HOPEFUL ADULTS WITH ADVANCED STAGE CANCER:
NATURE, INFLUENCES, FOCUS, AND
PATTERNS OF HOPE OVER TIME

by
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ABSTRACT

The diagnosis of terminal cancer begins one of the most complex and challenging individual experiences of human life that requires multiple coping responses, one of those being hope. There are limited knowledge and few studies that provide descriptions of hope over time for adults, ages 20-59, with advanced stage cancer. The purpose of this study was to describe hope as defined and experienced by adults with advanced stage cancer, evidencing high levels of hope.

This descriptive, longitudinal research study used the technique of methodological triangulation (semistructured interview, Stoner Hope Scale, Ferrans & Powers Quality of Life Index, Visual Analogue Scales, and participant observation) to define and describe hope in a convenience sample of 12 hopeful adults with advanced stage cancer. Data were collected over time once a month for 3 months.

By definition, this population exhibited high levels of hope at study entry. Hope scores did not change over time. Four qualities associated with the nature, influences, focus, and patterns of high levels of hope were identified: reliance on strong spiritual beliefs, maintenance of positive attitudes, accommodation of cancer symptoms, and the presence of supportive resource people. The emphasis or
importance of each quality was determined and defined individually.

Important in this study's findings is that hope goals are individually defined and are unique to the patient population, influenced by the phase of the illness and the developmental stage of the individual. Hope goals also vary in degree of expectancy and concreteness and require reassessment as conditions change. By identifying an individual's hope goals, nurses can then plan and implement interventions to move toward that hope goal.
Taking Good Care

of My Brother

I've exposed the whole underside
Of a fallen sparrow
With a flick of my boot's toe.
Maggots. The belly is raw,
Crawling with disease. The bird
Squawks and one brown wing beats time
Desperately at the dirt.
My little brother cries.
He believes I can heal it
If I want to. I believe
There is no hope.
They say when the time comes a bird
Will push her half-grown to the edge
And over. Who can blame her?
How could she possibly know
Something is so wrong? I can't make myself
Touch it. My brother,
Hands clamped over his ears,
Becomes pure vision,
Shutting out all reason.
And the terrible screeching
That comes from both their mouths
At once demands a miracle
I cannot provide. I scoop
The bird into a tin can
And carry it further
Into the yard where we are burning
Paper trash in a black oil drum.
My brother watching, I toss the thing
Quick toward the flames
And the bird, out of my hands,
Starts to fly.
Without hesitation, it flies straight
As if the miracle had happened,
Into the hot bright heart of the fire.

Corrine Hales
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CHAPTER I

INTRODUCTION

Jeff, a 36-year-old lawyer, was admitted to the hospital on Monday for a CAT scan. The results of the scan confirmed what he had suspected for the last week: his cancer had metastasized. Jeff remained in the hospital overnight and was discharged in the morning. At home he received intravenous narcotics for pain and supplemental oxygen and was placed on a high caloric diet. He made out a will, wrote several letters to friends and relatives, and made sure his physicians and family understood his desire not to be put on any life-sustaining machines.

Every morning Jeff chuckled over his favorite comics, looked forward to receiving a fresh rose from his rose garden, and appreciated the "World Class" chocolate malts smuggled into him by his hospice nurse. On Thursday evening, Jeff and his wife Mary talked about Jeff's death and Mary's future. They shared their feelings of anger and sadness as well as their unconditional love and commitment for each other. That night Jeff died.

Jeff's diagnosis of cancer forced the unpleasant reality that he was going to die. Influencing his dying
experience was the rapid and predictable nature of his cancer and his young age. Jeff experienced not only the feelings of frustration, anger, and fear, but he also experienced anticipation and hope. His hope was not directed towards a drug that would kill the cancer growing in him or an energy pill that would allow him to run again. His hope focused on laughing over the morning comics, smelling his summer garden rose, savoring an “illegal” chocolate malt, sharing his experience with Mary, and dying with dignity.

The most solemn experience shared by the whole human race is the inescapable fact of death. The diagnosis of a terminal illness is well-documented as a cultural and personal catastrophic life stress (Exell, Anspaugh, & Oaks, 1987; Holmes & Rahe, 1967) that carries with it a high degree of threat. For over 500,000 individuals in the United States last year, this fatal diagnosis was cancer (American Cancer Society, 1996).

The diagnosis of terminal cancer begins one of the most complex and challenging individual experiences of human life. The individual begins a continual adjustment to changes in the course of the illness towards a goal of adaptation. This adaptation has temporal dimensions, and the needs, concerns, influences, and responses of the person involved have a changing dynamic quality (Barton, 1977; Lazarus & Folkman, 1984) that includes multiple coping responses, one of those being hope.
Hope has been identified as an important emotion-related coping response in maintaining quality of life, regaining health (Dufault & Martocchio, 1985; Vaillot, 1970; Watson, 1979), and accepting illness-related limitations in patients of all ages: adolescents (Dibble, 1986; Hinds, 1988); adults (Nowotny, 1982; Raleigh, 1980; Stoner, 1982; Yancey, Greger, & Coburn, 1994); and geriatrics (Farran, 1985; McGill & Paul, 1993).

Not only has hope been observed in mentally ill (Jourard, 1970; Schneider, 1980; Shea & Hurley, 1970), chronically ill (Dibble, 1986; Raleigh & Boehm, 1994), and critically ill (O'Malley & Menke, 1988) patients but in terminally ill patients as well (Herth, 1990; Kubler-Ross, 1969; Stoner, 1982). In studies involving terminal cancer patients, neither the severity of the illness nor the prognosis correlated with significantly lower levels of hope (Herth, 1990; Mishel, Hostettler, King, & Graham, 1984; Nelson-Marten, 1988; Stoner & Keampfer, 1985). This hope research suggests that even in the terminal phases of the dying experience, individuals continue to have hope. What the nature, purpose, and outcome of that hope is, has been limited in part to the abstract, complex, and multidimensional nature of hope.

At present, there are no precise conceptual and operational definitions of hope (Hinds, 1988). The reasons for the lack of precise definitions are many. First, hope shares many common characteristics with other similar
emotions (Bruss, 1988; Campbell, 1987). It is difficult to identify specific affective, behavioral, and physiological qualities that are unique to hope.

Second, most of what is known about hope is theoretical in nature. Hope scales are primarily theory, not practice based. By being theoretically based, the scales and scores designed to measure hope do not examine or reflect the unique experience of the individual (Singer, 1984).

Finally, most researchers view coping responses, such as hope, as being relatively stable and are not temporally or contextually dependent (Morris, Greer, & White, 1977). Hope has traditionally been conceptualized as a static, linear, and unidirectional emotion-related coping response that involves only an antecedent and a future-oriented outcome. Most hope research designs do not reflect process, nor do they attempt to identify influences or changes of hope over time. Hope is usually evaluated by one measurement tool looking at one linear dimension.

Without a precise conceptual and operational definition of hope, the relationship between hope, health, and illness outcomes can only be theorized (Hinds, 1988). For nursing, precise construct definitions are vital. A clearer understanding of the concept of hope could equip nurses to influence hope purposely and positively. A clearer definition and understanding of hope could be used to assess the presence, absence, and degree of hope in a terminally ill cancer patient. From this, hope interventions could be
implemented and evaluated. Finally, a clearer definition of hope could add to the development and testing of nursing theory (Hinds, 1984).

For the terminally ill patient, hope and hope-nurturing interventions have the potential of being the most important nursing behaviors in helping the individual maintain his or her desired quality of life. Quality of life relates directly to the goals of nursing care (Varricchio, 1990).

**Conceptual Framework**

Lazarus and Folkman's (1984) Stress, Appraisal, and Coping Model provides the conceptual framework that guides and organizes the literature review and the overall research plan. Lazarus and Folkman's model views stress, coping, and adaptation as an ongoing, dynamic transaction between person-environment. The environment is constantly changing over time, so is the person and his or her relationship with the environment. Adaptation evolves based on cognitive appraisals and reappraisals. Coping strategies change based on these appraisals (Lazarus & Folkman, 1984). This dynamic transaction must be examined and defined within the context and structure of the experience and must be looked at as a process over time (Lazarus, 1991; Lazarus & Folkman, 1984).

Hope is conceptualized as an important emotional coping response to a perceived stress that can be influenced by internal and external events (Lazarus & Folkman, 1984; Moos, 1977). Hope as an emotion is manifested in predictable
patterns of feelings, behaviors, and physiological responses that lead to a specific goal related to adaptation (Plutchik, 1980). However, observations and descriptions of hope as a coping response must be examined within a specific context and studied in slices of time so that hope patterns can be observed as the encounter changes (Lazarus & Folkman, 1984). Figure 1 shows the visual representation of the relationships of hope, terminal illness and advanced stage cancer, adults, and health care within this framework:

Figure 1. Theoretical Framework. (Adapted from Stress, Appraisal and Coping, by R. S. Lazarus and S. Folkman, 1984, New York: Springer.)
Lazarus and Folkman's (1984) conceptual framework stresses process and context. It also requires understanding of the qualities, the influences, and the outcomes of hope. The following literature review covers the context of the cancer experience as well as the structures and dynamics of hope, including qualities of hope, influences of hope, and outcomes of hope.
CHAPTER II

REVIEW OF THE LITERATURE

The death and dying, coping, and hope literature is immense. The review of literature is divided into two sections. The first section focuses on the context of the cancer/terminal illness experience. This section provides evidence that supports hope to be a recognized coping response in the cancer and dying experience and that certain factors such as nature of the illness, timing of the illness in the life cycle, personal characteristics, and environment influence hope, the cancer experience, and ultimately quality of life during this experience. The second section focuses on the historical, theoretical, practice, and empirical qualities, influences, and outcomes of hope, with an emphasis on nursing.

From this literature review and Lazarus and Folkman’s (1984) stress model, specific research questions were developed and terms defined, and the research plan developed and implemented.
Terminal Illness

Cancer

The dying experience varies depending on the nature of the terminal condition and the individual (Fulton & Metress, 1995). For many, that terminal condition is cancer, cancer being the second leading cause of death in the United States (Parker, Tong, Bolden, & Wingo, 1996). Cancer is a group of diseases characterized by uncontrolled growth and spread of abnormal cells. If the disease is not controlled, cancer results in death. The "relative" survival rate of cancer is 51% (American Cancer Society, 1996). Cancer occurs in all ages, both sexes, and all socioeconomic groups, cultures, and geographic areas. There are many different types of cancer, including lung, pancreas, and stomach cancer, that carry with them a short survival time.

The individual diagnosed with terminal cancer is not usually confronted with a single stressful event but rather a continuing condition with a series of threats of varying intensity and duration over time (Barton, 1977). Initially, medical treatment is involved with staging of the cancer, and treatment is cure oriented. If primary treatment fails or if recurrent metastatic disease is discovered, there is a "crisis" or a "critical point" in which appraisal, adaptation tasks, and coping strategies are markedly changed (McCormick & Conley, 1995). It is noted that during this extended period of time, or "terminal phase" (McCormick & Conley, 1995; Pattison, 1977; Weisman, 1979), most patients
come to fully grasp what has happened to them and a new course of adaptation begins to take place. Associated with this phase are drastic changes in roles, health status and body image, limits in abilities and physical energy, withdrawal and isolation (Weisman, 1979), and preparation for bringing closure to life (McCormick & Conley, 1995).

Coping Responses to Cancer

The idea that a dying person develops coping and adaptation strategies is a relatively new area of study. Lazarus and Folkman (1984) define coping as "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (p. 141). Coping is either problem-focused, directed at managing or altering the problem causing the distress, or emotion-focused, directed at regulating emotional responses to the distress. Both efforts are used by everyone in virtually every stressful encounter; however, emotion-focused forms of coping are more likely to occur when there has been an appraisal that nothing can be done to alter the threatening or challenging environment (Lazarus & Folkman, 1984). According to Lazarus and Folkman (1984), emotion-focused coping strategies are most often used in the terminal phases of cancer.

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Hope as a Coping Response

As early as 1969, Kubler-Ross drew widespread attention to the psychological responses of the dying person. Based on her interviews of over 500 dying persons, five stages were identified: denial, anger, bargaining, depression, and acceptance. In addition, Kubler-Ross found that “the one thing that persists through all stages is hope” (1969, p. 122).

Lazarus and Folkman (1984) view these psychological responses as emotion-focused coping strategies. The purpose of these strategies is to decrease emotional distress. Hope, in combination with other adaptive coping strategies, can lead to expanded functioning, more positive, expressed thoughts and behaviors, and relationships with others may culminate in greater aliveness (Fromm, 1968). Numerous clinical research studies involving terminal illness have identified these emotion-focused coping strategies, and hope is almost always included (Hinds & Martin, 1988; Raleigh, 1992).

In a classic descriptive study by Martocchio (1982), 47 patients who were believed to have a limited time span were interviewed. Two adaptation patterns were reported: relief from uncertainty and escape. In the relief from uncertainty, patients had hope yet, at the same time, yearned for closure. They wished for life or for death. Escape was characterized by resignation and escape from loneliness and despair.
Payne (1990) used grounded theory to analyze coping responses of 24 women with advanced breast or ovarian cancer. Four predominant coping styles were used: positive/fighter, acceptance, fearfulness, and hopelessness. Hope was related to acceptance. Eight woman were realistic in their assessment of their disease and life chances. Acceptance was a toleration of the cancer. They expressed their wishes as hopes. Three women had abandoned hope. The imagery was of violence, and the individual perceived herself as a helpless, dependent victim. Payne's findings supported the earlier findings of Morris et al. (1977) who categorized women with primary breast cancer into four coping style groups: fighting spirit, denial, helplessness/hopelessness, and stoic.

Numerous studies suggest that patients with cancer report high levels of hope (Herth, 1991; Nowotny, 1989). High levels of hope are correlated positively with ability to continue to function in family and job responsibilities (Herth, 1989) and correlated negatively with uncertainty (Mishel et al., 1984). More recently, positive emotions such as hope are being linked to positive health outcomes (Cousins, 1989).

Hope and coping are inexplicably intertwined (Farran, Herth, & Popovich, 1995). The actual role hope plays in coping and in adaptation remains speculative and, to date, poorly defined and understood. However, a sense of hope can
provide meaning, direction, motivation, and a reason for being (Post-White et al., 1996).

Changes Over Time

Situational specifics and changes over time are important; consequently, coping responses must be evaluated over time. There are very few studies that have looked at coping and coping strategies at different times during the cancer experience.

One of the few studies that has attempted to evaluate changes of mood over time was conducted by Baugher, Burger, Smith, and Walliston (1990). This study contrasts responses to four general sets of questions about social concerns, self-concern, focus on the beyond, and mood states. The 1,110 participants differed in length of time until death from Time\(_1\) (1 day to 2 weeks) to Time\(_2\), (16-30 weeks). It was predicted that as they moved closer to death, responses would involve self and afterlife more than other people. What, in fact, the researchers found was that the dying person in his or her final time showed little fluctuation in mood and time spent with others and that source of strength was not with self or beyond as predicted.

Other studies that have looked at cancer patients over time involve quality-of-life changes. Sarna (1989) looked at quality of life and functional status of 24 lung cancer patients prior to first chemotherapy, 2 weeks later, and 4 weeks later. There were no statistically significant
differences in either their quality-of-life scores or functional status over time. Courtens, Stevens, Crebolder, and Philipsen (1996) looked at quality of life and social support of 51 cancer patients during 1 year of their disease course. Data were collected at 3 months after diagnosis and 1 year after the first measurement. There was a slight increase with the quality-of-life indicators, but the amount of psychological symptoms did not change significantly.

Traditionally, hope has been conceptualized as static and linear; however, as situations change and the individual's ability to adapt changes, does their hope change as well? This is an area that has not been sufficiently studied (Farran, Herth, & Popovich, 1995; Nowotny, 1989).

**Influences on Coping**

It is difficult to predict the psychological state of a terminally ill person because everyone brings to this experience unique life experiences (Kemp, 1995). It is recognized that there are an infinite number of variables that influence coping and adaptation. Lazarus and Folkman (1984) suggest the stress event, personal attributes, and environmental factors influence appraisal and coping. Pasacreta and McCorkle (1996) suggest psychological adjustment may be affected by physical signs and symptoms associated with cancer, timing in the life cycle, previous
coping strategies and emotional stability, and the existence of social support.

Nature of the disease. The impact of progressive disease can cause transient or permanent physical changes, symptom distress, and functional impairments in patients (Pasacreta & McCorkle, 1996). Most medical and nursing interventions during advanced stage cancer are designed to reduce the symptoms of distress, prolong life, and slow down the death trajectory (Kemp, 1995). The priorities of physical care include pain control, nutrition, and meeting basic hygiene needs. Pain is the symptom dying patients fear the most (Gavin & Chapman, 1995). The incidence of moderate to severe pain increases to 80% of patients with advanced cancer (Portenoy, 1989). Pain has especially been linked to specific coping responses, namely, depression and anger (Rankin, 1982).

In two studies, pain intensity, pain relief, and mood were evaluated. The reanalyzed data revealed a moderate correlation between pain intensity and mood disturbance (Fishman, Houde, Wallenstein, & Foley, 1987). In another study involving prostate cancer patients, a positive correlation was found between improvement in pain and quality-of-life scores (Tannock, 1990).

Timing in the life cycle. The timing of a terminal illness in the context of the individual's life and the life of the family has a significant impact on the experience (Ferrell, 1996; Gavin & Chapman, 1995; Germino, 1987;
Lazarus & Folkman, 1984). There is a major orientation that death occurs only at an advanced age (Kastenbaum, 1977; Schuster & Ashburn, 1992; Vander Zanden, 1997).

Approximately 10% of the 500,000 of those dying of cancer each year are adults between the ages of 20-59 (Schuster & Ashburn, 1992; Troll, 1985). Cancer is the leading cause of death in females between 35-54 and the second cause of death for men 35-54. Breast cancer is the number one killer of adult women and lung cancer is the leading cancer cause of death in adult men (Parker et al., 1996).

Timing in the life cycle has traditionally been synonymous with a chronological age, with "adults" being 20-59 (Cole, 1992). Current definitions of "adult" reflect normative-life events that take into account physical, cognitive, and psychosocial development (Vander Zanden, 1997). Early adulthood includes establishing personal and economic independence, career development, learning to live with others in an intimate way, starting a family, and rearing children. Middle adulthood is a time for expanding personal and social involvement and responsibility, of assisting the next generation, and reaching and maintaining satisfaction in one's career (Santrock, 1995). From this normative-life events theory, there is every reason to believe that the response of a 75-year-old is different from a 45-year-old (Phillips, 1989).

According to Pattison (1977), there are different emotional reactions toward death at different ages. Vaillot
(1977) believes coping becomes more effective and realistic with age. There is less dependence on immature mechanisms, such as projection and acting out, and more use of mature mechanisms such as altruism, humor, and suppression (Barton, 1977). However, there is little empirical evidence to support these theories.

In an early study on healthy adults by Kalish (1985), age differences were marked by how the individual would spend his or her last 6 months. The young expressed concerns for others, the middle-aged would not change their lifestyle, and the elderly would withdraw into prayer or contemplation.

In structuring research designs, researchers acknowledge that as time passes and developmental processes intervene, biological, social, psychological, and environmental events occur that cause the individual encountered at age 5 to be significantly different from an individual at age 25. Consequently, 5-year-olds and 25-year-olds are rarely treated as the same unit of analysis within a single sample. The same is not true at the older end of the age continuum (Phillips, 1989).

Research has been influenced by the principle of primacy (Birren & Renner, 1981) that major developmental changes occur prior to age 25, and beyond that an adult is an adult. As a consequence, "adults" ages 20-59 are usually subsumed under the "adult cancer population" and are not separated from elderly and geriatric adults >60 (Phillips,
1989). In many cases, statistical correlations of age to other variables are run, but because the findings are often not statistically significant, any further research is not pursued. An example is a study done by Sarna (1989) that looked at the impact of chemotherapy on quality of life of older adults (≥65 with those <65) with non-small cell lung cancer. There were no statistically significant differences in the disruptions of quality of life or functional status. Yet Ferrell's (1996) quality-of-life research involving breast cancer and coping has demonstrated a wide diversity in the needs between the 28-year-old coping with breast cancer, as well as with issues of fertility and a new marriage, and the 75-year-old confronting breast cancer and other issues of aging. As the way most research findings are typically reported, both the clinical relevance of the findings and the impact on specific individuals are obscured.

Wu (1991) attempted to compare the young (<58) and the old (>58) terminal cancer patients' dominant emotional states. An emotional rating scale included eight affect categories. Emotional patterns were found to be different. The younger group had significantly higher scores in bargaining and complaints and lower scores in depression and acceptance. The main effect of age was insignificant for hope and fears.

Little empirical information is available specific to the experience of terminal cancer and adults. What is
available does support differences between ages. However, more data are needed to understand what those differences mean.

**Coping strategies and emotional stability.** A person brings to the experience many characteristics that influence his or her ability to cope with cancer. Individuals with a history of poor psychosocial adjustment before developing cancer are at highest risk for emotional decompensation (Pasacreta & McCorkle, 1996). Clinicians have found specific personality characteristics, coping strategies, and life experiences to either enhance or inhibit positive adjustment to cancer (Penman et al., 1987).

**Social support.** Social support has consistently been found to influence a person’s psychosocial adjustment to cancer (Penman et al., 1987). Individuals with advanced stage cancer experience a heightened need for interpersonal support (Pasacreta & McCorkle, 1996). Individuals who are able to maintain close connections with family and friends during the course of the illness are more likely to cope effectively with the disease. The level of perceived social support is a variable that is viewed as a buffer to the effects of stress on the health of the individual (Northouse, 1988).
Coping Outcome: Quality of Life

Having hope has been associated with more effective coping and a better quality of life (Herth, 1989). Coping processes and strategies lead to adaptational goals and outcomes. The best coping is that which changes the person-environment relationship for the better. Poor adaptation is associated with lowering the threshold for perceiving or handling stress. Positive adaptation is associated with continued personal growth and maintenance of quality of life (Lazarus & Folkman, 1984). Quality of life is conceptualized as a multidimensional construct that encompasses health and function, psychological/spiritual, family, and social economics. They are not independent but are interrelated and overlapping (Ferrans, 1994). Quality of life is frequently associated with life satisfaction, with present-life circumstance as perceived by the individual (Ferrans, 1994).

Traditionally, cancer treatment has been directed towards prolongation of the patient’s survival. More recently, quality of life is being identified as the desired endpoint in many cancer treatment protocols and research (Cella, 1992; Van Knippenberg, 1985; Tannock, 1990; Varricchio, 1990). It is believed that even in the final phases of an illness, a realistic and important goal is to maintain and facilitate the upward quality-of-life trajectory (Benoliel, 1986). In studies comparing cancer patients to noncancer patients or cancer survivors, no differences were found with respect to most quality-of-life
indicators except those that were "health" oriented (Irwin, Gottlieb, Kramer, & Danoff, 1982).

End-of-life research is inconsistent in their quality-of-life findings. Some studies demonstrate decreases in quality-of-life scores (Morris & Sherwood, 1987; Morris, Sussa, Sherwood, Wright, & Greer, 1986) as individuals neared death. Other studies show quality-of-life scores decreasing slightly but not significantly. Health function scores generally decrease over time, but other quality-of-life subscores remain stable, suggesting that quality of life is maintained even towards the very end of life (Sarna, 1989).

**Nurses' Influence on Coping**

For persons who have a terminal illness, nursing care further involves helping them to try to achieve not just clinical health but a spirit of living life to the fullest extent possible (Hall, 1994). Fostering hope is recognized as an important way for nurses to aid in positive adaptation (Hicky, 1986; Miller, 1991; Vaillot, 1970). In theory it is believed that nurses can influence hope in patients with advanced stage cancer. Clinically, patients report that nurses have influenced their hope. Nurses share patient care experiences that exemplify hope being nurtured. Yet, there is nothing empirically to support this.

Based on clinical practices and experiences, interventions have been associated with nurturing hope. They...
include developing the professional-patient relationship (Jevne, 1991; Roberts, 1986), one-to-one conversation between patient and nurse (Schneider, 1980), therapeutic use of self and sharing information (Moos, 1977), caring (Pickett & Yancey, 1996), and creation of a positive and open environment (Dufault & Martocchio, 1985). Most of these interventions are consistent with those defined by a "therapeutic relationship" and are important in nurturing any type of positive nurse-patient intervention and are not unique to nursing.

