordinated in the water. So I would say that water is important to me in the environment.

Regarding places as hope-influencing factors, Angie mentioned "the country" both at her sister's and at her new home. Before building her home in the country, she stayed with her sister during rounds of chemotherapy. At her sister's, she did not feel isolated because family members and her animals were there. The country provides

Angie with beautiful views, pleasant aromas, peaceful feelings, and relief from her claustrophobia.

I also like to be in the country, probably foremost at my sister's, because I'm not isolated out there. And it's very familiar to me, and that's where a lot of my animals are. And I don't have to be alone there because her family's there... my niece. And I just don't feel isolated there. There's a lot to do in the country at her house, but I'm beginning to like to be in the country at my house. The only drawback is I'm very much alone out there, but it's very pretty – it's beautiful! I love to get up in the morning and look out over my seven acres and see the trees and the grass and the brook and the sun coming up and it's very quiet, very peaceful. It smells different than if you live in the city. I love the smells in the country... I'm a person that is very claustrophobic. I don't like small places. I don't like to sit in airplanes. I'm very claustrophobic. Believe it or not, when you live in the country, you don't feel claustrophobic at all.

Angie mentioned "mountains" as her final hopeful aspect of the non-human environment. She has been drawn to these powerful peaks since childhood and her college days. Angie senses power in the mountains.

I've always loved mountains, even as a little child... I just couldn't wait when we were driving to Colorado to see the tips of the mountains. I have a lot of good memories from my childhood in the mountains at a dude ranch. And I went back to school [college in Denver] so I could be near the mountains, and I don't necessarily mean hiking, or skiing. I just love to look at the mountains. They are very powerful.

The mountains were an important part of the ambiance at her national ovarian cancer retreat in Montana. "Every morning in Montana I would go and sit outside and just look at the mountains." The environment, at least for Angie, has a power to inspire, to uplift, and to facilitate hope in a spirit struggling to feel powerful in the face of serious health problems.

Marcia mentioned several inanimate objects as hope-influencing factors. All of

these were part of a very important place, her home environment. Here she escaped and rested after chemotherapy, an unavoidable negative experience for her. Her home, “just a mobile home” in her words, was really much more – a safe, comfortable refuge in which to relax and heal her spirit.

Probably just my home... I had lived there for nine years, but it was just my home, and everybody that came into my mobile home – it was just a mobile home – but everybody that came in there said it was so homey feeling. You feel so... it’s so relaxing in there. And I would go home from my treatments, and I would feel I didn’t want to go anywhere else. I was where I wanted to be, at home.

Music in her home was an added stress reliever for Marcia when she was going through treatment. “I found music was really relaxing. I like classical or jazz. I don’t like words, and I found last year it was really relaxing just to go home and just turn on the music and just sit there and relax.”

Several objects in her home brought Marcia comfort and beauty. The first thing she grabbed, hugged, and cried with after finding out she had cancer was her “big, huge teddy bear”, a gift from one of her coworkers several years ago. One can always find him sitting on her bed. “I still have him. I will always have him.” Another important object was a set of chimes given to her by her daughter.

They don’t hang outside. They hung in my bedroom. [She has recently moved since finishing chemotherapy and getting married.] A lot of times when I would get home from chemo, I would lay on my bed or sit on my bed, and I would watch my little chimes move in my bedroom, because when my air conditioner was on or my ceiling fan by the little heater vent, they would sort of move, and they made really pretty noise. So that was something I got a lot of enjoyment out of. As a matter of fact, I dug them out of a box this week. I thought, you know, I haven’t seen those little blue chimes, so I went digging

through some boxes, and I have them laid out in my bedroom, so I'm going to hang them again in my bedroom [of her new home].

Marcia wasn't able to have any pets in her mobile home, but had many plants.

"I've loved plants... I have two huge plants. And living in that mobile home, when people come into my house, and I have plants... They say it makes you feel more at ease, more homey... I love my plants."

Two final objects important to Marcia are her rocking chair and her outside swing. "I have a rocking chair. I sat in it a lot last year. I love my rocking chair... I have a swing outside underneath my trees." One assumes these brought relaxation and a change of environment from inside her home to outside under the trees.

Paul gains hope at home, working on his house, planting flowers, "all of those little things... I have flowers, I have herbs, I have fences." Even though some people might say, "Well, that's just planting flowers... To me, that's just another extension of your creativity." For Paul, an artist, expressing his creativity has been an important hope-sustaining factor during more than twenty-two years of coping with several types of cancer. When asked to say more about how these things helped him to be hopeful, he replied.

Like, if you plant flowers... I think it, well, especially on things that grow, like trees or whatever... To me, that is just another child, another friend, another part of the family... You don't have to listen to them because they don't talk... Well, they talk, but they don't talk like we think... But, I don't like to haul them around in the car, and they don't argue... And mostly what they are saying to me... is visual, because everything is very visual... is very positive... So I don't have any negative things about that.

Besides nature as friend and family, Paul feels all of nature is alive. “Even rocks have life.” Nature, flowers, and gardens – they are all visual and they provide images that inspire his creativity and artistic endeavors.

Maggy’s hope-inspiring objects were of a feminine nature – hats and shoes. “I’ve bought more new shoes since I started chemo... because it makes me feel good.” She bought a pair of shoes the other day. “I have absolutely nothing to wear with them, but they were on sale. I loved them... I said, ‘someday I’ll have something pink.’” So she bought them. “Now, I’ve got these real pink shoes with nothing to wear yet, but those things make me feel good!” One wonders, is it the pink shoes themselves or the possibility of future wearing that excites her?

When her hair fell out from chemotherapy, Maggy decided to wear hats instead of wigs or going bald. With amusement she explained, “I decided to be different and go with the hats, you know, I am an individual... and I have worn hats now since March, and will wear them until my hair is long enough to comb, which may be December.” Besides providing her another reason to go shopping and have fun, the hats give Maggy an immediate identity. Other cancer patients recognize that she is going through chemotherapy and they share thoughts about cancer. Some coworkers and friends have told her “they like them” and to keep wearing them. “I’m known as the hat woman now... I’m going to have a hard time turning them loose... I’m having a good time with my hats. I’ll tell you that!” She has shopped at a local store, bought several brown straw hats, and spray-painted them different colors. “I have one to

match just about every outfit now.”

Maggy’s last thoughts on the environment were of butterflies, “the sign of new life,” and of being outside. She frequently wears butterfly pins and uses a butterfly bookmark, given to her by a cancer survivor. The researcher was fascinated by her wonderful environmental analogy, describing a person’s dormancy during chemotherapy and a springing into life at its conclusion. She said this analogy “just came to me” during the interview.

Oh the environment... if we are talking about environment, I’m going to talk about being outside. Something as simple as a butterfly... because a butterfly is the sign of new life... That was a bookmark that was given to me by a survivor... It was a butterfly page clipper. She said, ”This is a sign of your life.” I wear the butterflies a lot – this pin [pointing to her lapel] – because of that. I’ve done that for years. I like the outside because I just like it out there. Whether it is getting cold and everything is turning brown, there is still life there. It’s dormant, it’s dormant... But it will spring back, and that’s kind of like when you’re going through chemo treatment. You get dormant for a while because of your treatment, and then when you get through with that, you start getting your energy back, and you start becoming a person again. Sometimes you feel like you’re not a person. You feel like you’re a pincushion. You feel like that... during chemo... and during radiation too... You can get to a feeling of... well, dormant is a good word because you feel like something is happening to you. You’re being worked on, you’re being covered, taken care of, and then all of a sudden, when you finish that, you spring into life!

Sheila, like Emily had a bad experience in the bone marrow transplant unit. Finding it hard to talk about years later, Sheila described a frightening psychotic drug reaction. One thing, which helped her to finally “come out of it,” was listening to audiotapes of church music. These were meaningful to Sheila because she was a

church choir director. Her family recognized improvement in her mental status when they noticed her “directing the choir” while still in restraints.

I remember parts of it... my tapes... One of the things that [husband] and Mom told me later was that they had music tapes of church music. And I am a church choir director... one of the things that they noticed when I was coming out of it was that, strapped down as I was, I was directing the choir... and that’s what brought me out of it.

A place of great significance and hopefulness for Sheila was her faculty office. Being diagnosed with leukemia and undergoing therapy necessitated absence from her teaching position. One time when Sheila was hospitalized, she was granted a dinner leave, and went to visit her office. Being in her office again reinforced the importance of her identity as teacher. “I came and sat in my office... just to convince myself I was still a teacher; I was not a cancer patient... I was still a teacher. And I came and sat in my office and cried. Then I went back... But that really meant something to me. That was a very hopeful thing to sit in my office.”

An inanimate object Sheila could hold in her hand that signified hope was her rosary. “That’s always been there... It’s been there the whole time.” Her rosary and its prayer beads remind her “that there is something beyond the here and now that we can turn to when things look a little bit out of control.” During one of her visits to a physician at a world-renowned cancer center, she shared universal feelings with a fellow patient from another culture and a different religious tradition.

I have told this story before, but there was a time when I was at [cancer center] and I had my rosary in my lap. It was just there, and there was another gentleman sitting in the waiting room... in Arab dress, an older man. And he

had, which I found out after I got back to school because I looked it up to find out... it's called a tazbay, and it's the Muslim prayer cord. He was doing exactly the same thing I was doing, and we just looked at each other and nearly laughed out loud because it was a way to handle it... We both knew that we were handling it in the same way... just in a little bit different words, that's all, but it was the same.

An environmental phenomenon, rarely seen in Texas, brought Sheila a sense of peace on an early December morning, when she was seriously ill and being transferred between hospitals.

We had that terrible freeze where everybody's bushes froze. That was the morning they moved me from [one hospital to another], and there was snow – ice and snow everywhere. I mean, there hasn't been a lot of snow in Texas, but that morning there was snow, and that was something that I thought about... that it was peaceful and quiet, because they moved me... about five o'clock in the morning.

Being in church is a commonly mentioned source of hope among participants. Sheila's hopeful faith institution was the hospital chapel at a large cancer center in south Texas, where she was often hospitalized or evaluated. She described this place as "beautiful" and "homogenized," a place "for everybody." When she was confined to her hospital room, she watched services on closed circuit television, comforted by the knowledge that her husband and mother were actually there.

The chapel... We would go to mass in the chapel. When we had our check-up... usually we timed it around going to noon mass... It 's a beautiful place. It is a very homogenized place. It's not some place that shrieks Catholic cathedral. It is a hospital chapel. It is for everybody, and that is fine... And, it was on the closed circuit TVs. So on the days that I wasn't up to going to mass, I could watch the mass. Sometimes I would watch the mass and know that my husband and my mother were there... That was a very special place.

