THE EXPERIENCE OF HOPE FOR ADULTS WITH CYSTIC FIBROSIS

by

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A thesis submitted to the
Faculty of the Graduate School of the
University of Colorado in partial fulfillment
of the requirements for the degree of
Doctor of Philosophy
School of Nursing
1996

This thesis for the Doctor of Philosophy degree by

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Date: 7-29-96

Tracy, Janet Perrin (Ph.D., Nursing)
The Experience of Hope for Adults with Cystic Fibrosis
Dissertation directed by Professor Joan K. Magilvy

In this highly technical biomedical era, advances in diagnosis and aggressive treatments have altered the survival age for many chronically ill people. What is the meaning of hope to people who have lived beyond their expected life span? The purpose of this study was to describe and interpret the meaning of hope in people who have beaten the odds of statistics. A hermeutic-phenomenological design as informed by van Manen and influenced by Watson and Parse, guided and unfolded the meaning of hope for this population. Dialogical engagements (phenomenological interviews) were conducted with sixteen adults ages 23-48 years living with Cystic Fibrosis. Interviews elicited participants' experiences of living with CF and hoping for the future. Narrative stories of participants were presented illustrating lived experiences. Three themes unfolded from the phenomenological-hermeneutic analysis expressing the meaning of hope for the individual who lived beyond an expected life span: **Fighting With Spirit and Energy**, **Connecting Through Self and Others**, and **Transcending Beyond the Statistical Odds** to accept the gift of life.

Reflection with the literature on hope revealed the fighting and connecting themes have much in common with other researchers' findings. A contrasting finding for my participants was the lack of a trigger point or a specific threat needed for hope. The use of support groups and the Internet were two other findings not previously reported. The third theme--**Transcending Beyond the Statistical Odds**--is the most unique finding of this study, expressing a focus on the meaning of life rather than the number of years lived. Participants contributed to the sense of greater community by volunteering for experimental drug protocols, lecturing to groups of patients, and lobbying for governmental assistance to the chronically ill.

Recommendations are made in the areas of nursing theory development, practice, and research. This study has relevance for other illnesses and conditions which extend the life span beyond the expected.

The form and content of this abstract are approved. I recommend its publication.

Signed [redacted]
Faculty member in charge of thesis

Hope is like a song of strength and courage...
Though it may be difficult to hear at times
It is always somewhere in the heart.

Janet Tracy

ACKNOWLEDGEMENTS

This dissertation evolved from the obstacles in my life. My first lived-experience of hope began through inspiration and perspiration as I grew into a hopeful person, strengthened in special ways by my father's life of hope for over eighty years. As a survivor, the spirits of my mother, Luella, brother, Brad, sister, Linda and her husband Roy remind me to make the most out of every day--any day could be the last. Mother May's message to "do the best with what you have" guides me.

I owe a mountain and ocean of thanks to my friends who were steadfast throughout this experience. In the mountains, Betsy Black lent her wisdom and encouragement, especially during my noncomputer days. Stan, Jean, and Doctor Bob were great supporters. At the ocean, Nancy and Carl Tillinghast helped with the parenting role and cooked many dinners. Michelle Jenny kept the positive energy flowing. A special hug to Eric and Chad, my sons, for being flexible during our summers together and apart. You were the competitive spirit urging me to graduate first!

Steve Stelling was my cheerleader, believing in me each step of the way. In the final weeks of writing, he helped me truly understand the fighting spirit and need for hope as he implemented the themes of this research in his daily

struggle with cancer. I thank him for his patience and caring.

My committee has been a tremendous help in my growing process. Thanks to Anne Matthews, Ruth Neil, and Marlaine Smith for their encouraging words. I appreciate the time Martha Stoner spent critiquing the manuscript and offering suggestions for refinement in the final days. I heartily thank Kathy Magilvy, my chair, for her untiring energy and countless hours of reading and counsel throughout the project. Thanks for believing in me!

I am grateful to Estelle Sikkema of the New Jersey Organization of Cystic Fibrosis who helped me locate participants for this study. My greatest debt is to the people whose stories appear in the following pages. I hope the reader senses their remarkable candor and openness with which they talked about their lives. I will never see CF in the same way I did before this project began. It now has many faces and voices!

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CHAPTER I

INTRODUCTION

> Statistics: Do they mean anything? When I was born, parents were told to take their kids [with Cystic Fibrosis] home and enjoy them because they wouldn't have them long...In my teens and twenties, I kept my eye on the 'life expectancy'. Every year the expectancy seemed to rise one year with me...50% don't live to the average age BUT the other 50% do--The trick is to be in the OTHER 50%. (Bucky, Study participant)

In this high-tech biomedical era, the tantalizing possibility of miraculous new cures dangles daily before our eyes. Still, because of other medical technological advances such as early diagnosis and aggressive treatments, many people who would have died a decade ago are now surviving serious illness. Nurses can develop proactive strategies and create new approaches in caring for these people who have beaten the odds and lived longer than expected. Caring for people when cure is not currently possible is part of the nursing domain. A need is indicated for nursing research on the meaning of living beyond expectations with life threatening illness.

This study was conceived over four years ago when I examined the experience of growing up with a chronic illness (Tracy, 1992a). Ten chronically ill young adults with Cystic Fibrosis participated in that study. Compared to the population at large, these young adults with Cystic Fibrosis were unique because of their shortened predicted life span.

I learned that their parents were told at the time of diagnosis their child with CF would live only a few years. Each milestone year reached was dealt with by their physicians by adding a few more years to the life expectancy. No one had received a prognosis for survival beyond twenty-one years (Tracy, 1992a). Since these people had beaten the odds by living into adulthood, they believed that conditions would continue to change in their favor. They put little faith in statistical predictions, although "common sense" would demand otherwise. They sought confirmation from other adults with Cystic Fibrosis and compared themselves with this group to bolster their hopes for the future. The primacy of hope in the experience was a central finding. As a result of that study, I concluded that more research was needed to understand this lived experience. The next logical step for my research was to ask the question, **"What is the meaning of hope for people who have outlived their life expectancy?"** A phenomenological study was conducted to address this question.

The phenomenological study described in this dissertation was particularly compelling since it followed an exploration of the experience of growing up with a chronic and incurable disease. Although numerous studies have focused on people adjusting to a diagnosis or learning to live with a disease, the critical issue of people living longer than expected remains unstudied. While research abounds about the grieving process in dying, and some literature describes the near-death experience, limited knowledge exists about living beyond an expected life span. The meaning of hope for the person who has lived beyond life expectancy was the intrigue of this study.

The Phenomenon of Interest

Hope is an emotion that allows a person to live and die with dignity. A hoping person expects to attain something favorable in the future that has personal meaning. The future level of expectation of action can exist only within the realm of knowledge that the individual possesses. In other words, the unknown can not be an object of hope (Ladd, 1915). Past learning experiences, especially those reflecting intelligence, culture, and environment also play a part in an individual's hopes. Evidence exists that hope can affect the physical state of being. Hall said that "hope is something all people need until they take their last breath" (1990, p. 178). According to Herth (1991), although hope is described in the literature as an intrinsic element of life, precise measurement of hope is impossible unless a clear conceptualization of hope exists.

When hope is missing, the future no longer exists and the present takes on foreboding dimensions. When hope is gone, one has a sense of profound loss. A loss of hope is frequently experienced by patients with stresses induced by physical anomalies such as disfiguring surgery or a diagnosis of a chronic or fatal disease. In a variety of illness situations, observers have noted that the perception of anticipated outcome plays a significant force in determining a patient's reaction to illness. The degree of hopefulness reflects the level of expectation or the person's perceived probability of achieving a goal.

Instances have been cited in the literature in which people trapped by fires realized that they were inescapably victims and sat down to await death. People in concentration camps experienced an inevitable sense of death and autopsy could not document a direct cause (Stotland, 1969). Frankl (1962) stated that those who lose the will to live seldom recover from it. These examples of loss of hope are extreme. The importance of hope as a prerequisite for action, even if the action is to avoid death, has been illustrated in animal behavior studies as well as human behavior studies. "Hope is a common human experience that propels a person toward envisioned possibilities in every day encounters with the world" (Parse, 1990, p. 12).

Research Question and Specific Aims

The purpose of this study was to uncover the ways in which adults with Cystic Fibrosis experience hope. The study focused on the perspectives held by the individual about the positive emotion toward future life events involving voluntary, flexible goal setting having personal meaning to the individual. The specific aims of the inquiry were: 1) To obtain a description of the hope experience from adults with Cystic Fibrosis, and 2) To interpret the lifeworld with insights that reflect the meaning of the hope experience for adults with Cystic Fibrosis. A goal of this study was to use the findings and understanding gained through this research experience to educate and subsequently, to sensitize health care professionals to the experience of hope as expressed by adults with Cystic Fibrosis.

Many researchers have studied the relationship of hope to patients who are terminally ill, especially cancer patients (Dufault, 1981; Herth, 1989; Hinds, 1988; Owen, 1989; Stoner & Keampfer, 1985); others have examined the relationship of hope to healthy individuals (Carson, Soeken & Grimm, 1988; Miller & Powers, 1988); yet none have studied the meaning of hope to people living beyond their expected life span. Hope, a universal phenomenon, is an expectation that something better is to come and serves as a guide to action for the hoping person. Limited research exists on how hope is structured by the individual whose life expectancy has passed.

Nurses, as primary caregivers, can listen actively to patients about their hopes and help them to direct their energy toward meaningful goals. This beginning work identifies the meaning of hope to the patient who has outlived his/her life expectancy and can then provide further direction to the context of the caring relationship.

Researcher's Perspective

As we enter the twenty-first century with sophisticated quantitative research methods, technology, and computers, Naisbitt & Aberdene (1990) predicted that the most exciting research breakthroughs would occur not because of technology, but because of an expanding concept of what it means to be human. The art of nursing is the creative focus on human interrelationships and hope is recognized intuitively as an important factor in this relationship. Hope is an integral part of healing. Evidence exists that hope can affect health. Achterberg (1991) stated that remission of disease is documented with the caring ingredients of hope, joy, love, and expectation. Watson (1988) stated that the nourishing of faith-hope includes the ability to "transcend space and time through one's mind, imagination, and emotions" (Watson, 1988, p. 46). Nursing is not doing or manipulating; rather, nursing is being open to what arises (Newman, 1989). Nursing is being with, not doing to others.

Caring involves a moral commitment to preserving human dignity (Watson, 1985). Nurses, in their caring, may reflect hope and influence the patient toward future goals. I value the internal-subjective world of the experiencing person and how both nurse and participant will perceive the experience. The opportunity for the nurse and patient to co-create hope needs to be explored and this study is the first investigative step.

My philosophical approach to this study was influenced by the work of Parse (1990). She believed that exploring the meaning of any health experience, relationships and hopes and dreams, is important to quality of life for each person. Parse viewed health as a process unfolding; illness is not discussed separately. Implicitly, it is one experience within health. These views are appropriate for people with a genetic chronic illness who have outlived their expected life span since the experience of illness and the disease have been part of their entire life. The ever increasing issues about the quality of life in today's society point to the complexity involved in understanding the meaning of hope for these people.

Parse (1990) used hope as the exemplar phenomenon in her first study of the man-living-health research methodology. In this study Parse elaborated on the meaning of hope as a lived experience for persons who were on hemodialysis. The concepts that emerged were imaging, transforming, and enabling-limiting (1990). Parse suggested that the lived experience of hope "might be studied in a variety of contexts" (p. 16) and that the core concepts might be further explored as lived experiences with participants in a variety of settings.

Based on my philosophy that nursing is a caring interaction and recognizing that hope plays a part in the healing process, this study is designed to generate new knowledge of the meaning of hope for people who have lived beyond their expected life span. When the lived experience of hope surfaces in the patient-nurse relationship, the nurses' ability to openly explore the possibilities with the patient is enhanced.

Life Expectancy

Chronic illness shortens the life expectancy of affected individuals. Cumulative losses suffered by chronically ill persons can lead to hopelessness. As the illness progresses and physiological deterioration and other losses continue, a person's hope can serve as a sustaining force against despair (Miller, 1983). Cystic fibrosis is a chronic disease that can generate enormous and sometimes overwhelming psychosocial problems for patients, families and significant others. Individuals diagnosed with Cystic Fibrosis in childhood have grown up with the knowledge that they will have a shortened life span. Uncertainty about future health and longevity causes recognized psychological burdens on people who have already outlived their life expectancy. Experiencing hope could positively influence their physical as well as psychological well being.

Cystic fibrosis (CF) is the most commonly inherited disease among Caucasians. One out of every 20-25 persons carries the CF gene. Cystic Fibrosis is the result of an autosomal recessive gene with over 300 known mutation variants. Cystic Fibrosis is one of the most insidious and unrelenting disorders to strike children and young adults. Moreover, the difficulty of accurately assessing prognosis and life expectancy contributes to both psychological and social stress for the patient and family. This disease acutely reflects the impossibility of applying aggregated prognostic information on an individual basis (Burke & Aitken, 1994).

In the fifty years since the disease was first described as a distinct clinical entity, CF has been transformed from an autopsy diagnosis, in which patients did not survive beyond the first year of life, to a chronic disease with one-third of the patients now over the age of 18 years. Prior to 1945, the majority of patients died in infancy. In 1966, the average survival age was eleven years. By 1985, 20% of all patients with cystic fibrosis were 15 years and older (Keller, Guzman & Culen, 1985). In 1994, the median survival age was slightly more than 29 years (Fiel, FitzSimmons, & Schidlow, 1994). Although late diagnoses of CF have increased over the past decade, most

CF-affected individuals are diagnosed in early childhood; in 1991, 76% of new CF diagnoses were made by age two years, and 90% by age 9 years (Marx, 1992).

Patients with CF are living longer, with the proportion of adults quadrupling between 1969 and 1990 (FitzSimmons, 1993). Given the continued aggressive use of chest physiotherapy and aerosolized antibiotic therapy, as well as vigorous attention to nutritional status, individuals born with CF today can be expected to survive well into their 40's (Collins, 1992; Elborn, Shale, & Britton, 1991). In the past decade alone, advances in antibiotic and pulmonary therapy have doubled the life expectancy of children who have the disease. Advances in clinical and genetic research continue to generate new knowledge. The impact of this new gene therapy, as well as other new therapies being investigated in clinical trials (notably the use of DNase) create great cause for optimism regarding the future for CF patients (Fiel, FitzSimmons, & Schidlow, 1994).

For the generation of individuals affected with CF who are now adults, dramatic increases in expectations of health and increased life expectancy have occurred during their lifetime. Parents of the adults living with CF today were told when their babies were diagnosed that adulthood was not possible. These children, born prior to 1973, grew up believing there was no adulthood for them. Predictions of life span, while appearing to be accurately based on physical findings, ignore social, contextual, and psychological facets, in addition to the rate of technological advances. The use of these probabilities and statistics for projecting life expectancy has become totally obsolete. People living with CF now experience great cause for optimism in their future. Indeed, adults with CF themselves represent a major source of hope to newly diagnosed and younger persons (Burke & Aitken, 1994).

At the same time, increases in survival have produced unexpected stresses. Children who were not expected to live to adulthood may have difficulty developing emotional maturity. The specter of disability hangs over future plans. Increased survival may make the nonpulmonary complications of CF more significant for individuals than in the past. Diabetes, long term complications from antibiotic therapy, and increased cancer risks are all problems increasing in this population (Burke & Aitken, 1994). The difficulty for many adults with CF is living with the reality of their own mortality, especially as they observe the deaths of their friends and siblings with CF, with whom they have bonded over the years. The possibility of survivor guilt, their own physical decline, and repeated hospitalizations can be discouraging and demoralizing. The possibility of future therapeutic advances also evokes a mixed reaction, recognizing that some breakthroughs may come too late to prevent their own death. How does one maintain and build hope in these situations? In this study, I explored the meaning of hope for these people who have confounded all predictions by going on to lead a full life into adulthood.

Significance of the Research

The results of this study contribute to our knowledge of hope and its healing potential by providing a description of the lived experience. This deeper understanding offers insights that sensitize others to the meaning of hope without classifying or categorizing the construct. When a nurse is able to understand the life experience and the meaning a client brings to that experience, theory and knowledge base are enhanced to guide nursing practice. Meaning is not subjectively held, but is already present in shared language and every day practices. By understanding the meaning of hope in this shared language, the nurse may explore different possibilities together with the patient.

The nursing literature contains many references to hope and the hoping process, guidelines about the importance of having hope, and the value of maintaining and restoring hope to patients. Nursing literature suggests that a hopeful attitude influences a positive patient outcome. However, the literature is sparse about how the process of hope is useful in guiding nursing action. In this study I explored the depth and breadth of hope in a unique population to increase knowledge and enlighten the science and practice of the discipline.

Framing the Question

Several reasons account for our limited understanding of the meaning of hope for persons who have lived beyond an expected life span. First, technology allows us to hope for conquering disease, with vast amounts of money and prestige devoted to cure rather than caring for those who are living day to day. Second, scientists who have studied the illness experience have used research methods rooted in the traditional science paradigm that are reductionistic in research methodology and that inadequately study holistic human experiences within the social context (Leininger, 1985; Morse & Johnson, 1991). Finally, past research was perhaps premature in that it focused on hope interventions (Brown, 1989; Hickey, 1986; Kim, 1989) rather than understanding the meaning of hope from the individual's perspective.