**Hope Literature**

Ever since hope was discovered at the bottom of Pandora's box, philosophers and scientists have maintained a safe but curious distance from the mysterious phenomenon of hope. From the beginning, the qualities, virtues, and values of hope have been debated from a humanistic as well as a scientific perspective (Godfrey, 1987). What is currently known about hope comes from a broad spectrum of disciplines and individuals. As a consequence, each discipline has defined hope within a limited framework, based on a unique and limited perspective.

**Theoretical Dimensions**

According to the philosophers Sarte and Camus, hope could not logically be associated with existential thoughts because of their beliefs that authentic man remains
necessarily and forever alone (Vaillot, 1970). Hope has traditionally shown up as a theological virtue given by God. Hope is not believed to be of this world or in this life but is in heaven and in afterlife. Hope is detached from the contingencies of the material future and from the possibility of disappointment in this world by the hope of salvation (Rycroft, 1979). Philosophers and theologians rarely addressed hope, believing it to be only wishful thinking or desire and not to be taken seriously.

An exception to this rejection of hope as unworthy of consideration is found in the works of several theorists. Marcel (1962) described hope as being unconditional in that it transcends all particular objects and is more concerned with a person as a being. Central to Marcel’s view of hope was its association with captivity and despair and the need to be delivered from some present condition or state. Although hope was described as an inner sense, Marcel believed that there must be an interaction between one who gives and one who receives hope. This intersubjectivity, or bond of love between self and others, is essential to hope as a mysterious but important inner force for human survival.

Lynch (1965) describes hope as something very definite and positive. Hope is an interior sense that needs a response from outside and has meaning only as it relates to others, an act of collaboration or mutuality and cannot be achieved alone. Hope is a necessary factor to redirect
society's fascination with despair. It promotes anticipation, which is a positive feeling, and contributes to growth and cultural advancements (Tiger, 1979).

Stotland (1969) views hope as a force in relation to other factors, such as motivation, achievement, and goal attainment. Hope is seen as an expectation greater than zero of achieving a goal. Hope is the perceived probability of success, a conviction that the desired goal is truly obtainable. Maslow (1987) alludes to hope as being the motivator needed to meet the basic human needs. Motivational constructs such as commitments and goals and beliefs in self and world help the individual move towards self-actualization, which is the ultimate and desired goal (Maslow, 1987; Plutchik, 1980). Theoretically, hope is a motivator, can be influenced by others, and wards off despair.

The actual "nature" of hope continues to be debated among emotion theorists. Several theorists suggest that hope is a prerequisite for effective coping and decision-making (Lazarus, 1960; McGee, 1984; Stotland, 1969). Is hope a primary emotion or an emotion-related coping response? This discussion revolves around the issue of: "Is hope an affective response to another emotion (i.e., fear?)" or "Is hope alone an emotion that carries with it its own unique patterns or strategies?" If a man diagnosed with leukemia takes laetrile, does he take it because he is afraid (fear)
of dying and hopes to be cured, or does he take the laetrile because his hope is to control his environment?

Theorists who support the idea that hope is an emotional state reinforce their observation by defining the cognitive, affective, behavior, physiological, and adaptive components. Mowrer, as early as 1960, likened hope to fear. He identified hope as one of four fundamental emotional drives along with fear, relief, and disappointment that generate a response. Fear and hope are alternative responses to situations in which a goal is threatened; the pessimistic individual responds to situations of this type with fear, while the optimistic individual responds with hope.

Most theorists support the notion that hope is the affective response of other emotions (Averill, Catlin, & Chon, 1990). In Mishel and Braden’s (1987) research on uncertainty, hope is considered an affective response along with other physiological and behavioral patterns. Beck (1963) views hopelessness as the affective response to depression.

Lazarus (1991) agrees that hope is a “problematic emotion” due to the difficulty of identifying action tendencies and physiological responses consistent with primary emotions, as well as the fact that there is so little research or theory on which to draw or understand the conditions under which hope occurs. Lazarus thinks that “perhaps it is [an emotion] and is not willing to abandon hope as a bonafide emotion” (p. 285).
Clinical Observations

What is known about the qualities and characteristics of hope comes primarily from clinical observations from the practice-oriented disciplines of psychiatry, psychology, and nursing. In the 1960s, clinicians began to write and publish their clinical observations and experiences of individual patients who demonstrated hope or hopelessness. Drawing primarily from the psychiatric population, the focus of most writing was on hopelessness and despair (Barckley, 1958; Boyajian, 1978; Buehler, 1975; Dubree & Vogelpohl, 1980; Jourard, 1970; Laney, 1969; Limandri & Boyle, 1978; Sobel, 1969; Vaillot, 1970). Enabling hope was recognized as a means to decrease pathological emotional states of hopelessness, helplessness, and depressions and to increase low morale (Greenberg & Safran, 1987).

Behavioral psychologists identified hope to be the motivator of learning and goal-directed behaviors. Seligman (1975) has associated helplessness to situations in which control over outcomes was independent of the individual responses. In a state of "learned helplessness," the person is slow to initiate voluntary responses, believes he is powerless and hopeless, and sees his future as bleak. He believes that he has lost control over pleasure and relief of pain and suffering. The result is despair and hopelessness and increases the risk of death.

Hope is noticeably missing from the psychoanalytic theories. The reason is believed to be that Freudian
psychoanalysis is concerned with causes, and causes are always located in the past. Hope is future oriented. Therapy also focuses on maladaptive or pathological responses, of which hope is not usually associated (Rycroft, 1979).

Averill et al. (1990), a social psychologist, attempted to distinguish hope from simple wants and desires. Categories of hope fell out, including objects of hope, importance of hope, and initiating conditions of hope. In another study, subjects were asked to compare the common and dissimilar features of love to hope. Differences included hope is more individual, less demonstrated; is not limited to specific people or actions; is easier to control; and is less real (Averill et al., 1990).

Medicine has been slow and skeptical in acknowledging any emotion as a valid practice or research variable. In 1959, Karl Menninger's classic article identified hope as "another aspect of life instinct, the creator of drivers which wars against desolation and destruction" (p. 481). He chastised physicians for not believing in the intangible and discounting the element of hope.

Within the last 15 years, a new area on medicine has emerged: psychoneuroimmunology. Emotions are being linked to the immune system. Some researchers believe that emotion can influence the pathogenesis of physical diseases such as cancer (Solomon, Kay, & Morley, 1986). Development of some tumors appears to be facilitated by catecholamine depletion and immunosuppression, whereas tumor inhibition may occur.
with increases in catecholamine activity (Vogel, 1986). It is theorized that positive coping-related emotions, including hardiness and hope (Kobasa, 1979), may prevent some illnesses (Cousins, 1989), slow tumor growth, and increase survival time in cancer patients (Solomon et al., 1986; Worden & Sobel, 1978).

Cousins (1989) attempts to bridge the gap between the clinical importance of positive emotions such as hope on health and functioning. Cousins maintains that positive emotions such as hope function as the healing power of the human spirit and suggests three reasons why this might be specifically so for hope. First, he suggests that hope functions as a challenge that gives a person a sense of control, rekindle the spirit, create new energies, increase the quality of life, and set the stage for new growth. Second, hope is an essential part of nourishing those who love a suffering person. Third, hope enhances the environment of health care. Hope is seen as the strongest ally that health care workers have and the hidden ingredient to any treatment or prescription. Hope involves the individual's reaching within him or herself for the best and accepting the challenge to confront a new situation.

Cousin's view of the value of hope in health care has been identified frequently by nurses. Miller and Powers (1988), Owens (1989), Vaillot (1970) as a vital ingredient for enhancing quality of life and for promoting health and

"Hope as a Healer" by Laney (1969) was the first article to point out that hopelessness was not only found in psychiatric units but that "hopelessness was also present in general hospitals, nursing homes, and at various times in the lives of all people" (pp. 45-46). A physician, Sobel (1969), reported in the *American Journal of Nursing* that hopelessness was present in critical care units and emphasized that "sustained genuine hopelessness . . . is very rare . . . but that intermittent feelings of hopelessness occurred fairly frequently" (p. 1440). What followed for nursing is best described by Morse and Doberneck (1995) as "a 'vast literature' on the nature and role of hope" (p. 277).

**Nursing Hope Research**

Beginning in the late 1970s and early 1980s, clinically oriented hope research began to appear in the nursing literature. This is due, in part, to other trends in nursing, including (a) an emphasis on health promotion and illness prevention; (b) a shift towards holistic and humanistic caring paradigms (Benner & Wrubel, 1989; Paterson & Zderad, 1976; Watson, 1979); (c) research activities being generated and implemented at the bedside by clinically oriented nurses who, like their predecessors, have observed in their patients the presence (or absence) of hope (Hinds,
1984); and (d) doctorally prepared clinicians who have the opportunities, skills, resources, theories, and encouragement to examine the abstract nature of hope in a scholarly, systematic, and creative manner (Dufault, 1981; Stoner, 1982).

Systematic inquiry regarding hope as a research variable has progressed in a logical and predictable manner. Initially, research focused on generating theoretical descriptions and dimensions of hope and identifying hope-nurturing behaviors qualitatively. Once the dimensions of hope were identified, measurement tools, based on theoretical descriptions, became available to nurse researchers. With instruments designed to measure hope, factors that influence hope could be evaluated quantitatively. More recently, hope is being looked at over time. What is noticeably lacking in the literature are hope outcomes and the next logical step in research development: implementing hope-nurturing interventions and evaluating their outcomes.

Theoretical descriptions of hope. One of the earliest qualitative studies was by Stanley (1978), who used a phenomenological approach in an effort to explicate the concept of hope in 100 junior and senior college students, who were asked to describe how they felt when they experienced hope:

The general structure of the lived experience of hope included a confident expectation of a significant future outcome . . . accompanied by a
quality of transcendence and interpersonal relatedness in which action to effect the outcome is initiated. (p. 165)

Stanley also identified several common elements of hope, including being confident, interpersonal relatedness, and transcendence (see Table 1).

Dufault (1981) and Dufault and Martocchio (1985) collected multiple descriptions of hope over a period of 2 years from 35 elderly cancer patients and 47 terminally ill persons with varied diagnoses. Analysis of the data revealed that hope is a "multidimensional dynamic lifeforce and . . . process-oriented" (p. 380). There are many manifestations of hope that Default and Martocchio conceptualize as being composed of two spheres having six common dimensions (see Table 1). These spheres are of "generalized hope" and "particular hope," and each of the six dimensions are conceptually and operationally defined by a set of components that structure the experience and process of hope (1985). Dufault’s spheres and dimensions are frequently used as theoretical definitions in other hope research projects. The strength of Dufault’s work is that the theory has been generated from individuals who are experiencing "illness" and that two different populations, elderly and cancer patients, were used to validate the findings. Dufault suggests that the "nursing challenge is to understand how hope may be operative, in order to facilitate and support this indispensable resource throughout the illness experience" (p. 391).
Table 1

Hope Qualities

<table>
<thead>
<tr>
<th>Common Elements (Stanley, 1978)</th>
<th>Levels of Hope (Hinds, 1984)</th>
</tr>
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<tbody>
<tr>
<td>Expectation of a future</td>
<td>Forced effort</td>
</tr>
<tr>
<td>Being confident</td>
<td>Personal possibilities</td>
</tr>
<tr>
<td>Taking action</td>
<td>Expectation of a better tomorrow</td>
</tr>
<tr>
<td>Comfortable feelings</td>
<td>Anticipation of a personal future</td>
</tr>
<tr>
<td>Uncomfortable feelings</td>
<td>Concern for and a focus on others</td>
</tr>
<tr>
<td>Interpersonal relatedness</td>
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<tr>
<td>Transcendence</td>
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</table>

Dimensions (Dufault & Martocchio, 1985) | Subthemes (Owen, 1989)
Dimensions of hope | Setting goals
Affective | Positive personal attributes
Cognitive | Future redefinitions
Behavioral | Meaning in life
Affiliative | Peace
Temporal | Energy
Contextual |
Owen's 1989 grounded theory research study was designed to develop generalized knowledge about the meaning of hope in patients with cancer. Subthemes and attributes of hope were identified by interviewing six oncology nurse specialists (see Table 1), and "energy" emerged as a strand running through each subtheme. Hinds has used well adolescents, inpatient drug abusers, and oncology patients to define hope (Hinds, 1984) and to clarify the concept of hopefulness in the context of health and illness (Hinds, 1988). Hope was defined as "the degree to which an adolescent believes that a personal tomorrow exists" (p. 360). Herth (1993) interviewed 24 patients receiving radiation therapy and found that patients lived on a fluctuating hope-doubt continuum.

Gaskins (1995) asked older adults to capture hope in photographs. By using this phenomenological approach, he identified several sources of hope, including spirituality, relationships with others, having one's health, positive emotions, anticipating the future, justice, resources, memories, special places, and service for others.

Overall, the dimensions and qualities of hope are similar but represent only one aspect of the phenomena. Nurses also need to understand what influences hope.

Influences of hope. Fostering hope is recognized as an important part of the nursing role (Hicky, 1986; Miller, 1991; Roberts, 1978; Vaillot, 1970). Watson (1979) identified instilling hope as 1 of 10 components in a
humanistic model of nursing. However, it has not been well understood how individuals generate and sustain hope and how nurses can nurture hope (Post-White et al., 1996). Hope-nurturing interventions for nurses have been identified from practice, by review of hope literature, descriptively though interviewing different populations, and theoretically based on research findings.

From clinical observation, nurses have identified caring, therapeutic interaction, and goal setting to be "hope-nurturing." Caring is characterized as being available and showing genuine concern for the patient as a person. Important conditions for caring include respecting the individual person, recognizing that man is always growing and creating; maintaining self-respect and personal dignity; and the presence of an implicit and explicit knowledge base (Gaut, 1986; Jevne, 1991; Watson, 1979). Caring is conveyed by tone of voice, touch, and eye contact as much as by words (Jevne, 1991).

The professional-patient relationship has a profound influence on the hope of a patient. An interaction with a patient is itself a hope treatment (Jevne, 1991). A one-to-one conversation between a nurse and patient will support the patient's feeling of self-worth. The therapeutic use of self and sharing information conveys respect and confidence and hope. Goal setting or planning within this relationship motivates and provides opportunities for achievement, all considered important in maintaining hope.
Several articles have been written suggesting ways to nurture hope. Poncar's (1994) review of hope literature supports the suggestions made from clinical practice. The "nurse can inspire hope by understanding the hoping process; offering nursing encouragement; and incorporating such skills as presence, touch, active listening, reality surveillance, and values clarification" (p. 38).

Empirical evidence that identifies factors that influence hope comes from several qualitative studies. An exploratory study by Miller (1989) identified the mechanisms used to maintain or increase hope while confronting a life-threatening event. Nine hope-inspiring categories were labeled and defined (see Table 2). The process of hopefulness was examined by Hinds and Martin (1988) in the adolescent population. The overall organizing construct of the process of hopefulness is labeled "self-sustaining." Herth (1993) explored the meaning of hope and identified "strategies" that terminally-ill individuals use in maintaining and fostering hope. These strategies include interpersonal connectedness, spiritual base, attainable aims, personal attributes, lightheartedness, uplifting memories, and affirmation of worth. Similar results are found in Hall’s (1994) research that identified "ways of maintaining hope" in HIV disease. They included miracles, religion, involvement, and support (see Table 2).
<table>
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<th>Table 2</th>
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<tr>
<td><strong>Hope Influences</strong></td>
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<tr>
<td><strong>Miller (1988)</strong> (Critically Ill)</td>
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<tr>
<td>Cognitive</td>
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<tr>
<td>Determinism</td>
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<tr>
<td>Personal philosophy</td>
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<tr>
<td>Spiritual</td>
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<tr>
<td>Relationship with caregiver</td>
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<tr>
<td>Family bond</td>
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<tr>
<td>Sense of control</td>
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<tr>
<td>Goal accomplishment</td>
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<tr>
<td>Miscellaneous</td>
</tr>
<tr>
<td><strong>Hinds (1988)</strong> (Adolescence)</td>
</tr>
<tr>
<td>Self-sustaining</td>
</tr>
<tr>
<td>Cognitive discomfort</td>
</tr>
<tr>
<td>Distraction</td>
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<tr>
<td>Personal competence</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td><strong>Nowotny (1989)</strong> (Cancer)</td>
</tr>
<tr>
<td>Confidence in outcome</td>
</tr>
<tr>
<td>Relate to others</td>
</tr>
<tr>
<td>Possibility of future</td>
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<tr>
<td>Spiritual beliefs</td>
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<tr>
<td>Active involvement</td>
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<tr>
<td><strong>Cutcliffe (1994)</strong> (AIDS nurses)</td>
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<tr>
<td>Reflection</td>
</tr>
<tr>
<td>Affirmation of worth</td>
</tr>
<tr>
<td>Creating a partnership</td>
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<tr>
<td>Totality of person</td>
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</table>
Other researchers have used other populations to identify hope nurturing behaviors. Cutcliffe (1995) interviewed nurses caring for HIV-positive gay men, asking them to identify hope-inspiring strategies and interventions. Four key concepts were identified: reflection in action, creation of a partnership, totality of the reason, and affirmation of worth using grounded theory. The conclusion of this study is that staff within this particular setting inspire and instill hope in terminally ill patients by means of these four key elements.

Patel (1996) asked 20 spouses of critically ill patients how they maintained hope. They identified the following: spiritual/religious, others, positive interactions with caregivers, devotion to patient, optimistic attitude, being present, and talking to others. Patel’s study is unique in that it differentiated “hope inspiring strategies” and “sources of hope.”

These studies are valuable in helping nurses to understand the process and factors involved with hope. However, these studies are misleading and have the potential for misuse for four reasons. First, most authors then take the findings one step further, based on the assumption that what individuals do to maintain their hope, nurses can also do for them. Only one study asked patients what nurses did to nurture their hope. Second, researchers do not seem to discriminate between internal (personal) and external (environmental) hope-nurturing factors. Some hope-nurturing
strategies appear to be from within the person. Examples include spirituality (Nowotny, 1989) and personal philosophy (Miller, 1988). Can nurses really influence a personal philosophy? Third, individual strategies and needs are completely subsumed under generalities. The "person" is lost--ironic for a discipline intent on meeting the holistic needs of a person. Finally, there is ambiguity between "where" hope comes from (antecedents of hope) and "what" maintains hope. More information is needed before nurses can confidently say "they are nurturing hope." Quantitative hope research adds one more dimension to this complex subject.

Measuring hope. One of the first clinicians able to bridge the "clinical practice observations" to "empirically tested research" in the early 1960s was psychologist Arron Beck. Drawing from Stotland's (1969) theory of hope and his own clinical observations of sociopathic, depressed, and suicidal individuals, Beck developed the Beck Hopelessness Scale (BHS) (Beck, Weissman, Lester, & Trexler, 1974). Even though the theoretical constructs, pessimism, optimism, and hopelessness were poorly defined, the BHS has been used for many hope-related research projects over the years, in all disciplines. Hopelessness has been correlated with other phenomena such as depression, self-concept, locus of control, and physical illness (Greene, O'Mahoney, & Rungasamy, 1982; Johnson & McCutcheon, 1981; Raleigh & Boehm, 1994). The psychometric properties of the BHS are well established (Durham, 1988; Holden & Fekken, 1988). The
tool has been modified for children and for hopefulness (Kazdin, 1987).

Other hope-related tools have been developed by researchers using Stotland's (1969) and others' theoretical constructs of hope and their own clinical observations. They include Erickson, Post, and Paige (1975), Gottschalk (1974), and Obayuwana, Collins, and Carter (1982) (see Table 3), and nursing's Stoner's Hope Scale (1982), Miller's Hope Scale (1988), Nowotny's Scale (1989), Herth's Hope Scale (1989), and the Multidimensional Hope Scale (1994), a modified Stoner Hope Scale (see Table 4).

Erickson et al. (1975) identified 24 oriented goals using Stotland's (1969) theoretical constructs of hope. Gottschalk (1974) composed a set of predetermined weighted categories indicating positive or negative levels of hope. To quantify hope, he used typescripts of speech samples relating to an interesting or dramatic personal life experience. The Hope Index Scale was developed by Obayuwana et al. (1982), who asked 500 telephone participants to describe in one word what hope meant to them. The most common responses are grouped and are used to assess cognitive, affective, and motor components of hope.

Stoner's Hope Scale (1982) is a self-report measure designed to assess perceived importance of 20 intrapersonal, interpersonal, and global goals. The Miller Hope Scale (1988) is a 40-item scale using a 5-point Likert format. Ten critical elements described in the literature were used for
Table 3

Theoretical Constructs of Nonnursing Hope Tools

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>• Feelings regarding future, affectively toned</td>
<td>• Hope in spite of adversity</td>
</tr>
<tr>
<td>• Loss of motivation, negativeness toward affect</td>
<td>• Future orientation of hope</td>
</tr>
<tr>
<td>• Future expectations, what life will be like in the future</td>
<td>• Hope vs. happiness</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Erickson, Post, and Paige Hope Scale (1975)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• Perceived importance</td>
<td>• Interpersonal sources of hope</td>
</tr>
<tr>
<td>• Perceived probability</td>
<td>• Hope and goal attainment</td>
</tr>
<tr>
<td>• Subjective estimates</td>
<td>• Hope and control</td>
</tr>
<tr>
<td>• Goals common to American society</td>
<td></td>
</tr>
</tbody>
</table>

Hope Index Scale (Obayuwana et al. 1982)

| • Ego strength | |
| • Human family support | |
| • Religious assets | |
| • Educational assets | |
## Table 4

### Theoretical Constructs of Nursing Hope Tools

<table>
<thead>
<tr>
<th><strong>Stoner's Hope Scale (1982)</strong></th>
<th><strong>Miller's Hope Scale (1988)</strong></th>
</tr>
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<tbody>
<tr>
<td><strong>Intrapersonal</strong> - interior resources</td>
<td><strong>Satisfaction with self, others, and life - term of self-competence, at peace with self</strong></td>
</tr>
<tr>
<td><strong>Interpersonal</strong> - that which occurs because of the transaction with external resources</td>
<td><strong>Avoidance of hope threats - lack of hope, overwhelmed</strong></td>
</tr>
<tr>
<td><strong>Global</strong> - goes beyond the person</td>
<td><strong>Anticipation of a future</strong></td>
</tr>
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<table>
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<tr>
<th><strong>Nowotny's Scale (1989)</strong></th>
<th><strong>Herth's Scale (1989)</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Confidence</strong></td>
<td><strong>Intrapersonal</strong></td>
</tr>
<tr>
<td><strong>Relates to others</strong></td>
<td><strong>Environmental</strong></td>
</tr>
<tr>
<td><strong>Future is possible</strong></td>
<td><strong>Illness-related</strong></td>
</tr>
<tr>
<td><strong>Spiritual beliefs</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Active involvement</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Comes from within</strong></td>
<td><strong>Multidimensional Hope Scale (1994)</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Intrapersonal</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Interpersonal</strong></td>
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<tr>
<td></td>
<td><strong>Global</strong></td>
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<td></td>
<td><strong>Spirituality</strong></td>
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<td></td>
<td><strong>State/trait</strong></td>
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the framework for generating the items. The Nowotny Hope Scale (1989) is composed of 47 items within six subscales based on six dimensions of hope from the literature. Subjects respond to objective statements by "strongly agreeing" to "strongly disagreeing." Raleigh and Boehm (1994) modified the Stoner Hope Scale to create the Multidimensional Hope Scale (MDHS). The MDHS adds an illness dimension to hope, as well as state/trait properties. The Herth Hope Scale (HHS) is a 32-item scale to which subjects respond either "applies to me" or "does not apply to me." Constructs being measured include positive expectancies, personal competence, and temporality (1989). Herth adapted the HHS in 1992 and developed the Herth Hope Index (HHI). The HHI is designed to be used in the clinical setting by reducing the number and complexity of items. Hinds' Hopefulness Scale for Adolescents is a 24-item, visual analogue scale with four subscales, designed to quantify the amount of self-reported hopefulness (1989).

The validity and reliability of these tools are questionable. Nurse researchers have found that the BHS and Erickson's Hope Scale, developed primarily for a psychiatric population who have abnormally high or low levels of hope/hopelessness, do not adequately reflect all the dimensions of hope as experienced by healthy and physically ill populations (Herth, 1989; Miller & Powers, 1988; Nowotny, 1989; Stoner, 1982).
Most of the above scales were developed theoretically. The advantage of that is the results are more generalizable. However, they do not examine a particular stress and do not exhaust all possible ways of coping (Singer, 1984). The ability of these tools to discriminate hope from other related constructs such as optimism and anticipation has not been empirically tested. Except for the BHS, most hope-related tools have had limited use and their psychometric properties are not well-documented. Finally, quantitative tools are not designed to capture dynamic change or process (Hinds, 1988), and hope over time has not been evaluated.