Listening to music helped Holly to stay hopeful as a daily strategy. On the way to and from work, she listened to Christian music tapes with songs such as “The Old Rugged Cross.” She loves to sing in church and in the car to her tapes. These help to strengthen her greatest source of hope, her “faith in the Lord.” Holly always wears personally meaningful, spiritually significant jewelry – a cross around her neck and angel pins. Other objects which help her to feel hopeful are the multiple family pictures in her home and her office.

Holly is currently seeking help from alternative therapies. Her brother and sister-in-law encouraged her to start “doing the herbs.” She believes the herbs are ancient medicines, with origins in biblical times.

Well, I just feel like He [the Lord] put the herbs on the planet in his time and the biblical people all lived from roots, trees, and the earth, and that is what I believe...I believe all of our medicines today have some type of herbs in them. We don't know how much or what kind, but I think that's... that is what I believe.

Color therapy is another alternative type of treatment being practiced by Holly. Part of this was having her hair analyzed, showing cancer in four body parts. As a recommendation of the color therapist, Holly was wearing purple clothing, drinking from a purple glass, and wearing purple sunglasses at the time of her interview. She also wore a gold cross around her neck.

Holly has a little doll at home, which she and her daughter call the “whammy doll.” When she is feeling down, the doll and her daughter help to lift her spirits.

If I do feel down, the oldest one [daughter] who is living with me, she'll get to talking to me. She'll say, 'You're letting the devil get into your mind, Mama. Get it out.' And we have this little doll, and we call it the whammy doll, and she starts beating on the body like a voodoo doll, and she says, "Satan, get out of my mother." And we'll start laughing and just cutting up and everything.

A low point in Bert's hoping process was spending twenty-three days in the hospital. Being discharged and returning home was the antidote. "As soon as I was able to come back home, immediately, back up on the scale [his hope rating]." A major part of this homecoming was being reunited with his wife and children. An additional positive factor, the environmental change, cannot be overlooked.

Bert takes time every day to look at the family pictures he keeps "all over my office." He believes "God's greatest gift is a memory", and the pictures of his wife, his children, and their activities trigger positive reminiscences. "Something that I do very frequently is like what you have around your desk... pictures... looking... I take time everyday, and I have pictures all over my office of my wife and my children, and of activities that we have done... I can sit there and look at those for hours. The family is just a major part of my life."

Other than his family pictures, Bert denies having inanimate objects of particular significance. Regarding objects one could hold or grasp, he did say, "I have received lots of those things, but I have taken those as beautiful gifts." He has not received these gifts as "signs of hope" inherent in the object itself. "But I have received them as a gift, and the hope that I have received from that gift was the individual coming in [to his hospital room.]"

Bert feels hopeful in mass at his church. Attending mass is an opportunity to be in the “house of God,” to focus and to concentrate. He and his wife have tried to teach their children that “this is God’s time to reach you in His house, and you need to give Him your undivided attention.” He admits that this can be difficult at times with four children and “somebody always doing something.” In spite of the distractions, this time in church is important to Bert. “It is time to be at peace with myself and try to concentrate... To me, with what I have been through and what I have seen, you have to do it... you have to be a little bit selfish and take the time... Going to mass is very important. It all starts there.”

Bert is a registered land surveyor, and his occupation takes him outdoors when not in his office. “I love being outside. I used to survey in areas around the state of Texas where there is not a lot of activity... I love being out in west and southwest Texas, in the hills around Big Bend.” Before cancer and before starting his business with Louis, he did a lot of surveying in these areas. “To me, that is as peaceful as it gets. It gives you plenty of time to think.” The memory is obviously pleasant and still with him. Remembering other things besides the wide-open spaces of Texas is also important to Bert – “just to sit back and remember family events, times with each individual child, ... with [his wife], ... and looking over the landscape... That helps.”

Every year Bert goes on a traditional camping trip to the Colorado River with his family and others. It gives him great pleasure to sit back and observe the happenings.

Going to the Colorado River with all of my family and our friends, and the tradition that it is moving to... It is getting better every year, so I would think that as far as something physical... that it is really an important event. It, by far, outshines... pheasant hunting every year, but that is just a bunch of guys... which is fun, but it is not like it is to watch children catch fish, or to watch little kids. We do not take toys... we are telling them to go out and create... [Wife's name] and I have always said, when we go camping, we leave all of the toys at home. No game boards, no bicycles... normally we give the kids a rope and a flashlight and tell them to go play a game... And to watch them play and be creative without sitting in front of a Nintendo game or a television, or Barbie dolls, or hot cars... kids can be great!

In warm weather, Bert enjoys being out on a beautiful area lake in his boat.

“That brings a lot of hope and enjoyment to my life.” He and his oldest son water ski avidly several times a week.

We could probably live on the water... We are very fortunate to have some beautiful lakes in this area. I think that probably ninety percent of the people who live here have taken that for granted... I grew up out at [named a lake]. I was on the ski team, and my parents, we were just always there. We had a barge. It was just a way of life for us... being outside is very important to us. So being on the water is as good as it gets... It is very pretty... It is great recreation... It is wonderful.

Walter mentioned several environmental aspects important to him. The week following this interview, he and his wife planned to go see the lights of Fredericksburg, Texas. Recently they had traveled to Ft. Worth, Texas to hear a large choir, the Gates of the Gospel Hour. “I don’t know if you are familiar with them or not, but I just fell in love with them.”

There must be sixty-five or seventy of them, a huge number of people who sing old southern gospel music. And they have all gotten together and formed a group that they call the Hour. And they sing all of these old gospel songs with some instrumental music and all, and I just go crazy over it... If they came within driving distance, I would go again.

Some of Walter's favorite retirement activities involve being outside, a frequently mentioned positive hope-influencing factor among participants. "I love to get out in the yard." He plants flowers "for his wife," but prefers growing a vegetable garden. Cutting wood out in the country and playing golf are two other outdoor activities he enjoys when feeling strong enough. During the interview, Walter mentioned that he and his wife "are into genealogy." He discussed this mainly as a hobby or interesting activity he enjoyed along with several other family members. Retirement has given him more time to become involved in genealogy, an activity not possible when he was practicing medicine.

My aunt had been into it for some time. I had not, but I had a sister in Kentucky who had spent a lot of time with it, so it was something that I could get involved in. The truth is that I spent so much time when I was working that I did not have any time for anything else. I would even get up at four o'clock to read my journals when the TV was not on. So, I have concentrated quite a bit on the genealogy. I have gotten my son interested in it, and he gets on that online network stuff, and he has increased the information for me. It is an information overload.

When the interview was over and the researcher was about to leave his home, Walter brought out his genealogy collection, including family pictures, newspaper clippings, and various other materials. He spent another half hour or so going over family history, especially important persons who had influenced his life choice of becoming a physician. He also showed additional family pictures, significant memorabilia, and talked more about his grandson.

As with so many others, nature and being outdoors is a source of hope for

Deana. “I love being outdoors... I like to pick up pecans.” She likes to sit in the swing by herself, just look around, or read a book. After her son died, this was an especially comforting activity. She talked about reading a particular book that dealt with life after death. “After [son] died, I just liked to sit outside in the swing or in the sun and listen to the birds, or read a book... A lot of people have not believed it, but I like to believe I can see him [son who had died] standing there.”

Deana stated that she likes growing plants. She likes to see them grow and do well and she becomes upset if they die. When asked if growing plants was a source of hope for her, she responded, “growing those plants...those two plants.” The two plants, to which she referred, had belonged to her son who had died.

I like living plants. I like to see them grow. I like for them to do well. I always get a little upset when they die. The two ferns that are out there [pointing to her front porch] are real special to me. The one that is hanging was one of [her dead son's]. I went with him to the nursery to buy it, and we watered it in his apartment, and it was dying, so I took it back to them and said it was dying, so they re-potted it. It has been here for six years. The one that is re-potted is in the ground. I do not take them in – I water them and cover them, but I do not take them in. I keep them warm so they do not die.

Karl didn't talk in much detail about the non-human environment as a source of hope. He did mention a planned family trip to the mountains in Colorado for snow skiing. When feeling strong enough, he likes to take walks outside in his gardens. Karl prefers being at home in his “own bed,” rather than being hospitalized.

For Louis, outdoor activities help to keep his spirits up. “I was always real healthy and semi-athletic and enjoyed being outdoors and doing all those kinds of

things – hunting, fishing, sports, golf and tennis – and then when you think you might not can do those things, it is kind of a downer.” When he was feeling weak and ill during chemotherapy, Louis realized that some modifications to his home environment would make things easier for him. He, his wife, his two small children, and several farm animals live in the country in a new home with several surrounding acres. Ordinarily, the barriers he discovered would not present a problem to a vigorous, athletic man in his late thirties.

At the time, we were constantly working on our place, as far as trying to get it a little nicer and a little more user friendly. We have a couple of gates you have to go through to get to our house. Anyway, because I was ill and would get treatment, I would come home and not feel like getting out, opening the gate, closing the gate, going up to the next gate, opening and closing it, while driving through... We did not even have garage door openers. The environment of our place – I saw a lot of things that I wanted to get worked on, so when I did get well, we got electric gate openers and an electric garage door opener. I was trying to think of things to accomplish that were things that I did not think were such inconveniences when I was in full health capacity, but when I got weakened, then all of a sudden those little things became huge, and I said, ‘We have got to get this fixed,’ so I had some projects planned, and I kind of pointed to that.

The “environmental goals” of fixing up his home and planting his spring garden were ”encouraging” to Louis. His chemotherapy occurred in the winter months and the prospect of warmer weather and springtime also encouraged him.

I guess spring was coming on and we had always had a garden, and my wife was not going to have time to deal with that, and so environment-wise, it was another goal to hurry up and get well so that I could get the garden planted. What else? The weather had been foul most of my illness and treatment – rainy, cold, yucky – and at the end of my treatment, April was starting. And the warmer air, and springtime in general has always made me in a little better mood anyway. And so that was probably, it probably worked out better that I

ended treatment in the spring than ending it in December, going into winter. So I think that was encouraging.

Cyberspace became an important source of hope and information for Louis during his cancer therapy. He regularly visited two websites focused on testicular cancer. Newspapers became other sources of information and hopeful stories about cancer survivors.

Well, one other hopeful thing, or positive thing, was the Internet, and I found Lance Armstrong's website, and he had the exact same kind of cancer... On occasion, there would be an article in [named two newspapers]... During my illness, there was some story on [mayor of a metropolitan area in Texas], and he had been cancer free for nine years, so that was positive to hear a true-to-life survivor story...

Watching television was something Louis could do that took very little energy and gave him more time with his children. "I am not normally really a big TV person. I will rarely watch it on the weekends when I am home, but because I was kind of stuck, I found something that they [his children] enjoyed watching with me... My little boy liked to see karate guys... we would watch Walker Texas Ranger."

Robin lives alone in the country. She fills her usually quiet auditory environment with "lots of music." She loves to play the piano for her own enjoyment and relaxation. "I play the piano a lot... Not for anybody but me... It is very relaxing, of course. Being here alone, you know, even in the middle of the night, if I cannot sleep, I get up and come in and play the piano."