Investigating the Lived Experience

In this study a phenomenological design was used to illuminate the essential meaning of the human experience of hope. Knowledge of the major philosophic foundations facilitates clarification and understanding of the concerns of human science research. Ray (1990a, 1991) stated that the emerging theory from phenomenological inquiry, rather than being a conceptual sum of its parts, reveals a process of possibilities. These possibilities can be captured as insight and represented as a narrative or model, which will enlighten the inner structure of meaning and understanding of the phenomenon.

To explicate human phenomena such as hope in a human health experience, the human science perspective is believed to be the most sensitive and open to studying the lived experience. Human science first emerged from the works of Dilthey in the nineteenth century. Dilthey defined human science as "the field of study of all of human life and all of life's expressions" (Dilthey, 1900, p. 107). He argued that human phenomena differed from natural phenomena and, therefore, required interpretation and understanding (hermeneutics), unlike natural sciences where external observation and explanation are used (Ray, 1994). Dilthey's concern was the question of what is appropriate empirical science for the study of human phenomena.

Watson (1988) stated that human science encompasses empirics, esthetics, ethical values, intuition and process discovery. Within a human science framework, nurses can choose methods that allow subjectivity in the human-to-human care response and enable the inner world of personal meaning to emerge between the nurse and the other. To participate in nursing care from a human science perspective, the nurse needs to discover the subjective, personal experience of the individual. Watson (1985) stated that human caring involves a higher sense of spirit of self. Caring, in her view, involves a moral commitment to preserving human dignity.

Nurturing hope for clients of nursing practice could mean creating "a sense of the possible" (Benner & Wruble, 1989). In Swanson's (1991) study of caring, the category of maintaining belief emerged. Swanson defined caring process as "sustaining faith in the other's capacity to get through an event or transition and face a future with meaning" (p. 165). She strongly recommended that the caregiver maintain a hope-filled attitude and offer realistic optimism.

According to Meleis (1986), the shift in world view from the traditional to the human science perspective has been affected by the shift from cure, illness and prescribed tasks, to care, environment, and perception of meaning for the client. She also stated that a shift has occurred from duality between the person delivering the care and the person receiving the care, to an active participation of both persons toward better health. Hope in the human science perspective focuses on the personal knowledge and experience and on the individual in context with the environment.

In summary, the philosophical context of this nursing study is rooted in the human science paradigm. Human science is an open world view that allows the researcher to co-participate in the exploration of meaning rather than studying the person from an objective stance. Using the human science perspective, and through the caring interaction, I explored the meaning of hope to participants in my study. Nurses have recognized intuitively that hope is an important factor in caring. We need to listen attentively to our patients about this human condition to help direct their energy toward meaningful life goals until their last breath is taken.

Overview of Remaining Chapters

In this chapter the problem was described and the stage was set. In the remaining chapters of this dissertation I describe and delineate the meaning of hope for adults who have outlived their expected life span with a related literature review, a description of the approach of the inquiry, the results of the inquiry and nursing implications and recommendations. Each chapter begins with a quote to focus the reader on the upcoming content.

In Chapter II, I explore and critique the literature on hope, present a concept analysis of hope, and explicate the significance of this research study. In addition, hope is discussed in the context of chronic illness.

In Chapter III, the methodological approach to the study and the framework which informed me as I developed the research question are delineated. Within Chapter III, I also describe the design and methodology of the study, data generation, and data analysis.

In Chapter IV, I present the individual stories in narrative form to reveal the essence of each participant's experience. These narratives were written after transcription and dwelling with the data. At the end of the chapter, a demographic table describes the participants.

Chapter V is focused on a reflective analysis of the co-created meaning of hope for the individual who is living beyond an expected life span. Here, discussion and heuristic interpretation of the selected themes and core concepts occurs.

The unique and universal aspects of hope as they relate to this study are compared to the literature in Chapter VI. The significance of the study and recommendations for nursing theory development, practice and research are also discussed.

CHAPTER II

SELECTED REVIEW OF THE LITERATURE

> I was told by some physicians that I'd never see my twenty-first birthday. I'm 36 now; I suppose my survival may have damaged the professional reputation of some of the "experts" in their field at the time. (Mark, study participant)

Hope is an emotion that allows a person to live and die with dignity. A current understanding of this universal experience will enhance the professional's ability to communicate with others. Hope has been the object of exploration in the disciplines of psychology, philosophy and theology. Researchers and theorists have examined the relationships between selected intrapersonal, environmental and illness-related variables and hope. This chapter begins with a selected review of the hope literature in disciplines other than nursing and a concept analysis of hope. Then the theoretical framework of hope within health and illness is addressed. Next, relevant nursing studies are reviewed. Lastly, the chapter concludes with selected chronic illness literature as it pertains to hope. Thus, in this chapter I will clarify the relationship between the proposed study and previous work conducted on the topic.

Theoretical Literature

Theoretical literature from several disciplines can strengthen the understanding of the existence and influence of hope, particularly as it applies to health and illness. In this section I briefly describe hope as viewed by psychologists, theologians, and philosophers.

Psychology: Psychologists have discussed hope as a connection between the past and the future. Stotland, a behavioral psychologist, believed that hope is based on previous learning or communications with others. In 1969 he wrote that although hope was not directly measurable, it was futile to argue that hope could not be used as a scientific concept. At the time the logical positivists believed that only what could be quantifiably measured existed. People in scientific circles made a determined effort to exclude hope from conceptual thinking because it was not an observable phenomenon. However, Menninger (1942) argued previously, that "all science is built on hope...man can't help hoping even if he is a scientist; he can only hope more accurately" (p. 215). Scientific hypotheses are based on the "hope" that something can be substantiated or relationships can be drawn. Without this positive feeling toward the hypothesis, researchers would not attempt to validate their hunches. Hope is the favorable and confident expectation of better things to come.

The anticipatory disposition of the future is a perceived probability of attaining a goal. Motivation toward a goal can result in anxiety if the probability of reaching that goal is low. If an individual lowers the importance of the goal, he/she tends to become depressed, apathetic, and withdrawn. On an overt level the individual may not act, and on a covert level he/she may disavow interest in the goal (Stotland, 1969). Lynch (1965) added to Stotland's concept that internal hope needed an outside response and had meaning as it related to others through collaboration.

One of the most recent contributions of psychology in the field of hope is the power of positive thinking. In 1989, Cousins wrote that "a biology of the EMOTIONS is coming into view" (p. 37). In the past decade, research shows that belief and suggestion can activate healing pathways. Examples of the placebo effect, biofeedback to improve the immune system, and positive emotion research are now commonly published. These and other similar discoveries have led to a new branch of medicine, psychoneuroimmunology, which integrates a mind-body-spirit approach to health and healing. This approach provided evidence that what one feels is as important as what one knows. This interconnectedness from within is currently being studied in a variety of clinical settings.

Theology and philosophy: Theologians and philosophers discuss hope in terms of an afterlife and the future. The theologian Moltmann stated "hope is summarized historically by means of the 'future'; ontologically by means of 'possibly', and anthropologically by means of 'freedom'" (1971, p. 182). Moltmann believed that Christian hopes originate in the event of the resurrection of Christ. Christians hope for the passing of evil and death and the coming of freedom and true humanity (Moltmann, 1971). In the theological view from the Judeo-Christian perspective, the present may be empty but the future is full of hope because of God's promises.

May (1953) presented the existentialist view that one's religious attitude is to be found at the point where "he has a conviction that there are values in human existence worth living and dying for" (p. 210). He believed that hope at its best is an energizing attitude, the bringing of part of the joy about some future event into the present. Through this anticipation, people can be "more alive and more able to act in the present" (May, 1953, p. 262).

The philosopher Erich Fromm (1968) believed hope only existed if found in faith. He attempted to understand the motivations of an individual over time, thus allowing for some prediction of future behavior. The emphasis on the influence of the past in determining an individual's character, in turn predicted future behavior. Fromm urged present-oriented hope with caution against hoping for something that cannot possibly be. He felt this passive waiting for another led to despair (Fromm, 1968).

Gabriel Marcel, a twentieth century existentialist, viewed hope as a shared experience between giver and receiver. This hope was not just for self, but was extended also to another person. Marcel stated that "hope aims at reunion, at recollection, at reconciliation; in that way, and in that way alone, it might be called a memory of the future" (1951, p. 32).

The Christian existentialist Paul Tillich (1959) brought the matter of time--past, present, and future-- all together by professing that God is all consuming and ever present. As is true in most of the Christian teachings, hope is likened to something that is time-released--a slow adrenalin that sustains power rather than a surge of power that quickly appears and disappears. In theology and philosophy, then, hope rests with a higher power and is a source of strength.

Concept Analysis

A concept analysis is essential for clarification and theory development related to hope. This concept analysis provides identified and theorized definitions of hope, delineates critical attributes, and concludes with my personal definition after analysis. The methodology follows

Walker and Avant's (1988) styling for the concept analysis process.

A beginning attempt to define and operationalize hope was accomplished by Obayuwana and Carter (1982). They categorized one word descriptions of the word hope into a list of 34 common responses. A cross-sectional telephone survey was used to randomly sample 500 participants. Responses were categorized into central themes and a hope pentagram was developed: "the state of mind resulting from the positive outcome of ego strength, religion, perceived family support, education, and economic assets" (Obayuwana and Carter, 1982, p. 232). These categories were compared to Kubler-Ross' (1969) five stages of dying with characteristics of fighting to retain hope and Engel's (1968) five characteristics of the giving-up/given-up complex with five characteristics in loss of hope. The two complimented each other with astonishingly similar terms and produced themes of spirited strength, positive self concept, group support, economic success and joyful anticipation to form the pentagram.

Hope is used as both a noun and a verb. When used as a noun, hope has been synonymous with a promise, ambition, faith, or belief. Dictionary definitions of hope include "the feeling that what is desired is possible; that events may turn out for the best" (Webster, 1989, p. 683). When used as a verb, hope can also mean to desire, anticipate, expect, or aspire. The Webster dictionary (1989) defined the verb form of hope as: to look forward to something with desire and reasonable confidence; to believe. A further explanation of hope against hope is to "Continue to hope, although the situation does not warrant it" (Webster, 1989, p. 683). These definitions are reflected in the literature by expanded phrases such as "hope is an anticipation, accompanied by desire and expectation of a positive possible future" (Stephenson, 1991, p. 1457).

Hope, as a phenomenon, may share some similarities with wishing, desire, and optimism, but can be distinguished as separate upon further examination. WISHING may be seen as similar to hope but implies a passive waiting and magical quality (Schactel, 1959, Metamorphosis) such as wishing before blowing out birthday candles. DESIRE may be similar to hope but implies impatient waiting without purposeful action toward achieving a goal. OPTIMISM is more of a dispositional trait and does not necessarily invest "self" in the outlook toward an event or the future. An optimist displays a certain attitude toward life that is not necessarily situational nor goal-oriented. After looking at similar terms, then, a more specific definition of hope is needed.

Although hope is described in the literature as an intrinsic element of life, the human response of hope may be more clearly understood through careful, systematic analysis of the phenomenon. Through concept analysis, five critical attributes common across authors were identified:

HOPE IS: 1. future oriented
2. variable and frequently changing
3. goal-oriented
4. energizing and motivating
5. internal and personal

Critical Attribute #1: Hope is future-oriented: In defining hope, many researchers specifically focused on the temporal dimension. Menninger (1963) operationalized hope as a concrete, realistic desire that seeks to mobilize energy toward meaning. Hope is a confident expectation that what the person wants will happen. Stoner (1982) defined hope as "a subtle, almost unconscious expectation about an abstract but positive aspect of the future" (p. 4). Hinds (1989) contended that hope is the degree to which one believes a personal tomorrow exists. Nowotny (1989) and Herth (1989) described a time-focused future orientation. Dufault and Martocchio's (1985) model of hope included generalized hope (positive overall view transcending beyond the limits of time) and particularized hope (specific time-valued outcome). May's (1953) existentialistic viewpoint posited that hope is at its best when the individual brings a part of the joy about some future event into the present. Through this anticipation, people can be "more alive and more able to act in the present" (May, 1953, p. 282).

Recent qualitative studies with seriously ill and terminal populations (Dufault & Martocchio, 1985; Hinds & Martin, 1988) suggested that when time-oriented hopes diminish, more global hopes replace them. This conceptualization is an expression of a succession of hope "like rungs on a ladder; if one breaks, even as we stand on it, there is always another within reach" (Rutledge, 1930, p. 6).

Critical Attribute #2: Hope is variable and frequently changes: The previous statements also speak to the second attribute of variability in changing hope. Herth (1990), in a longitudinal qualitative descriptive study, found that hope descriptions remained stable over time, but that not all persons identified hope-fostering strategies in all categories as their illness progressed. As people faced new situations or stressful events, their goals and expectations changed. As death approached, the focus of the aims changed. Their hopes increased if they saw options available (Nowotny, 1991).

Critical Attribute #3: Hope is goal-oriented: The experience of hope by the individual is a favorable and confident expectation of better things to come. This anticipatory disposition of the future is a perceived probability of attaining a goal (Dufault & Martocchio, 1985; Owen, 1989). Dufault and Martocchio (1985) distinguished between a generalized goal that has a general positive future and a particularized goal that focuses on a specific outcome. The identified goal serves as a motivational force and is attainable (Stotland, 1969; Miller, 1989).

Critical Attribute #4: Hope is energizing and motivating: Hoping persons not only search for goals; they develop directives for action. This motivating force is described in the literature as energy (Owen, 1989), action (Herth, 1989), and active involvement (Nowotny, 1989). The critical attributes of hope project a "sense of activity: energy, action, reaching, stepping, and extending" (Hasse, Britt, Coward, Leidy, & Penn, 1992).

Critical Attribute #5: Hope is internal and personal: Hope comes from within the individual and is personally important. Herth (1990) defined hope as "an inner power directed toward enrichment of 'being'" (p. 1250). In her study of terminally-ill patients (1990), participants delineated that a new awareness of hope developed what is possible in life. Sometimes hope emerged through important relationships. These terminally-ill patients defined hope as an inner power that facilitated the transcendence of the present toward new awareness and enrichment of being. Parse (1990), in a phenomenological hermeneutical study with adults on dialysis, expressed that hope was a "way of propelling self toward envisioned possibilities in every day encounters with the world" (p. 12).

Concept Analysis Summary

This concept analysis provided a foundational perspective on the phenomenon of hope and featured hope as multidimensional and complex. Foote, Piazza, Holcombe, Paul, and Daffin (1990) noted that the elements present in most definitions were futuristic, motivating, and action-oriented, involving expectancy of a future. In my own consideration of hope as a valuable concept and through the use of concept analysis, my definition is: "hope is a positive emotion toward future life events involving voluntary, flexible goal setting that has personal meaning to the individual" (Tracy, 1992b).

Connectedness holds promise for our understanding of intrapersonal and interpersonal relationships and their role in the evaluation of hope. In a simultaneous concept analysis of hope, spiritual perspective, acceptance, and self-transcendence published in *Image* (Haase, Britt, Coward, Leidy & Penn, 1992) connectedness was identified as a central theme across the four concepts. Connectedness was an antecedent of hope, a critical attribute of spiritual perspective, and a consequence of acceptance and transcendence. Recommendations included a need to develop nursing interventions designed to promote these four processes of health and a study designed to strengthen hope by enhancing connectedness during pivotal life events. This research underscored the importance of the multi-faceted dynamics of patient experiences and the necessity of the nurse's appreciation of the patient's experience in order to connect in a therapeutic relationship.

Theoretical Framework within Health and Illness

After deriving the definition of hope through conceptual analysis, the next step is to consider how hope has been used in conceptual models. The theoretical framework in studying hope is frequently placed in Lazarus'(1966, 1991) stress/coping paradigm. The literature identified hope as a pre-requisite for coping with the demands and challenges of illness. Hope is seen as a mediator that enhances the individual's ability to cope.

Concerned for a number of years with understanding psychological stress, Lazarus (1966, 1991) claimed stress largely arises from the manner in which events confronting persons are construed or appraised and that degree of stress experienced is a function of peoples' ability to cope. In 1980, Lazarus, Kanner, and Folkman began to focus on the positive emotions in the coping process, advancing three different personal patterns: breathers (those who take a break from coping demands), sustainers (those who persist with coping even when situations are extremely demanding), and restorers (those facilitating recovery from harm or loss by restoring depleted resources).

Lazarus' model has been used by researchers who study dispositional optimism as it relates to health (Scheier & Carver, 1985). In 1986, Scheier, Weintraub, & Carver connected optimism with Lazarus' model of stress and coping and found a positive association between optimism and the use of problem-focused coping. Optimism appeared to function as a buffer against the adverse effects of stress. The following year, a subsequent study indicated that "physical well-being is not a very potent determinant of one's level of optimism" (Scheier and Carver, 1987, p. 177). Optimism, however, as defined by these researchers, is a dispositional trait and mediates how well a person responds to stress. The interest of my study is on hope as it varies and changes, providing a personal motivation toward goal attainment.