Despite the noted limitations, the nursing hope scales have been used extensively. Farran, Salloway, and Clark (1990) examined four central attributes of hope by using two of the hope scales: Stoner's Hope Scale and the Hopefulness Scale, an adaptation of the BHS. The purpose of this study was to determine whether these scales reflect the apriori conceptualization of the central attributes of hope and whether the two scales could be summarized into one hope score for future analysis. The relationship between the two scales was only moderately positive. It was determined that the two scales measured two different hope constructs and that a combination of tools provided a more comprehensive understanding of the phenomenon.

Factors that influence hope. Recent studies using hope instruments have looked at hope in multiple patient populations defined by (a) health-related condition,
including mentally ill, acutely ill, chronically ill, and terminally ill patients (Farran, 1985; O’Malley & Manke, 1988; Raleigh & Boehm, 1994; Stoner, 1982); (b) physical symptoms, including function, activities of daily living, pain, and degree of illness (Farran, 1985; Hall, 1989; Nelson-Marten, 1988; Nowotny, 1989; Stoner & Keampfer, 1985); (c) different age groups, including adolescents, elderly, and adults (Herth, 1990; 1993; Hinds, 1984, 1989); (d) related psychological and coping constructs, including hopelessness, optimism, uncertainty, self-efficacy, and spirituality (Mickley, Soeken, & Belcher, 1992; Mishel et al., 1984; O’Malley & Menke, 1988; Post-White, Ceronsky, Dreitzer, & Mickelson, 1996; Raleigh & Boehm, 1994; Tollett & Thomas, 1995); and (e) environmental factors, including social support, living communities, and available resources (Dibble, 1986; Farran, 1985; Herth, 1987, 1989; Stoner, 1982; Yancey, Gregor, & Coburn, 1994) (see Table 5).

Post-White et al. (1996) collected data on 32 adults admitted to an adult oncology/hematology inpatient unit to receive active or supportive and palliative care for cancer. Subjects were expected to survive greater than 6 months. Data were collected using semi-structured interviews: Herth Hope Scale (HHS), Spirituality Index (SI), Antonovsky’s Sense of Coherence Scale (ASCS), and a Quality of Life (QOL) tool developed by Dartmouth Department of Community and Family Medicine. Unexpectedly, hope did not correlate with
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<tr>
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<td></td>
<td>156</td>
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<td>HHS* Interpersonal Support Evaluation List</td>
<td>Yancey, Gregor, Coburn (1994)</td>
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<td>Linear Analogue Self-assessment</td>
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<td>• Religious conviction</td>
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<td>54</td>
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<td>Mishel Uncertainty Scale</td>
<td>Mishel, Hostetter, King (1987)</td>
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<td>• Seriousness of illness</td>
<td>Seriousness of Illness Scale</td>
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<td>• Control over physical function</td>
<td>Degree of Control</td>
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<td>SHS*</td>
<td>Stoner (1982)</td>
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<td>• Social support</td>
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<td></td>
<td>• Hopelessness</td>
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<td>58</td>
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<td>Social support</td>
<td>SHS* Dimensions of Social Support</td>
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|            | 32  | 29-74     | • Spiritual beliefs  
|            |     |           | • Coherence  
|            |     |           | • Quality of life |  
| Breast     | 175 | 29-89     | • Religious well-being  
|            |     |           | • Existential |  
|            |     |           | Spirituality Index  
|            |     |           | Antonovksy’s Sense of Coherence Scale  
|            |     |           | Dartmouth Quality of Life Tool  
|            |     |           | HHS*  
|            |     |           | Spiritual Well-being Scale  
|            |     |           | Feagin’s Intrinsic/Extrinsic Religious Scale  
|            |     |           | NHS*  
|            |     |           | Post-White et al. (1996)  
|            |     |           | Mickley, Soeken, & Belcher (1992)  
| **CRITICALLY ILL (1988)** |     | Stress | Hospital Stress Rating Scale | O’Malley & Menke |
| Acute Myocardial Infarction |     |          | BHS* |              |
| **Cystic Fibrosis** | 59  | Adolescents | Social support | Dibble (1986) |
|            |     |           | Norbeck Social Support Scale  
|            |     |           | Wave General Health Rating Index  
|            |     |           | Hope Scale  
|            |     |           | BHS*  
| **ELDERLY** | 126 | 60-89     | • Stressful life events  
|            |     |           | • Social support  
|            |     |           | • Personal control  
|            |     |           | • Religiosity  
|            |     |           | • Health  
|            |     |           | • Change over time |  
|            | 88  | 65-86     | • Age  
|            |     |           | • Cancer  
|            |     |           | • Noncancer |  
|            |     |           | Stressful Life Events  
|            |     |           | Social Support  
|            |     |           | BHS*  
|            |     |           | SHS*  
|            |     |           | Personal Control  
|            |     |           | Physical and Mental Health  
|            |     |           | Activities of Daily Living |  
|            |     |           | Multilevel Assessment Instrument  
|            |     |           | MHS*  
|            |     |           | Farran (1985)  
|            |     |           | Farran & McCann (1989)  
|            |     |           | McGill & Paul (1993)  |
Table 5 (continued)

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<td>Tollett &amp; Thomas (1995)</td>
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<td>Beck Depression Scale</td>
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<td>Multidimensional Hope Scale</td>
<td>Raleigh &amp; Boehm (1994)</td>
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<td>• Trait vs. state</td>
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<td>• Spirituality</td>
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<td></td>
<td></td>
<td>• Time</td>
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<td>VAS-Stress</td>
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<sup>a</sup>Beck Hopelessness Scale. <sup>b</sup>Miller Hope Scale. <sup>c</sup>Nowotny Hope Scale. <sup>d</sup>Herth Hope Scale. <sup>e</sup>Herth Hope Index. <sup>f</sup>Stoner Hope Scale
the spirituality index nor with the coherence scale. Hope did correlate with quality of life.

Overall, hope has correlated at significant levels with social support, uncertainty, religiosity/spirituality, control over physical function, level of coping, recalled life experiences, and mental and physical health. Hope has not correlated with age, gender, seriousness of illness, perceived stress, degree of illness, performance of job/role responsibilities, stressful events, or activities of daily living.

Farran and McCann (1989) developed a causal model of hope, using many of the variables that have been previously studied, including mental health, physical health, personal control, social support, religiosity, activities of daily living, and socioeconomic status at Time₁ and Time₂. Four competing models of hope were then tested using linear regression equations. The optimum hope model was a three-stage model where the best predictors of hope were mental health, religious beliefs, and social support. The authors suggest that if mental health and hope can be maintained at one time, the likelihood is greater that a person will be mentally healthier and more hopeful later.

Even with the available instruments and suggestions related to hope-instilling nursing interventions, only one study has looked at a specific nursing intervention designed to nurture hope. Tollett and Thomas (1995) randomly assigned homeless veterans to a support group that met for 4 weeks or
to a no-intervention group. Hope and self-efficacy were measured before intervention and after the 4 weeks of group meetings. In the experimental group, there were significant positive changes in hope, self-esteem, and depression and no changes in self-efficacy. For the control group, paired t-tests revealed no significant differences between pretest and posttest scores of any of the variables. The authors acknowledge that there are many other factors that might have influenced hope scores, including medications taken during the study for 50% of the subjects. However, this study is important because it represents an initial investigation of determining if a specific nursing intervention to instill hope would positively influence levels of hope. It is important to note that other positive outcomes resulted from this intervention. Individuals were less depressed, maintained employment, and felt better about themselves. How many of the "other" outcomes are directly responsible for higher hope scores is not known.

Hope outcomes. From the theoretical literature and qualitative data, "hope goals" and "hope outcomes" are identified dimensions of hope. Fowler (1995) states that "hope outcomes are very specific to the individual" (p. 229). Yet most nursing literature focuses on positive adaptation and quality of life as the outcome variable, not what the individual identifies as his or her hopes.

Unique in the literature is a study by Raleigh and Boehm (1994) who asked 42 chronically ill people "what they
hoped for." Patients were able to identify their hopes related to family, friends, health, society, self-development, and spirituality. However, in reducing comments to categories, even with this information, the individual outcome is lost. Raleigh and Boehm also noted that hope will vary from situation to situation and that there may be an underlying stable level of hope.

Hinds (1989) asked adolescent substance abusers what they hoped for, and Herth (1990) asked terminally ill adults what they hoped for. Both groups were able to identify specific goals associated with their recovery and/or illness phase. In addition, identified goals for both studies changed as their subjects progressed in their treatments.

**Hope over time.** A few hope researchers have attempted to capture the dynamic nature of hope, by evaluating hope over time and as the situation or phase of illness changes. Three studies have looked at hope over time. The first study by Hinds (1989) looked at hopefulness over time in 24 adolescents receiving inpatient treatment for substance abuse. Data were collected at 24-48 hr after admission, 4-5 days before anticipated discharge, and 4-5 weeks after discharge. A second study by Herth (1990) collected hope data on 10 adults with terminal illness at admission to a hospice program, when they could no longer complete activities of daily living, and finally when death was likely to happen within a 2-week period of time. Finally, Herth (1996) collected hope data on 10 homeless families.
Initial data collection was 72 hr of entry into a homeless shelter. Time, occurred within 3 days of the family having moved out of the shelter and, finally, 6 months after entering the homeless program. Interestingly, there were no significant differences in the level of hope in any of the studied populations. However, qualitatively hope goals did change over time. None of the authors provide explanations for the discrepancies between their qualitative and quantitative data.

The third study by Farran and McCann (1989) looked at hope over time in developing a causal model of hope; specific hope levels and changes were not reported. Raleigh and Boehm (1994) attempted to capture state/trait properties of hope by asking "how do you feel today?" and then "how do you usually feel?" State and trait forms had very high correlations, and the trait form was omitted from further analysis.

Summary of Hope Literature

Each piece of the preceding literature review adds to the knowledge base and understanding of hope. Several dimensions/properties of hope have consistently been identified theoretically and empirically. They support the following ideas about hope: (a) hope is a multidimensional and complex phenomenon, (b) hope is influenced by internal and external events, (c) hope is an emotion-related coping
process, and (d) hope is future and goal or outcome oriented.

Several factors appear to be associated with hope. They include spirituality, social support, personality characteristics, and quality of life. Regardless of age, diagnosis, or phase of the disease process, almost all patients have hope.

In addition, the findings from the hope literature demonstrate a close fit to Lazarus and Folkman's (1984) Stress Model. Advanced stage cancer is a stressor that challenges an individual. Hope is often used as a coping response to this stress. Hope in this context is influenced by internal and external factors. Nursing can nurture hope. Quality of life is the goal of positive adaptation.

Implications for Hope Research Relevant to Adults With Advanced Cancer

The review of the literature identifies several limitations associated with hope research. First, hope studies generally examine one limited perspective and the resulting descriptions are often narrow and disembodied. They do not reflect the inherent complexities of hope nor do they reflect the person’s emotional and individual experience. Second, hope is often conceptualized as a static, linear, and unidirectional emotion-related coping response that involves only an antecedent and a future outcome. Discussions about hope do not address change over
time, specific internal and external influences, or process. Finally, hope has been validated in almost all patient populations, but few hope researchers have attempted to examine or define hope in seemingly "hopeless" populations.

There is an obvious need to further explore and understand hope within the unique experiences of younger adults with advanced stage cancer.

**Purpose of the Study**

The purpose of this study is to describe the nature of hope as defined and experienced over time by hopeful adults, ages 20-59, who have an advanced stage cancer.

**Research Questions**

1. How do hopeful adults with advanced stage cancer define/describe hope?
2. What influences the presence or maintenance of hope?
3. What do adults with advanced stage cancer hope for?
4. Do high levels of hope remain constant or change over time?
5. What feelings, behaviors, and/or activities (hope strategies/patterns) reflect the presence of hope in adults with advanced stage cancer?
Definition of Terms

The terms for this dissertation are as follows:

Hope: A subtle, if not unconscious, expectation regarding an abstract but positive aspect of the future; an anticipation, accompanied by desire and expectation of a positive possible future (Stephenson, 1991).

Hopeful Adult: An individual, male or female, between the ages of 20-59 (Cole, 1992; Schuster & Ashburn, 1992) whose visual analogue scale hope scores (1-10) are 5 or greater.

Advanced Stage Cancer: An advanced, irreversible, and life-threatening cancer that is progressive and is not likely to be controlled by antineoplastic treatment with a predicted life expectancy of less than 1 year (Stoll, 1987).

Underlying Assumptions

Important in planning and implementing the following research plan are the following assumptions about hope and the role hope plays in the advanced stage cancer experience: first, hope is considered a positive and desired emotional coping response that aids in positive adaptation; second, a dignified and respectful death is considered a positive adaptive outcome for the patient with advanced stage cancer; third, others can influence hope positively; fourth, some qualities of hope can be observed, described, and evaluated; fifth, qualities associated with individuals perceived as
having hope may help to understand and plan nursing care for those who are perceived as having less hope.

The following research plan guided by Lazarus and Folkman’s conceptual model as well as the literature review combines a variety of research methodologies in a manner that can best generate descriptions of the complex phenomenon of hope over time in adults with advanced stage cancer.

... and the bird, out of my hands, starts to fly

Without hesitation, it flies straight

As if the miracle had happened,
Into the hot bright heart of the fire.
CHAPTER III

METHODOLOGY

Research Design

A descriptive, longitudinal research design was used to generate descriptions and definitions of hope over time as experienced by hopeful adults, ages 20-59, with advanced stage cancer. The purpose of descriptive research is to clarify concepts and generate relationships by asking “how” and “what” questions within the context of the phenomenon (Diers, 1979). Longitudinal designs provide information on direction and shape of change and relatedness of earlier responses with later responses (Hinds, 1989).

Sample

Twelve subjects made up the final convenience sample of individuals who were identified as having “hope.” Hopeful individual’s were used in order to increase the likelihood that multiple realities of hope would be uncovered (Burns & Grove, 1993; Lincoln & Guba, 1985). It was important to identify qualities and factors--personal and environmental--that increase the likelihood of describing hope. In addition, individuals who are negative, depressed, or in
denial, in all likelihood, would not be willing to participate in a study about hope. Although their contributions may be valuable and important for future research, it is this “hopeful” population who are more likely to be willing to try to benefit from hope-nurturing interventions initially.

Final sample size and composition were determined by data saturation (Lincoln & Guba, 1985; Sandelowski, Davis, & Harris, 1989). There was a saturation of ideas and themes fairly early relating to general definitions of hope, influences of hope, and outcomes of hope among subjects. Specific examples and new ideas about hope continued to be shared as did clarification of discovered ideas. Because of the consistent answers about hope and behaviors reflecting hope between subjects, confident descriptions and conclusions about hope emerged.

Procedure

At an early stage in the research process, a proposal of the planned study was reviewed and approved by the Institutional Review Board at the University of Utah. Hospice home care agencies, outpatient cancer treatment centers, and oncology-related physician/nurse practices in Northern Utah and Central Washington were then contacted for referrals. Formal permission was granted by review boards of each agency or individual practitioners or both. Three subjects were referred by other study participants.
Contacts at all agencies were nurses. Initially, a desired level of hope in subjects was not stipulated; however, over the course of the study it became apparent that the contacts consistently referred individuals with high levels of hope. This was confirmed by high hope scores on the Stoner Hope Scale (SHS) and the Visual Analogue Scale-Hope (VAS-H) as well as two of the contacts saying they had "a person who would be great for the study, because they had so much hope." The nurses approached potential subjects and asked if they would be interested in participating in the study. Permission was then received to give out their telephone numbers and names to the researcher. Once a referral was made by the agency, practitioners, or study participants, the potential subject was contacted by phone. The study’s purpose and procedures were explained, and the individual was asked if he or she would be willing to participate in the study. Any questions were then answered about the study, and an appointment for the initial visit was made.

Of the 16 subjects referred, 2 did not want to be interviewed, stating they were tired of talking about their cancers. Two subjects completed the initial interview but, due to their "curable" cancers, did not meet the study's criteria.

Subjects were interviewed at their homes. Three interviews took place once a month over 3 consecutive months. The actual time between interviews ranged from 17
days to 65 days with a mean (\(\bar{x}\)) of 39 days. The time interval was often determined by the subjects' health status or other activities. Those receiving palliative care were seen at shorter time intervals (\(\bar{x} = 30\) days) because of their rapid physical deterioration and physical changes. Those who were more stable averaged 45 days between interviews. Those who were more stable were often involved with other activities or holidays that required working around their schedules.

During the initial interview, an informed consent was signed and a copy of the consent was given to the subject (see Appendix A), and demographics were gathered and medical history was taken (see Appendix B). Demographics included personal information such as family background, education, religious/spiritual beliefs, personal interests and hobbies, social support, and professional and educational background. Medical history included general health, diagnosis and treatment of cancer, and current health status.

Each visit included a tape-recorded semistructured interview (see Appendix C) with unobtrusive participant observation. Each taped interview lasted approximately 1 hr. After each interview the SHS and Ferrans and Power's Quality of Life Index (QLI) were left with the subjects with a stamped, addressed envelope to be completed at their convenience (see Appendices D and E). The subjects were also asked to complete visual analogue scales for pain (VAS-P), hope (VAS-H), and quality of life (VAS-QOL; see Appendix F).
Ten subjects completed all three interviews and VAS. One subject completed two interviews and VAS, and 1 subject completed only one interview and VAS. Both died before the next interview could take place (see Table 6). Their interviews and VAS scores are included in all the data analysis. Twenty-six (79%) QLI and 25 (75%) SHS of the 33 questionnaires were returned and analyzed. Reasons for not completing the eight questionnaires included “too sick” (n = 4), “I forgot” (n = 1), and “my answers haven’t changed since the last time” (n = 3).

Data Collection and Analysis Techniques

Hope is a complex and multidimensional phenomenon that cannot be measured by one instrument or limited to one data collection technique (Breckler, 1996). Qualitative techniques are important for generating rich descriptions and providing individual experiences as well as examples of hope. In addition, quantitative tools were used to provide an additional type of descriptive data to be used to further describe, explain, or clarify the qualitative material.

The following techniques and tools were selected because of their congruent theoretical definitions with the study’s conceptual framework and ability to elicit answers and descriptions that reflect each research question.

The quantitative and qualitative data were initially analyzed separately according to its own accepted principles and rules (Mitchell, 1986). Data were then reviewed and
Table 6

Completed Data Sets

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<tr>
<td>1x</td>
<td>2/3</td>
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</tr>
<tr>
<td>Total SHS / QLI</td>
<td></td>
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<td>25/26</td>
</tr>
</tbody>
</table>

VAS = Visual Analogue Scale  
SHS = Stoner Hope Scale  
QLI = Quality of Life Index
analyzed with regard to each research question for complementary and consistent data descriptions as well as variations or outliers.

**Qualitative Data Collection and Analysis**

Qualitative data collection techniques included semistructured interviews and participant observation. Interviews and observations generated well-grounded, rich descriptions and explanations of hope and hope-related qualities as they occurred within the experience of advanced stage cancer. Words, especially when they are organized into incidents or stories, have a concrete, vivid, and meaningful flavor (Miles & Huberman, 1994).

**Semistructured interview.** The semistructured monthly interview guide included open-ended questions designed to elicit descriptions and definitions of hope (qualitative), influences (antecedents and mediating factors) of hope, and hope outcomes, as well as questions about their current health and treatments, social support, psychological needs, activities, and planned events. Question areas were initially developed from the conceptual framework and the literature. The monthly question schedule between subjects remained the same. However, the substance, depth, and direction of each monthly interview varied depending on the subjects' physical health, responses, and previous data gathered. As the study progressed, subjects were asked to
elaborate and clarify previously collected research data and validate the study's conclusions (Sandelowski et al., 1989).

**Participant observation.** During the interview, artifacts, activities, and behaviors that reflected or symbolized a hope-related process or a completed hope-related product were recorded. Products of human activity provide important research data (Jorgensen, 1989). Examples included planning vacations, preparing for family visits, cooking special meals for family members, and continuing to be involved with hobbies and groups. Each activity was described within a context, its significance was explained, and a brief content summary was tape recorded immediately following each interview (Miles & Huberman, 1994).

**Qualitative data analysis.** Each taped interview, including the participant observations, was transcribed verbatim into a WordPerfect 5.1 format immediately following the interview. Each tape was then reviewed and compared to the typed transcript for accuracy, mood, and context. The transcripts were then edited for spelling, terms, and irrelevant information (e.g., the process used to register sheep dogs). Transcripts were then entered into Ethnograph', a computer program that allows text to be coded into segments that can be retrieved by common codes or combinations of codes.

According to Miles and Huberman (1994), ongoing analysis consists of three current flows of activity: data reduction, data display, and conclusion drawing and
verification. It is important to note that the process is ongoing and takes place simultaneously.

Data reduction refers to the processes of selecting, focusing, simplifying, and transforming the "raw" narrative data and participant observations (Miles & Huberman, 1994). The primary method used to reduce the data was "coding." Codes are tags or labels used to assign units of meaning to the descriptive information. Initially, first-level codes were defined based on specific research questions, the conceptual framework, and specific interview questions. These included definitions and descriptions of hope, influences of hope, goals or outcomes of hope, and changes of hope over time (see Table 7). Some data had more than one code. Questions relating to age, their reason for participating in the study, and suggestions for health care workers were similarly coded.

Ideally, coding takes place immediately after the interview; however, for this study, narratives were coded in blocks of four or five at a time. Each block of newly coded data was then reviewed with previously coded data and compared for consistency.

As coded information was analyzed and compared and tentative conclusions made, questions about meanings or a need to clarify or explain similar or different ideas would emerge. These "questions" would then be taken back either in a following interview to the same subject or, more often, to another one of the subjects to either validate the
Table 7

First- and Second-Level Codes

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<tr>
<th>Definition/Qualities</th>
<th>Influences</th>
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<tr>
<td>• future-related</td>
<td>• physical symptoms</td>
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<td>• religious themes</td>
<td>• others</td>
</tr>
<tr>
<td>• abstract</td>
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<tr>
<td>• positive feelings</td>
<td>• personal qualities</td>
</tr>
<tr>
<td>• not hopeless</td>
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<td>• physical being</td>
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<table>
<thead>
<tr>
<th>Outcomes</th>
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<td>• likelihood of achieving goal</td>
</tr>
<tr>
<td>• health goals</td>
<td>• stable versus dynamic</td>
</tr>
<tr>
<td>• interpersonal activities</td>
<td>• goals</td>
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conclusions or to clarify meanings or relationships. Under the code "influences," 2 of the study participants said that their support group influenced their hope positively. Another subject said that she was not involved with any groups. She was asked why she did not attend any groups, and her perspective was added to the understanding of support groups and hope.

As more transcripts were coded and reviewed and data compared, a second level of codes or pattern codes was developed within the first level of coding (see Table 7; Miles & Huberman, 1994). In addition, differences in
responses began to be noticed between those individuals receiving palliative care and those receiving active treatment. This became especially apparent in the segment codes relating to outcomes and goals of hope. As a consequence, the already coded data were reviewed again, consciously comparing the data between the two groups.

This ongoing search for descriptions and themes in the narrative allowed for discovery of commonalities across subjects, as well as a search for natural variation in the data. Recognition of the differences results in appreciation of individual meaning (Mitchell, 1986).

Finally, when all transcripts had been coded (n = 33) and subthemes identified, a data matrix was developed that compared second-level codes within each research question. Several similar themes and subthemes were present in more than one area, such as spirituality, others, and personal characteristics. At this point, all transcripts were reviewed again to find examples and activities that reflected these patterns, as well as natural variations or explanations or both for already coded data. Analysis and coding became very challenging. It was important to discriminate between those activities and behaviors that related to hope versus those activities and behaviors that related to other but similar or related responses. After chemotherapy a subject may have felt tired and unmotivated but did not feel less hopeful. Yet another subject specifically stated that how she felt physically after her
treatment directly influenced her hope. Having problems with
the insurance company was frustrating but did not really
impact hope per se. It became important to evaluate the
comments in context and in comparison to similar data.