Living out in the country in the home she once shared with her husband, who died of cancer, is a source of hope for Robin. Her home was a “comfortable place” where she could “relax and heal” after her own cancer surgery.

My home... I just remember that I spent lots of time in the bedroom in the recliner because sometimes it was difficult to lie in bed because of the mastectomy. I spent lots of time in the recliner, and it just was comfortable. It was a comfortable place. It is where I did my healing. Even when people came, they would visit me in the bedroom. We had the two recliners in there, so it was easy to have visitors in there... That is where I was comfortable. That is where I could relax and heal.

Robin likes the quiet environment of the country. During recovery from surgery, she sat or walked outside and exercised her arms in a swimming pool. The warm weather was also a positive factor in Robin’s recovery.

It is quiet [in the country], and you are not worried about other noises around you. You can go out and walk if you want to or sit outside. This was all taking place in May, so the weather was nice, and then as I was recovering, fortunately in the summertime, the pool helped me a lot, getting my arms back in full range of motion.

“Being in church” was another source of hope mentioned by Robin. She did not elaborate on this, but it probably has as much to do with her faith as the actual church building. “Faith in God” was Robin’s number one, overall, most important source of hope.

Pam was recovering at home from her cancer surgery during the Christmas season. The “comfort beauty” created by the Christmas music, lights, color, and poinsettia plants was a positive factor in her recovery and hoping process.

Before I went into surgery, which was November 30, we decorated the house (Christmas trees and everything), so that when I came home... I am very much moved by comfort beauty... So I had the beautiful Christmas music. I had the lights, the color, the plants, lots of poinsettias. People were kind and gave me lots of poinsettias. So, I had beauty around me, which was very positive. I remember it kind of got cold and all that, but it was very positive... As you notice, I have plants everywhere, so I still had my plants to look at. I could not do too much with them because I am right-handed, and I was not supposed to be using my right arm and right hand with my reconstruction, but they were ever before me.

More beauty was found on a Christmas trip to Colorado to visit Pam's daughter and family. Although the doctor was not so sure she should go and she didn't have much energy, "we did manage." Being in Colorado Springs for Christmas, brought Pam "the beauty of the snow and having my grandchildren all around me, that was very positive!"

Pam went back to Colorado in the middle of January for the birth of a new grandchild. Her oldest daughter was going to have a second child at home. This trip had less to do with the "beauty of snow" and more to do with the "beauty of childbirth" and the love of a grandchild and family. "I went to Colorado somewhere like around January 12th, and she had the baby on the 19th, and so just being with the family again, that is a very uplifting environment... a grandchild that adores Granny... It was just a good environment to be in... They are a happy, bright, cheery, noisy, active family."

Like Robin, Pam finds music to be a positive hope-influencing factor in her life. She likes to listen to classical music that is "uplifting to the spirit."

I like classical music that is mostly in the majors. What I mean by that is... that is uplifting to the spirit, such as Mozart... Bach... There is some type of classical music that I cannot listen to because it is very depressing. But like, mostly the seventeenth and eighteenth century composers – Haydn, Mozart, Brahms. That is very uplifting, very much so.

Pam's hope was low for several months after her mastectomy. She had trouble concentrating, blamed herself for getting cancer, and "had to fight depression." She felt as if she hadn't taken care of her body in many ways before getting cancer. Poor eating habits and obesity led her to seek guidance from nutrition books. She started taking vitamins and minerals for the first time in her life, with beneficial results. Her belief in a mandate from God for humans to be "whole," supported her efforts.

I think God wants us to be whole, and I think that there are many, many ways that he has provided. He has provided doctors, medicines, natural herbs, natural things in the environment... I began, for the first time in my life, to take vitamins. I began to take supplemental minerals, and I went around looking for specific nutrition books... I read and saw that there were some things that I could be taking, and I started taking colloidal minerals and vitamins, heavy in vitamin C and vitamin E, and other vitamins, and it was not three or four days – I started feeling wonderful – and I have been taking them ever since.

Music is important to Audrey as a positive hope-influencing factor in two ways. First is her husband's music. He is a professional musician, and listening to his music increases her hopefulness. The second way links her love of music, her faith, and her radio.

My husband and I joke about this. I always say that 'God talks to me through the radio.' Because I do not spend a lot of time reading the Bible, but I can feel things, and I can pray about things. Then I have the radio on, and then I can just switch it at a certain time, and there is a song that will come on that will be like an answer. My husband thinks I'm crazy, but that is my way that I do things. And I can remember different times throughout my diagnosis and

chemo and stuff, thinking things and feeling things and thinking, 'How am I going to do this?' And having things come on the radio that would be like, 'Yes, you can.' So, I guess God and the radio, I do not know.

Audrey, like so many others likes to be outside. "I like to go outside, whether it is being in the back yard in the swing, or just on the front porch. We live in the country." Significant objects include a necklace containing her children's pictures and a special Batman toy her five-year-old son gave her to take to chemotherapy. "Taking a long bath" was something she did during treatment. During the bath or while in bed, she used imagery to increase hopefulness. The image Audrey created for herself was of a sparking white light attacking the cancer cells in different part of her body and coming out of her toes as a purple light.

Positive hope-influencing factors from the external environment (human and non-human) trigger positive factors (thoughts, feelings, images) within the self, further supporting the notion that the realms of the total environment interact to create perceptions of hope. The following two sections cover aspects of the non-human environment felt to be of special interest to nurses and other health care providers. It is recognized that the overall therapeutic milieu of these places is influenced by human as well as the non-human elements.

Chemotherapy Room

A hopeful place, frequently mentioned by participants, was the chemotherapy infusion room. Only one participant (Marcia) could not find any way to feel hopeful there. To Emily, the infusion room was the place where, "I'm receiving the treatment

and care I need to fight the cancer.” Her friend, Angie, recognized the variety of patient perceptions. “I guess some people look at the chemotherapy room as a negative place, but to me it’s a place where you are actively fighting the disease. And I don’t consider the chemotherapy as poison like a lot of people do. I think of it as getting in there with a big stick and beating down the cancer.”

For Maggy, the chemotherapy nurses promoted the idea that “this is not a place to come and end. There’s hope in this place.” For that reason the, chemotherapy room was a positive place for her. She could go there for treatments and feel “as good as you could be in that situation.”

Holly feels that the chemotherapy treatment room is a hopeful place, “otherwise they wouldn’t have it.” She believes in it because “they’re doing something to try to cure cancer.” Even though she’s heard some people say not to take chemotherapy “because it’s just something that is going to extend your life,” she doesn’t believe that. “Yes, it does extend it, but it can also put it in remission, so you can live for years. I just feel like...that it’s gonna get rid of what I’ve got inside me.”

Deana did not express any feelings about the chemotherapy room in particular, but did have positive things to say about chemotherapy as a treatment. She chose to have it, when the physician said she “was on the edge” and having it or not “is your decision.”

I want the chemotherapy because I want to live as long as I can, and I want to do what I can right now to ward it off, so I would not have to worry about it. That was my feeling, you know, that I would not have to worry about it. And

I have never been sorry about the chemotherapy, and I have always said if I have to have chemotherapy again, then I will do it. I will never wear a wig again. I will paint a happy face and have a bald head.

Hospital

When asked about care environments and how she perceived the hospital, Angie expressed a lack of hope and confidence in hospital care, preferring to be at home when ill. She resists the idea of hospitalization, feeling that the hospital is a place where you get sicker. Angie agreed with the researcher statement that, “being at home is the best place for you to receive care.”

Emily had generally positive feelings about being in the hospital, except for the time when she had a bone marrow transplant. Marcia also tried to think positively about her hospital environment, by remembering all the helpful treatments she had received there and how well she was doing as a result.

I had talked to a woman who just hated [named a hospital], and I thought, well, I’m not going to do that... I guess I went to [named a hospital] everyday for six weeks for radiation... My thought on that place was ‘Well, I’ve had my surgery here, I’ve had my chemo here, I’m having my radiation, and I’m doing great, so I love this place.’ ... So, I’d drive over there every day and not dread going there... I’m going to think positive about this, that way I won’t dread the trip... And so now... I don’t dread it, when I go for my check up. I think a lot of the way I see things... it’s in your head. If I think I’m not going to like a place, I try to see why I’m not going to like it and look for the good points.

During her cancer treatment and complications, Sheila was hospitalized many times in several different acute care institutions in Texas. She was very ill at times, especially during her bone marrow transplant. With all this experience, her overall impression of hospitals is that they are safe, secure, reassuring places where you go to

get better. There were times when she did not want to leave, becoming dependent on the attention of caregivers and fearful of dying without anyone knowing it.

I knew in the hospital at least that I wasn't going to die in the middle of the night without anybody knowing it. I was wired... you know... people knew that if I ... if all of a sudden this pump stopped working and started beeping, then somebody would be in there to fix it. I wanted to find out why it wasn't working right... to do something. So that part of it was reassuring. At the same time, I could have gotten very dependent on that... It's a safe place... The hospital wasn't some place to go to die. The hospital was some place to go to get better... I never looked at it as a scary place... I don't have any of those experiences that other people talk about of... being in the hospital when their mother died, or their father died. I never had any of that.

Sheila's physician used to try to get her a hospital room with a view, ... "especially if I was going to be there for three to four weeks so I could see the sky... something other than half the wall, or the next window or building." Once when she was hospitalized for pneumonia at Christmas time, she remembers decorations outside the hospital. "All the lights and all of the angels that were outside the front door, became something that I could think about. You couldn't see them, except if you went down the hall you could see them. But I saw them as I went in." They were something beautiful that she remembered, that facilitated her hoping process.

The large cancer center to which Sheila was often referred, was an especially hopeful place. "There are things about [name of the hospital]... it's so huge, and yet it is so personable." She was there often for check-ups – every three months, every six months, and then every year. "I got sick, and was put back in the hospital at [name of

the hospital]... It was not a scary place for me either because it was where I went to get fixed.”

Karl talked of feeling as if he was being cared for by “his family,” while a patient in the hospital and clinic where he has been a practicing physician for the past twenty years. He has received most of his inpatient and outpatient cancer treatment in this institution until getting a recent referral for experimental chemotherapy in a south Texas facility.

Robin discussed only one aspect of the hospital environment that helped her to be hopeful. That was the presence of the many flowers sent to her postoperatively. “I am trying to remember after the surgery... All I can remember is that there were flowers everywhere... It was overwhelming. Everybody was coming through, and they would say ‘the lady with all the flowers.’” She remembered having a “mountain of thank you notes” to write.

Negative Hope-Influencing Factors From the Non-Human Environment

Participants gave fewer examples of negative hope-influencing factors from the non-human environment compared to the other two domains. Losses are again the overriding theme of negative factors from the non-human environment. The reader will note that some stories, previously told by participants, were comprised of integrated factors from all domains, e.g. Emily’s experience with the bone marrow transplant.