Lazarus' model was also incorporated by Herth (1989) in a descriptive investigation of the relationship between hope and coping with adults undergoing chemotherapy. She investigated the effect of setting (hospital, outpatient, and inpatient) in which the therapy was administered and the effect of intrapersonal, environmental, and illness-related variables on the patient's level of hope and coping response. Her subsequent Coping Process Nursing Model (CPNM) incorporated ideas from Lazarus and Folkman as well as Stotland's theory of hope. With this model the nurse can "assess the adequacy of each of the factors, determine influencing variables on these factors, and approximate if the client can mobilize coping resources and hope level" (1989, p. 68). The study stopped short, however, of investigating the impact of these variables on effectiveness of treatment or the quality of life for the patients.

Hope within illness has been researched by several nurses. From the human science paradigm, a search has been undertaken for the understanding of hope. Often patients may talk about "living beyond the disease" or "in spite of the disease." By qualitatively reflecting with people about their lives and individual experiences, the nurse can help the participant focus on some positive outcomes of the illness and hopes within that framework. Five illustrative studies reflect on hope within this paradigm. Stanley (1978), in an unpublished dissertation, found that hope for 100 undergraduate students was "a confident expectation of a significant future outcome, accompanied by comfortable and uncomfortable feelings, characterized by transcendence and interpersonal relatedness and in which action to effect the outcome is initiated" (p. 153). This seminal work on healthy individuals laid the ground work for later studies.

Parse's (1990) illustration of the lived experience of hope for ten hemodialysis participants found the structure of hope is "anticipating possibilities through envisioning the not-yet in harmoniously living the comfort-discomfort of everydayness while unfolding a different perspective of an expanding view" (p. 15).

In a search for the meaning of hope in the illness experience, Hall's (1990) phenomenological study of men with asymptomatic HIV disease revealed that "life is hope and that hope, in our culture, is an orientation toward the future" (1990, p. 180). She explored with these men the impact of this future orientation and the possible denial, uncertainty, and strategies for maintaining hope. Hall found very little evidence that people accept death and stated that the average life expectancy is an ecological fallacy (Hall, 1990). Hall concluded that for the diagnosed, terminally-ill person, hope is essential to life, even if not grounded in objective reality.

In Neil's (1993) action research study at the Denver Nursing Project, four themes emerged as sources of hope for clients following HIV diagnosis. All the themes centered around connectedness:

1. With a higher power or God
2. With someone or something (pets, friends, or hobbies)
3. With the eternity of nature
4. With the self through important memories

A group of clients being treated for AIDS in an outpatient nursing care center met and brought photographs depicting their ideas of hope. The act of the group meeting in and of itself was therapeutic. The members of the group decided together on photographs that communicated their discoveries. The captions under the photos were all quotations from the discussions. The finished product of a large poster represented visible sources of hope for the participants. One comment by a participant was a plea not to "analyze this too much...it takes the mystery and intrigue out of it" (Neil, 1993). Hope in this study was very personal, changing, and motivating.

In Smith's (1990) phenomenological study of families awaiting critically ill adults in the intensive care unit, the Parse method was used to uncover the concepts of hope. Smith found that hope for family members included: resolute intending, abiding in faith, unburdening-burdening, dwelling in the turbulence, nurturing relating, and confident view of the not yet. Smith suggests that further studies incorporate family members in explaining the meaning of hope.

Hope in Stress and Coping

Hope, then, has been framed in the health-illness theoretical model by a number of nursing and nonnursing researchers. Several studies have shown age, extent of illness, length of time since the first diagnosis, and interference in performing job role responsibilities were not related to patient level of hope or level of coping response. However, many early measures were based on a narrow definition of hope as an expectation of goal achievement and do not reflect the complexity and meaning of the phenomenon. More recently, hope and coping have been studied by nurse researchers with an increased awareness of its multidimensionality.

In a study of cancer patients, Herth (1989) found a co-variance of 64% between hope and coping response. Using the Herth Hope Scale and the Jalowiec Coping Scale (Jalowiec, Murphy, & Powers, 1984), a significant difference was found between those who received inpatient treatment, those who did not consider their disease to interfere with their job role, and those who expressed religious convictions compared to their counterparts. Previous reports about length of time since diagnosis and the hope level were conflicting and this study suggested the possibility that active participation in treatment might improve the relationship between coping and hope. Other suggestions for research made by Herth included the study of people with other diseases and people who were disease free, as well as determining other variables that might influence the level of hope and coping. Qualitative studies were also suggested to identify those nursing strategies that facilitate and support hope with the patient (Herth, 1989). The study described in this dissertation incorporated the qualitative dimension and also looked at a group of people not studied previously.

Hope has been operationalized (Miller & Powers, 1988; Stoner, 1988) and linked with other concepts into a framework that identifies antecedent and dependent variables (Dufault & Martocchio, 1985; Stoner, 1988). Antecedents for the concept of hope include "stressful stimuli such as loss, life-threatening situations, hardships, major decisions, future planning, or challenges" (Nowotny, 1989). Dufault and Martocchio (1985), in a qualitative descriptive study, identified six dimensions of hope with each dimension depicting a set of components that structure the experience of hope. These dimensions (affective, cognitive, behavioral, affiliative, temporal, and contextual) contributed to the multiple process of hope and may be simultaneously active within the individual at any given time (Dufault and Martocchio, 1985).

In addition to studying specific stressors on hope, Dufault and Martocchio identified generalized hope without linking it to any concrete or abstract object of hope. They defined it as an overall motivation to carry on life's responsibilities by casting a positive glow on life, extending beyond the limits of time. This generalized hope protected against despair and could be saved in reserve when particularized hopes did not materialize. Particularized hope, on the other hand, clarifies, prioritizes and affirms what a hoping person perceives as most important in life and encourages an investment and commitment to something beyond the moment (Dufault & Martocchio, 1985).

The contextual dimension of hope was in an actual or potential loss situation. The context of stress and crisis as related to loss established the occasion for hope or hopelessness. Hope and hopelessness were not conceived as opposites on a continuum, but rather some dimension of hope that was always present. "Only when hope is misconceived as unidimensional and trait-oriented...can one say there is no hope" (Dufault & Martocchio, 1985, p. 389).

The nursing literature contains many references to hope and the hoping process, guidelines about the importance of having hope, and the importance of maintaining and restoring hope to patients (Brown, 1989; Hall, 1990; Shubin, 1990). Most of the research in hope has been in the area of knowledge building with some theory generating (Dufault, 1985; Herth, 1989, 1990, 1991). Substantive theories may be evolving as a pattern emerges from the research. A critical analysis of some of the hope literature in nursing is presented in the following table (Table I).

TABLE I: HOPE LITERATURE

Author (Year)	Study Design	Population (n)	Discussion
Brown (1989)	Anecdotal Article	N/A	Provides operational definition; lists coping behaviors to ground hope in reality; suggest nursing interventions.
Bruhn (1984)	Anecdotal Article	N/A	Discusses the therapeutic value as a coping behavior; clarifies giving and removing hope; discusses limits of hope, social support, religion and sources to promote a hopeful attitude.
Dufault & Martocchio (1985)	Qualitative Descriptive	Cancer over age 65 N=35 Reanalysis of longitudinal data 47 terminally ill	Describes generalized and particularized spheres of hope plus 6 dimensions (affective, cognitive, behavioral, affiliative, temporal, contextual) with nursing strategies for each. Suggests that hope is multidimensional and a life force rather than trait-oriented and unidimensional.
Ersek (1992)	Conceptual model	N/A	Reviews conceptual descriptions, assumptions and theories of reality, assumptions about unrealistic hoping, denial, and illusion, potential and real outcomes of different types of reality negotiation, and the process by which reality is redefined and how unrealistic perceptions are threatened or abandoned. Includes suggestions for nursing practice and research.

Author (Year)	Study Design	Population (n)	Discussion
Farran, Wilken, & Popvich (1992)	Qualitative Descriptive	Community based elderly	Proposes a guide to clinical assessment with 4 central attributes (health, others, purpose, engaging process) Engaging further defined by goals, action, control, and time.
Farran & McCann (1989)	Correlational Survey followed by causal model	Senior citizens housing 60+ years old N=126 N=72	Explore dimensions of hope, relate hope to stressful life events, social supports, personal control, religiosity, selected demographic variables, and health. Examine if hope is an outcome or a mediating variable and determine extent retrospectively predictable on health and ADL's.
Farran, Salloway, & Clark (1990)	Qualitative survey & component analysis of 2 hope scales	Persons 60 years and above N=126	Examined 4 central attributes of hope: suffering, transcendence, rational thought process, & interaction. Principal components analysis was applied to Beck Hopefulness Scale and Stoner Hope Scale to determine if scales reflected central attributes of hope and to reduce into one hope score. Emergent issues: hope in spite of adversity, future orientation of hope, hope versus happiness, interpersonal sources of hope, hope and goal attainment, and hope and control.

Author (Year)	Study Design	Population (n)	Discussion
Foote, Piazza, Holcombe, Paul, & Daffin (1990)	Descriptive Survey	Multiple Sclerosis N=40	Demographics plus Miller Hope Scale, Rosenberg Self-Esteem Scale and Part II Personal Resource Questionnaire. Stat. significant (p<.01) relationship between hope and self-esteem, hope and social support, and social support and self-esteem. Employed persons had a higher level of hope and self-esteem.
Haase, Britt, Coward, Leidy, & Penn (1992)	Simultaneous Concept Analysis	N/A	Clarifies spiritual perspective, acceptance, self-transcendence, and hope. Antecedents, critical attributes, and outcomes were analyzed for interrelationships. Five common critical attributes: time orientation, energy, feeling, extrapersonal orientation, & intrapersonal orientation. Four antecedents and enablers: life experiences, inherent qualities, intrapersonal characteristics and interrelatedness. Five common outcomes: serenity, personal growth, connectedness, purpose and meaning, and self-transcendence. Across the matrix connectedness and intrapersonal characteristics emerged. Theoretical and methodological implications suggested.

Author (Year)	Study Design	Population (n)	Discussion
Hall (1990)	Grounded Theory	Stage II (a symptomatic) HIV disease N=11 men	Explicates hope and the role of hope in promoting health. Believes hope is appropriate only if it is realistic and opposing view that hope maintains well being in the face of ordinary and dire circumstances. Examines hope as denial, reestablishing hope, affective strategies, and implications for caring in nursing.
Herth (1992)	Develop and psychometric evaluation of an abbreviated instrument	Pilot: Physically ill adults 22-82 N=20 Study: 70 acutely ill, 71 chronically ill, 31 terminally ill.	Concurrent criterion-related validity run on Herth Hope Scale, Existential Well-Being Scale and Nowotny Hope Scale. Divergent validity determined by Beck Hopelessness Scale. Stepwise multiple regression showed length of illness, income, fatigue level, and marital status accounted for 27% variance in hope level. Found 12 item version to be as powerful as 30-item version on three original subscales: temporality and future, positive readiness and expectancy, and interconnectedness.

Author (Year)	Study Design	Population (n)	Discussion
Herth (1991)	Develop and refine Herth Hope Scale	Pretest: adults with cancer N=20 Pilot: adult with cancer N=20 inpt. N=20 outpt. Study: 120 adults receiving chemo in hosp., outpt, or home Study I: Well adults N=200 Study II: Adults 62-92 years Study III: Bereaved elderly N=75	Multidimensionality of construct was supported through factorial isolation of 3 subscales: temporality & future, positive readiness & expectancy, and interconnectedness. 4 point rating scale, 30 items based on Dufault & Martocchio's model of hope. Compliments and extends 2 other available hope scales (Miller and Nowotny). Promising results in a variety of settings with varied populations. Followed by response by Martha Stoner.

Author (Year)	Study Design	Population (n)	Discussion
Herth (1990)	Descriptive Qualitative	Terminally ill adults N=20 cross-sectional N=10 longitudinal	Hope was defined as "an inner power directed toward enrichment of 'being'. Interview responses analyzed for themes and clustered into categories validated by 6 terminally ill individuals. Hope fostering categories: interpersonal/ connected, lighthearted, personal attributes, attainable aims, spiritual base, uplifting memories, affirmation of worth. Hope-hindering categories: abandonment and isolation, uncontrollable pain and discomfort, devaluation of personhood. Nursing implications from study results and use of Herth Hope Index included.
Herth (1989)	Descriptive	Adults undergoing chemo in hosp., outpt, and home settings. N=120	Found a significant relationship ($p<.05$) between level of hope on Herth Hope Scale and coping on Jalowiec Coping Scale. Performance of family role responsibilities and strength of religious convictions were significantly related to hope and coping regardless of the setting. Length of time since diagnosis and performance of job role responsibilities were not significantly related to either levels of hope or coping. Suggestion to initiate studies to identify nursing strategies that facilitate and support hope.

Author (Year)	Study Design	Population (n)	Discussion
Hickey (1986)	Anecdotal article	Adults with Cancer	Definition and the need for hope established. Realistic vs. false hope discussed. Nursing approaches for enabling hope: developing an awareness of life, identifying a reason for living, establishing support systems, incorporating religion, incorporating humor, setting realistic goals.
Hinds (1989)	Triangulated quant and qual. Longitudinal, descriptive correlational	Adolescents receiving inpt. Rx for substance abuse. N=25 between 13-18 years.	Design had 3 data collection points 1) 24-48 hours after admit 2) 4-5 days before discharge 3) 4-5 weeks after discharge. Each point utilized Hopefulness Scale for Adolescents and interview. At second point, a set of structured questions to identify factors that influenced adolescent hopefulness. At the final two points, 2 estimation questions were administered to validate quantitative findings. Change in hopefulness seemed to occur because of awareness of negative influences rather than positive ones. Combined methods revealed hopefulness is dynamic, changing in amount and in its component parts.

Author (Year)	Study Design	Population (n)	Discussion
Hinds (1988)	Grounded Theory	Well adolescents N=17 Adolescents on an inpt. substance abuse treatment unit. N=42 Adolescents with cancer N=58.	Inductive definition was a comforting life-sustaining belief that a personal and positive future exist. 4 dimensions identified: forced effort, personal possibilities, expectations of a better tomorrow, anticipation of a personal future. Validation was estimated using the three populations, findings were shared with adolescents not in the study, and a panel assessed the conceptual sorting and coding. Adolescents with cancer had a focus on "other" which was not found in the other 2 groups.
Kim (1989)	Anecdotal Article	ALS	Emphasized the role of hope as a mode of coping in patients with ALS. Nursing role is to help the patient with a rapidly progressing fatal disease which has no known cure or treatment and obscure etiology. Using an existential framework informed by Frankl, nursing strategies include establishing trust, giving full concentration, absolute caring, and acceptance of each patient. Analysis of the hoping tasks through Wright's framework include: reality surveillance, encouragement, worrying & mourning. Proper balance of these tasks can be maintained when the family becomes actively involved in an atmosphere of mutual respect and sharing.

Author (Year)	Study Design	Population (n)	Discussion
Mickley, Soeken, & Belcher (1992)	Regression Analysis	Women with Breast Cancer N=175	The Spiritual Well-Being Scale, the Feagin Intrinsic/Extrinsic Religiousness Scale, and the Nowotny Hope Scale were administered in 2 outpatient oncology treatment centers. Hope was positively correlated with intrinsic religiousness (r=.363, p<.001) but not correlated with extrinsic religiousness. Hope was positively related to spiritual well-being (r=.661, p<.001) as well as religious well being (r=.443, p<.001) and existential well being (r=.732, p<.001). There was not a direct relationship between age and hope, religiousness and hope or date of diagnosis and hope. Nurses may help patients explore the meaning of illness and what can be learned from the experience. Further clarification of spiritual health is recommended.
Miller (1989)	Qualitative Descriptive	Adults 38-83 who had been critically ill and were now 2-4 days post transfer to intermed. care units N=60	20-item open-ended interview guide used to explore the experience of ICU and what helped sustain them. Hope-inspiring categories that emerged: cognitive strategies, determinism, world view, spiritual strategies, relationships with caregivers, family bonds, control, and goals. Patients identified threats to hope: physical deterioration, perception of having no one to care about them, negative hospital experiences, negative attitude of health workers, and negative self-talk. Direction for inspiring hope strategies is shared.

Author (Year)	Study Design	Population (n)	Discussion
Miller (1988)	Develop & psychometricaly evaluate a Hope instrument	University students Pretest N=75 Study N=522	40-item Miller Hope Scale with range of scores from 40-200 with high score indicating high hope. Construct validity established by correlating MHS to Psychological Well-Being Scale, Existential Well-Being Scale, and 1-item hope self-assessment. Internal consistency r=.93.
Nowotny (1991)	Anecdotal Article	N/A	Explains how the Nowotny Hope Scale (6 components: confidence in the outcome, relationships with others, belief in the possibility of a future, spiritual beliefs, active involvement, inner readiness) can be used to assess patients' hope. Suggests that hope assessment (29-item, takes less than 10 minutes) should be done during initial contact with pt. and overall plan of care derived accordingly. Strategies to facilitate hope were suggested for each of the subscales. Sources of hope and conflicts between the hopes of health care providers and cancer survivors are discussed. Ways of communicating statistics may be a challenge rather than a death sentence.