To validate these coding conclusions, two doctorally
prepared nurses familiar with qualitative analysis and
coding techniques were asked to review four transcripts for
the predefined first- and second-level codes. There were an
85% agreement and a 90% agreement between coders and
researcher.

Quantitative Data Collection Techniques

Quantitative tools include the SHS (Stoner, 1982),
QLI (Ferrans & Powers, 1985), and VAS-P, VAS-H, and VAS-QOL.
The numbers and scores from these scales provide valuable
descriptive information about "how much" hope or pain is
present over time and provide numerical values that allow
for trends and loose associations to be observed between
hope and factors such as pain, age, phase of illness, and
quality of life factors. These scores provide a numerical
descriptor that captures another dimension of hope.

Stoner Hope Scale (SHS). The SHS is a 20-item scale
that was designed by Stoner (1982) to measure importance and
probability of attainment of future-oriented goals.
"Importance" is the motivation to achieve future oriented
goals, and "probability" is the likelihood of attaining
those goals (Stotland, 1969). The scale items were developed
from the hope literature and in consultation with oncology and psychiatric clinical specialists (Stoner, 1982). The items reflect three domains of hope: intrapersonal, interpersonal, and global (Dufault, 1981; Lynch, 1965; Marcel, 1962; Stotland, 1969).

Intrapersonal hope is founded on interior resources and beliefs. Although intrapersonal hope may be influenced by external stimuli, hope arises from within the person and is not dependent on transaction with another being. An example of an item within the intrapersonal domains is: "To overcome fears that I have."

Interpersonal hope extends beyond the self and is dependent on transactions with external resources. Thus, interpersonal hope occurs because of the connection between individuals. An example of an item in the interpersonal hope domain is: "To have people seek me out as a friend."

Global hope refers to the broad scope of issues and concerns important to people in a general sense. Global hope goes beyond the person to the sphere of involvement. An item example of global hope is: "To see an end to the threat of nuclear war."

The response sets for both the importance and probability sections use a 4-point Likert-type scale. The SHS is scored by multiplying the importance score by the probability score for each item (goal). These products are then summed to yield subscale scores (intrapersonal, interpersonal, and global) as well as a total hope score.
In a descriptive correlational study of hope and cancer patients (Stoner & Keampfer, 1985), the SHS was used to collect data from 58 adult Caucasians who had cancer and were cognizant of their diagnoses. The reliability and validity of the SHS were evaluated with this sample. Criterion-related concurrent validity was used to estimate the relationship between the SHS and the Beck Hopelessness Scale (BHS) (Beck et al., 1974) as a measure of the same construct. The BHS has been used extensively, and the reported psychometric properties are acceptable. Moderate concurrent validity was demonstrated by the negative correlation ($r = -0.47$, $p < .01$) between the SHS and the BHS. A high degree of internal consistency of the SHS was demonstrated by the obtained Cronbach’s alpha coefficient of .93. For this study Cronbach’s alpha coefficient for the Total Hope Scale scores was .84.

The SHS was selected for several reasons. First, the three domains of hope--interpersonal, intrapersonal, and global--are consistent and complement Lazarus and Folkman’s (1984) schematization of mediating factors that include person and environment. SHS also evaluates the probability of achieving these goals, an important hope quality identified by Stotland (1969). SHS factors in “importance” of achieving a specific goal. Third, there is a belief that as an individual comes closer to death, he or she becomes more introverted. Changes in interpersonal (increasing) and global (decreasing) should be noted over time. Fourth, the
total hope score provides a numerical degree of the presence of hope. Finally, the scale was developed in consultation with oncology nurse specialists. An important goal of this study is to evaluate hope tools for assessment of hope in clinical practice.

Quality of Life Index (QLI). QLI, developed by Ferrans and Powers (1985), assesses quality of life in healthy individuals as well as those who are experiencing an illness. Thirty-five items, using a Likert scale, assess the importance and satisfaction of various dimensions associated with quality of life. These dimensions include life goals, general life satisfaction, perceived stress, and physical health. Satisfaction scores for each item are weighted by subjective importance of each item, yielding an overall quality-of-life score. Sample items include “How satisfied are you with your health?” and “How important is your health to you?”

There are many quality-of-life instruments available. The QLI was selected for several reasons. First, it conceptualizes quality of life as being multidimensional. QLI subscales are consistent with this study’s conceptual framework that the outcomes of coping include positive and negative adaptation related to physiological, psychological, and social factors. This instrument is unique in that it measures satisfaction and importance of each dimension. Second, the QLI also has strong psychometric properties.
(Cella & Tulsky, 1990; Frank-Stromborg, 1988). Finally, the QLI is an easily administered single instrument.

Psychometric properties of the QLI were completed on a healthy population of 69 graduate students, 20 dialysis patients (Ferrans & Powers, 1985), and 349 hemodialysis patients (Ferrans & Powers, 1992). Test-retest reliability coefficients of the graduate students at a 2-week interval and the 20 dialysis patients at a 1-month interval were 0.87 and 0.81, respectively. Internal consistency reliability of the entire QLI was 0.93. Students and dialysis patients were asked to rate their overall satisfaction with life using the QLI and a 6-point rating scale. Criterion-related validity was 0.75 and 0.77, respectively. Convergent validity between the QLI and an assessment of life satisfaction scores provided a strong correlation of .77. Construct validity using factor analysis found four underlying dimensions for the QLI: health and functions, socioeconomic, psychologic/spiritual, and family. Cronbach's alpha coefficient for Total Quality of Life Index scores for this study was .91.

Visual Analogue Scales: Hope, Pain, and Quality of Life (VAS-H, VAS-P, VAS-QOL). Three VAS were used as single subjective measurements of hope (VAS-H), pain (VAS-P), and quality of life (VAS-QOL). A VAS is a 100-mm horizontal line with right angle “stops.” Verbal unipolar anchors at either end represent a continuum of intensity (McGuire, 1984; Scott & Huskisson, 1976). Interval level data are obtained by
measuring the distance, usually in millimeters, from one end of the scale to the subject's mark on the line (Wewer & Lowe, 1990).

This method is capable of quantifying self-reported conditions, determining intrasubject changes, and facilitating intersubject comparisons (Hinds & Stoker, 1988). The VAS is useful for measuring a variety of subjective phenomena and has been used in pain (McGuire, 1988) and mood-related research (Priestman & Baum, 1976; Wewer & Lowe, 1990).

For the most part, the VAS is considered to be a reliable and valid measurement tool (McGuire, 1984; Wewer & Lowe, 1990). Reliability data regarding the VAS are somewhat varied and conflicting due to the obvious limitations of a single instrument attempting to measure a multidimensional phenomenon (Hinds & Stoker, 1988). However, results in comparative studies using other measures indicate that the VAS is useful in measuring overall subjective assessments and correlates well with patients' clinical status (Priestman & Baum, 1976). Horizontal VAS have been shown to produce more uniform distributions, are more sensitive to perceived feelings, and are easier to use when compared to other scales (Hinds & Stoker, 1988; Scott & Huskisson, 1976).

The VAS-P has been used frequently in cancer/pain studies and has correlated highly with the visual descriptive scales, verbal pain relief scales, and diary
format (Ahles, Ruckdeschel, & Blanchard, 1984; Littman, Walker, & Schneider, 1985), the McGill Pain Questionnaire (McGuire, 1984), and the numerical rating scale (Downie, Leatham, & Rhind, 1978). The VAS, when compared to a 4-point Likert scale to measure intensity of pain, was better able to detect the effects of medicine, had statistically less missing data, and the majority of participants expressed a preference for the VAS (McGuire, 1988).

The three VAS were selected for several reasons. First, the VAS-H and VAS-QOL scores were correlated to the SHS and QLI total scores for criterion validity and for within method triangulation. For this study, the VAS-H total scores at Time₁, Time₂, and Time₃ did not correlate highly with the SHS; however, the VAS-QOL and the QLI did have significant correlations at the >.05 levels at Time₁ and Time₃. Second, VAS scores provided numerical descriptors that could be evaluated as they related to hope and hope qualities. Third, VAS-H provided a numerical value to quantify the individual's perception of the amount of hope they had. Finally, VAS as a clinical assessment tool was evaluated. Overall, VAS are convenient, easy to administer and score, and are reliable and valid (Cline, Herman, Shaw, & Morton, 1992). For this study, there was a 100% completion of all VAS as compared to a 79% completion rate for the questionnaires. By having such a high completion rate, VAS maximizes the amount of data collected (Wewer & Lowe, 1990; see Appendix F).
Quantitative data analysis. Demographic, scale, and subscale scores from the VAS, SHS, and QLI were entered into the statistical program Crunch4™. Nonparametric statistics were used due to the small sample size and lack of variability within the sample. Scores were generated using descriptive, Kendal Tau correlational statistics and Wilcoxon matched-pairs signed-ranks tests.

Descriptive statistics were run on demographic variables including age, sex, phase of illness: active therapy or palliative care, SHS, QLI, and VAS scores. Hope scores and mean hope scores provided a numerical descriptor of hope. Comparisons of mean scores ($\bar{x}$), ranges of scores ($R$), and standard deviations (SD) provided numerical descriptions that were used to compare phase of illness and age groups (<50 vs. ≥50) to other variable means. Mean scores and standard deviations are valuable with such a small sample size to evaluate trends and loose associations.

Kendall Tau correlational statistics were run on variables that had been identified by the literature and the conceptual framework as having possible relationships with hope as measured by SHS total and subtotal scores and VAS-H. Those variables included pain, age, phase of illness categories, QLI total and subscale scores, and VAS-QOL. Data from these correlations are important in evaluating trends and loose associations of factors that may influence hope. However, any conclusions drawn from these data are limited due to the small and homogeneous sample.
The total hope scores provided a numerical degree of the presence of hope that was then compared to VAS-H, quality of life, and pain scores as a means of evaluating the influences of hope. The subscale scores also provided valuable information relating to the nature and outcomes of the individual's hope over time. It was hypothesized that subscale scores may change over time, but the total hope score would remain the same.

The QLI scores were used primarily as a means to assess hope outcomes. The subscale scores were also used to help clarify, validate, or explain qualitative data results relating to health, spirituality, and social support (see Appendix D).

VAS-P scores were correlated to the SHS and QLI scores. This information provided information regarding pain as an influence of hope.

Wilcoxon matched-pairs signed-rank tests were done on hope scores at Time1 and Time3 in an effort to capture hope changing over time. Scores were initially evaluated as a collective. Palliative versus active treatment groups scores were also compared.

Individual questionnaire scores were also evaluated. Scores were compared to previous individual scores. The data from these scores help to answer the research questions related to the nature of individual hope, patterns of hope, hope goals, and temporal qualities of hope. Subscale scores provided important information as to how individuals'
perceptions and coping responses change with the dying experience. Specific subscale items were used as individual descriptive data that helped explain individual comments over time. Items were used to complement qualitative findings. Finally, SHS items provided a means of organizing the qualitative data. The qualitative data provided narratives or examples of individual subscale items.

It is recognized that any conclusions based on these statistical tests are limited due to the small sample size (Munro, Vistintainer, & Page, 1986). Testing relationships, refuting null hypotheses, and finding statistical significance between variables were not the goal or purpose of this research project. The purpose was to generate descriptions of hope in hopeful adults with advanced stage cancer.

Quantitative and qualitative analysis. The analysis of data generated by multiple methods is challenging (Mitchell, 1986). Results of the two approaches were reviewed and analyzed for complementary and consistent data descriptions as well as examined for emerging universal or shared descriptions and definitions of hope. The integration of both data sets resulted in a more comprehensive conceptual understanding of hope (Mitchell, 1986) and produced greater credibility for the hope-related findings (Hinds, 1989).

Initially, all qualitative and quantitative data were looked at and analyzed as a collective. However, in addressing several of the research questions, the
differences as well as similarities between the people receiving palliative care versus those receiving active treatment were noted. Individual responses were also evaluated and reported with other findings.

Verification of Findings

Final conclusions for verification were taken back to the subjects through two mechanisms. First, a summary of the research findings, definition of hope, the analogy of hope to a heartbeat, categories of qualities of hope, influences of hope, and hope outcomes and goals were taken back to 2 of the participants: Molly and Maggie. Both subjects agreed with the overall definition of hope but felt it was too general. Both subjects liked the analogy of hope to a heartbeat, stating that it helped to understand and explain the complexity of hope.

Molly reinforced the idea that individuals go through different phases and as such had very different hope needs at different times. She sensed that change now because she was feeling better and appeared to be in remission. Not only were the people around her seeming to be different, but she felt more removed from her cancer. Maggie was surprised that it was not apparent that more individuals were involved in political and community activities. Both were pleased that spiritual beliefs were such an important part to this population's hope.
Study results were also verified when one of the subjects asked that the findings of this study be shared with her breast cancer support group. After the presentation, all members of the support group were asked for their feedback and comments about hope and the findings presented. Overall, they agreed that hope was an individual thing that changed according to how they felt and was influenced by the people around them. There was a great deal of discussion about lack of resources available to cancer patients while they were receiving chemotherapy. It was also noted during this discussion that many of the members, including 2 subjects who had participated in the study, were involved with public cancer awareness events and political activities.

Study Issues

Sensitive Topic and Vulnerable Population

Interviewing individuals with an advanced stage cancer is a highly sensitive, personal topic and experience (Burns & Grove, 1993). In contacting subjects initially, the purpose of this study was described in the initial communiqué as wanting to examine "hope" in individuals who are experiencing a "potentially life-threatening" illness. As the interviews developed, the questions and discussions focused on hope, not terminal illness, cancer, or dying.
Seriously ill individuals are a vulnerable population physically and emotionally (Burns & Grove, 1993). Subjects' privacy, confidentiality, and personal needs were acknowledged and protected. Mechanisms to ensure this included a review of the research plan by the University of Utah Institutional Review Board; signed informed and voluntary consent, the right to refuse to participate at any time; insured privacy and confidentiality; a personal copy of tapes if desired; and, finally, flexibility and adaptability in the research protocol to allow for individual needs. Tapes are locked in a fireproof box and will eventually be destroyed. Narratives are identified by initial or first name only. One individual asked to be referred to by her given name, not her common name. This request was granted.

The potential for psychological consequences is subtle and requires critical attention and sensitivity. The research process and interviews were structured to ensure psychological and physiological well-being. Building and maintaining trust included keeping appointments, staying within time frames, being flexible with schedule changes, and adapting to the personal needs of the study participant. All of the individuals in this study, like populations in other cancer research studies, were willing to talk about their experience and appreciated the opportunity to do so (Kubler-Ross, 1969; O'Connor, Wicker, & Germino, 1995). One
participant asked that the results be presented at her breast cancer support group.

Role as Researcher

In qualitative research, the researcher is an important and active participant in the process (Burns & Grove, 1993). There are several personal and research-related issues surrounding the researcher as data collector, participant, and evaluator of a highly personal, emotional topic and vulnerable population.

As a researcher, I brought to this study many years of critical care, academic, and nursing research experience. The interest in hope and terminally ill adults developed primarily from three past experiences. The first involved the death of an uncle. Richard was 37 years old, a nuclear physicist, and father of five. He died 2 weeks after being diagnosed with a rapidly occurring leukemia. The second involved a patient, Ron. He was 43 years old, a bank vice president, a father of four, and grandfather of one. He died approximately 1 year after being diagnosed with cardiomyopathy. The final experience involved a friend, Paul. He was 35 years old and a lawyer. He died 3 weeks after being diagnosed with pneumonia associated with AIDS. Their sadness and loneliness are easily called to mind and heart but so are their hopes and their humor.

Both past and present formal and informal experiences created a caring, empathetic, and professional researcher,
listener, and individual. However, it was unrealistic and inhuman to expect a completely objective, detached, clinical research demeanor with the research subjects. Some form of personal attachment did take place by nature of the experience. One subject was diagnosed with inflammatory breast disease in her 3rd month of pregnancy. Her baby’s due date was the same as my baby’s due date (her baby is now 1 year old). Her baby was delivered by C-section a month earlier. It was easy to relate to sleepless nights and unpredictable schedules of a new mother. One subject is a nurse. We knew many of the same people and often shared nursing philosophies and ideas about health care. This was all done in the context of a professional relationship.

As expected, there were times my role included some nursing care and teaching, therapeutic communication, and listening. One patient had a deep vein thrombosis, and his wife was concerned. I looked at the leg, helped put on a support hose, and suggested that their home health nurse be notified. On several occasions I helped people move or turn, or I would go to another room for something they needed. Oftentimes, I listened to their spouses and family members. Their comments are not included, but being available to them seemed important in maintaining a trusting relationship. I was very willing to help, and there never seemed to be a conflict or confusion as to my role as researcher.

It had been anticipated that the interviewing process would be negative, emotionally draining, and challenging.
For the most part, this did not happen. Perhaps as a consequence of the "hopefulness" of the group, the interviews were very positive and uplifting. There was an incredible amount of resiliency and positiveness expressed and witnessed in all homes and situations. Tears were also shed, and although there were times that I came away feeling sad or wanting to do something more, more often I came away feeling that anything is possible and that nurses have a very important role in helping this population maintain their hopes and achieve their hope goals. It also helped that data collection took place over 2 years. Interviews were spread out, and an emotional balance was maintained.

Benefit to the Subjects

This research study is important not only to society as a whole but to the individuals who participated in the study. The therapeutic value the interview had on the subject cannot be underestimated. Agreeing to participate in this research study is recognized as a positive and hope-related activity associated with the cancer experience. Recent evidence suggests that patients want to talk over their feelings and experiences with others in order to find their meaning (Mishel & Braden, 1987; Saunders & McCorkle, 1987). Often, family and friends involved with the terminally ill adult are not comfortable with death and dying and, as a consequence, are not able or willing to converse. Being interviewed not only allowed the individuals
to talk about their experiences, but for many they saw it as an opportunity to leave something of themselves, to contribute to society (Burns & Grove, 1993).
CHAPTER IV

STUDY RESULTS

Demographics

Characteristics of the Sample

Of the 2 men and 10 women who participated in the study, all were Caucasian, 6 lived in central Washington, and 6 lived in northern Utah. The mean age was 48.7; the range was from 29-59. All were married and living with their spouses except for 1 who was divorced and living with a daughter. For 5 subjects, this was a second marriage with 1 subject having been married less than 1 year when diagnosed with metastatic breast cancer. All had children, 5 had grown children with grandchildren, 3 had single, independent college-aged children living away from home, 3 had teenagers, and 1 had a 3-year-old and a 9-month-old (see Table 8).

All but 1 subject had completed high school; half had some post-high school education. All except 2 were employed at the time of their cancer diagnoses, and these 2 women had stayed at home to raise their children. At the time of the interviews, only 1 was working full-time and 1 was working 25% time. All stated they had strong spiritual beliefs,
### Table 8

**Demographic Data**

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</table>

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having been or were currently involved in organized church
groups, including Mormon (4), Protestant (4), and Catholic
(1). Three did not identify with a specific religious group
(see Table 8).

All subjects were diagnosed with a cancer that carried
a predictable fast and fatal course (see Table 9). Subjects
represented two different stages of the cancer experience.

Table 9

<table>
<thead>
<tr>
<th>Diagnosis and Treatment</th>
<th>n</th>
<th>%</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Palliative</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Metastatic breast cancer</td>
<td>3</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Brain (both male)</td>
<td>2</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Liver/pancreas</td>
<td>1</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td><strong>Active Treatment</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breast with node involvement</td>
<td>2</td>
<td>33</td>
<td></td>
</tr>
<tr>
<td>Inflammatory breast disease</td>
<td>1</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Ovarian</td>
<td>1</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Neck</td>
<td>1</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Bone</td>
<td>1</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>12</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Half (n = 6) of the participants were in the terminal stage of their cancers, having been diagnosed less than 12 months, and were receiving palliative care only. Five subjects had been diagnosed less than 6 months and were receiving aggressive chemotherapies or radiation or both designed to either slow down the progression of the disease or to put them in remission. Of this "active therapy" group, 2 had had stem cell transplants, 2 were considering stem cell transplants, and 1 was anticipating more surgery. Another subject included in the active therapy group had completed all treatments, but her carcinoembryonic antigen (CEA) values were continuing to rise. Diagnostic tests were being run to identify the cause.

**Individual profiles.** Interviewing 12 subjects over time permitted an in-depth and personal knowledge of the individual as well as obtaining rich, personal descriptions and information about hope. Knowledge of the individual helps the reader to understand their experiences and meanings. The following paragraphs include demographic information as well as self-descriptions about their physical, spiritual, emotional, and social beings. Those with (*) are receiving palliative care only. All others are receiving active treatment. Subjects gave permission to use first name or initials only in reporting their responses.

*Marisha (MJ) is 55. She has metastatic breast cancer and is bedridden. She is in a great deal of pain but does not want to be sedated with morphine. She has 8 children;
the youngest daughter is 16 and is still at home. Each night, her daughter sleeps on the floor by her mother and they talk about life. Marisha believes that nurses need to "listen to the Lord" when taking care of patients. Marisha loves flowers. She describes herself in the following way: (a) physically: "I've never been in good health. I don't feel good at all now"; (b) emotionally: "I'm very positive and I'm full of faith"; (c) spiritually: "The reason I am full of hope and joy is because I believe in Christ"; and (d) socially: "I'm very outgoing, but I don't go out--I've always had lots of people come to me."

*Michael (MP) is 38. He had just moved his family to Utah from California when he first noticed blurred vision and was then diagnosed with astrocytoma. He has severe headaches and is paralyzed on one side. His hospital bed is in the center of the family room. He has three children ranging in age from 8 to 14. He and his wife bought three gold rings, one for each child, to be given to them when they reach age 16. Each ring is engraved on the inside with "always your Dad." Michael wants all nurses to know that it is "O.K." to die. Michael loves the outdoors, camping, fishing, and boating. Michael describes himself in the following way: (a) physically: "Not very good. I have a headache that never quite goes away"; (b) emotionally: "Considering everything, actually I think I'm doing real well"; (c) spiritually: "I feel very good about the spiritual aspects of the things. We are both very close to
the Lord”; and (d) socially: “I’ve made some real good friends since I’ve moved here.”

Maurene (ML) is 52. She has ovarian cancer with liver metastasis. The first interview was in her living room, the second in her hospital bed. She was planning her funeral and deciding what music would provide the most peace to those attending her funeral. She died before the third interview.

Maurene describes herself in the following way:
(a) physically: “This body is getting out of hand”; (b) emotionally: “I’m sturdy emotionally”; (c) spiritually: “I know I am a child of the angels that have helped me and my life, and I feel like Heavenly Father has a plan for me and there is a certain mission I’m getting ready to do”; and (d) socially: “I’m a people oriented person but don’t like crowds. I’m good when I’m one to one.”

Murial (MG) is 54. She has stage 3 breast cancer and had a stem cell transplant at the University of Washington during the interview process. She lost her “humor bug” while hospitalized but got it back as soon as she was back home. Her two “kitties” get her up in the morning. She makes dolls for a living and collects clowns. Murial describes herself in the following way: (a) physically: “Right now I’m feeling pretty good and my energy is coming back”; (b) emotionally: “I feel a little bit in limbo, but making a go of it”; (c) spiritually: “There is a higher being, but I don’t have any religious beliefs”; and (d) socially: “I am a loner. I
can socialize or I can be by myself. It doesn’t make a heck of a lot of difference.”

*Alden (AR) is 59 and is also called “Punch.” He and his wife had just put a down payment on a house on the Oregon coast when he was diagnosed with a fast-growing brain tumor. He was going to retire next year. His passion is model trains. His sons installed special cabinets for him to display his extensive train collection. His love is a 3-year-old granddaughter named Nicki. Alden describes himself in the following way: (a) physically: “Not feeling good, not too much stamina”; (b) emotionally: “I’m not a mad getter, I’m an independent person. I have ups and downs”; (c) spiritually: “Strong, that belief is right there” (pointing to his heart); and (d) socially: “A homebody.”

Margaret (MC) is 48. She has adenocystic carcinoma. She was slow to be diagnosed because of the atypical symptoms. She has three teenage sons, ages 12, 15, and 17. She worries about Davey, the middle one, because he is so sensitive. She enjoys making costumes and has discovered that “Snelgrove’s Canadian vanilla ice cream in root beer” is the best medicine for a “very sore mouth.” She agreed to participate in this study because “I like to hear myself talk and I have a lot to offer.” Margaret describes herself in the following way: (a) physically: “Getting better”; (b) emotionally: “Pretty confident and upbeat, but I think that’s pretty fragile”; (c) spiritually: “If I didn’t believe in God, if I didn’t know that He’d take care of me I would be a wreck”;

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and (d) socially: "A page and a half of my day planner has names and phone numbers of friends, that on any given day, I could call and find somebody to . . . help me."