As previously described, Emily had a “horrible” experience in the bone marrow transplant unit for several reasons. Part of her distress was related to environmental characteristics. The walls were thin and there was no carpet on the floors. She could hear the suffering of other patients on the unit and was aware of their deaths. These things contributed to thoughts of her own possible impending death.

The hospital has very negative connotations for Angie. She resists the idea of hospitalization, feeling that the hospital is a place where you get sicker. “It’s just not a very hopeful or pleasant environment for me.” This attitude kept her out of the hospital during a time when she might have benefited from care in that environment for withdrawal from overuse of prescription drugs. Her perceptions of the hospital are influenced by previous difficult experiences. Her positive perception of the nursing care was not enough to overcome her fears of going to the hospital. One wonders about the possibility of Angie getting worse if admitted to the hospital against her will or without her knowledge.

The hospital is not a very hopeful place because you seem to get sicker in the hospital. I had an experience recently where I probably could have been hospitalized because I was exhausted and I was going through drug withdrawal, but I didn’t want to go to the hospital because, to me, you get sicker in the hospital. You get weaker... You come out of there feeling worse than when you went in... I will put up all barriers to go to the hospital... All my memories of being in the hospital... I was so ill and sick and hooked up and bags draining, and it’s just not a very pleasant or hopeful environment for me. Even though the nurses were the best thing about the hospital.

Marcia looked upon the chemotherapy room as a place where “you don’t feel a lot of hope.” Her usual cognitive strategy of “looking for the good in something bad”

did not work for that environment. Her negative thoughts seemed mainly to be triggered by observations of the unhappiness of other patients in the room. The loss of privacy of patients in this setting is also a concern. This brings into question the practice of having open patient cubicles rather than private rooms in chemotherapy departments.

Louis linked the prevailing weather at the time of his cancer diagnosis and treatment to his overall depressed feelings. Seemingly appropriate for his situation at the time, he remembered “the weather had been foul most of my illness and treatment – rainy, cold, yucky.” Winter months brought other problems for Louis and his wife. Living out in the country, Louis and his family had a donkey, twenty chickens, nine cows, and an eighteen hundred pound bull. Feeding the cows became impossible for Louis during his “down time” of chemotherapy and was a burden for his wife. “In the heart of winter, they needed hay all the time, and they got kind of obnoxious. She felt uncomfortable being around them to go give them hay, and they about knocked her over getting to it.” They sold the cows and bought sheep. Animals do not necessarily enhance hopefulness as they did for other participants.

Data obtained in answer to research question three have provided detailed descriptions of positive and negative hope-influencing factors from the external non-human environment. Pleasant sensory experiences, appreciation of beauty, comfort, relaxation, and power were some of the benefits of informant interaction with this realm. Knowledge of participant perceptions concerning health care settings is most

immediately useful for determining nursing interventions. However, awareness and appreciation of all that was meaningful to participants serves to further a capacity for empathy and understanding clients by health care providers.

The Hoping Process – How the Sources Influence Hope

Descriptive data describing personal sources and threats to hope from the three domains of environment have been presented with analysis, interpretations, and discussion. As shown, it is sometimes difficult to place data into single discreet categories and stories or vignettes frequently overlap and reflect more than one theme. Another noteworthy observation concerns interaction among domains of environment. The self interacts with other persons and with the non-human surroundings. There is interaction and flow among all three. The fourth research question concerned the process, or how these identified sources facilitated hopefulness. This question, presented in Chapter I, was stated as follows, “How do patients perceive that the identified personal sources of hope facilitate hopefulness in their life situations?” This was not always asked directly, but often came spontaneously as the informants explained particular hope-influencing factors.

How a particular source facilitated hope was often a part of the source description or the response to a researcher request to elaborate or “tell more about it.” When discussing a particular source, such as a person, it was natural for the participant to go on and describe how that person influenced hope. For instance, Holly listed her husband as a source of hope and immediately launched into explanation about his

“taking care of everything” and “cooking every night.” Bert gave “being in mass” as a source of hope helping him “to concentrate, to focus, to connect to God, and to feel peaceful.” With these types of articulate and reflective participants it was unnecessary to always ask directly how a source helped them, they had already answered that.

Some researcher interpretation of need satisfaction by listed sources was necessary, consistent with Maslow’s (1987) notion that satisfied needs are not in conscious awareness and no longer motivate behavior. “A want that is satisfied is no longer a want” (p. 18). For example, when a person is comfortable and pain free they are no longer aware that a lack thereof drains hopefulness and they do not seek relief.

Theoretical Model of Hope Development and Renewal

The theoretical model of hope development and renewal, as proposed in Chapter I (Figure 1.), was supported by the findings of this study. As demonstrated by this model, developed from the nursing grand theory, Modeling and Role Modeling (Erickson et al., 1983), hope has roots in developmental theory (Erikson, 1963, 1983), needs theory (Maslow, 1979), and object relations (attachment/loss) theory (Bowlby, 1969, 1983). The data for research questions one, two, and three provide illustrations of hope emerging from attachments to and trust in significant objects (concrete, abstract, or symbolic) that meet basic and growth needs of the individual. Examples will be provided from data obtained for each environmental domain of hope-influencing factors.

Internal Environment of Self

Within the internal environment, or the self, participants identified positive personal characteristics, thought patterns, beliefs, and self care activities that helped them to be hopeful. Within these are found a variety of character strengths, goals, careers, role models, religious beliefs, and valued activities developed individually over the lifetimes of participants. For instance, Paul is in touch with and very attached to his creativity, an abstract concept. This has provided many need satisfactions – a livelihood for himself and his family, self-esteem and accomplishment in the art world, and healing in his long battle with cancer.

Emily, Maggy, Sheila, Holly, Karl, Robin, and Audrey expressed great faith (trust) and connection to God through prayer, sacred writings and rituals. Faith in God was identified as the single most important source of hope for each of these seven persons. Attachment to God provided them several basic need satisfactions, including security, control, unconditional love, acceptance, and the promise of an afterlife (a better place). Participants with faith or trust (attachment to God) were, for the most part, secure, unafraid, and serene.

Goals for the future, such as seeing a family member graduate or watching children or grandchildren grow were important for Bert, Louis, Walter, Deana, Robin, Pam and Audrey. Being able to fulfill a life purpose through career activities and achievements was especially important and evident for Angie, Paul, Sheila, Bert, Karl, Louis, and Audrey. Reaching milestones for self or significant others and career

achievement met needs for self-esteem, respect, and actualization. Learning about their disease and treatment met needs for control as well as knowledge and understanding. Self-restoring activities relieved tension, fatigue, and boredom, providing many with joy and exhilaration.

External Human Environment

Within the external human environment, attachments to other persons who met participant needs in a variety of ways were obvious. Angie, Marcia, Sheila, Bert, Louis, Deana, Karl, and Robin displayed attachment to family, religious, and professional persons who provided support as well as role models to emulate. The concept of social support, well known to most health professionals, is evident in the variety of supports and services described by participants as important in maintaining hope. Basic need satisfactions such as food preparation, relief of discomforts, security, relaxation, presence, companionship, love, recognition, appreciation, and respect are achieved through interaction with other humans. Nurses, physicians, and other health care providers, sometimes identified as significant attachment “objects,” have the opportunity to meet needs at all levels in a variety of ways that are supportive of hope. They supply needed information, communicate therapeutically, care competently, and help the patient feel respected and involved in the treatment plan.

External Non-Human Environment

The external non-human environment provided some basic comforts and pleasures such as the warmth of sunshine, relaxation of water or music, and comfort or

inspiration from beauty (e. g. flowers, nature, sunshine, birds singing). In addition to relaxation, the environment was a source of power for some (e. g. water, mountains, and music tapes). Non-human living things (plants or pets) served as surrogate family members for some participants. Inanimate objects (crosses, prayer beads, pictures, toys) were symbolic and helped individuals feel connected to significant others (God, family members, friends). All participants were attached in some significant way to aspects of the non-human environment they believed supported their hope. All environmental objects of attachment can be linked directly or symbolically to a level of need satisfaction.

Negative hope-influencing factors usually represent some type of loss, the converse of attachment. With loss of significant individuals, participants lost loving companions and all the various need satisfactions they provided. Some losses were of valued human qualities such as comfort, strength, desired activities, life roles, self-esteem, respect or personhood. Some negative factors indirectly threatened security (e. g. dire statistics about cancer) or directly caused fear and anxiety (hearing other patients suffering and dying). Uncontrolled symptoms of pain, nausea, anxiety, and exhaustion represent unmet basic survival needs.

Given the illustrations above, reiterated from the findings of research questions one, two, and three; support is demonstrated for at least preliminary validation of this author's Hope Development and Renewal Theory (Figure 1), synthesized from ideas in Modeling and Role Modeling (Erickson et al., 1983). This mid-range theory provides

a view of the hoping process that is useful for nursing professionals and others to see more clearly how their actions may influence their clients' hoping processes. Nursing impact on hoping is through direct satisfaction of needs (nurturance), wherein the nurse becomes a potentially significant object; or through encouraging and facilitating client attachment and contact with other significant objects in their lives – aspects of self (personal internal resources) or external human and non-human resources. As shown by the model, attachments or losses facilitate or drain hope through need satisfactions or deficits. A high level of need satisfaction promotes human growth and development. The target developmental task related to hope is “trust versus mistrust” (Erikson, 1963). Since the process of growth and development continues over a lifetime, resolution of tasks is not final and fixed. Enhancement and renewal of trust and the stage-related virtue, hope, is an open-ended and ongoing process.

Rankings of Hope Sources by Importance

The fifth research question guiding this study asked for participant evaluation of the relative importance of personal sources of hope, “What do patients identify as primary, secondary, and tertiary sources of hope within each environmental domain and overall?” Data for this question were sometimes difficult to obtain and were initially incomplete for some participants and some environmental domains. Complete data were ultimately obtained for the rankings of hope sources by importance. Data for this question were completed through follow-up telephone conversations. Some participants mixed up the sources in domains of environment, and one (Holly) was too

ill to clarify her responses when she was called back in follow-up. One unanticipated benefit of asking for rankings was the further stimulation of thought. Several participants brought up new sources not previously mentioned when attempting to rank their sources. These data were added to the findings of research questions one, two, and three (hope-influencing factors). Reasons for the initially incomplete rankings and difficulty obtaining them are illustrated by the following examples.

Angie ranked only two self-sources (internal environment) of hope – “feeling physically well” first and “career” second. For the third requested source, she said, “I think the rest of them are all different at different times.” She could not differentially rank the significant people in her life (external human environment), thus they are listed as “ties” (Table II). Angie stated the three top sources were equal – her sister, her cancer survivor friend (Emily), and her support groups, one local and one in Montana (the annual retreat group with whom she regularly communicates by e-mail). Initially, Angie could not rank her overall sources of hope at all. “I can’t say specifically because they’re different at different times depending on how I’m feeling. One is more useful at one time than another time. It’s impossible to say... Depending on the people that I’m with, it just kind of varies. I can’t pinpoint one specific one overriding.” In a follow-up conversation, she obligingly attempted the ranking. For the human environment, Marcia said, “They’re all so close.” Maggy felt guilty ranking a coworker ahead of her husband. For the non-human environment, Sheila stated,

“Oh, it all runs together.” Pam had ties for the “overall” category and Audrey had ties for the “external non-human environment.”