Author (Year)	Study Design	Population (n)	Discussion
Nowotny (1989)	Develop an instrument	Well adults N=156 and adults with cancer N=150	Beck Hopelessness Scale was used to establish concurrent validity with the Nowotny Hope Scale to establish concurrent validity. NHS based on literature review of qualitative studies on hope. 6 subscales with a total of 29 items were identified. Reliability using Cronbach's coefficient alpha =.90. Correlation with Beck's Hopelessness Scale r=-0.47 (p<0.001). Includes suggestions for practice.
Obayuwana & Carter (1982)	Grounded Theory-Survey	Random numbers from phone directory N=500	Grouped words of what hope means and then derived central themes: religion, positive self-concept, group support, economic success, positive outlook which were then compared to Kubler-Ross' 5 stages of dying and Engel's 5 characteristics of the Giving-Up-Given-Up complex. Inferences and implications of the 5 central themes are shared as a "hope pentagram".
Owen (1989)	Grounded Theory	Oncology Clinical Nurse Specialists N=6	Attributes of hope were isolated through interviews and process recordings and coalesced into 6 subthemes: goal setting, positive personal attributes, future redefinition, meaning in life, peace and energy. Energy was the single unifying concept. Suggestions are made for nursing based on increasing the flow of energy to the patient, increasing physical energy levels, and conserving energy strategies.

Author (Year)	Study Design	Population (n)	Discussion
Parse (1990)	Phenomenological human becoming research method	Adults between 23-75 on dialysis N=10	Shares a research methodology evolved from man-living-health which is hypothesis generating focusing on the lived experience. Emphasis is on the human being's participative experience in cocreating health. Differences in Parse's method: dialogical engagement, multi-sensory immersion, heuristic interpretation to conceptualize using the concepts of the theory itself. Study of hope included as exemplar of method. The findings included three core concepts which formed the structure of the lived experience of hope as anticipating possibilities through envisioning the not-yet in harmoniously living the comfort-discomfort of everydayness while unfolding a different perspective of an expanding view.
Schaffeld (1991)	Anecdotal Article	N/A	A case explanation of a 36 year old male with cystic fibrosis who struggled for life and chose to control his own destiny. Author saw him cling to hope through complications and setbacks until he determined there was no more hope. "Hope means something different to each patient. We can't give it meaning for him-we can only try our best to help him maintain it."

Author (Year)	Study Design	Population (n)	Discussion
Raleigh (1992)	Exploratory Descriptive	Adults from 22-65 with cancer (N=45 and chronic illness (N=45)	Source of Support Interview and 1-10 hopeful scale was done in the home. No statistically significant differences were found in the two groups to the interview questions. Sources supporting hopefulness: family, friends, and religious beliefs. Specific cognitive or behavioral strategies to raise hope: get busy, pray, think about other things, talk to others, read, express emotions. Specific nursing interventions need to be tested.
Scheier & Carver (1987)	Research review linking optimism to positive health-relevant outcomes.	N/A	Designed the Life Orientation Test to measure optimism (Chronbach alpha=.76, test-retest r=.79) and tested to see if optimism promotes a higher level of physical well-being. Explores the idea that "people's actions are greatly affected by their beliefs about the probable outcomes of those actions. Optimism is negatively associated with symptom reporting and is not tied to physical well-being. Optimism seems to be a buffer between hostility and hardiness and health-related outcomes. Optimism was also described as it fits the Lazarus coping model and Bandura's self-efficacy theory.

Author (Year)	Study Design	Population (n)	Discussion
Smith (1990)	Phenomenology (Parse's method)	Family members of critically ill adults in intensive care units N=15	Utilized Parse's phenomenological method to uncover the concepts of hope: resolute intending, abiding in faith, unburdening-burdening, dwelling with the turbulence, nurturing relating, confident view of the not yet.
Stephenson (1991)	Concept Analysis	N/A	Reviewed definitions and contextual usage of hope as well at antecedents, attributes, and outcomes of hope. Explores hope as a theory and suggests that nursing interventions be designed to strengthen the hoping process without giving false reassurance.
Stoner & Keampfer (1985)	Correlational Cross-sectional design with one interview	Adults in various stages of cancer progression and treatment Ongoing Rx N=33 No disease N=11 Terminal phase N=11	Data collected on Stoner Hope Scale and open-ended interview question. Highest hope scores occurred when there was no evidence of disease and no recall of life expectancy. In contrast, recalled life expectancy combined with ongoing treatment produced the lowest scores. Levels of hope in cancer patients who recall life expectancy information were different from those patients who recall receiving no life expectancy information. There was no difference in hope between people in various phases of illness. Further investigation is warranted about disease/prognosis information.

Patient Strategies for Hope

Although much of the health related research focuses on the treatment of disease, more emphasis has been placed recently on living with the day to day symptoms of illness. Writers now speak of understanding the illness experience and the role of hope in the patient's recovery. Physicians (Klopfer, 1957; Siegel, 1986; Simonton, Mathews-Simonton, & Creighton, 1978) have written anecdotal narratives about the valuable contribution of hope to overcoming cancer. They argued that hope and positive emotions are integral to all forms of healing and should be included with the traditional forms of therapy.

My review of nursing literature suggested that a hopeful attitude influences a positive patient outcome (Hanson, 1990, Hickey, 1986). A lack of specific nursing research exists conceptualizing hope as an intervention. The literature is sparse about how the process of hope is useful in guiding nursing action. Several anecdotal articles have been written that suggest hopeful nursing actions (See Table I). In addition, two articles will be reviewed here.

Herth (1990) conducted a triangulated study to explore the meaning of hope and interventions to foster hopeful feelings. She interviewed 30 clients over 21 years of age, asking five probing questions to explore the meaning of hope and to identify those strategies that hindered and fostered hope. She identified seven categories of hope-fostering strategies and three categories of hope-hindering factors. She found that hope values increased slightly, although not significantly, as ten participants approached death, supporting findings (Kuebler-Ross, 1969; Owen, 1989; Stoner & Keampfer, 1985) that the dying person is not without hope. Herth's only variable that was associated with hope in this study was diagnosis: those with AIDS had a significantly lower level of hope than those with other diagnoses. Herth concluded that this difference is correlated perhaps with abandonment and isolation threats identified in the study. Although the research provided a screening tool to possibly assess hope level in patients, Herth focused only on the terminally ill.

The second article suggested nursing strategies for hope in a much broader context. In the Iowa Intervention Project, McCloskey and Bulechek (1993) organized 336 nursing activities into a taxonomic structure for classification of nursing care interventions. The resulting six domains and twenty six classes in the hierarchical cluster analysis included the instillation of hope as a nursing intervention. This example suggested that the nurse interact with the patient/family to facilitate "a positive outlook in a given situation" (p. 188). The eighteen activities involved in the intervention were prescriptive for the nurse and included internal and external behaviors to incorporate into nursing practice. This approach shared concrete ideas from which the nurse could select activities which may be appropriate with a given patient. The activities were based on work by Brown (1989) and Parse (1990) and are conceptual considering their "cookbook" approach. However, without a foundational understanding of the meaning of hope for an individual, nurses would be unable to develop interventions and supportive care.

Current Need

Although hope has been studied as a concept and measured as a construct, the meaning of hope to someone's life has not been researched in depth. Medical breakthroughs in this century have given us the gift of greatly extended life spans; now attention should be turned to the meaning of those extra years. Although patients are surviving beyond the five year "cancer cure", I did not find studies on these survivors. Only two studies were found that related to patient prognosis and hope.

Huebscher (1992) completed an interesting grounded theory study exploring the process of spontaneous remission of cancer. This study differed in that "survival" was defined as living five years after diagnosis and "spontaneous remission" meant living free of the disease without traditional medicine and without a specified amount of time. Huebscher reported that nine people transcended the implications of the cancer diagnosis and looked at positive life outcomes. Huebscher's four emerging categories contributed to the generation of data on the process of spontaneous remission and her participants spoke about "deciding on life while alive" (p. 138). She recommended a change in how information is given to patients regarding their prognosis and keeping statistics on who survives well, along with who does not survive.

In a correlational study on prognosis, Stoner and Keampfer (1985) explored the relationship between recalled life expectancy information and level of hope in fifty-five cancer patients. Their findings revealed that those individuals having no recollection of receiving information regarding their prognosis were more hopeful than those who did recall the prognosis information. The question remaining unanswered was whether hope influenced the level of recall or if recalling the information made the person less hopeful. They identified that life expectancy information was a factor influencing hope in their group of cancer patients and suggested additional research "to add to the understanding of the effect of life expectancy information on the level of hope in people who have a life-threatening illness" (Stoner & Keampfer, 1985, p. 273).

Cancer is now considered a chronic disease. Prognosis information and cumulative losses suffered by chronically ill patients can lead to hopelessness. As the illness progresses and physiological deterioration and other losses continue, a person's hope can serve as a sustaining force against despair (Miller, 1992). The nature of hope within the chronically ill population and its relevance to this study are described in the next section of the review.

Chronic Illness

Approximately thirty percent of the adult population in the U.S. suffers from a chronic illness. Pitzele (1986) describes a chronic illness as

> (1) permanent (2) the cause of frequent and costly medical intervention (3) the cause of substantial modification of lifestyle, life goals, vocational choices and opportunities, recreational activities, interpersonal relationships and family role or position (1986, p. ii).

Chronic illness is a continuous series of unfamiliar stresses and challenges requiring adjustments. Unlike acute crises where denial can pervade, chronic illness brings a reorganized "confrontation with reality, adaptation and participation in therapy" (Miller, 1992, p. 231).

Persons with a chronic illness share many complex social and psychological problems. The experience of chronic illness often affects every aspect of daily living (Corbin & Strauss, 1988). Individuals living with an incurable health problem suffer not only from a crucial loss of health status and body function control, but also from a loss of role function, self esteem, social relationships and independence. Maintaining hope despite a downward physical course is a challenge for chronically ill people.

The changing pattern of disease in the U.S. from parasitic and infectious diseases to chronic illness has now lengthened the time between the onset of illness and death. Increasing longevity and increasing numbers of survivors have advanced a quality of life issue with ethical dilemmas for the chronically ill. A potential exists for progressive dehumanization along with progressive losses. What it means to be human and how to cope with the increasing losses becomes the dilemma of those with a chronic illness.

In the area of chronic illness, hope has primarily been studied in relation to social support. Hagedorn (1993) studied the family's lived experience of childhood chronic illness. Families described their hopes for a cure, a long life for the child, and the strength and wisdom to endure the challenges brought about by the chronic illness. Hagedorn (1993) suggested further development of the deep meaning of her metathemes including hope and courage within the lives of families living with childhood chronic illness.

Katz and Lowe (1989) documented that patients with a stronger "will to live" are characterized as having greater involvement with family and friends, suggesting that involvement with significant others provides the impetus to go forward in the face of devastating health-care circumstances and against the unbeatable odds. The literature is replete with studies of social support demonstrating that this variable protects people from the harmful effects of stress, improves well-being, and increases levels of adjustment to chronic illness (Bloom & Spiegel, 1984; Corbin & Strauss, 1988; Pearlin & Aneshensel, 1986).

For some chronically ill people, health care personnel may serve as surrogate partners. At times, health care personnel or the partner may experience hopelessness for the chronically ill person. If everything has been done for the patient, the nurse might stop mobilizing energy toward patient goal attainment. Watson (1988) stated that caring-healing is communicated through the consciousness of the nurse to the one being cared for. Nurturing hope in the nursing practice arena could mean creating a sense of "the possible" for patients (Benner & Wruble, 1989) and for the nurse. This cocreation of hope can perhaps be a richer experience by studying the meaning of hope in a group of people who grew up with chronic illness and are now living beyond their expected life span.

Summary

In this chapter I reviewed related literature on the phenomenon of hope from the disciplines of psychology, theology, philosophy, and nursing and presented a concept analysis of hope. The review revealed a wealth of descriptions of hope in a variety of populations. In the discipline of nursing, an awareness exists of hope as a phenomenon of concern, as well as a variety of descriptions about its nature. These varying descriptions, which emanate from nursing theoretical conceptualizations and clinical investigations, include a concrete perspective of hope as a positive life force, a procedural perspective of hope as an intervention, and hope as a prerequisite for caring.

Although health care researchers have amassed much valuable information about hope as a phenomenon and an intervention in life threatening situations or crises, no literature focused on groups of people who are surviving beyond their expected lifespan. Multiple clinical investigations of hope exist at specific points in time in the life of a person, such as at the time of diagnosis, a hospitalization, or a treatment but hope without a trigger event in the chronically-ill has not been studied. Loss of hope threatens the integrity of being. While dying was covered extensively in the literature, not dying or living beyond expectations, was a concept not studied. Based on the literature review, an insufficient understanding exists about the experience of hope in the person who has outlived a predicted life span. Therefore, this research addresses the question: **What is the meaning of hope for people who have outlived their life expectancy?** The design and methods of the investigation are discussed in Chapter III.

CHAPTER III

CONCEPTUAL FRAMEWORK AND METHODOLOGY

> If you really want to help somebody, first of all you must find him where he is and start there. This is the secret of caring. If you cannot do this, it is only an illusion if you think you can help another human being. Helping somebody implies your understanding more than he does, but first of all you must understand what he understands. If you cannot do that, your understanding will be of no avail. All true caring starts with illumination. The helper must be humble in his attitude towards the person he wants to help. He must understand that helping is not dominating, but serving. Caring implies patience as well as acceptance of not being right and of not understanding what the other person understands. (Kierkegaard, 1848, p. 27)

To uncover the experience of hope, a hermeneutic phenomenological design was used. In Chapter III, I describe the conceptual framework and methodology used in this study to address the research question: **"What is the meaning of hope in the adult person with cystic fibrosis who has lived beyond the expected life span?"** Hermeneutic-phenomenology yields a rich description of the experience through a unique method of presence and dialogue between the researcher and the participant. The experience of hope was explored through descriptions provided by the participants, whereas the meaning of hope was uncovered by the researcher through a hermeneutic or interpretive process.

Watson viewed nursing as a human science and explored the philosophy, science, and art of human caring (Watson, 1985; Munhall & Oiler, 1986). Hermeneutic-phenomenology offers a view of the "lifeworld" through which the nurse can understand the meaning of a human experience of another. The conceptual framework for this study arises from the philosophical perspectives of Watson (1985, 1989), van Manen (1984, 1990), and Parse (1981, 1992).

In the following section, a description of Watson's human caring theory and an overview of hermeneutic phenomenology are presented. A specific description of van Manen's technique and a discussion of Parse's method of inquiry as it relates to the process of dialogue and data gathering is provided. Finally, a specific description of my activities during the process of analysis is shared.

Watson's Human Caring Theory

The art of nursing is the creative focus on human interrelationships. Watson's Human Caring Theory (1985, 1989) informed this study through describing the human caring process as transpersonal and emphasizing the "high regard and reverence for the spiritual-subjective center of the person" (Watson, 1988, p. 73). Central to her theory is the belief that human experiences may not relate to the external physical world to the same degree as to each person's inner lived world. Each person involved in the human caring process brings with her or him a unique causal past. Experiential moments become incorporated into the past and help to direct the future. Caring-healing consciousness takes place during a single caring moment. An interconnectedness occurs between the one cared for and the one caring (Watson, 1988).

The notion that the creative focus of human interrelationships expresses the art of nursing is demonstrated in the nurse-client relationship in which empathy and transpersonal caring predominate. Watson posited ten carative factors such as human altruism, sensitivity to self and others, and faith-hope. She contended that the nourishing of faith-hope is part of the caring and curative process. The consequence of hope, according to Watson (1988), includes the ability to "transcend space and time through one's mind, imagination, and emotions" (p. 46). This consequence of hope and the process of caring informed my thinking in this research.

Watson's view of nursing as a human science merges well with the cocreated meaning of phenomenology. The meaning of the experience frames her nursing perspective. Caring, in its most significant sense, is defined as helping another to grow and actualize herself or himself (Mayeroff, 1971) and to achieve human potential. By the use of phenomenology to explicate the meaning of hope, the inner world of experience is part of the method. The notion that caring values and actions can be contagious (Watson, 1988) underlies the philosophy of cocreating the meaning. Therefore, this study used the caring framework with a phenomenological approach.

Hermeneutic Phenomenology

Hermeneutic phenomenology is both descriptive and interpretive. This method allows us to be sensitive, understand and interpret the lived experience. van Manen (1990) used the term phenomenology to include both the interpretive and descriptive element. To van Manen, this method is the "application of language and thoughtfulness to an aspect of lived experience" (1990, p. 33). van Manen (1990) defined thematic understanding as to "see meaning." I used van Manen's hermeneutic phenomenology design in my research to discover, describe, and understand the experience of hope in the lifeworld of those who have lived beyond their expected prognosis. van Manen's philosophy of the unique and personal facilitated my understanding of the person as a whole.

van Manen's (1990) hermeneutic phenomenology combined aspects of phenomenological and hermeneutical traditions into one research design. Phenomenology focuses on a systematic attempt to describe and illuminate aspects of internal meaning and lived experience (van Manen, 1990), whereas hermeneutics is directed toward interpreting meaning of a phenomenon (Gadamer, 1986; van Manen, 1990). When phenomenology and hermeneutics are combined, as in this study, the researcher is attentive to both aspects of the method. The researcher seeks a full description of the experience from the participant and then interprets that description to arrive at themes in the researcher's language (van Manen, 1990).