Molly (MK) is 44. She has cancer of the bone. Eight years earlier she had been treated "successfully" for breast cancer. A 60s hippie, she is now a nurse and a mother of two sons, one in college and one a junior in high school. Her bargain with God is to "stay around until my teenager graduates." Her passion is clogging (dancing), and she rearranges her chemotherapy schedules to accommodate her weekly classes. She describes herself in the following way: (a) physically: "Pretty good for somebody who is terminal. I have to pace myself a whole lot more"; (b) emotionally: "I'm going to live every day. I don't know how many days I have, not necessarily to the fullest . . . cuz I still get caught up in the . . . laundry and bills"; (c) spiritually: "I'm a firm, firm, firm believer in God and Jesus and the whole ball of wax"; and (d) socially: "I'm a professional lunch date. I'm still involved with the choir, dancing, and church."

Pat (PB) is 50. She is divorced and moved from California to Washington to be closer to her daughter after she was diagnosed with ovarian cancer. Philosophically, she is very much into naturalist healing and meditation. It has been a struggle to balance traditional Western medicine with her nontraditional view of body-mind-spirit. She believes it is "O.K. to cover all of your bases." Pat describes herself
in the following way: (a) physically: "I feel strong because I’m able to tolerate what I’m going through"; (b) emotionally: "I’m happier--this is going to sound weird--I’m happier now than I’ve ever been in my life"; (c) spiritually: "I believe I’m a spiritual being having a physical existence on this earth"; and (d) socially: "I can be a real isolationist. I have to work hard at making myself stay in a social situation."

Maggie (MT) is 55. She has three grown children and has been married to her husband since she was 14 years old. When she was diagnosed with breast cancer, they found 19 out of 23 of the lymph nodes involved. She has completed chemotherapy and a stem cell transplant. Her oncologist has told her she has active cancer because her CEA’s are elevated, but they cannot find anything. She is working full time and hula dances once a week. Maggie describes herself in the following way: (a) physically: "I still have a low energy level. I don’t have any reserve"; (b) emotionally: "I have a lot of joys and I have a lot of neat things happen to me, and I get angry too"; (c) spiritually: "I walk pretty close to God. I know that there is something more and that I’m not going to walk it alone"; and (d) socially: "I have a really good support group. I have a group of women who come out and we play at it."

*Trisha (TB) is 46. She and Joe had been married less than a year and had just bought a small general store and delicatessen when she was diagnosed with metastatic breast
cancer. She cried when she talked about selling her store. She makes beautiful coats out of Pendelton wool and breeds sheep dogs. During the interview process, she was able to go to Las Vegas and see her only daughter get married. She describes herself in the following way: (a) physically: "Pretty tired, but relieved that the radiation is over. The pain is pretty much under control"; (b) emotionally: "I’ve always been the strong one. I’ve had to kind of keep everybody together"; (c) spiritually: "There’s a nice little church up in Adamson, and they have been really supportive. I try to get up there, but it is hard"; and (d) socially: "I belong to two support groups. I like being with people and getting out."

*Marlene (MIP) is 54. She has metastatic breast cancer. She is very proud of her son who is completing a master’s degree in psychology. She misses her job, because she likes to be around people. She likes to play the accordion and piano. She died before the second interview. Marlene describes herself in the following way: (a) physically: "I tire out easily, but I keep busy"; (b) emotionally: "I don’t think negatively. There isn’t any reason to be negative"; (c) spiritually: "I pray and I pray very hard and ask for help and strength to give me the courage to follow each day through"; and (d) socially: "I’m not a very social person, I’m more a homebody."

Pam (PF) is 29. She was diagnosed with inflammatory breast disease at the end of her first trimester of
pregnancy. The oncologist who diagnosed her told her that she had to choose between her life and the life of her baby that night. A second oncologist told her that because she was through her first trimester, she could be treated and could continue to carry her baby. Five months later, "Chance" was delivered by C-section. She is the youngest and only subject with preschool kids. Her other son is 4 years old. She misses her job and her friends and sleeping all night (not because of the cancer but because of the baby). Pam describes herself in the following way: (a) physically: "I’m tired"; (b) emotionally: "I found I’m a lot stronger than I thought I was"; (c) spiritually: "I feel very strong spiritually. I feel like I’m getting a lot out of church"; and (d) socially: "I like talking with my girlfriends. I’m shy around people. I like to laugh and have fun."

Overall, this convenience sample of hopeful adults was very eager and willing to participate and share their cancer experiences--good and bad. As a whole, they were very positive, well-educated, motivated and involved, financially secure, and stable with strong family support and very strong spiritual beliefs. Two subjects were asked why they thought others perceived them as "hopeful." Molly said that she has always been positive and upbeat. "I never really thought I was ‘hopeful.’" Maggie never saw any need to be angry about things that she could not change. "It wastes too much of my energy." By the study focus, the results of this study reflect a hopeful population and may limit the
generalizability to the experience of all adults facing advanced cancer.

**Research Questions**

**Question 1: How Do Hopeful Adults With an Advanced Stage Cancer Define or Describe Hope?**

The presence of hope was quickly established. During each interview, each person was asked, "Do you have hope?" All (100%) said yes. The degree of emphasis ranged from "a little bit" to "yes," "uh-huh" to "absolutely," and "a ton of it." Their verbal responses were strongly supported by their ability to quantify their hope using a VAS-H where 0 meant no hope and 10 meant high hope. The overall VAS-H sum $\bar{x}$ was 8.67 (SD 1.2); scores ranged from a minimum of 5.30 to a maximum of 10. Even Alden, who died 2 weeks later, scored a 9.3 on his last VAS-H. The results of the SHS are similar. The SHS measures the likelihood and importance of completing specific life goals. Maximum possible points is 448. Of the 25 completed questionnaires, the overall mean ($\bar{x}$) sum score was 279 (SD 43.97), with scores ranging from 164 to 374. Overall, hope scores from both tools were at the higher end of scales.

The limitations of any tool used to measure an abstract phenomenon such as hope are obvious. As one of the subjects asked, how can one measure "something that is just there?" Subjects were then asked to define or describe hope further.
Immediate responses included "that's a hard question," "that's a big word," and "I've never really thought about it." Despite their initial hesitancy, all subjects were able to provide rich and insightful descriptions, definitions, and qualities of hope. As a collective, several descriptors or qualities emerged including future related, religious themes, abstract nature, and positive feelings (see Table 10).

Table 10

Key Descriptors of Hope

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Defining Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Future Oriented</td>
<td>• Functions as a motivator, helps in identifying and achieving goals</td>
</tr>
<tr>
<td>Religious/Spiritual Themes</td>
<td>• Provides similar terms to define hope</td>
</tr>
<tr>
<td></td>
<td>• Source of hope</td>
</tr>
<tr>
<td>Abstract Nature</td>
<td>• Uses other abstract words or metaphors to describe hope</td>
</tr>
<tr>
<td>Associated Feeling</td>
<td>• Identifies positive as well as negative feeling associated with hope</td>
</tr>
</tbody>
</table>
Future-related themes. Future-related themes were those terms that reflected planning or anticipation of the future but not necessarily in the temporal sense. Future-related themes of hope were identified the most often by the subjects. For many, hope was viewed as a motivator that helped in identifying and planning goals--not in a temporal sense but as defined by tasks. An example is provided by Molly, who said, "Hope is having--I wanted to say--a positive future, but for some people positive may not be as good as an 'improving future.'" Pat describes it as a "continuous journey." Several view hope as a promise of good things or that things will get better. As a consequence, it gets one "through the day" and helps one "move ahead and want to continue." Hope was associated with "learning something new" and "to keep increasing my understanding of what this reality is all about." For two individuals, hope is considered necessary for life: "Without hope, people do not live."

Religious/spiritual themes. For half the subjects (n=6), hope was associated with religious/spiritual themes or terms. Religious or spiritual terms are words or phrases that come primarily from a secular orientation. They do not necessarily reflect an organized religion. These terms were used primarily to provide examples about what hope was similar to or to represent what hope was not. Terms were also used to define degrees or continuums of hope. An example of this is: "I get faith and hope mixed up" (Pam).
Two subjects identified spiritual themes as the source of hope: "Hope is faith in Christ" (Marisha), and "It's a spiritual thing--it has a lot to do with my faith in God" (Molly).

Abstract nature. The abstract nature of hope represents the difficulty individuals had in articulating their personal meanings of hope as well as demonstrating how complex and multidimensional the idea of hope is. Most of the subjects found it difficult to find adequate words to describe hope. As a consequence, hope was described in either ambiguous or equally as abstract terms, conflicting terms, or as a metaphor to something else.

Three subjects said hope was "just there," "can't prove it," and "I don't know how it is different from anything else." For some, descriptions were inconsistent. Pam believed hope to be "not as concrete . . . as faith," but for Molly, "hope is more concrete than faith." Six subjects likened hope to a feeling: "It's really intoxicating" and "it's just something that's there." Hope was likened to faith, optimism, joy, life, and well-being. Metaphors were also used to describe hope. Examples include "a basic grain," "a desire," "an aura," "a light," "a lesson," and "a belief."

Associated feelings. Associated feelings reflected most often an affective quality; however, the very nature of being was also associated with hope. Affective qualities were also associated with hope positively and negatively.
Positive feelings associated with hope included it feels "right" or "OK," "a sense of well-being," "I feel positive," or a feeling of "joy," "ease," "peace," and "a light in my heart." Hope is part of a good mental constitution. Hope also wards off negative feelings of panic or worry. Ironically, the simplest evidence of hope's presence was the individual's physical being: "I'm alive today, I'm here"; "if you no longer have hope, you would die."

Hope was also described in terms of the negative feeling that would be associated in terms of how it would feel not to have hope: "If I felt hopeless, I think that would be the worst thing I could ever feel." Two participants said they do not know what it would feel like not to have hope. Pat had experienced that feeling: it was a "monotone life."

Although all subjects gave definitions and partial descriptions of hope, Margaret captures its overall complexity:

Hope is looking for things that you’re not sure of. And looking for things to come that you can’t prove out by any rational or concrete means. The quality of life that you’ve got now. There’s also the future part of it; you can’t prove that in any way. But hope is the faith of things that are pretty much a state and strong in the faith. I know, pretty much that I’ll feel better for at least a few months. And that’s really intoxicating to me. So there’s that hope.
Question 2: What Influences the Presence or Absence of Hope?

Subjects' verbal responses to "what influences your hope?" were evaluated and compared to VAS-H, SHS total, intrapersonal, interpersonal, and global subscale scores, as well as the health function and psychological subscale scores from the QLI. Gender, age categories <50 (n = 6) and ≥50 (n = 6), pain, and treatment categories of palliative versus active treatment were also compared to hope scores. Several categories of influences of hope emerged from these data. These categories include physical symptoms, others, spiritual beliefs, personal qualities, and societal factors (see Table 11). Most categories were identified in both the qualitative and quantitative data; however, some, like societal factors, were identified only from the SHS. Subjects noted that all of these categories influenced their hope positively as well as negatively.

Physical symptoms. There were at least 18 references to signs and symptoms associated with either cancer progression or its treatment or both. Physical symptoms included general fatigue, nausea, pain, and "just not feeling good." The most commonly identified influence of their hope by the subjects was "how they felt." Maggie thinks that "the better your body feels, the more that you can hope." As cancer symptoms decreased, perceived hope increased.
Table 11

Key Categories of Influences of Hope

<table>
<thead>
<tr>
<th>Category</th>
<th>Specific Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Symptoms</td>
<td>• Reflecting how they felt physically as determined by disease progress and/or side effects of treatment</td>
</tr>
<tr>
<td>Support Persons</td>
<td>• Interacting with and being supported by family, friends, animals</td>
</tr>
<tr>
<td></td>
<td>• Being involved with support groups, social groups</td>
</tr>
<tr>
<td></td>
<td>• Utilizing other resources such as health care providers</td>
</tr>
<tr>
<td>Spiritual Beliefs</td>
<td>• Relying on personal beliefs and practices but not necessarily in a religious sense</td>
</tr>
<tr>
<td>Personal Qualities</td>
<td>• Exuding positiveness in activities and philosophies</td>
</tr>
<tr>
<td></td>
<td>• Associated with age and gender</td>
</tr>
<tr>
<td>Societal Factors</td>
<td>• Being interested or involved in environmental or community activities</td>
</tr>
</tbody>
</table>
The doctor told me my blood is returning to normal and my liver functions are normal. It makes me hope that much more. It may be lurking somewhere, but we have a handle on it. It [hope] really changed the most drastically when I got the good results which I didn't expect from the ultrasound. (Molly)

News of a decreased white blood cell (WBC) count had a negative effect on Pam's hope, as did "feeling tired," low energy levels, and all-round "aches," "pains," and "how my body is doing."

In addition, treatment demands and side effects determined their daily schedules and activities as well as long-term plans. An example of this was Molly, who danced with a group every Thursday night. Chemotherapy was planned so that she would have the energy to participate.

No specific measurements were administered to evaluate physical well-being; however, a subcategory in the QLI evaluates health function. There was no correlation between health function and VAS-H or SHS total scores.

Only 2 subjects even mentioned pain as an annoyance, and neither person reported that it influenced their hope significantly. VAS-P scores for this sample overall were unusually low for cancer patients. The overall mean (X) score was 2.45 with a range of 0-9.5. There was no correlation between VAS-P scores and the VAS-H scores or SHS total scores. Margaret, who had the highest VAS-P score of 9.5 on visit 3, had a VAS-H score of 9.75; Pam and Molly, who had VAS-P scores of 0.0, had VAS-H scores of 9.8 and 10, respectively. Alden, who had the lowest VAS-H of 5.35 on
visit 1, had a VAS-P score of 0.00. Margaret was asked why her pain score was so high. She responded that her "mouth hurt worse than usual."

Subjects were also evaluated by their current treatments: palliative care or active treatment. There were no significant correlations (p < .05) between treatment category, pain, and total hope scores. However, VAS-H and SHS hope score means for those receiving palliative care were consistently less than those receiving active treatment. Initial SHS total score for the palliative group was 275 as compared to those receiving active treatment scores of 305.7. Initial VAS-H for the palliative group was 7.79 as compared to the active treatment scores of 9.07. The difference in scores were not statistically significant. However, lack of statistical significance may be due to the small sample size.

Those receiving palliative care overall had higher VAS-P scores and lower health function scores. There was a positive correlation (p < .05) between treatment categories and health function. In addition, the Wilcoxon matched pairs test demonstrated that there was no statistical significance (p > .05) between treatment groups at Time1 and Time2. Even for the 3 subjects who knew they were close to death and did die within 3 weeks of their last interview rated their last VAS-H scores as 9.3, 8.5, and 9.2.

Support persons. The second largest influence of hope identified by the subjects was other people. Support persons...
include relationships and interactions with family, friends, and animals. Other important resources included support groups, social groups, and health care providers.

All subjects gave examples of how their immediate family members influenced their hope. Pat says her family's energies work with her. Three subjects identified their kids as influencing their hope. All subjects gave examples of how family members influenced their hope. Marisha's daughter sleeps on the floor at the foot of her bed every night; Alden's sons come over every day to help him shower, and they usually end up laughing uncontrollably.

Maggie's husband gives her hope and encouragement: the fact he "will reach out and touch me." "My husband goes to work at 4:30 a.m. so he can go with me to chemotherapy" (Molly); and "Joe drives me 40 miles to the cancer center 4 times a week" (Trisha).

Several also discussed their husband's lack of understanding as influencing their hope negatively. Margaret, for example, told of the time her husband celebrated her last chemotherapy by having a beer and pizza party. Her feelings were that he thought things would be "back to normal" and that pizza and beer were not anything she would even want to eat. Molly mentions that as she feels better, her husband seems to forget that her disease is life threatening. By their husbands acting like things were "back to normal," both subjects felt their cancer experiences and
their hope associated with the experiences were in part negated.

Other family members were also mentioned as supportive. "My mother came for the summer and my brother and sister-in-law came for Christmas just to help" (Margaret); "My in-laws park their motor home in our driveway and help with the kids" (Pam). However, Molly does not talk about her cancer around her mother.

Eleven of the 12 were involved in group activities, including church groups, community classes, support groups, and personal hobby and interest groups. Maintaining these activities was important. Friends were also identified as sources of hope. Pam meets with friends from work weekly, and Molly is "permanent lunch date" (Pat).

Positive interactions with others help their hope: "When someone comes over and says 'you really look great today,' that reinforces that positive thing"; "knowing people are praying for me"; "just telling me that I am doing better"; and "they [my friends] just drop by to see how I'm doing and to let me know they are thinking about me."

The most angst noted during the interviews was by Trisha and Murial. Trisha had recently moved to an isolated area and was often unable to get to her support group and church. She missed the interaction. Murial appeared to be most isolated socially. Although her husband provided a great deal of support, she rarely mentioned friends and family unless asked specifically about them. She sounded the
most sad when asked what she had learned from her experience and she said "to let others know you love them."

"Resource" people were also identified as important influences of hope: Three subjects belonged to cancer support groups, citing a need to build a network of people--because we do not have all the answers. "It helps to talk to someone who has been through it." Three subjects specifically mentioned their dislike of support groups because they did not want to talk about their cancer all of the time. They did mention they got support from professional referrals or professional and nonprofessional friends.

The presence of the interpersonal interactions was identified by the SHS interpersonal subscale. Total scores were 109.68 (SD 10.68). Palliative and the active treatment group scores were similar. Scores remained relatively unchanged over the three interview periods.

Other resources that influenced their hope included alternative health interventions. A few changed their diet, used meditation, or positive imagery--several mentioned inspiring books. Molly mentioned that her music teacher told her to eat 10 almonds every day. She did not see "how they could hurt."

Two of the subjects specifically mentioned their dogs or cats as important motivators. Eleven of the 12 subjects had house pets. In at least four homes, the dogs or cats
were in their laps or at their feet being petted or talked to during all interviews.

Health care providers were mentioned as being able to influence subjects' hope. Comments associated with hope nurturing behaviors include "being listened to," "treated like an individual," "caring," "believing in what they are doing," "calling me by name," and "laughing." However, most of the subjects gave specific examples of people, experiences, and behaviors that nurtured their hope.

Rene, a hospice nurse, instilled hope in Maureen. "She's a very positive person. She smiles. She laughs. She wants to comfort me. She is not a miracle worker, but she walks in smiling and she just shows the caring of a human being." Maggie had a little red head. "She just flat out told me, 'you're going to be one of them that's going to make it. You've got attitude.' Made me feel like, you bet, I'm gonna." Pam liked that the nurses posted your white count on the wall, so every day you could see that you were gaining. Maggie tells of the nurses and techs who have a weird sense of humor about dying and death. . . . We know we're living on borrowed time and . . . they just kind of fall in with it . . . they spoil you rotten. They cover you up with blankets and they bring you snacky poos and heating pads and anything you want, but they're very positive. They are very caring, very positive, and that means a lot.

Being "treated like real people" and having a "personal relationship" are important. "They just treat me like a normal person with two kids at home and dirty dishes and
laundry to do" (Pam). "When you arrive or when they speak to
you, they call you by name and recognize you and know who
you are" (Trisha). "In Seattle, they give you a team and so
one of my gals has been with me for 30 days. You don’t have
different nurses."

Finally, Marlene explains how a cancer center can be a
hoping environment that feels like home:

My hope--this is terrible, but the cancer center
has been a wonderful relief for me. I feel secure
here. I do--just like home. They are here to help
and they share with you. They have become friends
to me too.

Spiritual beliefs. Ten out of 12 subjects said that
their hope was influenced by their spiritual beliefs. These
beliefs did not always reflect an organized religion but
more a personal philosophy of life. Hope was influenced by
"my faith in God"; "reading my bible"; "my relationship with
God"; and "my belief in my spirituality and my absolute
believing as I do." Hope was influenced each time "I pray"
and "every time that I go to church or believe in God or see
the flowers come up I know I have hope." Margaret tells "the
nurses about my faith in God. My Christian friends say this
is a mission for you. Even when you’re out, and you can’t do
anything else, you pray." Marisha suggests that all nurses
"should just go in and say a little prayer, and ask the Lord
to bless them."

The SHS does not assess spirituality or religion;
however, the QLI subscale psychological/spiritual does
evaluate spirituality. Although not statistically
significant, there did appear to be a positive association between hope mean scores and the psychological/spiritual subscale scores.

**Personal qualities.** Positive attributes such as optimism, problem solving, and focusing on personal and environmental things that they could control were apparent in this population and influenced their hope. All subjects portrayed positive attitudes and philosophies relating to life and life events, and their illness and prognosis, regardless of the phase of their cancer. They created positive environments, surrounded themselves with positive people, and took a very active role in their cancer experiences. These qualities were uniquely identified by participant observation. These observations were then supported by reviewing entire transcripts for the following examples of this “positiveness.”

Maggie “made up my mind to do it, you either bring it forward or it just sits there.” Despite the fact that Pam was struggling with the death of two close friends to cancer, she still had a VAS-H at Time3 of 10 and a SHS total of 336. Most had a positive view on life. Pam had a “down day last week, but it’s not worth getting worried about.” Maggie sums up with this attitude:

I had never found anything on positive thinking and finally found where I could get tapes that would teach me how to do that. I used them regularly and I still do to relax. I believe that the positive imaging, the positive attitude, the tremendous positive support that I got all the time, and the growth in my faith, the prayers that
I received, and that is a power that they haven't understood yet, worked.

Although several used humor, it was not a noticeable quality with all subjects.

Subjects did not rely on positive attitudes only; they also created positive environments or avoided negative ones. A few made a distinction between positive people and a need to "be selective around people who I allow into my experience." "I get tired of being around people that all they want to talk about is how ill I am."

Maureen told of the "ornery receptionist in her doctor's office. She acts like she was being put out and didn't really smile. We were determined we were going to make her smile." Trisha was taking a painting class at the community center once a week. She wanted to "get away from the sick people." At the center, she was just another art student.

Despite their "positiveness," there were also moments with each where tears were shed and their losses, changes, and potential future were discussed. Five subjects shared specific examples of when their hope was at a low levels during their cancer experience.

Subjects were also very verbal and responsible for their choices regarding their cancers and their lives.

Marisha said:

I do not want to take morphine and yet you know most people in my condition want it. So it is hard for most people to understand that I don't want it. If I want to take it I am glad it is there and
I can take it, but, I don’t want to be pressed to take it. I am in more pain by not being alert and awake to be able to talk to people. It is more important to be awake and alert and bless somebody’s life than it is to be without pain.

Pat commented:

I don’t know. It’s about me making choices for myself. I want to know things. When you go out the door, there is a high possibility that you are going to get rained on. Well, maybe I’ll get my umbrella. It gives me some options here.

Maggie felt strongly that her cancer is “mine. Nobody owns it but me. If I decide that I don’t want to take any treatment, then I ask for your support. I do not ask for you to agree with me. It is my choice.” Molly wants to “start figuring out why people survive [cancer]. We probably have a pretty good idea why they die.” For Michael, “it is all right to die. There is nothing wrong with that.”

In addition, all subjects stressed the importance of maintaining normal schedules and activities as much as possible. Comments were made about shopping, vacations, and family time together. When Margaret could not sleep, she would make “gourmet” sack lunches for her high school age kids.

The presence of intrapersonal attributes was identified by the SHS intrapersonal subscales. Total scores were 119.77 (SD 22.53). Palliative and the active treatment group scores were similar and on the higher end of the scale. Scores remained relatively unchanged over the three interview periods.
Age was a variable identified by the literature as influencing hope. When asked how they felt age influenced their cancer experience and their hope, 5 said "age had no bearing." The others saw age as a motivator, especially if they had kids at home. Those with teenagers (n = 3) had a particular need to "be there for them." Two stated that their younger age allowed them to "fight the cancer better," and 3 felt they were "being robbed" of their good years. One felt her age affected those around her more than her. None identified their younger ages as a factor influencing their personal hope.

Age did not appear to correlate with any hope measurement. The group was divided into those <50 (n = 6) and those >50 (n = 6). Mean (x̄) VAS-H scores were 8.46 and 8.87, respectively. SHS total mean (x̄) scores were 279 and 278, respectively.