Paul, an artist and teacher, also had some difficulty when asked to rank sources of hope from within himself (internal environment) by importance.

I have difficulty narrowing it down to one thing. It is like working with the different mediums in art. I think all of it has a definite positive reaction on my life. Like through all of this search and creativity, is also a search to understand myself... I may find things out about myself that I may not necessarily like, but I try to correct that as best I can... I take in everything that I think I can absorb. I store everything else mentally because some of it I don't fully understand, but I don't throw it out because I think what I'll learn is down the road... Some of that may occur to me, and I want to draw it from the mental resources and utilize it in a positive way. In the long run, I think, the whole thing is very humbling, and... everything together, all of the personalities and the influx of everybody working together is a tapestry of positiveness, so to speak.

Paul did comply with the researcher's request to rank sources in the internal environment. For the first and second hope sources, he said, “expressing creativity,” and “planting flowers.” Beyond those two, he said, “All else varies.”

The difficulty and hesitancy with which many participants answered these ranking questions support another theoretical perspective on the hoping process that emerged from the data of this study – a view of the hoping process as cyclical and involving various phases. This will be presented in Chapter V. Depending upon where a person is in the process, sources vary in importance. In her study of sixty older adults, Herth (1993a) also found that participants relied on more than one hoping strategy, depending on the situation.

Time and circumstances determine the type of need deficits experienced and the potential of various sources to facilitate need satisfaction. For instance, a person in pain needs a nurse for assistance in relief, not a best friend to have fun with. A person feeling lonely and unsafe needs the presence and companionship of family or significant others and not teaching by the nurse. Participant rankings of hope sources by importance (primary, secondary, and tertiary) are presented in Table II. Informants were asked to rank their hope sources in each environmental domain immediately after exploring them by domain. The researcher used summarization and minimal cueing to remind them of sources discussed. At the conclusion of their interviews, participants were asked to rank all their sources of hope in an overall category. See Appendix A for the specific questions used to elicit the ranking data found in Table II.

Perceived Level of Hope

Data for the sixth research question, “What is the perceived level of hope in each individual participant?” were obtained by asking informants to rate their current perceived level of hope immediately after gathering personal profile and demographic data, just before beginning the exploration of sources and threats to hopefulness. The following grid shows participant responses to the question “If you consider hopefulness on a scale from one to ten, with ten being that you feel filled with hope and one being little or none, how would you rate yourself today?” The researcher had some difficulty with the range of this scale, often inadvertently substituting “zero” for “one,” seemingly to match “none” as the lower limit of the scale. This did not seem to

Table II.
Rankings of Participant Sources of Hope by Importance
And Domain of Environment

<u>Internal (Self)</u>	<u>Human</u>	<u>Non-Human</u>	<u>Overall</u>
<u>Participant #1: Emily</u>			
1. Faith in God.	1. My oncologist.	1. My dog.	1. Faith in God.
2. Needed by son.	2. Office R.N.'s	2. Hospital.	2. Needed by son.
3. Emotional strength.	3. Best friend.	3. Support group.	3. Oncologist.
<u>Participant #2: Angie</u>			
1. Physical feelings.	(1.) My Sister.	\ 1. My animals.	1. Phys. Feelings.
2. Career.	(1.) Emily.	(tie) 2. Water.	2. Positive people.
3. (All else varies.)	(1.) Support groups.	3. Mountains.	3. My animals.
<u>Participant #3: Marcia</u>			
1. Prayer.	1. My daughter.	1. Growing plants.	1. People.
2. Reading.	2. My husband.	2. Rocking chair.	2. Prayer & Bible.
3. Reading Bible.	3. My mother.	3. Wind chimes.	3. Hospital people
<u>Participant #4: Paul</u>			
1. Express creativity.	1. My wife.	1. Earth & nature.	1. People.
2. Planting flowers.	2. Friend of 30 years.	2. Sensory experience.	2. Creativity.
3. (All else varies.)	3. Coworkers.	3. Creative inspiration	3. Human emotion
<u>Participant #5: Maggy</u>			
1. Faith.	1. Coworker friend.	1. Work environment.	1. Faith.
2. Will to live, survive.	2. My husband.	2. Churches.	2. My family.
3. Keep busy, activity.	3. Boss at work.	3. Outside environ.	3. Friends at work
<u>Participant #6: Sheila</u>			
1. Stubbornness.	1. Husband & mother.	1. Religious music.	1. Faith.
2. Desire to learn.	2. Oncologists.	2. My rosary.	2. Family.
3. Helping others.	3. Nurses.	3. Hospital chapel.	3. Desire to learn.
<u>Participant #7: Holly (Mixed up the categories, too ill when called back to clarify.)</u>			
1. Husband.	1. The Lord.	1. The Lord.	1. Confidence in The Lord.
2. Daughters.	2. Husband.	2. Alternative Therapy	2. Family.
3. Grandchildren.	3. Daughters.	3. Believing.	3. Treatments.

Table II. (continued)

<u>Internal (Self)</u>	<u>Human</u>	<u>Non-Human</u>	<u>Overall</u>
<u>Participant #8: Bert</u>			
1. Prayers of others.	1. My wife.	1. Mass at church.	1. Prayer/Spiritual
2. Thoughts of family.	2. My children.	2. River camping trip.	2. Family.
3. Helping others.	3. Deacon friend.	3. Water skiing.	3. Friends.
<u>Participant #9: Walter</u>			
1. Faith.	1. My wife.	1. Treatments.	1. Religion.
2. Comfort.	2. Friends.	2. Outside activity.	2. Family.
3. Reading.	3. Grandson.	3. Religious music.	3. Friends.
<u>Participant #10: Deana</u>			
1. Journal writing.	1. Al-Anon sponsor.	1. Outdoors.	1. Survivors.
2. Reading.	2. Cancer survivors.	2. Plant care.	2. Al-Anon.
3. Prayer.	3. (Grand-)/Children.	3. Cooking.	3. Journal writing.
<u>Participant #11: Karl</u>			
1. God.	1. My wife.	1. Hospital/workplace.	1. God.
2. Faith.	2. Physicians/nurses.	2. Home.	2. My wife.
3. Reading.	3. Friends.	3. Church.	3. Workplace.
<u>Participant #12: Louis</u>			
1. Prayer & faith.	1. Wife & children.	1. Work environment.	1. Immed. family.
2. Endurance.	2. Chemo nurses.	2. Internet.	2. Back to work.
3. Positive outlook.	3. Notecard lady.	3. Home environment.	3. Notecard lady.
<u>Participant #13: Robin</u>			
1. Faith in God.	1. My husband.	1. Country home.	1. Faith in God.
2. Living without fear.	2. Friend with cancer.	2. Church.	2. Husband.
3. Piano & stitching.	3. Friend with cancer.	3. Pool at home.	3. Friends.
<u>Participant #14: Pam</u>			
1. Goodness of God.	1. (Grand-)/Children.	1. Comfort beauty.	(1.) Scriptures. \
2. Prayer/Holy Spirit.	2. Church family.	2. Music.	(1.) Prayers. (tie)
3. Religious thoughts.	3. Physician prayers.	3. Diet supplements.	(1.) Communion./
<u>Participant #15: Audrey</u>			
1. Fighter spirit.	1. My kids.	(1.) Radio. \	1. God in radio.
2. God in the radio.	2. Mother & aunt.	(1.) Outside. (tie)	2. Fighter attitude.
3. Motivation to learn.	3. Nurse clinicians.	(1.) Batman. /	3. Kids.

present any problem for respondents. They answered this question easily and without deliberation. The following values were obtained as reported levels of hopefulness.

7-8	8	9	10	10+	8- 10	9- 10	9.5	8	10	10	10	10	10	10
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Using 7.5 for 7-8, 10 for 10+, 9 for 8-10, and 9.5 for 9-10, the mean for level of hope calculated from the sum of this group's individual ratings is 9.37. The individual values and mean indicate a very high level of hopefulness for these informants, at least on the day of their interviews. One person gave a number rating of "two" to his low point of hopefulness, although this was unsolicited data. Since there was no hesitation by any informant in answering this question, the scale was judged to be easily understood. Individual participant ratings for level of hope are also included on the table of demographic data presented in Chapter III (Table I.).

Summary

Chapter VI has presented the analysis, interpretation and discussion of participant data for the six research questions. Data concerning sources and threats to hope have been presented as analyzed, categorized, and interpreted. Both positive and negative hope-influencing factors (sources and threats) from the internal and external (human and non-human) environmental domains have been presented with themes that emerged from the data. Related research findings have been integrated into each category description and discussion preceding the participant illustrations. The fifteen adults living with cancer who were interviewed for this study, described a myriad of

ways in which they sustained hope from within themselves through personal qualities, cognitive strategies, sustaining beliefs, and self-care activities. They described interactions in many types of relationships that supported their hopefulness. Special attention was given to the impact of health care providers and environments (the chemotherapy room and the hospital) on the participants' hoping processes. The non-human environment was explored for sources and threats to hopefulness, contributing data for a little studied area. Themes were developed for self, other humans, health care providers, and the non-human environment as sources of hope. Negative hope-influencing factors revealed a common theme of loss for all environmental domains.

Research question four concerned the hoping process or how the identified factors supported or drained informant hope. This was examined by comparison of the data to a theoretical model, The Development and Renewal of Hope, introduced in Chapter I (Figure 1.). Examples of data from the findings of the first, second, and third research questions were provided, supporting this model. Findings of the fifth research question were presented as a list of primary, secondary and tertiary sources of hope by importance identified by participants. Participant difficulties in responding to this question were discussed and reasons for the difficulties examined. The sixth and final research question queried participants for a rating of their perceived level of hope at the time of their interview. Results were presented, revealing the question to be appropriate and easily understood, and study group to be high in perceived level of hopefulness (mean=9.37 on the 1 to 10 scale) at the time of the interviews.

CHAPTER V

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

In this closing chapter the study is summarized. Conclusions are presented as drawn from the findings and interpretations of data and from consideration of the methodology employed in this study. Implications for nursing practice and education are proposed, and recommendations for future research are discussed.