A distinguishing feature of hermeneutic phenomenological human science is that it assists one to gain an insightful description of an experience in the world without an artificial means of structure such as taxonomizing, classifying, or abstracting (van Manen, 1990). Moreover, hermeneutic phenomenological human science offers the researcher possible insights that bring the researcher into more direct contact with the individual's interpreted world (van Manen, 1990). van Manen proposed six research activities that I used to access the lived experience. These activities are described in the following section.

van Manen's Six Research Activities

The six research activities in the hermeneutic phenomenological method proposed by van Manen (1990) are not meant to be linear in nature, but six dynamic activities used throughout the research process. Through these activities I understood and discovered the meaning of the lived experience.

The first activity is to turn to a phenomenon that interests us and commits us to the world. van Manen (1990) believed that a deep question is asked in relation to a certain aspect of human existence, leading to the researcher's single interpretation, but recognizing that other richer or deeper complementary descriptions could exist.

The second activity is to elicit a description of the lived experience. Investigating life's living dimensions can be accomplished through personal experiential accounts, descriptions of lived experiences, interviews, and observation. During the interview the participant reflects on the topic and together with the researcher cocreates meaning about the experience (van Manen, 1990).

van Manen's third research activity relates to reflecting on essential themes that characterize the phenomenon. Reflection is an activity or process in which an individual gains meaning about the experience. Phenomenological reflection includes clarifying and explicating the structure of the lived experience. The identification of themes also facilitates the evolution of meanings and experiences related to a phenomenon. Themes are representative or focal points of meaning in an experience. Themes answer the question "what is the nature of the lived experience?" Contrary to some methods, themes in hermeneutic phenomenology are not solely responsible for meaning. Meaning is viewed as a process in which the researcher's subjectivity involves discovering or "seeing" more than the sum of the parts, a process that moves the researcher beyond the concrete to the abstract. This process requires the researcher to make an interpretation about the concealed meaning inherent in the subjects' description.

The fourth activity is to describe the phenomenon by writing and rewriting phenomenological text. This process requires one to be sensitive to the subtle verbal undertones and allow these things to speak for themselves through reflection and writing in order to make an experience explicit (van Manen, 1990). Through writing the researcher is oriented to the lived experience, enabling the researcher to "see" the hidden meaning or experience. van Manen identified five ways writing assists the researcher to "see" embodied knowledge in phenomenological research: a) writing creates a dialectic between what is known and what is not known, b) writing distances the researcher from the text in order to discover the structures of the experience yet deepening the understanding through reflective awareness, c) writing moves the researcher into the universal rather than focusing on the particular, d) writing assists the researcher to obtain a higher level of abstraction in order to facilitate understanding, and e) writing objectifies something that has engaged the researcher's subjective understanding.

van Manen's fifth activity is to maintain a strong relationship with the phenomenon of the study. The abundant information collected in a qualitative study often distracts the researcher and causes the researcher to lose sight of the question. However, van Manen believed that in hermeneutic phenomenology, the researcher can remain in strong relation towards the phenomenon if four conditions are met. These conditions include: a) the researcher needs to assume a stance that does not separate knowledge development from the real world, b) the text needs to be strong, responding to an orientation that enables understanding, c) the richness of the text needs to engage the reader to the point that it seems to require a response, and d) the text must be deep enough to move beyond the concrete and force the reader to "meet with it, go through it, encounter it, suffer it, consume it and, as well, be consumed by it" (van Manen, 1990, p. 153).

The sixth and final activity is balancing the research by considering the parts and the whole. The researcher's challenge is to compare significant parts to the overall text structure. van Manen offers a variety of approaches to examine the text: a) examine themes or analyze reconstructed life stories that highlight a theme, b) identify essential structures to more fully explicate the phenomenon, c) utilize the literature and personal experience to reflect on the understanding of the meaning of the phenomenon, and d) weave phenomenological descriptions against existentials such as temporality (lived time), spatiality (lived space), corporeality (lived body), and communality (lived relationships) (van Manen, 1990). The researcher may use any or all of these approaches to facilitate interpretation, and according to van Manen, they can occur out of sequence and intermittently or spontaneously. Phenomenological hermeneutical methodology, then, is an inductive descriptive approach to creating knowledge. The methodology focuses on exploring, extracting and interpreting essences and meaning of a phenomenon as lived experience.

Parse's Influence

Parse's phenomenologically based approach to inquiry influenced the methodology of this study. Parse's approach to inquiry is an inductive approach to creating knowledge specifically designed to be congruent with the ontological foundations and assumptions of the theory of human becoming.

My study was influenced by Parse's conceptualization of dialogical engagement because her perspective does not focus on human experiences as a crisis or stressful event, but assumes that personal reality is coconstituted (Parse, 1981, 1987). The meaning of reality is always a personal perspective and will be shared through the lenses of the participants and myself. Although Parse's dialogical engagement notion was used, my interpretation was not restricted to her theory of human becoming. Parse's philosophy guided my thinking upon entering the participants' world, but van Manen's method was used in the analysis of the data. I chose van Manen's method for the interpretation, as it offered a variety of approaches to examine the text and allowed for a closer resemblance to the actual text of the participants. This final interpretive step balanced the parts and the whole to reflect creative knowledge.

Methods

The specific methods used in this study including the sample, ethical considerations, setting, and data collection procedures will be described in the following sections.

Sample: Sixteen participants were selected based on three study criteria: a) a diagnosis of cystic fibrosis made in infancy or early childhood, b) a current age of 21 years or more to qualify as an adult and to assure that life span information given to them did not include a prognosis of living to adulthood, and c) a willingness to express personal feelings and experiences. Participants were volunteers solicited through word of mouth, the Cystic Fibrosis Foundation, the New Jersey State Organization of Cystic Fibrosis, and a Cystic Fibrosis mailing list run by a revised LISTSERV processor.

Sample size was determined by the completeness of the data, not by the number of participants. Saturation of findings began to occur from the eleventh interview onward. That is, data that differed in thematic content were not elicited from respondents. I chose, however, to continue beyond saturation with the ultimate belief that additional participants would enable approaching confirmability of previous findings.

Consistent with phenomenological design, the sample was purposeful, voluntary and convenient, rather than representative and circumscribed. The results were not used to generalize, but to explore the depth and richness of meaning, thereby allowing for a unique sampling. The sample was comprised of both females and males in a variety of life relationships. Only one participant had children. The educational background ranged from not completing high school to completion of professional education and doctoral work. Employment ranged from full time to unemployed and several persons were on government disability assistance. (Table II in Chapter IV displays demographic data.)

Ethical considerations: Approval to conduct this study was obtained from the Colorado Multiple Institutional Review Board (COMIRB). Written consent from each participant was obtained before the interview began. (See Appendix A.) Participants were assured confidentiality and pseudonyms were used to identify all participants and others named in the interview. Tapes were kept in a locked file cabinet and will be destroyed following the completion of the study.

The participants were fully informed about the nature of the study. They were informed of the study's purpose, the nature of the unstructured dialogue, and the possibility of an additional follow-up phone call. Additionally, they were told of their right to leave the study or to stop the discussion at any time without consequences.

No risks to participants were foreseen in this investigation and none occurred. Likewise, no specific benefits were anticipated. Several participants said new discoveries of enriching self-knowledge occurred through the dialogue. Several also shared that the dialogue had been meaningful in helping them gain perspective on their past.

Setting: This study was conducted on the East coast in the Newark/Greater New York metropolitan area and by telephone to people outside this area. Participants lived in seven U.S. states. Ten interviews were conducted in person, five on the phone, and one interview was conducted on the Internet computer system. Dialogic engagements (phenomenological interviews) were scheduled at a mutually convenient time when the participant could relax and be in privacy. The locations included participant's homes, places of employment, and restaurants. I insured that the setting was quiet enough to allow adequate audio taping. The telephone conversations were directly recorded by a tape recorder inside the telephone. Internet communications were intermittent over the course of several weeks and printed out directly on the computer printer. Dialogic engagements ranged from 45 minutes to two hours by mutual consent.

Data collection procedures: In this study, I contacted individuals who met the criteria to discuss the meaning of hope as a lived experience for persons who have lived beyond their expected life span. At this time the study was explained and an initial verbal consent was obtained to set an appointment. A request was made to tape record the session. Upon meeting, the participant signed the consent form (See Appendix A) and again received the full explanation of the study.

Prior to each interview, I centered myself in order to become open and focused. I listened to each conversation thoughtfully and participated intermittently. I used silence and nonverbal techniques to focus on the participants and their stories. My role was to encourage and support the participant with open and receptive attention to the what and how of the dialogue.

Open ended, minimally structured questions were used to invite participants to explicate the meaning of hope as it related to each participant. Study participants were asked to describe their experience of hope throughout their life with Cystic Fibrosis. They were asked to think about a situation of hope they had experienced prior to the interview and to include their recalled thoughts, feelings, and perceptions. Participants were asked what hope means to them. Clarifying questions were asked at appropriate times during the course of the dialogical engagement, but suggestive or leading questions were avoided. For example, I informed the clients that I was interested in understanding their experience with hope. Thoughts, feelings, perceptions, and actions associated with the experience of hope were explored as fully as possible. Discussion focused on the hoping experience, what it was like, and what it meant to the individual. I tried to be present with each of them in order to understand what they were experiencing.

Questions were asked as needed in the dialogue for expansion and development of the topic. Examples of these questions included: "What did this experience mean to you?" or "What did this experience feel like for you?" Such questions revealed the internal meaning of the participant's lived experience. Closed-ended questions were avoided. Near the end of the discussion, participants were invited to add any other thoughts or perceptions regarding the hope experience.

After summarizing the hope discussion, participants were asked what they would like health care professionals to know about Cystic Fibrosis patients. I informed them I was a nursing instructor and asked, "What should I teach my students about taking care of adults living with Cystic Fibrosis?" Participants were also encouraged to contact me if they had additional thoughts or experiences they wanted to share. Two of the participants did recontact me, one by phone and one by E-mail. Information provided by these two participants clarified and expanded several ideas from their previous interviews.

Data Analysis

Continuous transcription and data analysis were used throughout the data collection period. Although the data analysis steps are described in a linear fashion, the actual process of analysis was quite interactive and non-linear. This process is described in the next section.

The process began and evolved with the stories. The taped interviews were transcribed by a hired transcriptionist and audited by me to ensure transcription accuracy. The right half of the transcription page was left blank to facilitate recording information and thoughts during the analysis phase. I took great care that the interview transcripts were verbatim. I began my analysis by simultaneously listening to the tape recordings while reading the transcriptions. The voice tone, pitch, intensity and rate of the words added greater depth of meaning to the written word. I made notes about these findings on the transcripts (see Appendix B). Phrases and key expressions were noted on the right half of the paper as I examined the individual stories. Underlining and highlighting also enhanced the thematic analysis. I remained sensitive to the subtle verbal undertones and allowed the stories to speak for themselves. Data analysis at this point was pain-stakingly detailed to preserve the participants' words.

Both holistic and selective approaches to isolating the themes of hope were used in this study. The holistic approach allowed me to examine the text of each participant's interview as a whole and to begin to understand the overall meaning of hope to each person. This understanding was accomplished by listening, reading, and recovering the theme or themes with each dialogue. The approach helped me to identify specific groupings that appeared to be an integral part of the lived experience of hope. These recurrent ideas, or transcript themes, then became a focal point for meaning (van Manen, 1990).

Next, I began to look at the experiences across the participants. I then divided the data into meaningful units among the many transcripts. The process of unfolding new themes was very slow in an attempt to not lose data by early closure. van Manen (1990) suggested, "phenomenological research/writing requires a high level of reflectivity, an attunement to lived experience, and a certain patience or time commitment" (p. 114). This process resulted in development of preliminary themes as illustrated in Appendix C.

I then began to create a dialogue between what was known and not known. I distanced from the text to deepen the experience and reflect on it. I moved from the particular into the universal, searching for a higher level of abstraction. Then, I returned to the individual transcripts and captured the essence of each person with a narrative description.

After centered reflection on the tapes and narratives, the intuitive meaning unfolded three essential themes. These themes were written and re-written, remaining close to the text and true to the participants. Throughout the analysis phase, writing clarified and deepened the level of abstraction to facilitate understanding.

Summary

The purpose of this research was to understand the meaning of hope for people who have lived beyond their expected life span. To explicate this human phenomenon, I used the human science perspective with caring interaction to explore the meaning of hope with adults who have Cystic Fibrosis. My intent was to uncover meanings in everyday life in such a way that they "are not destroyed, distorted, deconceptualized, trivialized, or sentimentalized" (Benner, 1985, p. 6). My search for understanding was co-created with the participants through our open-ended dialogue.

Since the research question is grounded in participant perceptions, I selected hermeneutic-phenomenology as the appropriate design for this study. The six step method of van Manen served as a guide, informed by the influence of Parse (1992) and Watson (1985, 1989). Each step of the analysis was guided by two concerns: 1) to characterize the essential meaning of hope as revealed by the participant in caring interaction and 2) to remain as faithful and centered as possible to the participant's characterization of the meaning of hope as a lived experience.

A distinguishing feature of hermeneutic phenomenological human science is that it attempts to gain an insightful description of an experience in the world without an artificial means of structure such as taxonimizing, classifying, or abstracting (van Manen, 1990). For van Manen (1990), essence is understood as an artistic endeavor that captures a lived experience through linguistic description that is both "holistic and analytic, evocative and precise, unique and universal, powerful and sensitive" (p. 39).

In this chapter I presented the conceptual framework of the study, comprised of a synthesis of the work of two nurse theorists, Watson's Human Caring Theory and Parse's Human Becoming Theory. The steps in van Manen's phenomenological hermeneutical methodology were also discussed as a foundation for the design. I then described the methods I used in this research including the sample, setting, data collection procedures, and analytic process. After transcription and engaging with the data, summary narratives were written. In Chapter IV, I will introduce the sixteen participants through their stories.

CHAPTER IV

NARRATIVES

> We are all in some denial, we hope for the best and deny facts that stand against us. Life deals some hard facts to people with CF, such as life expectancy. We can either accept those facts as true, or we can deny them the right to ruin our lives. That's what I've done. I realize that 'by the books' my life will not last as long as most healthier people. I have found that the only way to get past those 'facts' is to deny and ignore them. (With permission, Shane Robinson, Cystic-L subscriber)

In this phenomenological study I sought to understand the meaning of hope for people who have lived beyond their expected life span, specifically adults with Cystic Fibrosis. To explicate this human phenomenon, stories told by the participants captured the essence of the experience and are shared in this chapter in shortened version to give the reader a snapshot of each person. The stories enabled me to understand deeply the structure of the hope experience and to recognize the other as a unique individual. The dialogical engagement created an opportunity for me to reflect with the participant about the experiences of hope and co-create the findings.

The narratives were constructed from the dialogical engagement between the researcher and the participant, as described by Parse (1990), and are part of the data analysis. The research participants are described in narrative style in present tense as a means of enabling the reader to "know" the people individually and to preserve their uniqueness. As I introduce the participants, pseudonyms are used to protect their identities and yet lend a personal feeling about the lived experience congruent with human science. In the next chapter, thematic results of data analysis across participants is presented to give a sense of the collective experience.

Kitty's Story

The first participant is Kitty, a 32 year old female who has a goal to live into her 60's.

> You meet people with CF in their 60's and think if they can do it, I can...It's something to shoot for. My whole life I have been the average age for people with CF. The time line is following me. In other words, I'm 32 and I think the average age for someone with CF is 30.

In reflecting on her diagnosis, Kitty says her mother noticed that her baby was different from all of her friends' babies. "She tried telling the doctors but they all told her she was overreacting. I was having horrible bowel movements and would get tired when I nursed. Finally after about a million ear infections, they discovered I had CF."

Her childhood was "normal" except that her mother wrapped her medication with her lunch. The kids never really inquired and she took a matter of fact attitude about taking the medications so no one ever teased her. In high school she was selected as the poster child for CF so she met many others with the disease and openly acknowledged living with CF. At that time she did postural drainage and nebulizer treatments (both respiratory treatments common to persons with CF). As she grew older, she rebelled and by the time she entered college she was not doing any treatments. She refused to be in a gene study because she feared the bronchoscopy, but did participate in an autogenic drainage study that taught her a new form of chest physiotherapy and she has continued with these treatments. She feels as if "the treatments might be beneficial. It seems like if something's helping, then even if it isn't, it has a better chance." Kitty believes that:

> A lot is in the mind set. I read a lot of books. I pick my friends as upbeat people. I praise and reward myself for doing treatments. Sometimes I reward myself with a cup of tea!

Her self-identified goal is to stay married to her husband of four years. And she confesses that his goal is to keep her doing her exercises. "CF is a part of my life, but not my whole life. I try to keep happy things around me. I've observed others and sense that some people may run away if I tell them I have CF (as one boyfriend did.)"

Health care professionals help Kitty feel valued by listening to her and giving positive feedback about her goals and ideas. She related a story about talking with a social worker regarding having a family. The social worker volunteered to get her information on adoption. Kitty believed that this was an excellent way of truly listening to what she wanted and giving her the power to go forward with an option.

Elaine's Story

In 1960 when Elaine was born, her mother was told by doctors that her daughter wouldn't make it to 3 years old. At 14, Elaine's life expectancy was extended to 18. As she approached 18, she remembers thinking defiantly she would not succumb to her disease. At 21 when Elaine saw people with CF who were 23 and 24 dying, it was a reminder to her that she could be next. Rather than to dwell on death, Elaine says she developed a "cocky attitude!" With a firmness to her voice, she says, "I wouldn't allow CF to run my life. I refuse to be a victim!"