No conclusions can be drawn relating to hope and gender. Only 2 subjects were male, both receiving palliative therapies for brain tumors. In their descriptions and comments, both appeared to have no more or less hope than the women.

Societal factors. SHS assesses global or society related influences of hope. Subjects did not mention any environmental, community, or political activities or concerns of which they were involved in. Two subjects mentioned the lack of "interest" doctors had for breast cancer. Maggie stated that "doctors don't seem to be too
impressed with it [cancer] . . . 186,000 women will come down with breast cancer and 43,000 of them are going to die, but they’re still treating it like a cold.” Molly “suggested” that if “‘it’ were the doctor’s testicles being cut out, they wouldn’t be so complacent.” Michael was frustrated because his insurance company was refusing to pay some of his bills. These issues affected their cancer experiences but did not appear to influence their personal hope. Lack of interest in global hope was supported by overall low global hope subscores.

Overall, from subjects’ comments, participant observations, as well as measurements of hope, the hope of adults with advanced stage cancer can be influenced positively and negatively by physical symptoms, others, spiritual beliefs, and personal qualities. Societal factors do not appear to be important in influencing their hope. All subjects stated that they felt that health care providers can and did influence their hope.

Question 3: What Do Hopeful Adults With Advanced Stage Cancer Hope for?

Subjects were asked “what do you hope for?” Answers to the SHS and QLI were also evaluated as descriptors of hope goals. Several hope goal/outcome categories emerged, including life expectations, interpersonal activities, routines and events, and health goals (see Table 12). In addition, two very distinct “type” of goals were identified.
<table>
<thead>
<tr>
<th>Category</th>
<th>Defining Characteristics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life Expectation</td>
<td>Reflects desire for meaningful life, inner peace, and maintaining quality of life</td>
</tr>
<tr>
<td>Interpersonal Activities</td>
<td>Desire to be involved with others, such as family, friends, groups</td>
</tr>
<tr>
<td>Routines/Events</td>
<td>Desire to maintain a sense of normalcy and structure</td>
</tr>
<tr>
<td>Health Goals</td>
<td>Desire to feel better, not necessarily get better</td>
</tr>
</tbody>
</table>

Identified goals by the active treatment group were very different from those in the palliative care group. Most of those subjects receiving active therapy had been diagnosed with a highly fatal cancer for less than 6 months. They are still receiving therapies that have the potential of slowing down the disease progression and/or possibly
Table 13

Comparison of Hope Goal and Outcome Qualities Based on Treatment Groups

<table>
<thead>
<tr>
<th>Population Qualities</th>
<th>Active Treatment(^a)</th>
<th>Palliative Care(^b)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stated Goals</td>
<td>Specific, concrete</td>
<td>General, abstract</td>
</tr>
<tr>
<td>Involvement in Goals</td>
<td>Active participant</td>
<td>Passive observer</td>
</tr>
<tr>
<td>Temporal Orientation</td>
<td>Future - days or months (not years)</td>
<td>Present - today</td>
</tr>
<tr>
<td>Life Events</td>
<td>Family and work roles</td>
<td>Death, afterlife</td>
</tr>
<tr>
<td>Focus of Goals</td>
<td>Self and others</td>
<td>Others</td>
</tr>
</tbody>
</table>

\(^a\)Active interventions to slow disease progression or put into remission.

\(^b\)Terminal stage of disease, receiving supportive care only.

putting their cancers into remission and possibly cure. The active therapy group’s goals tended to be more specific and concrete. They were often defined in temporal terms or in specific and normal activities of which they were generally active participants. These activities frequently reflected those typical of the younger adult such as managing family roles.

The palliative group, on the other hand, was primarily in the terminal phase of their diseases. Treatment and care
were supportive, only requiring help in activities of daily living. Defined goals from the palliative care group tended to be general and abstract. The goals were rarely defined in temporal terms and focused on either the immediate daily needs or a readiness to die. Goals involved others where they tended to be a passive observer. Examples of these differences are noted as each category is discussed.

Life expectations. Life expectations is a general term for areas frequently associated with quality of life goals. They include individual life goals and general life satisfaction. All subjects talked about their personal desires and life goals. For those receiving active treatment, all made comments about wanting to live a "good life," "the best life," and to "continue my spiritual growth . . . I hope for enlightenment." Those receiving palliative care, however, are ready to move on. Trisha asks for "peace within myself--just that peaceful feeling." Maureen, who died 1 week later from liver cancer, said:

I have hope for dying. . . . I know I'm going to see my relatives on the other side and I'm excited about that and I want to see the flowers . . . . I want to see the singing and music. I'm looking forward to that. That's special to be able to experience that. I've wanted to for a long time, but it's not that I have hope for it. I know I'll have it, so it's not a hope. I was hoping for a while that maybe that I could have a miracle, but that's not in the offering. It's just not going to be given.

SHS intrapersonal subscale scores were on the higher end of the scale and support the verbal responses. There were no significant differences in scores between the
palliative and active treatment groups (see Table 14). Subjects did not specifically mention quality-of-life goals. However, the relationship between hope and quality of life was supported statistically. VAS-QOL and SHS total correlated at Time₁ and Time₃. QLI and SHS total correlated at Time₃ only. Correlations between hope scores and QLI scores are shown in Table 15.

**Interpersonal activities.** Interactions with others were important hope goals to all subjects. Michael said, "If you are touching anybody's life at all, I don't think you are in a hopeless situation." Molly always prays for others. All subjects wanted to help others. When asked, "Why are you willing to participate in this study?" several (n = 7) stated they wanted to help "others," especially those with cancer and health care providers. Murial wanted to "give

### Table 14

<table>
<thead>
<tr>
<th></th>
<th>Total (X)</th>
<th>SD</th>
<th>Palliative (X)</th>
<th>SD</th>
<th>Active Treatment (X)</th>
<th>SD</th>
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<tr>
<td></td>
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<td>(n=9)</td>
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<td>(n=16)</td>
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<tr>
<td>SHS Total*</td>
<td>278.77</td>
<td>43.97</td>
<td>261.24</td>
<td>48.20</td>
<td>293.37</td>
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<td>Interpersonalc</td>
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<td>115.42</td>
<td>24.37</td>
<td>123.38</td>
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*p value = NS

*p value = <0.05

*p value = NS

*p value = NS

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Table 15

Quality of Life and Hope Correlations

<table>
<thead>
<tr>
<th>VAS-H</th>
<th>VAS-QOL</th>
<th>SHS</th>
</tr>
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<tbody>
<tr>
<td>Time₁</td>
<td>Time₂</td>
<td>Time₃</td>
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<th>Time₁</th>
<th>VAS-QOL</th>
<th>SHS</th>
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<th>Time₂</th>
<th>VAS-QOL</th>
<th>SHS</th>
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<table>
<thead>
<tr>
<th>Time₃</th>
<th>VAS-QOL</th>
<th>SHS</th>
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</tbody>
</table>

* = p ≤ .05; ** = p ≤ .01.

VAS-H = Visual Analogue Scale-Hope

VAS-QOL = Visual Analogue Scale-Quality of Life

SHS = Stoner Hope Scale

QLI = Quality of Life Index
someone else inspiration”; Molly wants to “make a difference in somebody else’s life—we need to find some kind of a handle to give them.” If Maureen could “help somebody by my comments, I wanted to.” Maggie believes that “the more you guys [nurses] know, I truly think you can make a big difference.” Michael stated, “If you can understand what drives it [hope], then maybe you can really put your mental faculties together.” Marlene said, “It is important for people to learn about different situations and how people react to different situations.”

For those receiving active treatment, they hoped to be an active participant with their families—not necessarily to live forever: “I want more from my family, I want to give more, more probably than I ever have before.” Pam “wants to build memories.”

For those receiving palliative care, however, their hopes for their families are more as observers or outsiders looking in. For Michael, his hope now is mostly centered around my family. The hope that they will be able to get through all of this without it tearing them apart cause they’re so young and my wife is so young and she’s got four young kids that she’s completely responsible for now, so my hope is that she’ll feel the strength in her to be able to stand up to all these things that she’s going to have responsibilities for and hope for my kids to be strong enough to follow her and not be overly influenced by other people cause they’re getting into the ages now where they’re going to.

Several still desire to help others. Marisha, who has metastatic breast cancer, has “a more clear picture in my
mind of different people’s needs”: “I really, for my sake, would like to go, but I will not go until I’ve been able to do what I need to do to help the people who need help.” Even in preparing her funeral, Maureen wants “to teach at the same time. I don’t want it to be just music. I want it to mean something. I want them to know the meaning I have for it.” Trisha worries about her husband Joe. “I hope he will be OK.”

SHS interpersonal subscale scores supported the verbal responses and were on the higher end of the scale. Interpersonal subscale scores of those receiving palliative care versus those receiving active treatment were not significantly different.

Routines and events. All subjects hoped to maintain activities related to routines and normalcy. For those receiving active treatment, many of them hoped to stay active with tasks associated with their ages. For example, Pam desires to return to the “simple, stupid, or normal things that people take for granted.” Molly just wants to be able to function and do “what I want to do, when I want to do it.” Pat at age 50 “deserves a mate in my life.” Their roles as mothers were very apparent. Pam, who has inflammatory breast disease, wants to be able to watch “my kids grow up and graduate and go on their first date.” Molly and Margaret want to survive long enough to get their teenage sons through high school. “That was my bargain with
God" (Molly). For 3 subjects, returning to work was an important goal.

Trisha, like the other subjects who are terminal, has no expectations. She said,

I made a list of things I was going to accomplish. . . . some of them are just kind of wishful thinking more than hope . . . well, like I'd like to see my daughter settle down and happily marry. So you know that's kind of pie in the sky, but it sure would be nice to know that she was happy.

Others felt good if they "survived another day," "got dressed," or "did something new." Those receiving palliative care did not seem to focus on developmentally related tasks. They were more involved realistically with getting through each day the best they could. There was no measurement that reflected activities or events per se.

Health goals. Only 2 subjects receiving active treatment specifically mentioned cure or recovery. Maggie said, "I never hoped that I'd live." Others hoped for remission and a healthy life and to "just feel good" and not to "feel so tired." For those receiving palliative care, their comments included, "I really, for my sake, would like to go" (Marisha), "I look forward to the day when I get rid of the headache that I have," (Michael), and "just freedom from this pain" (Trisha).

Global or societal issues. None of the subjects mentioned involvement in political or community issues. Although most agreed to participate in the study to help others, they did not identify a "grander" goal. This lack of
identified global goals is strongly supported in overall low
global hope subscale scores. In addition, global subscale
scores were statistically different at a $p < 0.05$ level
between the palliative and active treatment groups.

Hope goals and outcomes were easily identified by the
individuals. Qualitative differences were noted between
those receiving active therapy and those receiving
palliative care; however, statistically there appeared to be
no significant differences (see Figures 2 and 3).

Question 4: Do Hope Patterns Remain
Constant or Change Over Time?

During each of the three interviews, each subject was
asked if his or her hope changed over time. Of 31 responses,
20 (60%) said yes; 6 (18%) said no; and 5 (15%) said maybe
or "I don't know." All but 2 of the subjects were
inconsistent with their answers from one interview to the
next. Murial said at Time₁ that she "supposed it did"; on
Time₂ she "didn't think so"; and at Time₃, "Well, everything
changes over time."

Quantitatively, the group hope scores on the whole
tended to be unchanged over time. A paired $t$ test was
performed on all hope scores at Time₁ and Time₃. Time₂ scores
are included in Table 16 but were not evaluated
statistically due to a poor return of the questionnaires at
Time₂ ($n = 6$; 5 from the active treatment group, 1 from the
palliative group) and a small sample size. The average time
<table>
<thead>
<tr>
<th>Time</th>
<th>Interpersonal</th>
<th>Intrapersonal</th>
<th>Global</th>
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<tbody>
<tr>
<td><strong>Time1</strong></td>
<td><strong>Total (N=11)</strong></td>
<td><strong>Palliative Care (n=6)</strong></td>
<td><strong>Active Care (n=5)</strong></td>
</tr>
<tr>
<td></td>
<td>115</td>
<td>118</td>
<td>112</td>
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<td></td>
<td>121</td>
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</tr>
<tr>
<td></td>
<td>56</td>
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<td>71</td>
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<tr>
<td><strong>Time2</strong></td>
<td><strong>Total (N=8)</strong></td>
<td><strong>Palliative Care (n=3)</strong></td>
<td><strong>Active Care (n=5)</strong></td>
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<td></td>
<td>51</td>
<td>23</td>
<td>57</td>
</tr>
<tr>
<td><strong>Time3</strong></td>
<td><strong>Total (N=8)</strong></td>
<td><strong>Palliative Care (n=3)</strong></td>
<td><strong>Active Care (n=5)</strong></td>
</tr>
<tr>
<td></td>
<td>102</td>
<td>98</td>
<td>104</td>
</tr>
<tr>
<td></td>
<td>123</td>
<td>112</td>
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</tr>
<tr>
<td></td>
<td>47</td>
<td>21</td>
<td>63</td>
</tr>
</tbody>
</table>

**Figure 2.** Stoner Hope Scale and Subscale Scores Over Time.
Visual Analog Scores (VAS)

Figure 3. Visual Analogue Hope Scale Scores Over Time.
### Table 16

**Hope Scores at Time₁, Time₂, and Time₃**

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Palliative Care</th>
<th>Active Treatment</th>
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</thead>
<tbody>
<tr>
<td><strong>SHS</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Time₁, N = 11</td>
<td>291.66</td>
<td>276</td>
<td>304.71</td>
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<tr>
<td></td>
<td>(N = 11)</td>
<td>(n = 5)</td>
<td>(n = 6)</td>
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<tr>
<td>Time₂, N = 6</td>
<td>269.06</td>
<td>241</td>
<td>274.68</td>
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<td></td>
<td>(N = 6)</td>
<td>(n = 1)</td>
<td>(n = 5)</td>
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<td>Time₃, N = 8</td>
<td>273.32</td>
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<td>(N = 8)</td>
<td>(n = 3)</td>
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<td><strong>Global</strong></td>
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<td>Time₁, N = 11</td>
<td>55.76</td>
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<td>51.17</td>
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<td>56.8</td>
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<td>Time₃, N = 8</td>
<td>47.22</td>
<td>21</td>
<td>62.87</td>
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<td><strong>Interpersonal</strong></td>
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<tr>
<td>Time₁, N = 11</td>
<td>114.54</td>
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<tr>
<td>Time₂, N = 6</td>
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<tr>
<td>Time₃, N = 8</td>
<td>101.94</td>
<td>98</td>
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Table 16 (continued)

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
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<tbody>
<tr>
<td></td>
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</tr>
<tr>
<td><strong>Intrapersonal</strong></td>
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</tr>
<tr>
<td>Time₁, N = 11</td>
<td>121.35</td>
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<td>122.90</td>
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<td><strong>VAS-H</strong></td>
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between Time₁ and Time₃, was 60 days. It was hoped that changes might be greater and the hope statistical scores may be sensitive to these changes.

Overall, VAS-H and SHS total and subscale scores did not change over time (p > 0.05). The only exception was the global subscale scores. This score tended to influence the overall SHS total score as well as global and total hope scores declined slightly over time while the VAS-H scores increased slightly over time. There is also a high correlation between global subscales and treatment category at Time₁ (0.71, p < .05) and at Time₃ (0.92, p < .01).

Participant observation also supports the stability and ongoing presence of hope. Over all visits (N = 33), individual perceptions of hope did not seem to waiver, as noted by their ability to quantify their hope easily on the VAS-H as well as their enthusiastic responses to the question "do you have hope?" On only two occasions did individual participants seem less "hopeful." The last interview with Pam took place in the same week as the death of two friends, both members of her cancer support group. In addition, her white blood cell count was not going up, and an anticipated stem cell transplant had been postponed once more. Despite both significant events, her VAS-H score was 10. Her SHS total was 374.7. On Murial's last visit, her affect was greatly changed from the first two sessions. She was curt, almost unfriendly, and she did not want to complete the questionnaires, saying her answers had not
changed. She did complete the VAS-H with an 8.50, up from Time₁ and Time₂ of 7.30 and 7.70, respectively. Even though she was given an opportunity to talk about how she was doing, she did not account for the change. For the rest of the participants, their positive demeanors and hopeful responses did not seem grounded at all in denial, ignorance, or a desire to please. Their responses seemed well thought out and sincere. Even Alden, who had difficulty answering questions and could not complete the questionnaire due to the rapid progression of his brain tumor, blurted out quite clearly at Time, that he “had a ton of hope.” He confidently marked 9.3 on the VAS-H. He died 2 weeks later. Some hope qualities do change, as Pat describes so eloquently: “I think it [hope] might ebb and flow a little bit . . . but overall, I think that my hope for life actually keeps increasing.” But for Trisha, hope is also constant: “I never thought of hope as something that could change--like one continuous thing. It either is or it isn’t.” And for Maggie, “if you don’t have hope . . . you die.”

Despite verbally acknowledging that hope changes over time, hope scores did not capture those changes.

Question 5: What Feelings, Behaviors, or Activities (Hope Strategies/PATTERNS) Reflect the Presence of Hope in Adults With Advanced Stage Cancer?

Several patterns and qualities of hope repeat or overlap or both in multiple aspects of hope as described by
these hopeful adults with advanced stage cancers. Specific patterns and descriptions related to hope as well as personal and environmental factors that are present in this hopeful population have been identified. The patterns and descriptions include health and illness factors, relationships with others, spiritual beliefs, and intrapersonal qualities. It is also noted that hope qualities are contextual and can be dynamic and/or stable (see Table 17). Capturing these qualities has required multiple methods of data collection.

Health/illness factors. Cancer and the phase of illness influences hope positively and negatively. Health and illness factors also determine personal goals and outcomes of hope. These health/illness factors appear to be dynamic in their ability to influence hope and define hope goals. Their influence on hope and hope goals is easily described by the subjects qualitatively but does not appear to be easily captured quantitatively.

Relationships with others. The importance of others is seen in two areas related to hope: as supporters (or nonsupporters) and resources for their hope as well objects of their hope goals and outcomes. Relationships with others appears to be dynamic, and its importance is captured both qualitatively and quantitatively. All of the subjects in this study had strong, supportive, and stable family and social structures in place.
Table 17

<table>
<thead>
<tr>
<th>Qualities of Hope</th>
<th>Influences of Hope</th>
<th>Hope Goals and Outcomes</th>
<th>Dynamic (D) / Stable (S)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Related Factors</td>
<td>++</td>
<td>+</td>
<td>D</td>
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<tr>
<td>Relationships With Others</td>
<td>++</td>
<td>++</td>
<td>D/S</td>
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<tr>
<td>Spiritual Beliefs</td>
<td>+</td>
<td>+</td>
<td>S</td>
</tr>
<tr>
<td>Personal Qualities</td>
<td>+</td>
<td>+</td>
<td>S</td>
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</table>

+ = moderately present  ++ = strongly present

**Strong spiritual beliefs.** All subjects talked about their deep and personal spiritual beliefs. These beliefs are reflected in all dimensions of hope, including personal definitions of hope, sources and influences of hope, and outcomes/goals of hope. Spiritual beliefs appear to be more stable in nature but are captured both qualitatively and quantitatively.

**Intrapersonal qualities.** All of the subjects portrayed positive attitudes and philosophies relating to life and their cancers. This attitude, although not obviously noted in the qualitative data or quantitative data but through participant observation, is a part of all aspects of hope, including definition and descriptions of hope, influences of
hope, and hope outcomes. However, these qualities appear to be stable, being present before their cancer experience.

Definition of Hope

For the hopeful adult, ages 20-59, with advanced stage cancer, hope is an abstract, positive, and complex phenomenon that is always present and necessary for life serving as a guide. Hope has stable qualities as well as dynamic qualities that can influence hope positively and/or negatively as the disease, person, or environment changes. Nurses can influence hope. Hope goals and outcomes are uniquely and individually defined.

Description of Hope

The best way to understand this definition of hope as described by this hopeful population is to liken it to a human heartbeat: necessary for life and always present. In a healthy and stable heart, the heartbeat, an electrical impulse, is usually initiated regularly at the sino-atrial node, at a predictable and stable rate of 60-100. This impulse stimulates the myocardium to contract, allowing oxygen and nutrient-rich blood to be pumped to all organs of the body. However, rate and rhythm are also dynamic. They can be influenced internally by infection, biofeedback, and disease and externally by medication, exercise, stress, and technology. If a heartbeat's rate and rhythm varies, it is measured directly by pulse, electrocardiogram, or
echocardiogram. Other ways of evaluating heart rate are to assess associated objective and subjective symptoms, such as blood pressure, level of consciousness, color, and chest pain, or predictable outcomes of an ineffective heartbeat like fatigue, shortness of breath, or edema. Interventions are then planned to improve overall cardiac functions.

Important in the above analogy is the presence of stable and predictable as well as dynamic and changing qualities of the heartbeat. The heart impulse follows a predictable course with predictable consequences; yet, arrhythmias can appear and disappear quickly. With continuous cardiac monitoring, these changes can be recorded. The dynamic qualities of hope are not as easily captured. Hopeful adults appear to have a hope structure that, like a heartbeat, has stable qualities associated with the individual, such as strong spiritual beliefs, a positive view of life, and strong interpersonal interactions. However, other factors can also influence hope either positively or negatively: age, disease process, environment, and other people, but unlike a heartbeat, there is, at this point, no direct way to measure hope.

Summary of Findings

Data examination revealed that hope has been well-defined and described by this hopeful population in five important areas: hope's qualities, influences, outcomes, dynamic abilities, and universal patterns and themes.
However, these data also generated unique and new questions, observations, issues, and limitations related to hope and hope research. The following chapter will discuss these issues in-depth.
CHAPTER V

DISCUSSION

In this chapter, significant findings of the study will be discussed as they relate to existing research studies and conceptual framework; application to nursing practice, education, and research; and finally, strengths and limitations of the study.

Findings Relative to Existing Research and Conceptual Framework

Presence of Hope

This study confirms other study findings that hope is present in adults with advanced stage cancer. The presence of hope is strongly supported in this study by SHS (X) scores of 279 (SD 43.97), where the maximum possible points is 448. These scores are consistent with Stoner's (1982) study also involving cancer patients. Total SHS score means for that study were 312 (SD 63). McGill and Paul (1993) and Beckerman and Northrop (1996) used the Miller Hope Scale (range 40-240) in cancer and noncancer and elderly populations. Reported scores were 174.38 and 155, respectively. Herth (1990), using the Herth Hope Index, and
Post-White et al. (1996), using the Herth Hope Scale, reported overall mean scores of 39 (SD 4.34, with maximum possible points of 48) and 79.2 (SD 6.9, maximum possible points not reported). In addition, for this study, VAS-H overall ($\bar{x}$) score was 8.67 (SD 1.2, with a maximum score of 10). These findings are similar to Stoner (1982) and Raleigh (1992), who both used self-assessed hope scales similar to a VAS-H with end points of 1 and 10. Scores were 7.3 and 8.4, respectively. Although this study’s sample was identified as being "hopeful," their hope scores are consistent with other populations. Not only do these scores reflect the presence of hope, but these scores suggest high levels of hope (Yates, 1993).

Knowing that patients with advanced stage cancer, as well as other patient populations regardless of diagnosis, have hope is important for nurses caring for these populations. Much of the psychological response literature related to life-threatening illnesses has historically focused on negative coping responses such as anger and denial. Nursing care is frequently guided by the patient’s negative coping responses involving expressions of "powerlessness" and "hopelessness." Recognizing that a patient has hope provides the nurse with a new perspective or attitude in establishing a therapeutic relationship as well as planning interventions that focus and build on the patient’s positive experiences and qualities, and not the negative aspects of the cancer experience.
Qualities of Hope

In this study, the subjects' definitions and descriptions of hope and hope qualities included future-related, spiritual themes, hope's abstract nature, and hope associated with positive feelings and physical presence. These qualities are similar to those found in the hope theory literature as well as those in current hope research. These qualities reflect Dufault and Martocchio's (1985) classic dimensions of hope that include affective, cognitive, behavioral, affiliative, and temporal. The identified qualities of hope are similar to previous qualitative research studies (Hinds, 1984; Stanley, 1978). This study is unique in the importance spirituality plays in defining hope, as well as being the source of hope, in adults who are perceived as having hope.