Summary of the Study

The purpose of this naturalistic study in nursing was to explore and describe the impact of factors from the internal and external, human and non-human environments on the hoping process utilized by persons living with cancer. Given the current health care environment and nature of difficulties encountered by persons living with cancer, hope was identified as being especially important in managing life with this diagnosis. For purposes of this study, environment was divided into internal (self) and external (human and non-human). Positive and negative factors from the total environment were explored using semi-structured interviewing techniques in a purposive sample of fifteen adults living with cancer. The nursing practice theory and paradigm, Modeling and Role-Modeling (Erickson et al., 1983), provided a philosophical foundation and theoretical orientation, and corroborated methodological choices for this study. This nursing grand theory integrates ideas from theories of human development (Erikson, 1963, 1982), human needs (Maslow, 1970), and

attachment and loss (Bowlby, 1969/1982), synthesizing them into a unique nursing perspective.

Six research questions, found in Chapter I, were developed to guide this study. Questions one, two, and three were designed to guide exploration of the cancer patient's hope-influencing factors from each of the three domains of environment. Question four sought to determine how the identified sources of hope facilitated the hoping process. Question five asked for participants to rank primary, secondary, and tertiary sources of hope by importance within each environmental domain and overall. Finally, question six sought to determine the perceived level of hope in each individual participant at the time of the interview.

Relevant literature from several disciplines was reviewed in Chapter II to integrate nursing concerns with the concept of hope into a multidisciplinary perspective. The significance of hope to holistic health was emphasized and validated from the literature. Nursing research studies investigating sources and threats to hope were reviewed and grouped according to the environmental domains conceptualized for this study – internal (self), external human (other persons), and external non-human. Previous research has provided insufficient guidance to nurses seeking to promote hopefulness and prevent hopelessness in clients. Review of literature affirmed the need for more research about the hoping process and hope-influencing factors, especially the influence of health care providers on hope and the impact of the external non-human environment on hoping.

The research questions developed to guide this study were best addressed through a methodological design choice of naturalistic inductive inquiry using qualitative methods. The parallel nature of nursing practice, Modeling and Role Modeling theory, and naturalistic inquiry according to Lincoln and Guba (1985) was demonstrated, supporting the design choice for this nursing inquiry. The implementation of this method in the current study was described in Chapter III, including population and sampling, procedures, data generation, data analysis, and measures of trustworthiness.

Fifteen persons living with cancer were interviewed utilizing a semi-structured interview guide developed by the researcher. Informants were recruited from a cancer support group, nursing colleague referrals, and participant referrals. Interviews ranged from one to two hours each and were completed over an eight-month period. The data were audio taped and transcribed by an independent, professional transcriber. Participants were referred to by pseudonym only and tapes were kept in a secure location, labeled only by number and pseudonym. Each person was asked for brief demographic profile data and a general background description of their personal illness experience. The sample group had a variety of cancer diagnoses and ranged in age from thirty-three to seventy-five. There were five males and ten females with years of education between twelve and twenty-three.

The majority of data obtained consisted of detailed descriptions of positive and negative hope-influencing factors with situations, events, interactions, feelings and

thoughts illuminating their impact on the hoping process. After discussing the positive and negative factors, participants were asked to rank these factors by importance (first, second, and third) for each domain and overall, the most difficult question for them. This difficulty was felt to be primarily related to the dynamic nature of the hoping process itself. Hope-influencing factors vary in importance due to time and circumstances, a phenomenon difficult to capture with research methods other than longitudinal approaches.

The first research question concerned factors from the internal environment (self), and the second and third concerned factors from the external environment, human and non-human, respectively. During analysis of data for these first three research questions, broad theme categories with sub-themes were developed for grouping positive hope-influencing factors. Four broad theme categories were developed for positive hope-influencing factors from the internal environment -- personal characteristics, uplifting thoughts, sustaining beliefs, and self care. Human relational groupings, other than health care providers, revealed six broad themes including encouragement, companionship, love, gifts, communications, and role modeling. For health care providers, broad themes were competence, caring and compassion, and recognition and respect. For the external non-human environment, six broad theme categories emerged from the data, including pleasant environmental stimuli, symbols, comfort, safety, power, and surrogates. Three to six sub-themes were developed under each broad category. All negative hope-influencing factors are

linked to a common theme of loss. Two doctorally prepared nurses, experienced in qualitative research, reviewed the investigator's audit trail of coding and categorizing leading to the development of these themes and sub-themes.

Participant data for hope-influencing factors have been compared to the theoretical model, Development and Renewal of Hope, synthesized from ideas in Modeling and Role Modeling (Figure 1.). The data for research questions one, two, and three provide rich illustrations of hope emerging from attachments to and trust in significant objects (concrete, abstract, or symbolic) that meet basic and growth needs of the individual, supporting the model. Further theory emerged from the data describing the cyclical and dynamic nature of the hoping process from an energy and environmental perspective. This new theoretical model was termed, Phases of Hope Emergence and Growth (Figure 2.), and will be discussed later in this chapter. Both of the theories developed are mid range and substantive rather than formal or grand, having immediate usefulness to nurses in everyday practice situations. Data analysis has also revealed interaction among all three domains of environment – the self interacts with other persons and with the non-human surroundings. Additionally, it must be remembered that participant perceptions of hope-influencing factors are all filtered through the self or internal environment of the person. Data analysis and interpretations for the six research questions are presented in Chapter IV.

Findings from this study have added to the knowledge base of nursing science, achieving broadened perspectives from which to assess and understand the hoping

processes of persons living with cancer. Many areas are evident for nursing intervention to positively influence the hoping processes of clients with cancer. Special attention was given to the impact of health care professionals and environments on participants' hoping. It is hoped that health personnel from all backgrounds will read these results and become sensitized to the importance of promoting hope in persons living with cancer, and informed as to how their behavior impacts that hoping process. The present study has expanded knowledge of the overall hoping process by looking at the total environmental impact on hope, a broader perspective than previously found in the literature.

Theoretical Conclusions

The following conclusions are drawn from the findings and interpretations of data for the six research questions -- participant hope-influencing factors (sources and threats), how the sources and threats impact the hoping process, rankings, and ratings of hope. After further reflection about these findings and the ease or difficulty with which they were obtained, another theoretical perspective emerged, and was named "Phases of Hope Emergence and Growth" (Figure 2.). This theory of the hoping process was not conceptualized prior to collecting data, as was the model presented in Chapter I, "Development and Renewal of Hope" (Figure 1.). The a priori theoretical perspective viewed the development and renewal of hope as evolving from linkages of attachment, need satisfaction, and developmental growth. Hopefulness is an outcome

with no consideration of fluctuations in level of hope or of the varying importance of sources at different times in the lives of persons with cancer.

The environmental, energy-based model, Phases of Hope Emergence and Growth, is a time sensitive process of hope emergence and growth, described as a cyclical progression of phases. An environmental analogy suggested by the fifth participant, Maggy, supports this model. When discussing sources from the non-human environment, she talked of hope becoming “dormant... but it will spring back” after completing chemotherapy. This new process gives consideration to the ebb and flow of hope, the “energizing life force” defined in Chapter I. Herth (1993a) found that individuals reporting severe fatigue had significantly lower levels of hope than those reporting high energy to moderate fatigue levels. This finding suggests the need for energy in order to hope. The waxing and waning of hope and energy in the present study have been noted in participant descriptions of setbacks and challenges such as chemotherapy, surgery, bone marrow transplant, and reoccurrence of cancer. Not all participants experienced setbacks. For some, the hoping process continued to evolve in a positive direction. For others, frequent episodes of chemotherapy or surgery “beat them down” again and again. Cancer reoccurrence could be worse than the initial diagnosis. Hope ratings on the one to ten scale were high (mean=9.37) at the time of the interviews, but hadn’t always been so as demonstrated by Karl’s statement of having been a “two,” during simultaneous radiation and chemotherapy. The phases

of hope emergence and growth, synthesized from data in this study, are presented in Figure 2.

The difficulty and hesitancy with which many participants answered the ranking questions support the theory of hope as a cyclical series of phases. Depending upon where a person is in the process, sources vary in importance. The relative importance of sources of hope are time and circumstance dependent. Depending upon where a person is in the process, ratings for level of hope vary from low to high. The first phase, Emergence, is the one of least energy and least hope. As the person with cancer progresses through the phases, greater energy is developed and level of hope increases. A person may progress continually forward (upward in the model) or cycle back as setbacks occur, necessitating re-growth of hope. This new theory accounts for the cyclical emergence and growth of hope, germinating from a little seed of promise to a full blooming life flowing energy.

Methodological Conclusions

Two methodologic experts have urged qualitative researchers to be sensitive to time. Miles and Huberman (1994) discuss "life as chronology." Sandelowski, (1999) encouraged researchers to determine "how temporal factors inform the events under investigation" (p. 79). "Our understanding of the human condition depends, in part, on the recognition of the temporal flow and shape of events" (p. 79). In grounded theory studies of basic psychological processes, Sandelowski asserts that the importance of time is even more pronounced. "The researcher conducting grounded

theory studies is oriented to action and change and to viewing the target event under investigation as a process, dynamic and occurring in and over time” (p.80). The theory, Phases of Hope Emergence and Growth, fulfills Sandelowski’s urging to become time sensitive.

The present research study was conducted primarily in the naturalistic tradition of Lincoln and Guba (1985). One of these authors’ fourteen characteristics of naturalistic inquiry was preference for “the guiding substantive theory to emerge from (to be grounded in) the data because no a priori theory could possibly encompass the multiple realities that are likely to be encountered” (p. 41). This was found to hold true in the present study. The a priori theoretical model was supported and is useful for nursing practice and research, but participant descriptions pointed beyond to suggest and support the additional model of hoping. The second model was not predetermined but emerged from the data.

The mean for level of hope calculated from this group’s individual ratings was high, 9.37 on a one to ten scale. The individual values and mean indicate a very high level of hopefulness for these informants, at least on the day of their interviews. One person gave a number rating of “two” to his low point of hopefulness, although this was unsolicited data. The use of this scale as a quick screening tool to measure an individual’s feeling of hopefulness was suggested for use in clinical situations by Farran et al. (1995). No research studies were found that reported using this particular scale in measuring level of hope. The scale does not provide direction for

specific interventions, but could provide clinicians and researchers with estimates of clients' or subjects' current perceptions of hopefulness. Use of this scale could help the clinician achieve greater sensitivity to the intensity of a client's state of decreased hope and a measure for evaluation of improvement or further loss. As suggested by the participant in this study who used the scale to rate his low point, it may also be useful to establish a range of hope fluctuation in retrospective analyses of hoping processes. The observation that level of hope fluctuates with time and circumstances, supports the theory of hope emergence and growth in cyclical phases (Figure 2.).

Sample Group Hopefulness and Mental Health

The characteristics of the study group, fifteen adults living with cancer, led the researcher to draw several conclusions. First, the high level of hope expressed by all participants was unanticipated. Cancer was a definite reality in the lives of the majority of these participants. Of the fifteen, six had active disease and were in current treatment. Seven were not in current treatment but had had active disease within the past four years. Two had not had active disease for over five years. Seven had experienced reoccurrences at some time in their disease trajectory. In spite of the multiple threats to hopefulness created by life with cancer, this group of adults reported that they were very hopeful. They identified many more sources of hope in their lives than threats to hope. With relative ease, they were able to articulate a multiplicity of positive hope-influencing factors in their lives.