Today at 35 years of age, Elaine works three hours a day as a medical transcriptionist. She left home when she was 17 and now lives with her dog, two cats, and a hamster. She talks of her love of playing the violin and gardening when the disease "lets me be the active person I am." Her apartment is cluttered with apparatus, some to help her breathe, some to help her cough.

Last January, Elaine started on an experimental CF treatment. She believed after several bouts of pneumonia with no warning signs, that she was losing control of her disease. Elaine realized these setbacks must be due to the new treatment and discontinued it. She feels much stronger, more energetic, and has better blood oxygen saturation levels since she resumed her former routine. Elaine believes during that period she lost total control over her disease and gave up a lot of quality of life. "I lost the ability to do everything I had done just six months before--hiking, dancing and working." Now she is on the transplant waiting list with medication throughout the day, oxygen throughout the night.

Elaine has a strong sense of self and an ability to tell and sell her story. She started fund raising for her double lung transplant in the barber shop below her second story apartment. She played the violin next to a sign that read "I'm playing the violin for you, but what I really need is an organ." From this, she received an outpouring of people cheering her on!

Elaine loves her flower garden; she explained,

> It's important to see things grow and live. The garden keeps my mind off myself. I nurture the flowers because I can't be a mother... as dependable as I used to be. I can't be counted on anymore to be places. I worry who will take care of my pets if something happens to me--that motivates me to get out of the hospital!

Through the technique of imagery, Elaine can see her antibiotics working. She visualizes how to get rid of plugs in her lungs. She looks toward the future and says, "I never thought I'd be 35; never made plans past 32. Now I'm motivated to live to the year 2000! I CAN BE 40! I think of CF as meaning Chronically Feisty!"

Vi's Story

Vi's childhood wasn't fun. The seat on the bus beside her was always empty. "It was like I had leprosy or was contagious," she explained. This concept of discrimination carried over to Vi's later choice to join a convent. She again felt those unwelcome feelings when the Mother Superior said they wouldn't accept her because of her "health problem."

Now 43, Vi believes that other people gave her hope and that her own strength of conviction helped her to heal. Vi distinctly remembers her mother's constant encouragement and praise as she grew up. She recalled her sister urging her to get better so she could be a bridesmaid in her wedding. She also spoke of times when she "willed" herself better. "My stubbornness may have helped me to survive," she shared, "I was too ornery to die!"

Vi married in 1969 and dealt with the statistics of chances for children. She was told "there's a 90% chance you won't live through the pregnancy." In her typical approach to life she replied, "that's O.K. I'll be in the 10%." She never did become pregnant and eventually divorced. Two subsequent marriages also ended in divorces. After a serious bout of depression and a need for full time oxygen, she began counseling.

> I was really at a low point. Even though I had been handicapped all my life, I didn't look handicapped. I was out of breath, but it wasn't outwardly visible and then all of a sudden I had to carry this damn thing

> around in my nose (oxygen). Maybe I'm vain, but I didn't even want to go out to work.

Even when she was depressed, neighbors and friends urged Vi to surround herself with people. Vi began to experience hope through belonging to a group and recognizing that healthy and non-healthy people often experience similar problems such as anger and depression. Support group members badgered her to do her CF treatments daily and took turns doing her chest percussion. They also helped her run errands and take out the garbage. Vi told of an instance in which she was depressed during a hospitalization and wrote letters to people telling them how much it meant to be friends with them. They interpreted this as a good-bye and rallied around her. "I couldn't give up on life--they wouldn't let me. My hope came from them for a long time. Now it's in me!"

After waiting 18 months on a transplant list, Vi was given a double lung transplant and "another birthday" as she puts it. She lived disabled for 43 years and is now learning to live healthy. She acknowledges her dependence on friends over the years, and describes changes in friendships over the course of her illness. In her health, Vi expresses some sadness about a change in the intensity of the friendships, but recognizes that bonds change, but do not break. She's been given a future. That's something she never had before!

Barbara's Story

When Barbara, at the age of twenty, joined an NIH study for CF patients and met a woman who was fifty-seven years old, she expressed hope. Barbara had heard she "wouldn't make it" (live) past 13, then 21. Until she met that 57 year old, she wasn't hopeful because she didn't know anyone else with CF and she seemed so different from other people. In fact, she didn't plan ahead for the future or make any goals for herself. Meeting this woman meant "they're wrong about the age too."

Barbara was also more hopeful when she read Give Me One Wish, a story by Jacquie Gordon about a teenager growing up in the 1970's and early 1980's with Cystic Fibrosis. Up until that time she thought no one understood her. After she read about this courageous teenager, she connected with the emotional, mental and physical aspects in the book and it was like reading "my whole life story." She identified with the teen who lived every day like it was her last day. Barbara was having trouble feeling understood. Reading this book validated her experience. Although her father seemed comfortable in his denial of the disease, she asked him to read it and they discussed the book together.

Although Barbara survived her childhood, her parent's marriage did not. Reflecting on this period, she struggled to hold back the tears, and failed. She paused, gained her composure and spoke about how her fiance gives her hope. He urges her to gain weight. They work together and he encourages her to hike or bike when sometimes she would rather be sleeping. He also does her chest physical therapy. "He's always there when I need him," she commented. She never really gave any thought to getting older, getting married, or having kids until she met her life's mate. "He was the missing piece in my life," she grins, "and since I was carefree and didn't plan for the future, we're having trouble getting credit now to buy a house!"

Participating in the NIH drug studies also gives Barbara hope. "When I'm healthy enough to qualify," she says, "then I know they feel I'm worth saving." Because she met the pre-established criteria to be accepted into the NIH studies, she felt healthier when selected to participate.

Working in the Cystic Fibrosis Foundation office gives Barbara a chance to meet many parents of children with Cystic Fibrosis and also allows her to keep close tabs on the latest research and funding. "It seems like no matter where we go, I know someone," Barbara says. "There are so many new things they're doing right now--with the cure around the corner. The Foundation is focused on the cure right now...completely changed their philosophy from helping people directly." Barbara says she's staying in good shape, working out, and maintaining 80-85% lung capacity to be ready for the next helpful step toward a long life.

Leah's Story

Leah is a well dressed business woman who met me in New York City for lunch during her business day. She is on a high calorie diet, yet her underweight frame appears to be a fragile cluster of bird bones. She is cordial and ready to talk and tells me that she is honored to be able to help me with this project.

Leah was diagnosed at nine months of age and her parents were told that she would not "make it" to puberty. Leah grew up being told by her parents that she had a "mild case" of CF. Although she knew she wasn't normal, she thought that a pill would make her "all better." She remembers a time in Biology class when she was 13 and her instructor related the day's experiment to genes, similar to those people with CF, "but they only live until about 12 years old."

In her adolescence, Leah revealed that she rebelled against her treatments and believed that she was "gonna die anyway so I might as well live it up!" She had yearly hospitalizations throughout college and when she began working, spent more time in the hospital than out of it.

At about 23-24 years, she realized how fortunate she had been compared to others with CF her age who were significantly sicker. "I decided I better take care of myself at that point." Since then, Leah has been running from the life expectancy. When she was 20, the life expectancy was 20; now that she is 30, the life expectancy is 29. "I'm in denial a lot of the time," she commented, "it works for me most of the time."

When her lungs started bleeding, the doctor suggested that Leah go on the transplant list. She explained,

> I've been on the list 9 months. The first 6 months, I was really depressed. Now I'm saving for a computer at home as a way to work part time. As my health deteriorates, I figure I can work free lance.

Leah attributes her optimism and attitude to her mother and enjoys being with her family and friends. She expressed a desire to tour Europe with her mother someday. She believes that hope is positive thinking. To stay optimistic, Leah uses visualization and reads inspirational books. She takes responsibility for her health. She tells me that health care providers should: "listen to the patient's interpretation; and don't imply that it's not normal to live this long!"

Leah believes goal setting is important and is very busy fighting for herself and her health. The doctor wants her to use oxygen at night, but she is resisting. She believes that to be on oxygen means to "admit I'm sick."

As a graphic artist, Leah would paint a picture of hope as herself "sitting on a pile of lottery money!" Someone once told her how lucky she was to be alive. "They said I should congratulate myself, because people like me are rare! That made me feel good because I AM special and I'm being good (behavior) so that makes me feel good."

Sean's Story

I met Sean at the front door of his trailer behind his sister's house on her farm property. We chose the trailer because it was a hot July day and the air conditioning was an absolute necessity for Sean to breathe. At 35 years of age, Sean is now on oxygen at night and has the additional complication of diabetes mellitus on top of his CF.

Sean's parents discovered that he had CF when he was 13 months old. They were told that he would probably die before the age of 6; then as he grew older the prognosis changed to age 12 and eventually 20. Although Sean states now that this was a "gloomy-doomy kind of deal," his parents never transferred their concerns to him. In fact, he was an adult before they discussed prognosis with him.

Sean never thought that he would die young. The first time he ever realized that he might die of CF was during a hospitalization at age 16. He explained that when a girl down the hallway died, he thought: "she has CF and she died, and I have CF..." Although Sean didn't believe that he would die immediately, he did believe that he was one of the oldest people to live with CF.

At the end of Sean's twenty-seventh year, he had three pneumothoraxes (collapsed lungs) within two weeks and lost a lot of lung capacity. By age 28, Sean was declared disabled and eligible for disability payments. He became involved with the "CF cause" in adult issues and bringing the community together through an adult CF support group and quarterly newsletter.

Sean started his active fight against the disease when he encountered a physician whose pessimistic philosophy stimulated a strong reaction. Sean decided he would prove the physician wrong and live:

> When I was very discouraged and down to 18% lung capacity, I just wanted some compassion--not a miracle cure. And when they started making fun of my attempts to get better--to improve my lung capacity-- I got angry, left that doctor and that hospital and wrote them a letter to prove them wrong. I had to give opportunity a chance. I was following that little thread of hope...

Taking charge of his treatment routine, Sean kept track of his medications, inhalations, chest physical therapies, and symptoms. "I took the bull by the horns. I started to push the boundaries to see if my behavior could influence my health. I took charge, took control, started thinking positive!" And with the new doctors, Sean was able to mobilize his chest wall, maximize his lung capacity, and attend to every detail. As Sean puts it, "I was like a swimmer shaving his head to decrease the water resistance ...you just don't know til you try..and you don't realize what you have til you lose it."

To Sean, CF is a lifestyle.

> It's a daily routine for me. There is no vacation from CF. When I go away for a weekend, I have to take all my nebulizer equipment, my pills...I am constantly fighting back. CF treatments take 4 1/2 hours per day...that's time I could be doing something else.

Sean is very gracious in appreciation of people who have helped him. He says he came to the realization one day that "if I didn't have CF, I wouldn't know that I was loved so much...it has made me more sensitive, more caring.."

Sean enjoys living longer than he was supposed to. "I get a kick out of it. When I went for prescription glasses, it was great--I've lived long enough to need them!" And when he turned 30 and found a grey hair he was delighted to get the chance! Life is precious for Sean, with no guarantees, but many hopes. He's outlived expectations. "When I was born my life expectancy was 6, so middle age for a 6 year old is three. At 35, I now tell people I reached middle age 32 years ago!"

Monica's Story

Monica, who will turn 33 in the next few months, and her apricot poodle greeted me at the door of her apartment. Monica did not have a "thin look." She obviously places a high priority on her physical appearance, possibly related to her job as a product promoter in grocery stores.

When Monica was ten the mother of one of her peers told her daughter that people with CF die at age 16 and the girl told Monica's classmates. This situation and teasing by the other children led to Monica's enrollment in private school. Monica said that although she was not given the information directly, she somehow knew she could die from CF. Growing up, Monica hated the treatments and in her teenage years she heard "you don't live past 18" so she stopped her treatments and medications and started smoking cigarettes and pot. At 17 she moved out from home and by 18 she was married.

By age 19, when Monica realized she "wasn't that sick and might live even longer," she began to take better care of herself. Not until she was 24, after the loss of a close friend with CF, did Monica begin to take her care more seriously. "Someone at the same age as you, dying of the same disease you have is very hard." Monica now takes her medicine more consistently and acknowledges she needs 8-9 hours sleep every night. She also does preventive treatments and acts more quickly when she feels exacerbations coming on.

Monica's business has helped increase her self esteem and helped her support herself. Running a product promotion business gives her flexibility to call in someone else as a backup. Being sick means not being able to work. In looking toward the future, Monica hopes to maintain her health.

As a youth, Monica did not have educational goals but thought about having a family. When she married at 18, she hoped to have children, but she couldn't get pregnant. Eventually she realized that it worked out for the best... "I think the woman's health suffers during the pregnancy.

What happens if you get sick and the child is sick? Who's going to take care of you and the baby at the same time?"

Sometimes she just gets sick of IV's, aggravated, tired and worn down. She talks with her boyfriend or her friends but is no longer connected to anyone in the CF community since her best friend with CF died nine years ago. The home care nurse who visits Monica helps primarily by listening. Monica says she "dumps" on her and they just talk. To Monica an ideal health care worker would take the time to understand her feelings and moods. In response to questioning Monica about outliving her life span, she says she can not talk about it. Her quality of life now is to live in the present and enjoy life while she can.

Jamie's Story

You'll know Jamie by his car license plate: "SUPER CF!" People who know Jamie's past, understand that CF means Cystic Fibrosis. More recent acquaintances, think it's "super chef!" Jamie is the new proud owner of a restaurant.

When Jamie was diagnosed at 5 years of age, his mother got the news from the family doctor by phone. It was a hot July day in the summer of 1966 and he told her not to buy any Christmas presents for Jamie because "he wouldn't be around to open them." Jamie says his parents consulted an encyclopedia and found that CF was a "salt problem" and he would not survive to school age. His parents were totally unfamiliar with Cystic Fibrosis and because he was adopted, they had no knowledge of family genetics.

His parents told him the breathing treatments, physical therapy, and enzymes would help him grow up to be like an astronaut. "At least when I was little I didn't know. I had the usual colds, measles...and at 10 I got pneumonia. Then when I was 15 I was back in the hospital again for two weeks." During this hospitalization he attributes a male nurse's aide who took a special interest in him as the one who "kind of changed my life."

> He was close to my age and related to me at my level. He convinced my parents to let me take karate even against the doctor's advice. My father finally realized if I'm going to die anyway in a year or two, I might as well die doing what I want. That was a major turning point in my life because I started getting into health and physical fitness...questioning my lifestyle and reading books. I discovered I should be eating vitamins, minerals, electrolytes, enzymes, raw fruits and vegetables...I took control of my illness!

Jamie learned to stand up for himself and fight back, believing that the pain was temporary and the power was permanent. He used energy to fight the disease. He visualized death as the devil in a fightable form, believing that if he surrendered his life and soul, he would lose. However, if he won, the devil would cure the CF. Jamie used this visualization as a motivation technique to do "just one more" situp or pushup. "It's a mind game, but I would visualize death and try to beat it," he recalls.

Jamie considers his physical health status to be poor. "According to my x-rays, I should be dead." His pulmonary functions are low and although oxygen has been recommended several times, he considers using oxygen as "giving in" to his body. He explains that eventually his body will adapt to the lower levels so he chooses to withhold it. He also refuses a central line for intravenous therapy because it may interfere with his work as a chef and his karate, two activities that keep Jamie focused and hoping toward a future.

When he talks to parent groups in his community, Jamie offers them hope just by his presence:

> I guess I come in and offer a lot of hope to them...I'm older, successful...but I look at quality, not quantity. I could die next week and be happy because I've done so much in my life. I guess when you grow up knowing you could die within a week or two, you look at things differently. I'm happy with myself even if I didn't get my Corvette, show house on the water, or a boat.
>
> When asked about time, Jamie says:
>
> We CF's don't waste time...See something? Go for it! I guess when you know you could die tomorrow, you can't waste time. There is no time to waste! I have always had this gusto for life! Even in the bad times, there's been good times. I know what's best for me--I've grown up with CF. I've always beat the odds, so I figure I always will.

His "Super CF" license plate is an accurate reflection of Jamie's hopeful attitude and approach to life.

Mae's Story

Born in 1957, Mae was only seven when she began asking questions that her parents couldn't answer. Mae concedes:

> Mother was possibly in denial, but if I was the parent, I think it's better to educate the kids about CF as much as possible--not the harsh reality--but you gotta answer questions. They hid things from me and I always felt there was something I didn't know.

Mae struggles for control over her life. Her parents convinced her as she grew up that she was different from other kids who had CF, as well as different from her older sister who didn't have CF. They took booklets away from her and told her she wasn't sick "like them":

> There were things I wanted to do growing up and I wasn't allowed to do them. I had no control over my life...my body, soul, emotions, mind... When I went to the doctor's office, my mother used to come in with me. I would open my mouth to answer the doctor's questions and the words would come from her mouth. At 16 I finally insisted on an adult doctor and she asked my parents to leave during the exam. My mother almost had a heart attack.

The first time Mae felt that she gained control was at age 25. After gall bladder surgery, she was diagnosed with liver problems and diabetes. She explains the two options she thought she had: "I had to make a choice--either to stay home and give up my job to live longer, or work for a shorter time and live a life with less quality." She chose life and quit her job. During her long recovery period she made out a will and became eligible for disability funds. She started doing treatments "twice a day, every day, and since then I haven't stopped," she proudly reported. Now she is like an evangelist advocating self care.