This population's description of hope does not provide evidence to support the notion that hope is a primary emotion as debated by emotion theorists. This is especially interesting in view of the fact that the sample is representative of individuals with high hope. According to Lazarus (1991), an emotion needs action tendencies, affect or subjective experience, and physiological responses. Action tendencies, moving toward an image or idea, are what make an emotion embodied (Lazarus, 1991). Comments from this population reflect a sense of moving toward something as described by a "subjects' readiness to move on" or an identified goal with actions in maintaining or moving...
towards normalcy. For this population, hope does seem to "move" a person forward. The affect or subjective experience of hope in this population is equally ambiguous. Although many of the individuals' definitions of hope shared similar themes and qualities of hope, there did not appear to be high agreement in specific feelings associated only to hope. Hope does not appear to have obvious physiological responses. The heart does not race; facial expressions do not change. Subjects describe having hope as being "peaceful" or having a "sense of well-being" or being "physically alive," raising such questions as: Is being alive not a physiological response? This lack of physiological evidence is most likely related to a lack of measures sensitive enough to capture changes at an immunological level. Although these study results do not refute the idea that hope is a primary emotion, the results do not provide strong evidence that it is not a primary emotion.

It is also interesting that definitions of hope provided by this population did not reflect the individual's current life-threatening cancer experience. The descriptions of hope are very "normal" and universal. Even as a collective, it was difficult to differentiate between those receiving palliative care and those receiving active treatment except for the slightly lower but not statistically significant hope scores of those receiving palliative care. An example of this consensus can be seen in
comparing Maureen’s and Pat’s views of themselves as active participants in their hope. Maureen believes hope is “something that you want, and you’re not so sure you’ll get it but you want to put some effort into bringing it about if you possibly can.” Pat’s definition is similar: “Hope is wanting to continue, to be available to live my life. To live it rather than just let it happen.” Yet Maureen’s next sentence is, “I feel comfortable in the fact that I know that I am going to go now.”

Influences of Hope

In many areas, this hopeful population is not unique in identifying qualitatively what influences their hope and, in fact, many of the findings are similar to other studies. Relationships with family, friends and support systems, spiritual/religious beliefs, and positive attitudes have been identified in Hind’s (1989), Herth’s (1990), and Post-White et al.’s (1996) studies as well. Unlike these other studies, this present population also identifies control of physical symptoms as an important influence of their hope.

Although this group stated that their hope could be influenced positively as well as negatively, the focus was primarily on positive influences of hope as compared to both Hind’s (1989) and Herth’s (1990) populations who identified specific hope hindering influences such as being all alone or devaluation of personhood. This is possibly due to this population’s identified hopeful natures.
Both qualitative and quantitative data support the presence of hope-related variables identified by the oncology literature and as assessed by the SHS and QLI, including physical symptoms, pain, disease progression, gender, age, spirituality, and relationships with others.

This study and several other studies reported no statistically significant correlations between age, gender, phase of illness, and hope (McGill & Paul, 1993; Mickley et al., 1992; Post-White et al., 1996; Stoner, 1982). Also consistent with other hope research was a positive correlation of hope to the psychological/spiritual influences. However, in evaluating the results of this study and other studies, it is important to look at all of the data and weigh the quantitative (statistical) findings with the qualitative (descriptive) findings as to the clinical relevance and practical applications. As noted in this study, many individuals may share similar circumstances and similar hope scores, but hope goals are consistently unique and individual. This is seen in comparing the results of Pam and Marisha at Time2. Statistically, their cases are very similar. Both have a VAS-H of 10 (0-10 scale). Their scores are the same; they arguably have equal amounts of hope. They even share very strong spiritual beliefs. Both are married and have children. They both have breast cancer. However, Pam is the mother of a 3-year-old and a 1-year-old, and she is still receiving active chemotherapy for inflammatory breast disease. Marisha is in the end stages of metastatic
breast disease and is bedridden. What they hope for and what
influences and nurtures their hopes are very different.
Pam’s hopes are focused on her white blood cell count and
going the baby to sleep all night. Her support system
includes her in-laws who have moved in to help take care of
the children. Marisha’s hopes are “determined and answered
by the Lord” and focuses on being able to turn in bed
without dislocating her hip. Her 16-year-old daughter sleeps
on the floor at the foot of her bed. To the nurse caring for
each, their hopes would not be the same. Statistically,
however, there is no difference.

In discussing this difference between clinical
relevance and statistical significance, it is important to
recognize that statistical methods used in evaluating
relationships generally represent linear relationships among
variables (Breckler, 1996). These numbers and correlations
are valuable, especially in a descriptive study such as
this, as a way to organize and summarize data that might
suggest trends and “loose” relationships. However, Lefort
(1993) documents that there is a growing recognition that
statistical significance testing is not always meaningful
from a clinical point of view. Lefort also takes the
position that clinical significance is best defined by
clients and families and emphasizes the importance of
context.

Breckler (1996) also cautions that it may be another
mistake to conclude that two variables are not related
because the correlation between them is not significant. "A variety of nonlinear relationships are possible and may be important" (Breckler, 1996, p. 20). The literature and this study agree that physical symptoms do impact hope. However, for this study, neither the VAS-P nor the health function status subscale correlated with any hope measures. A similar discrepancy was noted in the study of Post-White et al. (1996). There was no correlation between spirituality scores and hope score, yet 75% of the study population identified spirituality as an important source of hope. Breckler suggests that although these "moderator variables" do not have a linear relationship to the psychological variable, they do influence it.

This apparent inconsistency between clinical and statistical significance is faced by nurses every day in planning effective care. Data from this study are important in guiding and suggesting factors that have been identified as influencing hope; however, the nurse must evaluate each individual situation and, more importantly, must evaluate the specific hopes of the individual.

**Hope Goals and Outcomes**

This study includes specific findings that will benefit nurses in planning the individual and personal care for hopeful adults with advanced stage cancer. These findings indicate that hope goals and outcomes vary according to the
patient population, the phase of the illness, and the age or developmental stage of the individual.

This study revealed that hope goals and outcomes varied widely according to the type of patient population. In comparing advanced stage cancer patients from this study with other patient populations from the nursing literature, it became apparent that hope outcomes were unique to this cancer group. For example, a typical hope outcome for this group involved improving or adapting to physical symptoms related to their cancer or to their cancer treatment. Maggie hopes "not to be so tired." However, it is important to note that subjects' comments and scores strongly support the idea that hope is not tied exclusively to physical well-being but includes personal qualities and interpersonal interactions. These findings are similar to Raleigh and Boehm (1994) who asked 42 chronically ill patients what they hoped for. Answers included family, friends, health, society, self-development, and spirituality.

Hind's (1989) study involving adolescent substance abusers also identified specific hope goals. The results from her study are useful in general understanding of the difference between patient populations and hope goals and outcomes. Her patient population hope goals included sobriety, getting along with others, and satisfaction with self. However, the fact that her population is not suffering from a disease, per se, limits its ultimate usefulness in
helping nurses address the needs of terminally ill cancer patients.

Herth's (1990) study supports the findings of this study concerning the importance of self and others in individual hope goals during their terminal illness experience. However, because Herth's population included individuals dying from a number of different diseases such as AIDS and cardiovascular diseases, her hope-related goals reflect a slightly different population and demonstrate the difference between patient populations and hope goals.

This study reinforces the findings of other studies that the phase of the illness is of crucial importance in understanding hope outcomes. This population is divided into two very distinct groups: those receiving active treatments and those receiving palliative care only. Hope goals varied distinctly according to their phase of illness. Those subjects in the active treatment group talked about hope goals in terms of probability of realizing their goals in the future. Pat hopes to see "my children mature and my grandchildren graduate from high school." In contrast, those subjects in the palliative care group talked about hope goals in terms of daily expectations. Maureen hopes "people will come and visit with me today."

Herth (1990) and Hinds (1989) similarly report that hope goals varied according to the phase of illness. Herth defined phases in terms of activities in daily living. Those who were still able to be up and about had specific aims
such as cleaning the closet. The aims of those with more pronounced physical changes focused less on self and more on others. When death became imminent, specific aims included a desire for serenity and inner peace. Hinds also noted changes of hope goals during different phases of recovery. On admission, a goal was to maintain sobriety. Different categories of hope emerged at 4-5 days after admission and after discharge.

This study also revealed that specific hope goals varied significantly according to age and developmental stage, a variable not explicitly addressed in other hope studies. Age, not in the chronological sense but in the developmental life span sense, is an important variable that should be considered in understanding distinctions between individual experiences. Those receiving palliative care "hoped" to be comfortable and to spend time with close family and friends. Those receiving active treatment, however, mentioned goals primarily focused on "life span"-related events commonly associated with adults ages 20-59. These included family roles and responsibilities, work roles, and as many normal activities as their health would allow.

The difference between these two groups is explained by Kemp (1995) who considers "advanced disease" as an important development stage and likens it to Erickson's last stage of development: integrity versus despair. What is known about
this stage is minimal, and even less is known about the transition to this "terminal" stage.

In addition, this study reveals the extent to which hope goals vary according to the individual's expectation of attaining goals as noted in the differences in comments and the differences noted in the global hope scores. Those individuals in the terminal stages appear to have little expectation of completing global activities as defined by the SHS. Although neither group specifically mentioned long-term future goals or worldly concerns, those receiving palliative care did talk more about the "when," not "ifs," of their death. For example, they "probably" would not "see a decrease in unemployment in the U.S." (a global subscale question). This is most likely due to a realistic view expressed by the palliative group that in probability global goals would not be accomplished. This statistically significant change over time may reflect more the terminal disease stage than actual changes over time. Subject comments support this. Maureen had "hoped I would live, but now I'm not. So no, I do not have hope in the living. I have hope that I will be helped to get through this . . . with the respect that I need."

This study also demonstrates that hope goals vary according to whether they are expressed in concrete or abstract terms, a quality that also correlates with phase of therapy. Those receiving active treatment defined concrete goals relating to physiological changes, such as increased
WBC counts, or family activities, such as planning a trip. Activities were planned in temporal times as next week or next month. Those receiving palliative care, however, tended to define hope goals in abstract terms. Trisha hoped for "peace within myself," and Trisha hopes for "freedom from this pain." Both Hinds (1989) and Herth (1990) observed similar responses in their populations. Initially, Herth's participants who were able to get about identified specific tangible and focused goals. A final change was noted as the aims were discussed in terms of "being" rather than having or doing. In Hind's study, as her subjects started responding positively to substance abuse treatment, hope goals became more defined and realistic. For an example, an admission hope goal was to obtain "fame and fortune"; by the end of 4 weeks of therapy, a defined goal was to "get along with their parents."

As a consequence, there is a need for nurses to identify hope goals for planning, implementing, and evaluating appropriate and individual nursing care. The idea that there are different goals in cancer therapy is not new. However, including hope-related goals as part of cancer therapy is new. Coluzzi and Rhiner (1996) state that "oncology practices must . . . provide direct care based on realistic goals set by the patient, family, and health care professionals . . . and offer either curative, active palliation, or palliative/hospice care" (p. 1324). The goals of palliative/hospice care as defined by Coluzzi and Rhiner...
include symptom control, psychosocial/medical/spiritual support, and prolongation of life (unlikely). The goals of active palliation include symptom control and prolongation of life (possible).

Hope goals are dependent on the patient population, phase of the illness, and developmental stage. Hope goals also vary in degree of expectancy and concreteness. The oncology nurse clinician must consider all of these factors in implementing hope nurturing interventions.

Hope Over Time

It is generally believed that as individuals come closer to death, their hope will decrease. However, the results of this study that looked at hope scores at two time intervals, as well as both Herth's (1990) and Hind's (1989) studies that measured hope scores at three time intervals, demonstrate qualitatively and quantitatively that many hope qualities remain stable over time, such as personal definitions of hope, spiritual beliefs, personal qualities, and interactions with others. Overall, hope scores also remained stable, reflecting only slight increases and/or decreases at different time intervals. However, this study has also demonstrated that hope goals are not fixed but are continually being redefined and refocused.

There are several possible explanations as to why hope scores seem to remain constant over time. However, any
explanation must account for the relationship between the
dynamic and stable qualities of hope.

Other researchers have tried to capture hope changing
over time (McGee, 1984; Nowotny, 1989). Raleigh and Boehm
(1994), in an attempt to differentiate state versus trait
qualities of hope, modified the SHS to include two forms:
one that asks the question "how do you feel now?" and "how
do you usually feel?" They hypothesized that hope would vary
over short periods of time, but there may also be an
underlying stable level of hope based on individual
differences that depend on personal, situational, and social
factors. In fact, at Time, there was a very high correlation
($r = .90; p < .001$) between the two forms and, because there
was no support for the state/trait hypothesis, the trait
form was omitted from further analysis.

Another explanation may be due to the way "change" is
being evaluated. In an attempt to measure change, this
study, as well as other studies, attempts to evaluate these
qualities by equating "dynamic" to "constant change over
time." This partially inaccurate view of change is strongly
supported by Lazarus and Folkman's (1984) transactional
model of coping. They argue that coping responses change
constantly with ongoing appraisals and reappraisals of the
specific situation. It is assumed by many that change and
coping are expected to occur in a smooth and orderly fashion
that has temporal duration and sequence and that "change" is
a modification in quantity, either in size, volume, or
length. As such, change can be measured objectively as a difference between two or more positions on the temporal continuum (Slife, 1993).

Slife (1993) believes "that a 'quantitative' view is only one conceptualization of change. By contrast, 'qualitative' change refers to the sudden alteration of an entity's basic nature or quality" (p. 234). Qualitative changes are not typically temporal because no passage of time (or sequence of observations) takes place. The change process occurs in "instantaneous" shifts between states or qualities. This implies that qualitative change can take place and be observed all at once and is not linear in nature (Slife, 1993). This helps to understand the differences (not discrepancies) between the quantitative data and the qualitative data.

Another way to understand the difference is to liken hope to a "gift" in a box. The box has visible, predictable quantities by virtue of being a box. It has eight corners, is three dimensional, is enclosed on all sides, and holds a "gift." The gift is unknown, abstract; it cannot be seen and cannot be separated from the box until the box is opened. The quantitative scores of hope provide a view, dimension, or degree of hope. However, it is the individual's responses to the interview questions that open the box to show the gift, their hope, as described by goals, definitions, and influences. It is their hope for that moment. Over time, the box remains basically unchanged. There may be a nick here, a
new color of paint, but each time the box is opened, the gift may have a different meaning or usefulness or purpose for that moment or that context. Although some quantities and qualities of hope may be the same, others will not be. Although it is understandable to want to define and describe all aspects of hope, it is impossible. There are too many qualities and dimensions of hope that simply cannot be described. Yet, by understanding the nature and qualities of hope and identifying those qualities that can be assessed and influenced, nurses can then focus on nurturing that dimension of hope.

An understanding of how hope changes over time can be gained by observing individuals as they move from one phase of an illness to another. Their hope goals change not as a result of time but as a result of the progress of their disease. Or perhaps as hope goals change, the disease phase also changes. However, because it is difficult for researchers to document the transitions between phases, researchers tend to focus on the initial diagnosing phase and terminal phase of cancer, paying less attention to those who have been diagnosed with a highly fatal cancer or the transition process.

Hope's stability over time and the discussion relating to hope goals and outcomes suggest a dichotomy. Numerically, the SHS purports to measure hope goals. However, this study, as well as other studies, qualitatively reports that hope goals absolutely do change depending on the circumstances,
person, and environment. The results are really not contradictory but in fact reaffirm the complexity and multidimensionality of hope and emotions. This study, in fact, supports Lazarus' (1991) metatheoretical themes of emotion that identify two interdependent principles: "process and structure referring to the idea that there are stable and recurrent emotional patterns in the same individual" (p. 39). For this population, the stable qualities of hope represent "structure," and the changing hope goals represent "process."

Although these results are congruent with current nursing research and Lazarus and Folkman's Stress Model, this study is unique in suggesting that hope goals and stated outcomes are what define hope for the individual. This study also explains the difficulty of numerically evaluating the dynamic nature of hope and sheds light on the importance of considering context in understanding hope changes over time.

Special Needs of Those Receiving Active Therapy

The hope experiences and needs of those who are aware that their diagnoses carry relatively poor prognoses but are still pursuing active treatment to date have not been addressed in the literature. These individuals live with an awareness that life may be foreshortened (McCormick & Conley, 1995). Their challenge is to make sense of sudden
changes and losses in health status and roles and expectations, as well as trying to maintain a sense of normalcy. This experience is not unique to cancer patients. For example, HIV is a disease that has a long latency period and HIV patients, too, are forced to live their lives with a constant eye toward their own death (Hall, 1994).

Unlike their terminally ill counterparts, who have access to hospice-type support designed to meet most of their psychological and physical needs, the active therapy patients' interactions with any health care provider are generally limited and task oriented. Active therapy patients usually see their physicians monthly for diagnostic tests, test results, and treatment changes, and their nurses three to four times per week for chemotherapy. Unfortunately, both of these health care professionals, despite good intentions, are limited by time constraints and workloads.

Most oncology research deals with terminal cancer patients during the period of time immediately preceding their death. A small exploratory study by McCormick and Conley (1995) interviewed 6 patients and identified a "living with an incurable illness phase" before turning to a palliative care mode. One patient defined the transition as being "incurable" versus "terminal." "'Incurable' meant I would live with knowing I was going to die. 'Terminal' meant it was time to prepare myself to die" (p. 241). The authors suggest that patients' perspective shows heightened anxiety and communication as they precede through these phases. The
authors also believe that psychological and social support are especially important at these times.

All 6 subjects in the present study who were receiving active treatment for their cancer verbalized a need for a professional person to whom they could ask questions about treatment options, ways to treat cancer and chemotherapy symptoms and side effects, what to expect during this time, and how to deal with their feelings. Two were attending a breast cancer support group which did provide a valuable informal network. Those who did not want to associate with a support group found other resources. Pat reconnected with a nurse practitioner friend in California who focused on holistic health. Margaret utilized several professional friends; one referred her to an oncology nurse clinician. Molly is a nurse herself and utilized her informal professional network.

It is clear from their comments that there was a strong need for an oncology specialist nurse/counselor with advanced practice skills who was knowledgeable in treatments, medical and alternative interventions, community resources, and counseling, in other words, a resource person. The importance of individual therapy is supported by a review of 17 cancer studies by Hill, Kelleher, and Shumaker (1992) that evaluated the effects of psychological interventions. Fifteen of these studies provided evidence that psychosocial interventions (11 with one-on-one counseling) reduced psychological distress.
A community-based advanced practice nurse is the logical person to do this work. Although this role has been developed in larger oncology environments like Salt Lake City and Seattle, for the larger number of people living in smaller communities like Ogden and Roy in Utah and Kennewick and Walla Walla in Washington, there is no nurse specialist available. As a consequence, the needs of a group of individuals—not a large group, but a group experiencing one of life’s greatest crises, a life-threatening illness—are not being addressed by health care. Comments in this study support the idea that health care providers (nurses) can impact hope in a positive way during this experience either by positive and caring interactions, by helping to plan realistic goals and suggesting ways of meeting those goals, or by implementing a plan of care that will help the patient feel better physically (Ferrans, 1994). Although evaluation of the effectiveness of this role may be difficult overall, it may influence not only personal hope but result in a longer survival time and higher levels of quality of life.

Nursing Implications

Nursing Practice

Data from this study include valuable information that can aid oncology nurses in assessing, identifying, planning, and evaluating hope-nurturing interventions. Even though the data reflect the experiences of hopeful adults, many of the following suggestions for nursing practice would be
appropriate with any patient population with a terminal illness.

Assessment of hope. The study results strongly suggest that the use of similar qualitative and quantitative assessment techniques can be used in the clinical setting, namely, the use of VAS-H and questioning. Both techniques are valid means of assessing individual patient hope during initial and ongoing health assessments.

An important tool for nursing practice is the VAS-H. Because there are certain hope qualities that appear to be "stable," a VAS score provides at least a general idea and a numerical descriptor of the person's perceived level of hope. This hope score provides valuable baseline or screening information that is useful in identifying a person who might be "at risk" who reports an unusually low hope score.

The VAS-H is easy to administer. In addition, the VAS is fast, easy (for this study a 100% completion rate), and reliable. VAS marks did not seem to be thoughtlessly placed. The VAS has become a commonly used instrument for evaluating subjective feelings (Cline et al., 1992).

However, the VAS has limitations. As seen with this study, the VAS-H does not appear to discriminate between individuals who "have hope." Initially, it needs to be evaluated as a screening tool. The VAS should not be used to evaluate hope-nurturing interventions or changes of hope...
over time. Hope scales do not appear to be sensitive to the
dynamic influences and qualities of hope.

Assessment must also included evaluating and
reevaluating those hope factors that change as the cancer
progresses. This study demonstrates that "phase of illness"
affects many of the dynamic hope variables that need to be
assessed as they relate to the individual’s hope, including
physical symptoms of the illness (e.g., pain vs. fatigue),
type of support needed (hospice care vs. support groups),
psychological and spiritual needs, family and support
resources, and desired learning (relaxation techniques vs.
side effects of treatment). The stage also affects outcomes
or goals of hope such as goals in therapy (being made
comfortable vs. maintaining normal activities). Finally, the
stage of illness affects and helps to understand the dynamic
and individual nature of hope.

Identifying hope goals. One of the most valuable
findings of this study was the importance and ease of
identifying hope goals as they related to life expectations,
relationships, routines/events, and spiritual goals.
Clinicians must ask each individual, "What do you hope for?"
and "What can I do to nurture your hope?" Personal goals
related to hope change in accordance with one’s life
situation and must be reassessed as symptoms and
circumstances change (Nowotny, 1989).

The only way to identify these goals is to ask what
they hope for. Hummelvoll and Silva (1994) believe it is
"vital to get hold of the client's wishes and hopes in order for the nurse and client to agree on the objectives that should guide the nursing plan" (p. 13).

**Measurement of hope outcomes.** Outcome measurements become extremely important as the current health care system trend is moving toward using outcomes as a means for evaluating effectiveness of care (Micek et al., 1996). Historically, nursing performances were measured by accomplishment of nursing activities. Patient care-plans focused on completing these nursing tasks (Micek et al., 1996). As a consequence, hope-nurturing interventions have always been difficult to evaluate because they are individual and contextual. However, this study indicates that although hope cannot be measured directly, hope can be measured indirectly by using a related outcome.

An example involves Molly who, when asked what she hoped for, stated that she "didn't want to miss any of her clogging classes on Thursday night." Treatment schedules were rearranged, rest times were encouraged, and she was able to get to all clogging classes in December. One hundred percent attendance is the measurable outcome, and her hope was nurtured. Similarly, Pam hopes to see her 3-year-old son go on his first date. Given her diagnosis, she knows this is not likely. Nursing interventions might include suggesting that she write a letter to him now to be read at the time of his first date. The letter then becomes the measurable outcome. Their admission VAS-H scores probably would not
have changed, but their perceived hope or sense of accomplishment has increased and the practitioner has at least an observable, hope-related outcome. Overall, the perceived abstract nature of hope should not inhibit or deter nurses from nurturing hope; it only requires a new way of assessing and evaluating hope.

**Clinical Example of Hope Assessment. Goals, and Outcomes**

**Assessment.** Trisha is seen at her home by a hospice nurse. During the assessment, the nurse asks Trisha if she has hope and what she hopes for. Trisha responds that she does have hope and hopes to be pain free and comfortable. Trisha is asked to complete a VAS-H and a VAS-P. From examining Trisha’s scores of 6.7 and 2.5, respectively, the nurse learns that Trisha does have hope and that her pain is considered mild.

**Hope goals.** Trisha hopes to be pain free. Once the goal is identified, a plan of care can be developed and implemented. Interventions that addressed Trisha’s pain needs included relaxation techniques, use of a long-term analgesia, and better scheduling of personal hygiene activities.

**Evaluation of hope.** These nursing interventions implemented for pain control could also be considered “hope-nurturing.” However, a hope scale would probably not reflect any change. Because the quantities of hope are difficult to
measure objectively, the amount of pain becomes the objective, quantifiable variable. As pain decreases, hope is influenced positively. Being pain free is the measured outcome.

**Nursing Education**

Hope is an important nursing practice concept in the oncology patient as well as any patient who is adapting to a potentially life-threatening illness. Nursing curriculums should include hope theory, qualitative and quantitative assessment techniques of hope, planning interventions based on patients’ hope goals, and, finally, evaluation of hope in the clinical setting. In graduate education, hope must be recognized as an important research variable and hope research must be supported and encouraged.