In the judgment of this researcher, this group exemplified mental health within an illness trajectory. The concept of “health within illness” was discussed by Moch (1989). “The perspective called ‘health within illness’ views illness as an event that can expand human potential” (p. 23). Paterson (2001) describes two perspectives on chronic illness, “wellness in the foreground” and “illness in the foreground.” “The wellness in the foreground perspective includes an appraisal of the chronic illness as an opportunity for meaningful change in relationships with the environment and others” (p. 23). Paterson’s concept of “wellness in the foreground” aptly describes persons living with cancer in the present study. Participants did not deny having difficulties or periods of decreased hopefulness, yet they were able to regain and maintain hopefulness most of the time. The Hogg Foundation at The University of Texas at Austin (1992) has described the mentally healthy individual as one who can “bear up under the floods of life.” Characteristics of mental health, consistent with Hogg Foundation descriptions, judged to be present in this study group, include maintenance of a positive outlook, appreciation of what matters in life, and recognizing the transient nature of disappointment.

Many parallels have been drawn between themes emerging from these data and characteristics of self actualizing people described in Maslow’s (1987) study of psychological health. This group of fifteen persons with cancer has shown many “self-actualizing characteristics” -- fresh appreciation for life, peak experiences, human kinship, autonomy, creativity, openness, altruism, security, fun and gaiety.

Hope and the Domains of Environment

The amount of data obtained for positive hope-influencing factors from the internal environment (self) was larger than for either of the other two domains. This was somewhat surprising due to the prominence of other persons and social support as factors influencing hopefulness in previous research. Raleigh (1992) found family to be the most commonly mentioned source of hope in her study of persons with cancer and chronic illness. The importance of self as a source of hope is consistent with the observation that all perceptions of hope are filtered through the self. The nature of hoping as a "self-sustaining process" was noted in the grounded theory study of adolescents with cancer by Hinds and Martin (1988). They identified four steps in the overall process -- cognitive discomfort, distraction, cognitive comfort, and personal competence. In this adolescent group, the origins of hope were felt to be within the resources of self, or the internal environment. The present study findings support this conclusion and extend the nature of the hoping process to incorporate the impact of the total environment. In the present study, hope-influencing factors from the total environment (self, other humans, non-human) were found to interact with each other to facilitate hopefulness.

After reviewing the literature, a paucity of formal research studies on hope-influencing factors from the non-human environment was found. Dufault and Martocchio (1985) mentioned elements of the non-human environment in an article describing the spheres and dimensions of hope based on clinical data from cancer

patients. These authors included certain physical aspects of the environment, or "beauties of creation" and non-human living things (pets, wild animals, birds, plants, and trees) in a dimension of hope they termed "affiliative or relational." This dimension also included other persons and God. Participants in the present study identified a multitude of hope-influencing factors from the non-human environment – pets, animals, plants, nature, water, mountains, and the outdoors. Significant places included homes in the country, church/chapel, hospital, and the chemotherapy department. Jewelry (cross, rosary, butterfly, rings of hope) and home furnishings (rocking chair, recliner, one's own bed, wind chimes) were reported to increase hopefulness. The non-human environment had a powerful impact on many participants, increasing perceptions not only of hopefulness, but also of safety, comfort, coordination, love, and joy. The present study clearly extends knowledge of the hoping process to more fully incorporate the non-human environment.

However one chooses to classify or conceptualize hope-influencing factors is not nearly so important as recognizing and utilizing the wide variety of potential hope sources for the benefit of individual persons living with cancer. There were many commonalities in the participants' stories and descriptions of hope-influencing factors evident in the groupings of data into themes. At the same time, the reader will notice nuances and variations in the descriptions under each theme. Within each person's model of the world, that unique self care knowledge, are potentially healing, hope

instilling factors. Each participant in this study is a very special and unique human being for which the researcher is forever grateful!

Implications for Nursing Practice and Education

Nurses in today's health care arena are practicing during a nursing shortage, resulting in inadequate staffing, heavy workloads, frequent overtime hours, and a "crisis of soul" in the workplace (Green, 2001a, 2001b). Each workday, nurses face the "fairly depressing reality of the current status of the health care environment" (Green, 2001a, p. 17). The nature of this practice environment has implications for both nurses and their patients. The ability to effectively care for patients may be impaired by a lack of time for nurses to care for themselves. Nurses who feel a loss of hope in themselves related to stressful work environments, may have difficulty inspiring hope in their patients. In spite of this context, there is much that can be done in the way of basic care to facilitate hopefulness as learned from the participants of this study.

Practice implications from this study are best determined by reading the actual words and illustrations of the participants in Chapter IV. The participant data have been presented in the manner described by Sandelowski (2000) as "qualitative description," comprehensively describing events in everyday terms, staying "close to the data." Much is to be learned from informant stories of positive and negative hope experiences. Starting at the most basic level of need, nurses are clearly informed about the importance of prompt and sufficient pain relief, alleviation of nausea and vomiting,

and other discomforts. Loneliness and isolation in hospital environments may be accentuated by restrictive visiting hours limiting contact with hope supportive significant others. Working to change restrictive policies or making exceptions to allow important positive persons to visit would be helpful. Inept practitioners, unskilled in technological procedures such as venipuncture, may threaten patients' confidence in their caregivers and sense of hopefulness. Nurses and physicians who remember their patients by name and personal things about them help them to feel respected and safe. Knowledgeable caregivers who explain and answer questions competently and completely meet client needs for knowledge, understanding, and control. Nurses who attend to the environment, providing order, privacy, or a pleasant view enhance hopefulness. Exceptions to visiting policies for pets and other significant attachments could help. Talking with patients and triggering memories and thoughts of positive hope-influencing factors from the environment is a helpful cognitive strategy. Assessing and reinforcing strengths such as faith in God or fighting spirit will help the patient tap into his or her own internal resources. Finding out what is meaningful to a patient's life takes time, but affords opportunity to reinforce what a person has to live for. Family members could be encouraged to bring objects and pictures personally meaningful to their loved ones. The list could go on and on. In the most succinct evaluation, using the Modeling and Role Modeling terminology, determining clients' "models of the world," including their "self-care knowledge," is essential to promote hope within their frames of reference. In a recent study of

oncology patient's perceptions of quality nursing care, Radwin (2000) found "optimism" as one component of sense of well-being, an outcome of quality care. "With excellent nursing care, patients could achieve increased fortitude and a sense of well-being, including trust, optimism, and/or authenticity" (p.189). Walker, Wilkes, & White (2000) found oncology patients value warm, personal relationships with nurses.

Administrators should ensure that patients in various health care settings have opportunities to evaluate caregivers. Unskilled practitioners, either technologically or in communications, need to be further educated, counseled, or dismissed. Chemotherapy patients who frequently visit the outpatient department for infusion of cancer fighting drugs should not have to dread getting a particular nurse, as did two participants in this study. The hygiene, communication, and technological skills of all professional nurses should be consistently excellent.

Having taught nursing at the associate degree and baccalaureate level for over twenty-five years, this author has seen very little emphasis in nursing curricula on the concept of hope. All nurse educators and nurses know intuitively the importance of facilitating hopefulness, but have received little formal education about the concept. What is known comes from life experiences and family upbringing. More emphasis needs to be placed on this critically important aspect of care from the very beginning of nursing education. Perusal of several recently published introductory and fundamentals nursing textbooks revealed only one, designed for associate degree programs, that discussed hope and cited some fairly recent research on the concept

(Kozier, Erb, Berman, and Burke, 2000). Promoting hope is basic to nursing care and, as determined by this study, is inherent in other key nursing interventions such as comforting, relieving pain, alleviating fears and anxiety, and promoting feelings of belonging and respect.

Recommendations for Future Research

Some recommendations for future research arise from the relatively homogeneous characteristics of the sample in this study. Previous research suggested that finances might have implications for hoping (Ballard et al., 1990). All participants in the present study described income as “adequate,” so the influence of inadequate income is not known. All had health insurance, so the influence of lack of this resource is not known. It is recommended that this study be replicated in a group of impoverished and /or uninsured individuals.

The study participants had at least twelve years of education up to a maximum twenty-three (mean=16.1), so the influence of lesser amounts is not known. Findings of two previous studies, Piazza et al. (1991) and Vandercreek et al. (1994), showed subjects with higher levels of education had higher levels of hope, with education found to be a significant predictor of hope by Piazza et al. It is recommended that the study be replicated in a group of informants with less than college educations to determine level of hope and explore their hoping processes.

The sample was homogeneous in ethnicity so the nature of hoping processes in diverse ethnic or cultural groups is not known. The sample in this study consisted of

adults between thirty-three and seventy-five. Narrower age ranges could be investigated for hope-influencing factors to determine if age-related adult developmental differences exist. Patients with other types of chronic illnesses besides cancer, such as systemic lupus erythematosus or amyotrophic lateralizing sclerosis, could be interviewed about their hoping processes. A recent study by Bays (2001) explored the phenomenon of hope and associated factors in older adults after stroke. Persons living with new technological devices, such as implanted automatic defibrillators, could be asked about their hoping processes.

This study started with a theoretical model synthesized from ideas in the nursing theory, Modeling and Role Modeling (Erickson et al., 1983). Replication by another researcher without this initial perspective framing would be interesting to determine if a similar or different theory emerged from the data. The theory developed in this study might be tested with appropriate quantitative measures, using existing tools or possibly tools developed from data in this study.

One multiuse tool that could be developed from these data is conceptualized as a "Hope Resource Inventory." This would consist of a listing of the many potential sources of hope from all realms of environment identified from this study. This could be used clinically to assess clients' hope resources, educationally to inform students of the diversity of hope resources to look for in clients, and in research to determine the magnitude of a subject's hope resource "bank." Level of hope on the one to ten scale could be compared to the magnitude of the resource bank or to hope as measured by

other hope scales (Herth, 1991; Herth, 1992; Miller & Powers, 1988; Nowotny, 1989).

In this study, hope-influencing factors were found to vary in importance due to time and circumstances. It is difficult to fully capture this phenomenon with cross sectional designs. Retrospective designs are dependent upon accuracy of memory. It is recommended that longitudinal approaches be used in which informants are interviewed multiple times at selected intervals to determine the dynamic nature of hope-influencing factors in their lives. An in-depth single subject case study analysis would also be helpful to understand the dynamic nature of hoping (Newman & Benz, 1998). "The case study design is dependent on the circumstances of the case but usually includes the element of time" (Burns and Grove, 1999, p.197).

Secondary analyses could be performed, looking at these data from a different theoretical perspective (Polit, Hungler, & Beck, 2001). For example, the temporal model developed by Anderson, Maloney, and Redland (1993) in their study of hope in burn-injured patients could be used to reanalyze the data. Findings of their study showed the majority of hope-influencing factors evolved from the present dimension as compared to the past or the future dimensions.