During a hospitalization when she was 27, Mae became interested in all of her physical tests, laboratory values, and statistical parameters. When she began to question her doctor, he replied, "you really didn't think you were going to live to be 60 now, did you?" She felt hopeless at that moment, but her mother showed ultimate faith in Mae and Mae resolved to continue her fight for the sake of her family.

Mae's disease continued to progress. She began to compare herself with other CF individuals and discovered she was on lower doses of antibiotics, more conservative medications, and was hospitalized more frequently than others her age. The progress of her disease no longer fit her self concept. After seeking a second opinion, she learned that education was her best defense and she keeps copies now of all laboratory and drug results. In the last 12 years Mae has "controlled" her CF by educating herself and doing her own treatments. "I guess I'm in a moderate stage now, but if I'm going to go down, I'm not going down without a fight!"

Mae identifies connecting with others as a source of support and hope. Through the CF Foundation, Mae started a support group where she enjoyed talking to others who had similar experiences. Currently, she participates in CF fund raisers. Her aunt once used humor to bring her out of self pity. "You gotta snap out of it! I'm gonna dance at your wedding some day!" she declared, "When I gave up on myself, she would not give up on me."

Mae still feels held back by the CF:

> I feel like I'm trapped. I'm under my mother's thumb. CF throws you in a financial hole, makes you dependent for certain things...food stamps for food, Medicaid for drugs...I control my treatment. I don't want to be dependent on somebody else to help me breathe...

Mae wants the nurse to share in the balance of the education with the patient. "We want to be self sufficient if we can. We don't want to be talked down to, treated as kids." She wants to be treated as an equal adult, not patronized. Her best memory of a nurse was one who "acted like a friend. We sat on the floor, and she was just there--a good ear piece and a good shoulder."

Windsor's Story

Windsor, at 25, is the oldest of three children and the only one with CF. His mother greeted me and wanted to talk before Windsor finally asked her to leave. This family knows of no history of the disease. Windsor was diagnosed at birth with CF, liver jaundice, meconium ileus and other problems. At three months he had an ileostomy and at one year he weighed twelve pounds. His mother thought he was a miracle, who once taken home and fed, would recover. Her doctor suggested placement in a facility for people with special needs but she could not consider the prognosis or special needs. "No--I really didn't succumb to it," she shared. "One doctor told me they don't live past teens, I really didn't think about it. It's hard to foresee a future."

After Windsor requested that his mother leave the room, he explained that as he grew up his family incorporated his special treatments into their daily routine, raising him the same as his siblings except for his mealtime medications. Windsor told his swim coach that he had CF, but otherwise, none of his teachers or peers knew. He didn't plan beyond high school so attending the local community college was an acceptable and natural extension of his education. He participates in volunteer fund raisers, bowls in the winter and plays softball in the summer. He doesn't enjoy clubs and social events with his friends where there is heavy smoking. And he's met some girls who "are O.K. with the CF until they tell their parents." The parents say "he's a sick boy and who knows how long he's gonna live?" Windsor says he doesn't think about dying.

Windsor does get depressed when he thinks about people who have CF who have died before him--some were older, some were younger, one was even post transplant. "I think about his parents a lot...all the money for that transplant. They're gonna be paying forever..." He wonders why these people died instead of him, but he fears if he dwells on this too much, he could be next. The others appeared to take better care of themselves and he feels guilty about that too. When he loses the motivation to take care of himself, his friends mostly push him. He relates, "My family probably coulda pushed me more, I'll be 25 soon and I'm still not exactly sure what I'll do. Maybe I didn't think I was gonna live this long..."

Windsor likes to visit others in the hospital. He checks when he's in the clinic to see who is in the hospital--then tries to visit them. "But my mom hates it when I do that...she says I'll catch so many germs....But I do it anyway." Although he admits the present research studies look promising, "I don't think I'm ever going to be cured. They might be able to control it," he concludes.

Bucky's Story

As a child Bucky perceived his condition was "bad" just from the mood of the household. He didn't believe he would live past 14 years of age and felt different than his three older brothers and two younger sisters who didn't have to sleep in mist tents and do postural drainage. He characterizes his personality as stubborn, seeking immediate gratification, and wanting to achieve something.

He lived in a dual world of not expecting to live, yet with fear of not being able to support himself someday. He actually didn't expect to live long enough to do anything useful! At 27, Bucky married and at the urging of his wife, quit his secure job and began law school. He already had a dual-major bachelor's degree and a master's degree. He pushed hard to stay in an exercise routine in lieu of chest physical therapy and that year ran a 26.2 mile marathon. He gets frustrated with people who don't take command of their lives.

> I struggle when I feel I'm not moving in life. I'm probably a classic overachiever. In school I was wearing myself down. I'd get bouts of sickness for extended periods. I would get frustrated from being tired a lot.

At 39, Bucky sees a "good chance" he can live at least another five years.

> What's more important to me is quality of life rather than length of life now. My quality is pretty good right now. I get frustrated sometimes, wish I could do more, but I'm sure everyone does.

He and his wife have opened their own business which gives him more control over his own financial security. Always a self-starter, when Bucky became involved with a support group for teens, he was shocked at their lack of planning. The group focus was on medical regimens and restrictions rather than on future plans. He told them to push as hard as they could, to "use the medical gifts that are given to you right now in the best way you can, but push yourself as far as you can." He saw his involvement with them as hope in two ways: his presence as a role model with a productive life and the discussion of "be all you can be."

When Bucky took his oath as an attorney, he felt a sense of accomplishment, pride, and duty to the client. "I can't think of a better path that I could have chosen," he said as he reflected on his 39 years of life. He not only created expectations along the way, he exceeded them.

Bucky's advice for survivors is to "go after life!" Don't latch onto the disease as a crutch, but rather see yourself as a person--not a disease! He feels that his sense of a fighting spirit has helped him accomplish many of his goals--"like the marines on the merchant marine ships in World War II, those who survived were those who expected to!" Bucky envisions death as those too tired to breathe, who don't have the energy to keep up the fight.

Mark's Story

Mark preferred to toot his baritone in the marching band rather than to do his chest physical therapy for CF as he was growing up; in fact, he never has done therapy and he is now 35! "You can't teach an old dog new tricks," he retorts, "but when I talk to a group, I toe the line. You can't say you don't believe in it...there are those who do better with it."

Mark preserves his public image because he does a lot of speaking at fund raising meetings and lobbying at the state capital on behalf of the Cystic Fibrosis community. He claims he's a victim of a "numbers game" since he has no living relatives with Cystic Fibrosis, though he has two sisters. He surmises that both of his biological children are probably carriers, but they have not been tested. "I wasn't supposed to grow up, get married, and have children," he muses. "Someone should write a book about me, since I don't fit the typical picture." And yet, Mark is a slightly-built, sandy-haired auto parts salesman whose frequent throat clearing and occasional cough are very common features of all people with Cystic Fibrosis.

Mark's attitude of dealing with events as they happen may have come from his childhood. His parents put the statistics "on the back burner" when he was ten; they were told he would live to sixteen. Antibiotics and enzymes were incorporated into Mark's daily routine and he even had a hospitalization beginning the third day of his honeymoon! Mark never made long range plans because he didn't want to take time away from the productivity of making money to learn:

> If I were to go back almost 20 years, as incredible as that sounds...when I was graduating [from] high school, if I'd known I'd be living another 20 years, I probably would have pursued college or at least gotten a trade. That was never drilled into my head...You never prepared yourself for the social aspect.

When I asked Mark what keeps him focused and gives him energy and hope, he replied,

> Just the constant battle of getting through a day, or life itself...you need to take a certain amount of medication, you should be doing a certain amount of physical therapy, not to mention everything else because you're not a normal person ...if we were transparent and had zippers, you could see our lungs, our digestive system...you could certainly play on the sympathy of the public...because even though we look normal, we're not!

Mark's great commitment to research surfaces as he talks about the fact he is considered a senior citizen of the CF community.

> If parents could see what it was like living in a mist tent at night and...the medicines we had...we were stone age...you need to take an interest in our needs today, because we're the ones to provide answers to cure your kid... It's my generation that is the guinea pigs to try the drugs out.

Mark smiled, amused that he has outlived his supposed fate. He has admitted he would do some things differently if he had his life to do over again. However, he's done a lot more than was ever expected of him. He has enjoyed watching his doctors get grey hair and jokes, "Doctors usually bury their mistakes. In our case, it's the mistakes that live!" He completed the interview by handing me his business card that he uses as a volunteer for the Cystic Fibrosis organization. Under his name he has the words "Still Alive!"

Dorothy's Story

Dorothy has outlived three hospital mergers and three physicians. She believes the secret to living with her CF is a positive attitude, and a partnership with God and her physician. She doesn't ask God to heal her, only to help the antibiotics do their job. This expresses the partnership of God's work, the physician's medical tools and her will and attitude to do her part.

She recalls wanting to learn more about CF as she grew up. Her mother kept all the printed literature away from her because "the magazines had the worst case scenarios to elicit public sympathy for fund raising." She always accepted her CF, so when her high school counselor suggested that funds might be available for college through vocational rehabilitation, Dorothy's reaction was "but I'm not handicapped!" Her parents helped to frame this in a positive light by sharing that her earlier prognosis had been 13 years and how lucky they were that she was ready for college.

Dorothy says her brother paved the way for her independence by challenging her to take care of herself and role modeling as a patient. Her brother, dying of AIDS, encouraged her to have a positive attitude, volunteer for an experimental study, or try a different diet regime. He was the one who asked her, "why are you sick now?" and he answered for her "because you haven't taken care of yourself." Dorothy took the message to heart and took the disease under her control.

Taking care of herself was very empowering. The more people told her she looked good and hardly coughed, the more she was motivated to do aerobics classes, treatments, and personal exercise.

> Coughing used to make me really self conscious and one time someone gave me a cough drop in class just to shut me up. Then I learned to laugh it off--I would just say I'll have to give up those cigars! Now when I

> cough in exercise class, the group realizes they're getting warmed up!

The most "adult feeling" Dorothy had was when she had a bronchoscopy without her mother.

> My mom was gone with my brother who was in intensive care and my doctor said I absolutely had to come right away...so I went and then I realized I could take charge myself. The distraction of my sick brother and my determination to go visit him helped me through this crisis without my mother.

Dorothy focuses on the things she wants to do in order to get through the present. She wants to have a good time because "it's important to have fun." She considers time a precious commodity and worries about the day when she won't be able to ski and do the things she loves.

In reflecting on her life goals, Dorothy acknowledges that life is a series of trade offs. She didn't finish college and she never moved away from home, but she is able to ski and drive to the beach. She has been out of the hospital for two years and is not currently on oxygen.

> Maybe you don't end up doing what you thought you would do at 18, but it's okay as long as you are healthy and happy. I've reached where I want to be, so the only goal I have now is to find a man.

Dorothy's advice to health care professionals is to include the patient. She feels patients should be asked questions, be informed of what's going on and be invited to look at x-rays and test results.

> I appreciate the nurse who gives me credit for my knowledge. It's part of staying healthy to know what is going on in your body, with your condition, and if your lungs are getting worse.

Evelyn's Story

Evelyn, at 30, has been married for seven years and is a practicing attorney specializing in representing people with disabilities in discrimination cases. She shares her knowledge from her chronic illness every day through work, through a periodic column in an international CF newsletter, and by traveling to speak at seminars around the country.

Evelyn and her sister were both diagnosed at the same time, although they were different ages. Their parents told them they had a mild case of CF and reassured them that with treatment there would be no problems. Although she recognized from observations in the doctor's office that some people were more affected by CF than others, when Evelyn passed out during her first week in the non air-conditioned college dorm, the physician, who was a CF specialist, informed her there were no "mild cases." In retrospect, she realizes her parents didn't want the CF to get in her way, so they treated her like any other child.

Although her father is a physician, he didn't always know about the latest treatments. He was fearful that she might be unnecessarily exposed to other organisms and made a concerted effort not to introduce her to anyone with CF or send her to CF camp. In fact, except for her sister, she had no connections with people who had CF until she was 28. Her thoughtful statements about her first support group meeting reflect the philosophy with which she had been raised:

> This was my first hospitalization and this wasn't good for me to talk about these serious things. I'm trying to cope with just being in the hospital for the first time and those people were very, very sick. They should have never put me in there with those people. They just weren't thinking.

Now, two years later, Evelyn has started her own support group. She recognizes the hope she gives parents when they ask her questions about their child with CF and see her as a successful adult.

Upon graduation from law school Evelyn started working for a large firm. The cigarette smoke in the building, the exhausting eighty hour work week, and a hospitalization, convinced Evelyn she had to disclose her illness to the members of the law firm. When her health declined and she asked for a medical leave, her boss became angry about her CF and reinforced the notion that disclosure to the public was a "bad" thing. Evelyn was barred from big cases because she might "leave them in the lurch." Evelyn finally concluded that she couldn't work at the fast pace of a legal office any more. When she started to take care of herself, she realized that even with self care, she was getting sick.

> That was the bad part of how my parents had raised us; if we took care of ourselves everything was supposed to be fine...and that led to blaming myself...I was taking care of myself and I realized I better get a grip on CF--I'm going to be sick! And it seemed I had met my life expectancy and I was dying. It seems when I get sick it's not a month any more. It takes 3 to 4 months to get better.

Evelyn sees herself as a fighter. She definitely hates CF and would be happy to be rid of it. She, however, has a very high quality of life and is surrounded by wonderful friends and family. In her career, she is able to focus on fighting for the group and she maintains close "grass roots contact" through her CF support group. Her advice to health care workers is to teach that this is a disease to be dealt with as part of life. "Don't say I'm so sorry your child has CF," she advises, "and certainly don't expect to sit around and see us die!" she concluded.

Susan's Story

Susan is Evelyn's younger sister. While growing up she did respiratory treatments, but didn't start chest physiotherapy until she started college. She wanted to go to medical school, but didn't think she could finish before she died. She "settled" for academia because she thought it was more flexible in scheduling and would have automatic life and health insurance. Additionally, she wanted to get out of school and start her life. Now, two years into her doctoral work in history, she sees her friends starting their medical residencies and she is still studying. She is also beginning to see the pressures of an academic appointment. She admits recognizing an urgency of time with an anticipated ending point but not a specific age or time.

Susan has set goals of wanting to finish her Ph.D. work, become employed, get married, and travel to Israel. She is eager to find a life partner and had a recent crisis when she broke up with a significant other. He was nervous that her restricted life style would affect their social life:

> I told him once I couldn't go into a bar because there was smoke...and I don't stay out really late because I have to come back and take the treatments...and he was neurotic because I wouldn't commit to having children. He just let fear totally overcome him and decided to break up with me before discussing it with me...That's the fourth break in a relationship related to CF...But discrimination doesn't make you feel worse. It makes you want to show your pride. And fight harder. In Hebrew you say 'daska'--in spite of it.

Susan studies hard and does

> 50,000 things at once. I don't consciously think that I'm running out of time, but I'm very involved. Last year I was head of an organization, organized a conference, took my comprehensives, and wrote my proposal. I work out at the gym...and I enjoy yoga.

Her faculty advisor calls her somewhat "neurotic" about grades and school, but she has earned a Fulbright scholarship to go to Israel for six months to study. She is very excited about this opportunity and hopes to extend the funding for a full year.

Susan believes that people need more education about Cystic Fibrosis and this should begin with health care workers. She is offended at any implication that she does not deserve something or it is a waste of time because she has a chronic illness. Once she was asked, "Why waste your time if you have CF?" She hopes education to care givers and the public will remedy the philosophy of limited expectations because of a given life span. Susan "wants to make a difference in someone's life" and has high hopes and goals set for that path to success.

Bill's Story

Bill was a participant interviewed via the Internet. He lives in California and introduced himself as a twenty-seven year old, happily married, computer science engineer. He reported that sinus infections, intestinal complications, and ear infections were the three primary reasons for his hospitalizations in the past. He also admitted that growing up he was more comfortable with adults than with his peers.

Bill describes his life as a roller coaster, but he is fortunate to have his wife in the seat beside him. In addition to CF, Bill has glucose intolerance, which he controls with diet. In his early years he participated in exercise programs designed for the handicapped so he could proceed at his own pace and be rewarded for intent and effort, not ability. He built himself up to swim over 100 laps and lift over 200 pounds per day and he says, "I knocked my CF out cold!" During his college years, he rode his bike over 80 miles per ride. "I was on top of the world," he exclaimed. One day when Bill was riding he became very ill. That "took a lot of heart" out of Bill. He has not been swimming or on a bike since that day.

Bill works long hours at his engineering career to show he is a team player and to be eligible for promotions and bonuses. He says every day he finds more of his limits, though he tries to stay positive and focus on personal strengths. His greatest desire is to be "normal." He yearns to live a long life because he doesn't want those he loves to live it without him.

Bill is currently experiencing some abdominal pain for which he is undergoing tests. He focuses on his inner strength.

> I concentrate on the love for my wife, mom and brother. My spirit hurts too. I give myself completely to those I love, which can hurt, but when I feel, I know that I am still alive and kicking. Spirituality is your foundation. It does not need to have a name or a religious organization. Discover and nurture it. Promise yourself: I will never give up!