**Further Research**

An important goal of descriptive research is to generate ideas and provide direction for further research and scholarly inquiry. This study identifies several areas appropriate for further research.

This study sample is limited in size and diversity. By increasing the numbers and expanding the characteristics of the sample to include a more representative group of all types of advanced stage cancer patients would provide a more comprehensive understanding of hope. Further research must also include more males, minorities, different socioeconomic
levels groups, and those who are not married. The diversity would add validity as well as generalizability to this study’s findings.

Using a similar research design, hope needs to be studied in other patient populations, especially those who are perceived as having little or no hope. Comparison of study results would provide very important information relating to the nature of hope.

Most cancer research is done during the time immediately preceding death or right after diagnosis. Little is known about the psychological and physical needs of the individual who has been diagnosed with a predictably fatal cancer but has not transitioned into a terminal care phase. More information is needed regarding that transition. Continuing with this study and adding more subjects would capture two important areas of further research. The first is related to finding out more about the process associated with transitioning from active treatment to terminal care. In addition to finding out more about how and when hope goals change, it is important to discover other factors that may be unique to this experience.

The second area would focus on survival issues. Of the 6 subjects involved in active therapy during the time of data collection, all are currently alive and none have appeared to have transitioned to a terminal care phase. The last interviews occurred between 6 months and 18 months ago. As Molly stated, “Let’s find out why some people survive.”
follow-up descriptive study could be directed at identifying not only their perceptions of why they are still alive when others with similar diagnoses have died but could also attempt to identify other environmental, personal, and social factors contributing to their survival and the role of hope in this process.

**Strengths of the Study**

A strength of this study is the use of qualitative and quantitative data collection and analysis techniques. The use of multiple methods and multiple measures over time is paramount not only in establishing valid and reliable results associated with quantitative research but in establishing the "trustworthiness" of qualitative data. However, by using a small sample to generate the rich qualitative data, the large numbers necessary to obtain the needed power for statistical tests for the quantitative data were not achieved. By using triangulation, the data collected and the findings generated create a comprehensive view of a complex subject and reflect the true state of this human experience (Boyd, 1993).

Psychometrically, triangulation of measurements increased both content and construct validity of the instrumentation used because a greater proportion of the conceptual domain of hope was included without compromising depth and breadth (Jalowiec, 1990). Using multiple methods resulted in an increased ability to rule out rival
explanations of observed change and reduced skepticism of change-related findings (Hinds, 1989) and explained or confirmed dissimilar data. The integration of methods increased the potential for identifying the overlapping or common variance as well as finding the variance unique to each type of method (Mitchell, 1986). Finally, triangulation lessened the significance of potential researcher bias.

Similar research designs have been used by Pam Hinds and Kaye Herth, both well known in the hope research literature with established research programs, and they have used similar data collection techniques, including semistructured interviews and hope scales developed by themselves for their practice and research populations. Their studies, like this study, asked questions relating to sources/influences of hope and hope goals and have looked at hope over time (see Table 18). However, neither Herth's nor Hind's populations are similar to this study's population.

Theoretical triangulation involved the use of several different frames of reference or perspectives in the analysis of the research data (Duffy, 1987). Several domains of hope were examined: hope as an emotion and a coping response, influences and goals of hope, temporal aspects related to hope, and the theoretical constructs of hope. Data were analyzed in terms of the study's conceptual framework (Lazarus & Folkman's [1984] Stress, Appraisal, and Coping model), to hope-related literature, and, finally, to the study population for validation of congruent conclusions.
<table>
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</thead>
<tbody>
<tr>
<td><strong>Sample</strong></td>
<td>12: 26, 10&lt;sup&gt;6&lt;/sup&gt; Adult with advanced stage cancer 6 - palliative tx 6 - active tx</td>
<td>32: 19&lt;sup&gt;6&lt;/sup&gt;, 13&lt;sup&gt;6&lt;/sup&gt; Adult cancer patients with ≥ 6 months to live 24 - active tx 6 - palliative tx</td>
<td>24: 20&lt;sup&gt;6&lt;/sup&gt;, 5&lt;sup&gt;6&lt;/sup&gt; Adolescent substance abusers 30: 8&lt;sup&gt;6&lt;/sup&gt;, 22&lt;sup&gt;6&lt;/sup&gt; Terminally ill adults 11 - cancer 8 - COPD 7 - AIDS 3 - neuro 1 - cardiac</td>
<td></td>
</tr>
<tr>
<td><strong>Measurement Tools</strong></td>
<td>Stoner Hope Scale  Quality of Life Index  VAS-Hope, Pain, QOL</td>
<td>Herth Hope Scale  Spirituality Index  Cohesive Scale  Quality of Life Scale</td>
<td>Hopefulness Scale for Adolescents</td>
<td>Herth Hope Index</td>
</tr>
<tr>
<td><strong>Semi-Structured Interview Questions</strong></td>
<td>Define or describe hope  What influences your hope?</td>
<td>What does having a sense of hope mean to you?  What gives you hope? What inner resources do you draw upon for hope? Does faith or a belief in a higher power influence your hope? Who in your family contributes to your hope?</td>
<td>What impacts your hope?  What kinds of things impact your hope (-)?</td>
<td>What does hope mean to you?  What is a source of your hope? What things cause you to lose hope? What helps you maintain hope?</td>
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</tr>
<tr>
<td></td>
<td>What do you hope for?</td>
<td>What are you hoping for now?</td>
<td>What kinds of things do you hope for?</td>
<td>Does your hope change over time?</td>
</tr>
<tr>
<td><strong>T₁</strong> = Initial interview</td>
<td>None</td>
<td>T₁ = 24-48 after admission to detox unit</td>
<td>T₁ = Entered Hospice able to do ADL (30 subjects)</td>
<td>Do you perceive any changes in your hopefulness?</td>
</tr>
<tr>
<td><strong>T₂</strong> = One month</td>
<td></td>
<td>T₂ = 4-5 days before discharge</td>
<td>T₂ = Severe impairment of ADL (10 only)</td>
<td></td>
</tr>
<tr>
<td><strong>T₃</strong> = One month</td>
<td></td>
<td></td>
<td>T₃ = 4-5 weeks after discharge</td>
<td></td>
</tr>
<tr>
<td></td>
<td>T₁ = Death imminent (10 only)</td>
<td></td>
<td></td>
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</tbody>
</table>

Table 18 (continued)
or explanations for alternative findings. Most findings were consistent between different frames of references. This also increased data analysis and researcher credibility (Duffy, 1987; Miles & Huberman, 1994).

Ongoing data collection and analysis increased overall credibility for several reasons. First, there were ongoing opportunities to return to the data again and again. This allowed time for integration and synthesis of information that yielded new insights and understanding to the data. Second, collecting data over 3 months provided multiple opportunities to collect depth and breadth of information related to the "personal" experience of death and dying as well as specific information related to the nature of hope. Finally, repeat visits provided opportunities to take back to the subjects research observations and conclusions for verification or clarification (Lincoln & Guba, 1985).

Limitations of the Study

Sample Size and Diversity

It is recognized that qualitative research generally deals with small samples, nested in their context and studied in depth (Miles & Huberman, 1994). With a sample size of 12, results from the qualitative and quantitative data must be used cautiously when identifying and evaluating specific hope-related interventions. True to the purpose and design of this study, the data do provide general descriptions and trends that may be used to provide ideas or
direction for possible hope-nurturing interventions as well as for future research.

It had not been anticipated that the convenience sample would reflect such a homogeneous group. Subjects had similar high levels of hope, and they demonstrated as a collective strong spiritual, social, economic, and family support. What cannot be concluded from this study is whether these qualities are common in all adults with advanced stage cancer or only "hopeful" adults with advanced stage cancer of similar racial, cultural, and age categories.

**Measurement Issues**

**Appropriateness.** Long questionnaires, such as the SHS and QLI, are not appropriate for very ill people. This became apparent when one half of the palliative care subjects and one fourth of the active treatment subjects did not complete the questionnaire at least once. These questionnaires tended to be time consuming and cumbersome, inspiring some questions regarding their relevance. This is not unique to these two tools. The Miller Hope Scale was designed to provide health care providers with an objective tool to assess the concept of hope. In one study involving the elderly, the average time it took to complete the questions was 20-30 min and 40% required assistance (Beckman, 1996). Raleigh and Boehm (1994) rearranged the SHS to enable the respondent to complete the questionnaire in
one 5-min reading. How this was accomplished and how effective this was are not reported.

The usefulness of questionnaires as a research or an assessment tool in a clinical setting may be enhanced by using alternative ways to collect the data, such as having the investigator verbally ask the questions during the interview or calling the subject later and completing the questionnaire over the phone rather than leaving the scales to be completed by the subject as was done in this study.

The incomplete data sets limited the evaluation of hope over time. Without complete data sets, it was not possible to look at hope over Time1, Time2, and Time3. However, there was enough to compare Time1 to Time3. Regardless, these data provide general trends and descriptions. The information that was completed is valuable for validation of qualitative information. It became apparent from this study that the selection of measurement tools for research and clinical practice must include not only the tools' validity but also the tools' appropriateness as well.

Validity. Another measurement issue is the validity of the hope tools in general. Do the scores really reflect hope and hope qualities? For the SHS, validity is an important issue. SHS did quantify the presence of certain qualities; however, dynamic changes were not captured. Convergent validity was not supported in that SHS and VAS-H did not correlate significantly with each other at Time1, Time2, or Time3. Subjects commented on the lack of relevance of some
of the SHS questions. Especially noted were the global subscale questions. By comparison, VAS-QOL and QLI did have significant correlations at $p < .05$.

Because of the high correlation between the hope scales and quality-of-life scales, there is the question of whether the SHS is measuring hope or quality of life or another related construct. Quality of life shares many similar dimensions. In a content analysis, Haase, Britt, Coward, Leidy, and Penn (1992) found that hope shares five common factors: four antecedents and five outcomes with spiritual perspectives, acceptance, and self-transcendence.

Ultimately, this becomes more of a theoretical discussion relating to an abstract phenomenon. Most experts find, and this study supports, that it is difficult to capture only "hope" due to hope's complex and abstract nature.

**Conclusion**

This study has described and defined the experience of hopeful adults with advanced stage cancer. Most of the information is consistent with and validates previous research of other patient populations and Lazarus and Folkman's (1984) conceptual model of stress, appraisal, and coping. This study also adds new knowledge to the hope literature. Important in this study were the findings that hope goals are individually defined and are unique to the patient population, influenced by the phase of the illness and developmental stage of the individual. Hope goals also
vary in degree of expectance and concreteness and require reassessment as conditions change. By identifying an individual's hope goals, nurses can plan and implement interventions to move toward individual hope goals. In addition, this study presents new ways of evaluating and viewing hope. Finally, this study provides potentially helpful, preliminary information that can be used clinically by nurses working with individuals experiencing a life-threatening illness.

Sandelowski (1993) states that a "good qualitative data reduction grabs the 'essences' of a phenomenon" (p. 3). The challenge has been to communicate the human "essence" of hope and cancer in a manner that is scholarly yet personal. From this study, nurses are better able to understand the meaning of a Sunday morning comic, a summer rose, and a chocolate malt to a man named Jeff.
Dear Potential Research Subject:

Background: My name is Mary Anne Hales Reynolds. I am a registered nurse conducting research as part of the requirements for completing my doctorate in nursing from the University of Utah. My area of research involves "hope" in adults (ages 20-59) with advanced stage cancer. The purpose of this research study is to describe "hope" as defined and experienced by this younger cancer population.

Study procedure: Participation in this study would involve me coming to your home (or a location to be determined by you) to do three personal tape recorded interviews, once a month for three consecutive months. You will be asked to describe and give examples of your personal hope. With each visit you will be asked to complete two questionnaires and three short rating scales. Each interview period should last approximately 1/2-1 hour and will be scheduled at your convenience. You may decide not to participate at any time. This study does not require any procedures, treatments or interventions.

Risks: This research involves minimal risk to you, the subject. There is no remuneration. You may experience psychological distress in discussing your cancer experience. Participation in this study is completely voluntary and you may discontinue participation at any time.

Benefits: There are several potential benefits to you and others. You may find talking about your cancer helpful in understanding and integrating your experience. The information you share may help others with advanced-stage cancers in the future. Finally, you are contributing valuable and important knowledge regarding the cancer experience, hope and nursing care.

Confidentiality/Privacy: Confidentiality of the records and data pertaining to you, the subject, will be maintained in the following ways: a) you will be identified by first name or initials only. Your actual name will be known only to me, the researcher; b) actual or raw data will be available only to the researcher c) at the completion of the study tapes, narrative, artifacts etc., will be secured in a locked cabinet, e) you may request a copy of your tapes and artifacts after the research is completed.

Person to contact: If you have any questions about the research or related matters please contact: Mary Anne Hales Reynolds, RN at [redacted] or [redacted], any time of the day.
Institutional Review Board: If you have questions regarding your rights as a research subject, or if problems arise which you do not feel you can discuss with the investigator, please contact the Institutional Review Board Office at (801) [redacted].

Voluntary participation: Participation is voluntary. Refusal to participate will involve no penalty or loss of benefits to which you (the subject) are otherwise entitled. You may discontinue participation at any time and still receive the same standard of care that you would have otherwise received.

**************************************************

INFORMED CONSENT

I have received a copy of this consent document and related materials and agree to participate in the study. I also give Mary Anne Hales Reynolds permission to use my first name and/or initials only, personal quotes, examples, artifacts and scores in the writing up and presentation of her research findings.

YOUR SIGNATURE

WITNESS

DATE

DATE

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APPENDIX B

FIRST INTERVIEW/DEMOGRAPHICS
A. Personal Information
   a. background (family history; where born, etc.)
   b. education
   c. religious/spiritual beliefs
   d. personal interests and hobbies

B. Social Information
   a. family
   b. friends
   c. important/significant others

C. Professional Experiences

D. Medical History
   a. general medical history
   b. diagnosis and treatment of cancer
   c. current status

E. Can you tell me a little about yourself?
   How would you evaluate yourself?
   a. physically
   b. emotionally
   c. socially
   d. spiritually

F. How do you think being (age: ___) affects your illness experience?

G. a. What are the most meaningful events right now?
   b. How has this changed since your illness?

H. a. Who are the most important people in your life right now?
   b. How has this changed since your illness?

I. What have you learned from your illness thus far?

J. What do you think is important for people (like me) to know or understand about your experience?
APPENDIX C

SEMISTRUCTURED INTERVIEW QUESTIONS
Every visit questions

Initials:___________________________

1. How do you feel today?
   a. physically
   b. emotionally
   c. socially
   d. spiritually

2. What has changed or happened since I was here last?

3. What are some of the things you did last week (or since I was here last?)
   a. people
   b. things
   c. events

4. What is a typical day like?

5. What gets you up in the morning?

6. What keeps you going?
   a. during the day?
   b. throughout the week?

7. What makes you smile?

8. What makes you feel down?

9. Do you have hope?

10. a. How do you know you have hope?
     b. How do you know you do not have hope?

11. What do you hope for?

12. a. How does it feel to have hope?
     b. How does it feel not to have hope?

13. Does your hope change?

14. Give an example of how hope changes.

15. What influences your:
    a. hope
    b. hopelessness?

16. What can others do to increase/nurture your hope/s?

17. How do you define or describe hope?
18. What do you hope to accomplish
   a. today
   b. this week
   c. in the future

19. What are some of the things you are planning this week?

20. Who are you planning on seeing this week?

21. What are the most meaningful events right now?

22. Who are the most important people in your life right now?

23. Why did you agree to participate in this study?

24. What have you learned from your illness thus far?

25. What do you think is important for people (like me) to know or understand about your experience?
APPENDIX D

STONER HOPE SCALE
**STONER HOPE SCALE**

**Part I.** Listed below are 30 sentences which contain goals which any person might want to achieve in his/her lifetime. Choose the opinion which best describes how you feel. As you read each sentence, think about your own future and about what is important to you. Please mark your answer by circling the number.

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

<table>
<thead>
<tr>
<th>HOW IMPORTANT IS IT FOR YOU TO:</th>
<th>Not Important</th>
<th>Somewhat Important</th>
<th>Quite Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. See a decrease in unemployment in the U.S.?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Have open communication with the people who are important to me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Feel good about my life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Have other people enjoy having me around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. See a decrease in crime and violence?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Resolve conflicts with the people who are important to me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Have people seek me out as a friend?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>8. See a decrease in the threat of nuclear war?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>9. Overcome fears that I have?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>10. Believe in myself as a person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. See an improvement in efforts to resolve problems with pollution of the environment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Have better education in our schools?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Have the courage to deal with my life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Resolve conflicts within myself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

(Please Go to Next Page)

Note: Adapted from Erickson, R. C., Post, R. D., and Paige, A. B. (1975)
<table>
<thead>
<tr>
<th>Question</th>
<th>Not Important</th>
<th>Somewhat Important</th>
<th>Quite Important</th>
<th>Extremely Important</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Have better programming on television?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. Have people come to me for help with problems?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Be free from pain?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. Make lots of new friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Have access to cultural facilities like symphonies, theaters, and art museums?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. Be mentally alert and always learning?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. Have local government agencies be responsive to people in neighborhoods?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. Be at peace with myself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. Have other people respect and admire me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. Spend more time with the people who are important to me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. Be persistent in solving my problems?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. Be in control of what happens in my life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. Participate in political activities?</td>
<td>1</td>
<td>2</td>
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<td>28. Share joys and sorrows with the people who are important to me?</td>
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<td>4</td>
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<td>29. Have better mass transportation in our cities?</td>
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<td>4</td>
</tr>
<tr>
<td>30. Have friends who will provide help when I need it?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

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Note: Adapted from Erickson, R. C., Post, R. D., and Paige, A. B. (1975)
Part II. Listed below are 30 sentences which contain goals which any person might want to achieve in his/her lifetime. Choose the opinion which best describes how you feel. As you read each sentence, think about your own future and about what is likely for you. Please mark your answer by circling the number.

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

<table>
<thead>
<tr>
<th>HOW LIKELY IS IT FOR YOU TO:</th>
<th>Cannot Possibly Be Realized</th>
<th>Probably Will Not Be Realized</th>
<th>May Be Realized</th>
<th>Definitely Will Be Realized</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. See a decrease in unemployment in the U.S.?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Have open communication with the people who are important to me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Feel good about my life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Have other people enjoy having me around?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. See a decrease in crime and violence?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Resolve conflicts with the people who are important to me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Have people seek me out as a friend?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. See a decrease in the threat of nuclear war?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Overcome fears that I have?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Believe in myself as a person?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. See an improvement in efforts to resolve problems with pollution of the environment?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Have better education in our schools?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Have the courage to deal with my life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Resolve conflicts within myself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Have better programming on television?</td>
<td>1</td>
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<td>3</td>
<td>4</td>
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Note: Adapted from Erickson, R. C., Post, R. D., and Paige, A. B. (1975)

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### HOW LIKELY IS IT FOR YOU TO:

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<th>Question</th>
<th>1</th>
<th>2</th>
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<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>16. Have people come to me for help with problems?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Be free from pain?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. Make lots of new friends?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>19. Have access to cultural facilities like symphonies, theaters, and art museums?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. Be mentally alert and always learning?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. Have local government agencies be responsive to people in neighborhoods?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. Be at peace with myself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>23. Have other people respect and admire me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>24. Spend more time with the people who are important to me?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>25. Be persistent in solving my problems?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>26. Be in control of what happens in my life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>27. Participate in political activities?</td>
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APPENDIX E

QUALITY OF LIFE INDEX
**Ferrans and Powers**  
**QUALITY OF LIFE INDEX**

**Part I.** For each of the following, please choose the answer that best describes how satisfied you are with that area of your life. Please mark your answer by circling the number. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>HOW SATISFIED ARE YOU WITH:</th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Your health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>2. The health care you are receiving?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>3. The amount of pain that you have?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>4. The amount of energy you have for everyday activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>5. Your physical independence?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>6. The amount of control you have over your life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7. Your potential to live a long time?</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
<td>6</td>
</tr>
<tr>
<td>8. Your family’s health?</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>6</td>
</tr>
<tr>
<td>9. Your children?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>10. Your family’s happiness?</td>
<td>1</td>
<td>2</td>
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<td>6</td>
</tr>
<tr>
<td>11. Your relationship with your spouse/significant other?</td>
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<td>6</td>
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<tr>
<td>12. Your sex life?</td>
<td>1</td>
<td>2</td>
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<td>6</td>
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<tr>
<td>13. Your friends?</td>
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<tr>
<td>14. The emotional support you get from others?</td>
<td>1</td>
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<td>6</td>
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<tr>
<td>15. Your ability to meet family responsibilities?</td>
<td>1</td>
<td>2</td>
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<td>6</td>
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<tr>
<td>16. Your usefulness to others?</td>
<td>1</td>
<td>2</td>
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<td>6</td>
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<tr>
<td>17. The amount of stress or worries in your life?</td>
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<td>6</td>
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<tr>
<td>18. Your home?</td>
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</tbody>
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© Copyright 1984 C. Ferrans and M. Powers (Do not use without permission.)
**HOW SATISFIED ARE YOU WITH:**

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<tr>
<th>Question</th>
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<th>3</th>
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</thead>
<tbody>
<tr>
<td>19. Your neighborhood?</td>
<td></td>
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<tr>
<td>20. Your standard of living?</td>
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<td>21. Your job?</td>
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<tr>
<td>22. Not having a job?</td>
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<td>23. Your education?</td>
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<td>24. Your financial independence?</td>
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<td>25. Your leisure time activities?</td>
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<tr>
<td>26. Your ability to travel on vacations?</td>
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<tr>
<td>27. Your potential for a happy old age/retirement?</td>
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<tr>
<td>28. Your peace of mind?</td>
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<td>29. Your personal faith in God?</td>
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<td>30. Your achievement of personal goals?</td>
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<td>33. Your personal appearance?</td>
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<td>34. Yourself in general?</td>
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</table>
**Part II.** For each of the following, please choose the answer that best describes how important that area of life is to you. Please mark your answer by circling the number. There are no right or wrong answers.

<table>
<thead>
<tr>
<th>HOW IMPORTANT TO YOU IS:</th>
<th>1</th>
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<th>3</th>
<th>4</th>
<th>5</th>
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<tr>
<td>1. Your health?</td>
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<td>2</td>
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<td>6</td>
</tr>
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<td>2. Health care?</td>
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<tr>
<td>3. Being completely free of pain?</td>
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<td>4. Having enough energy for everyday activities?</td>
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<td>6</td>
</tr>
<tr>
<td>7. Living a long time?</td>
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<td>6</td>
</tr>
<tr>
<td>15. Meeting family responsibilities?</td>
<td>1</td>
<td>2</td>
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<td>6</td>
</tr>
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<td>16. Being useful to others?</td>
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<tr>
<td>17. Having a reasonable amount of stress or worries?</td>
<td>1</td>
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<td>6</td>
</tr>
<tr>
<td>20. A good standard of living?</td>
<td>1</td>
<td>2</td>
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<td>5</td>
<td>6</td>
</tr>
<tr>
<td>21. Your job?</td>
<td>1</td>
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(Please Go to Next Page)
### HOW IMPORTANT TO YOU IS:

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<tr>
<th></th>
<th>Very Dissatisfied</th>
<th>Moderately Dissatisfied</th>
<th>Slightly Dissatisfied</th>
<th>Slightly Satisfied</th>
<th>Moderately Satisfied</th>
<th>Very Satisfied</th>
</tr>
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<tr>
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<td>2</td>
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<tr>
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<td>Your education?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<tr>
<td>24</td>
<td>Your financial independence?</td>
<td>1</td>
<td>2</td>
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<td>5</td>
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<td>25</td>
<td>Leisure time activities?</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>5</td>
</tr>
<tr>
<td>26</td>
<td>The ability to travel on vacations?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>27</td>
<td>Having a happy old age/retirement?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>28</td>
<td>Peace of mind?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>29</td>
<td>Your personal faith in God?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>30</td>
<td>Achieving your personal goals?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>31</td>
<td>Your happiness in general?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>32</td>
<td>Being satisfied with life?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>33</td>
<td>Your personal appearance?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>34</td>
<td>Are you to yourself?</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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APPENDIX F

VISUAL ANALOGUE SCALES
INSTRUCTIONS: For each statement, place a single mark (—_) on the line for the response which best indicates how you feel right now.

I have:

No Pain ———— The Worst Pain

I have:

No Hope ———— High Hope

I have:

No Quality of Life ———— Excellent Quality of Life