Specific categories of interest, identified from this study, could be further investigated to expand knowledge of hoping related to individual factors such as creativity or faith. The influence of specific human sources, such as health care providers or chemotherapy nurses, could be explored more fully. Hope-influencing

factors identified by nurses could be compared with those identified by their patients to see if perceptions are consistent.

If this study were to be replicated by this researcher, a few changes would be made. The one to ten hope scale, judged to be easily understood and valuable, would be used to more accurately determine the range of hope fluctuation in the lives of persons living with cancer. When participants are asked for examples of their highest and lowest experiences of hope, this would be accompanied by a request for them to rate their level of hope at those times. This would give an even more accurate picture of the range of hope fluctuation in persons living with cancer.

One factor identified by two informants in this study was sense of humor. This was not listed among the themes due to the limited number of contributors. All themes discussed for the internal environment had six or more contributors. In light of the work and experience of Cousins (1989) and Miller (1992), the nature of humor and hoping needs closer investigation. Hafen et al. (1992) point out many research-based health benefits of humor and laughter, both physical and psychological. A larger sample could be studied to expand knowledge of hoping and humor or other factors. Memory, known to be important in reminiscence therapy, was especially important to one participant in this study (Bert), but was not mentioned explicitly by others. Herth (1990b) found “uplifting memories” to be a source of hope in ninety percent of terminally ill adults studied.

Whatever direction future research on hope takes, the most important consideration is not to lose sight of the purpose and goal of all nursing research endeavors. The knowledge gained needs to be used by nurses and other health personnel to enhance human well-being, especially in persons struggling to maintain hopefulness in the face of the adversity that life eventually deals to all of humanity.

Summary

This chapter has presented a summary of this research study with theoretical, methodological, and study sample conclusions drawn from the findings. Important implications are evident for the current and future practice of nursing and for nursing education. Finally, recommendations for future research have been made. Using the concluding words of several participants in this study, “I hope this helps somebody.”

Appendix A
INTERVIEW GUIDE

Part I. Introduction

Hello, _____. As you may recall, I'm a nursing doctoral student conducting a dissertation research study at the University of Texas at Austin School of Nursing. This study is concerned with how persons with a diagnosis of cancer gain and maintain a hopeful attitude during the challenges and changes of living with and managing their health problems. I anticipate that it will take about an hour to go through these questions. I want to make sure you're comfortable before we begin. As I told you before, I will be tape recording the interview.

Part II. Background Information

First, I need to get some background information that will help me to understand your particular situation better.

Name: _____ Date of Birth: _____

Gender: _____ Marital Status: _____ Children: _____

Education: _____ Occupation: _____

Employment Status: _____ Income Adequate (yes/no): _____

Health Insurance/Medicare/Medicaid: _____

Place of Residence (private home, apartment, other) _____

Religious Preference: _____

Church Membership: _____ Attendance: (Regular/Irregular) _____

Diagnosis: _____ Approximate Date of Diagnosis: _____

Therapy Received for Cancer (Chemotherapy, Radiation, Surgery, Other): _____

Recent Losses: _____

Care Environments since diagnosis (with approximate dates) in which you have had contact with nurses, e.g. hospital, ICU, extended care, nursing home, doctors office, home care, or any other setting: _____

Participant's Self Rating of Current Perceived Level of Hopefulness:

(10=filled with hope) 10—9—8—7—6—5—4—3—2—1 (1= little or no hope)

Describe a time when your level of hope was as high as you can remember:

Describe a time when your level of hope was as low as you can remember:

Part III. Hope-Influencing Factors (Sources and Threats): For the purposes of this study, I have grouped hope-influencing factors by categories – individual, other persons, and the external environment. I will ask you to identify personal sources of hope, coming from within **yourself**, characteristics and actions of you alone, not involving other people. Then I will ask about how **other persons** have influenced your sense of hope. For example, what persons in your life are now or have been sources of hope for you? Have any persons threatened or decreased your sense of hope? Then what about the **external environment** – places or things, animal or plant, concrete or abstract, anything other than yourself or other persons – how do these things influence your sense of hope?

A. Individual/Personal/Self: What comes to mind as something about yourself that enhances your sense of hope? _____

Name as many of your **personal characteristics, qualities, actions, behaviors, beliefs, or thoughts** as you can think of that help you to gain or maintain a hopeful attitude: _____

Please say more about **how** these sources of hope work for you to help you feel hopeful: _____

Is there anything about yourself that threatens your sense of hopefulness or causes you to feel less hopeful? _____

A. Ranking: Of all the sources of hope we have talked about from within yourself, what is the **greatest (most important) source of hope** in your life?

(1) _____, **second** (2) _____, **third** (3) _____.

B. Other Persons: Who in your life, which **other persons**—family, friends, health care professionals, anyone you can think of, serve as sources of hope for you? _____

Please say as much as you can about **how** each person helps you gain or maintain a hopeful attitude. _____

Does anyone, or has anyone, threatened or caused you to lose hope? _____

If so, how? _____

How have **healthcare professionals**, especially nurses, affected your feelings of hopefulness? (Please explain with examples of incidents or interactions.)

B. Ranking: Of all the sources of hope we've talked about related to **other persons** in your life, who is your **greatest (most important) source of hope**?

(1) _____ **second** (2) _____ **third?**(3) _____.

C. External Environment: What **places, objects, or things** help you to stay hopeful? This could be **anything living (plant or animal) or non-living other than yourself or other persons.** _____

Please say as much as you can about **how** each helps you stay hopeful? _____

Does anything in the non-human environment **threaten** your hope and, if so, how? _____

Considering the various **care environments** you listed earlier, have your feelings of hopefulness varied in any particular place where you've received care?

What about the care environment affected your feelings of hopefulness? _____

Significant objects which you have collected that help you stay hopeful: (please tell how each works for you) _____

Is there anything about the external environment which **threatens** your hope?

Anything else that influences your feelings of hopefulness? _____

C. Ranking: Of all the sources of hope we've talked about from the **external environment**, which one is your **greatest (most important) source of hope?**

(1) _____ **second?** (2) _____ **third?** (3) _____.

D. Overall Three Most Important Sources of Hope:

Of all the sources of hope you've identified, which is the **most important source** of hope in your life at this time? (1) _____

second? (2) _____

third? (3) _____.

Thank you very much for your time and valuable contribution to this study. You have helped me a great deal to understand the hoping process.

Appendix B

COVER/INFORMATION LETTER TO POTENTIAL PARTICIPANTS

A Qualitative Study of Hope and the Environment of Persons with Cancer

You are invited to participate in a study about factors that influence hopefulness. My name is Lucia Tipton and I am a graduate student at the University of Texas at Austin, School of Nursing. This dissertation study is part of the requirements for the doctoral degree in nursing. From this study I hope to learn more about ways that persons with cancer gain, maintain or lose hope as they manage their day-to-day life and health problems. You have been asked to consider becoming a participant because you have been living with a diagnosis of cancer for at least six months. Approximately 20 individuals over the age of 18 will be invited to participate in this study. Your name was obtained as a recommendation from another participant, a nurse, or a physician; or as a self-referral after you learned about the study from your support group or through your church. Participation in this study is totally voluntary and you should feel no pressure to take part.

If you decide to participate, I will schedule a time to talk with you in your home or in another location of your choice. The interview will take approximately one hour and will be scheduled at a time that will not interfere with your treatments, work, or personal activities. If more than one hour is required to complete your interview and you do not wish to continue beyond one hour, an additional time can be scheduled with your permission. You will be asked to think about experiences that have influenced your sense of hopefulness both positively and negatively since you have been living with the diagnosis of cancer. The questions in the interview will ask you to identify sources and threats to hope from within yourself, from other persons, and from the external environment (everything else—objects, things, places, etc.). For example, one question is, “How have health care professionals, especially nurses, affected your feelings of hopefulness?”

No cost or money compensation is associated with the study. You may benefit from contact with a nursing professional who is interested in the experience of persons with cancer, and especially their feelings of hopefulness. You may become more aware of sources of hope for yourself and how others stay hopeful. Your participation will add to knowledge of how persons use the total environment to gain hope. The only anticipated inconvenience to you is the time it takes for you to answer the interview questions. During the interview, if you experience fatigue or any other discomfort, just let the investigator know. You may rest, terminate the interview, or reschedule for another time if you so desire. The only anticipated risk is the possibility of minor psychological discomfort when discussing threats to hopefulness or in recalling an incidence of decreased hopefulness. The investigator is a professional Registered Nurse and will be available to discuss your feelings or concerns during and after the interview.

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission. The interview will be recorded on an audio cassette tape, identified by number only. Your name will not appear anywhere on the audio tape or typed transcript. The tape will be kept in a locked file and only the investigator and possibly the supervising professor, typist, and auditor will listen to it. After the tape is transcribed and typed by a secretary, the tape will be erased. Your name will not appear anywhere on the transcript or final report. The data from your interview will be used in a dissertation research report and may be published as a journal article or become part of a presentation.

You may stop the interview at any time and may decline to answer any question asked during the interview. If you decide to participate you may discontinue participation and withdraw from the study at any time. Your participation is totally voluntary and will not affect your relations with the University of Texas at Austin or any facility at which you may be receiving health care.

If you have any questions or concerns now or at any future time, I will be happy to answer them. You may call my home ([REDACTED]) or my office (University of Mary Hardin Baylor, [REDACTED] and speak to me or leave a message either place and I will return your call. You may also contact my dissertation supervisor, Bonnie Rickelman, EdD., RNCS, LMFT, CGP, Associate Professor at the University of Texas at Austin School of Nursing, 1700 Red River, Austin, TX 78701, telephone number [REDACTED]).

You may retain this Cover/Information Letter that explains the nature of your participation and the handling of the information you supply.

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Vita

Lucia Elizabeth McClure Tipton was born in Bloomington, Illinois on January 4, [REDACTED] the daughter of Lou Ann Lloyd McClure and David Stephenson McClure. Following graduation from Bloomington High School, she enrolled in Southern Methodist University in Dallas, Texas. She transferred to the Baylor University School of Nursing and achieved the Bachelor of Science degree in Nursing in 1971. In 1973 she entered Texas Woman's University and in 1975 was awarded the Master of Science degree with clinical majors in psychiatric mental health and adult health nursing with a functional area of teaching. She began doctoral study at the University of Texas at Austin School of Nursing in 1988. Her clinical practice has been primarily in critical care settings at several institutions in Texas. She has also worked as supplemental staff for many years at Scott and White Hospital in Temple, Texas. The career achievement of which she is most proud is her contribution to the nursing education of over one thousand baccalaureate nursing graduates. She has taught nursing at McLennan Community College in Waco, Texas and at the University of Mary Hardin Baylor in Belton, Texas, where she has been employed for the past twenty-five years.

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This dissertation was typed by the author.