Bill uses his "will" to overcome the demands of his physical illness. He visualizes his strength and power coming from his mind rather than from his body. Martial arts, his physical outlet, helps his mind to be "in the chase" when his body runs out of steam.

Bill, in his organized, focused and concerned way had a caring, sharing dialogue over the Internet in order to tell this story. He preferred that method to direct dialogue as he thought it would accommodate his work schedule, a three hour time zone difference, and a chance for "emotional breaks" from the intensity of the discussion. I believe he shared his heart and soul in the hopes he could inspire others with CF.

Summary

In Chapter IV, the sixteen participants have been presented individually in the narratives. Each has expressed his/her uniqueness and yet common themes have emerged from the collective stories. While the unique is preserved in the stories, the derived themes express the essential nature of the lived experience for these participants. The purpose is not to generalize, but instead, to capture the essential meaning of hope for these people who have lived beyond their expected life span. Hope offers no promise of immortality but is proof of the uniqueness and opportunity to experience full growth and meaning out of life.

These exceptional people who have Cystic Fibrosis have thrown statistics aside to say they can survive even when a physician said they could not do so. Chapter V reveals a more in depth discussion of these themes and their meaning to the individual who has lived beyond an expected life span.

TABLE II: PARTICIPANT DEMOGRAPHIC DATA

Name	Age	Marital Status	Co-morbidity	Occupation	Personal statements
Kitty	32	Married	Unknown	part-time computer programmer	I surrounded myself with optimistic, happy people to mold my attitude.
Elaine	35	Single	Diabetes	not employed	I'm playing my violin but what I need is an organ.
Vi	43	Divorced	Lupus post-transplant	full-time word processor	I had another birthday at 43!
Barbara	24	Engaged	Unknown	part-time secretary	I lived carefree - now I have credit problems.
Leah	30	Single	Scoliosis	full-time graphic artist	Hope is sitting on a pot of lottery money.
Sean	35	Single	Diabetes	part-time editor	I regard my lungs as real estate.
Monica	33	Divorced	Allergies, arthritis	part-time product promoter	Being sick means not being able to work.
Jamie	34	Married	Unknown	full-time restaurant owner and chef	I love my super CF license plate.

Name	Age	Marital Status	Co-morbidity	Occupation	Personal statements
Mae	37	Divorced	Diabetes	part-time dental assistant	I want control of my CF through knowledge.
Windsor	25	Single	Ileostomy	college student	I'm not sure what I'm gonna do. I didn't think I'd live this long.
Bucky	39	Married	Unknown	self employed consultant, attorney	Go after life! Death occurs when you're too tired to breathe.
Mark	36	Married	None	full-time retail sales	Life is a constant battle but I'm still alive!
Dorothy	34	Single	Unknown	full-time pharmacy technician	My brother inspired me to take control of my CF
Evelyn	30	Married	None	self employed attorney	I would be happy to be rid of CF but I do have a wonderful life.
Susan	27	Single	None	college student	When I feel discouraged because of CF, I want to fight harder.
Bill	27	Married	Diabetes, Abdominal Tumor	full-time engineer	Promise yourself: Never give up!

CHAPTER V

DATA ANALYSIS AND FINDINGS

> The more a person realizes that he is facing odds others have overcome, the more he will realize he is not alone and will have the strength to fight. (Jamie, study participant)

The purpose of this study was to uncover the ways in which people who live beyond their expected life span experience hope. In this chapter, I describe the process involved in illuminating the meaning of hope by revealing selected themes. The themes capture the essence of the phenomenon and a meaning of hope emerges as it is lived by the people who have outlived their life expectancy. Heuristic interpretation of the findings of this study are posited within a nursing framework.

After examining the individual stories, I began to write and rewrite the themes of the stories as suggested by van Manen (1990) and explained in Chapter III. This phase required sensitivity to the subtle verbal undertones and allowed the stories to speak for themselves through reflection to make the experience more explicit. I distanced myself from the text to deepen the experience and reflect on it. I moved from particular into the universal, searching for a higher level of abstraction. Reevaluating the individual transcripts, I captured the essence of each person and examined how each fit into the total theme. My goal was not to generalize, but rather to capture the essential meaning of the experience. The mental process of living with the data is elusive and totally emersing. Analysis at times was like a roller coaster--from a mountain top of new discovery to the pits of disillusionment.

The phenomenologic reflection on the descriptions of hope beyond the expected life span unfolded three overall essential themes across the stories: **Fighting with Spirit and Energy, Connecting with Self and Others, and Transcending Beyond the Statistical Odds.**

Fighting with Spirit and Energy

The energy surge when the participants discovered they were not going to die was astounding! Over and over again, they told me of their refusal to be "victims." Those who questioned statistics, doctors, and their parents seemed to be the ones to get, give and live! They called themselves "Chronically Feisty", "Super CF'ers," "Spirited Fighters," and people with "Coughing Fits." One of the participants asserted:

> I was supposed to succumb to CF at age 5 and then age 10 and so on. In a never-ending battle not just to survive, but to subdue my stubborn disease, I learned to fight!

The fighting energy has had both positive and negative effects. The positive has maintained the spirit, increased the hope, and accommodated for setbacks. The qualities that made for perseverance in the face of adversity also made it difficult at times for others to deal with the participants as they displayed negative behaviors. The self-reported qualities of being inflexible, obstinate, stubborn, opinionated, and willful were noted by participants as they reflected on their style of problem solving.

The **Fighting with Spirit and Energy** theme subdivided into lethal energy and healing energy. My interpretation of lethal energy incorporated the risk taking behaviors that could be life threatening. The lethal energy was sometimes experimental and lasted only during a phase of adolescence. Sometimes the lethal energy coexisted with healing energy that was reflected in the person's values and decisions.

<u>Fighting with lethal energy</u>: Many participants reminisced that as teenagers they took risks and did crazy things that might have had lethal outcomes. Although much of their behavior could be considered adolescent rebellion, a thread emerged about playing with death in a more fatalistic way than teens who typically think they are never going to die. The attitude that pervaded was "What do I have to lose? I might as well..." For instance, experimenting with smoking cigarettes and marijuana took on a much more serious brush with death when the lung capacity was already seriously compromised. Leah stated, "I figured I was gonna die anyway, so I might as well live it up!"

Monica started smoking cigarettes and pot and stopped her medications and treatments in her later teenage years. "I heard you don't live past 18 anyway, so when I was 16 I figured I'd die in a couple of years and whatever I did wouldn't have much of an impact."

Lethal energy was illustrated by Jamie as he explained about his parents' overly protective attitude. They wouldn't let him outside if it was raining or let him participate in sports. This led to a lot of teasing by the other boys and Jamie would call his sister to "beat them up." He decided the treatments and sacrifices were not worth the aggravation, so he began doing drugs and drinking. He thought this would lead to his acceptance by the other boys.

> Needless to say, that played havoc with my health. For about a year I was in the hospital, home for 2-3 weeks, back in the hospital for 2-3 weeks, then back home...at that point, I was almost 16, they gave me less than a year to live.

Jamie describes his stubbornness as a "battle." He subsequently tried Chinese water healing to "purge his system", bullet water to "make water wetter", and a vegetarian diet. In the meantime, he also turned his energy into a positive form by taking up karate. In karate, he realized he could get hit, lose his breath and get up again. He began to realize that "something that was supposed to kill me didn't, so now I'm Superman!" The battle for Jamie acknowledges the danger and opportunity coexisting within his experiences.

When Jamie's girlfriend with CF died, he gave up mentally. He tearfully admitted that CF killed her and that it was going to kill him. He spent the next six months either in the hospital on IV therapy or on home IV therapy. At that point the doctors gave him a prognosis: "it doesn't look good. Six months, maybe a year tops." He stopped karate, stopped lifting weights, and started drinking and partying again. He was afraid of getting hurt and began having repetitive dreams about fighting and struggling with death in the form of a snake and getting locked in a room, unable to escape. He awoke in sweats and fear and even as he described it years later, his eyes widened, his voice tone raised, and his fingers twitched with anxiety.

The loss of a well-known friend with Cystic Fibrosis was a pivotal point for several participants. Moving through the experience with another, heightened the participant's awareness of the possible death threat and increased the energy-- sometimes resulting in lethal energy such as in Jamie's case, and sometimes in healing behaviors and better self care. Significant insight was gained by participants who moved through severe illness episodes and realized that they had received the gift of more time than they had originally expected. Participants seemed to make the connection that in order to live, they needed to take better care of themselves.

Fighting with healing energy: The positive healing efforts of energy permeated the stories of all. Many spoke of accenting the positive while acknowledging the negative. Bill contributed:

> All of us are chosen for something very special and powerful. The true test is not letting CF control my mind and spirit. It may play havoc with my body at times, but it will never control my spirit because I will never give it the pleasure!

Although the medical aspect of progress is readily acknowledged, the participants equally recognized that drugs are not the greatest weapon. "The battle is for hope!" one participant exclaimed. Sean added:

> CF is fought 20% medicine and 80% heart and mind. I have played the hand that was dealt to me, but I don't deny the dealer (CF). I don't ignore the CF or my health, but I do ignore the facts and statistics so I can stay on the positive side this horrible disease.

The statistics and facts seemed to take a back seat to these people who had lived beyond their expected life span. They visualized their battle in a much more graphic and artistic way than numbers. Sean visualized his fight for lung capacity as a piece of real estate property.

> As the lungs grow bigger your real estate property expands. I perceived CF as having an agenda which is diametrically opposed to my agenda. CF wants to fill my lungs up and destroy them. My agenda is to preserve my lungs and keep them healthy. Real estate is your lung capacity and right now I have about 45% of my own lung capacity and CF has claimed the rest. I'm fighting with a rebellious spirit to keep that real estate and sometimes even claim more. I was very angry in 1988 when I lost what I had--Had to give up work, go on disability, lost relationships, and the opportunities of dating.

When participants could channel their energy, they were released from entrapment of the disease that could not be ignored, but was invisible and constantly changing. Those who focused their energy on life often used their minds toward work or study to become excellent students. Those who focused on their bodies were frequently in the marital arts.

Several participants used mental energy to fight CF. Jamie has focused his energy on his new restaurant and entrepreneurial skills. After working many jobs as a busboy, waiter, chef and head cook, Jamie at 34 finally has the opportunity to own his own restaurant. Our dialogical engagement was in the dining room during mid-summer and Jamie admitted he needed to be on IV therapy. The heat of standing over the broiler 12 hours a day, the dehydration from an extremely dry summer, and the first few months of opening a business of his own, evidenced their toll by Jamie's weight loss, deep and frequent cough, and sighs of exhaustion. However, his satisfied smile seemed to overshadow the dark side, when he stated,

> I'm a workaholic. I was always told I would never work because of CF so I developed an attitude...when I have to, I work with a 103 degree temperature and an IV in my arm!

Bill attributed his mother with encouraging his academic skills so that he could excel mentally rather than through physical prowess. He says today his mind is his only weapon.

> I want to lead others with my intelligence and skills. I perform twice the work I'm given and never look back. My creativity and excitement in the pursuit of an idea make up for my health. But I can last for only so long before my body decides to slow me down.

Mark described a roommate he met in the hospital who shared his philosophy of life "Embrace the battle." But when the roommate was told he would need surgery to have a catheter inserted for antibiotics, Mark said "something snapped in him and he gave up on life." He died the next day. The experience convinced Mark that the only way to survive was not to consider death an option. "That's the common thread of old-time CF patients," Mark revealed. "We embrace the battle of staying alive."

Over half of the participants have been involved in some way with martial arts or other ways of channeling physical energy. They described this physical outlet as doing wonders for the psyche and helping them to achieve a sense of balance and calm. Bill said he used martial arts to focus his strength and power into his mind.

> I force myself to relax physically while I'm in the chase mentally, since my body runs out of steam first. I use my will to overcome the physical stamina it requires...I find myself unable to participate continuously because of the difficulties I face in lung capacity. I push myself very hard, but I must admit that it builds my confidence when I can attend, because I can build my strength and endurance and it helps to flex a few muscles in front of my woman *grin*.

The participants' need to be in self-control as well as control of the illness and the treatment, was evident in this group who felt powerless over certain aspects of their disease. They even bore the burden of guilt for surviving beyond the published norm knowing others who did not survive. Their need to control was noted in their knowledge of laboratory tests, pulmonary function results, and desire to be equal partners in their health care with their physicians and other health care providers. "I knew I needed a culture," Dorothy stated, "so since I work in the lab, I just did one." She faxed the physician the results and they conferred about her medication regime. Dorothy decides when she needs to see the doctor and when she needs to be on antibiotics.

Elaine stated she needed control to balance her life.

> I've always had a strong sense of self. I have to be my own best friend and look out for me...I have to have my hand in on the care I'm receiving because I don't want to mess up my balance.

The most basic control was explained by Vi in her early post-transplant days. She recalled that her patient-controlled analgesia was the only control she had over her body. She didn't breathe on her own or go to the bathroom but there was "a piece that needed to be in control of something in my life" and this pain management system allowed that control.

The theme **Fighting With Spirit and Energy**, evidenced as lethal and healing energy was multidimensional and influenced the hope created as these participants lived beyond their expected life span. As they focused on themselves first and their disease second, the participants embraced the battle like vigilantes and used their energy to fight for control over life.

Connecting with Self and Others

The word connection means to bridge or bring together. In making connections, the participants reported making an attempt to heal through wholeness. This connection means the acknowledgement and merging of body and spirit within oneself and a bridging with others by reaching out beyond personal boundaries.

Connecting with self: The challenge of maintaining a balanced inner self is to keep a positive attitude. "That's stubborn with a twist," one participant exclaimed! The overall theme of connectedness seemed to entail listening to one's body and making self-awareness a priority or at least equal to scientific evidence. Several participants expressed an ability to know when they were feeling poorly and a frustration that testing procedures could not validate their actual state of well-being. Jamie underscored that notion as he explained his current physical state:

> My lungs, by x-ray are horrible. I should be dead, according to my x-ray...When I'm at my healthiest I can get my forced vital capacity up in the low 60's. My forced expiratory volume is always in the upper 20's, low 30's, but not that great. I'm a little short of breath now but this store has taken its toll over the summer...I need to be on IV now. I know by how I'm breathing now I need a tuneup.

Several people expressed a desire to focus on physical fitness to connect with their body rather than to think about the therapy for Cystic Fibrosis. The emphasis on daily total body fitness exercise seemed to have a healthier connotation than chest physiotherapy.

> Notice how if you keep fit you feel real good! I think how good my swim felt, not how productive it was in terms of my CF! I just take my pills and have a great excuse to stay fit!

Dorothy enjoyed her aerobics class three times a week followed by lifting weights. She did an additional treatment on days she didn't attend class. She said, "in doing all we can to give ourselves as much life as we can, we mustn't forget to live!"

Two participants articulated the concept of spiritual connection using metaphors. Mae said:

> If I begin to get discouraged, I open the doors and windows of my mind and invite those unwelcome feelings to leave. Then I ask the Lord to fill those empty spaces with His peace, light and love, and He does!

Sean's metaphor was very graphic and illustrated balance:

> I see CF as a three-legged stool. The first leg of the stool is the patient. The patient needs to be positive and do all that's within his power to stay healthy. The second leg is the medical aspect...all the physicians, antibiotics, chest PT, the clinics. The third leg is fate or God's will or whatever you want to say. Neither you nor your doctor have control over the third leg. The stool represents CF in your life. If one leg falls out, and the stool falls over, then you die.

<u>Connecting with others</u>: Participating in this study was one way these people sought connections. Their willingness to help began with the first inquiry about the study, most often by e-mail or letter. Several people said they would be honored to be chosen. Sentiments frequently expressed could be represented by the following quote by Bucky:

> I feel that my experience with CF has made me pay close attention to my lifestyle and my body's own individual quirks, and so I have come to a deeper appreciation of myself and my position is life. I would be very happy to participate in these studies, for whatever I could offer to fellow CF patients. I would be very grateful if I were considered to help.

Several also inquired about other participants in the study when they spoke with me. One asked me to try to find a friend for her in a similar age bracket from the study group, one female wanted "male connections," and several sought general information about numbers of people working full time and what percentage were married. These participants were given support group information and newsletter information, but no specific individuals participating were identified. Curiosity was also a concern with disclosure of the illness, how and when others were telling friends. Several felt that potential mates had been frightened away and reasons given for divorce usually included Cystic Fibrosis. Normal adult activities were interrupted and sometimes prevented due to effects of CF or the fears that the person was too fragile. Reproduction was also an issue with males being concerned about the high risk of infertility, and females concerned with conception and delivery. Several participants discussed the CF genetic link in family planning.

Vi found participating in this study was helpful in analyzing her own thoughts. She realized some of the thoughts she could share with people waiting for transplant.

She increased her awareness of the need for her control. "I hadn't been sharing the control issues with the transplant list candidates when I speak to groups," she mused. "I'll start doing that the next time."

Some spoke of isolation from others with CF as they grew up. Most had been told by parents that they were different from all the others and were not encouraged to socialize. Monica reflected on this philosophy:

> The longer you are in contact with others the more you come into contact with people who are sicker than you and sometimes these people die. Eventually you may follow a similar path--that is a scary realization! I know I chose to be isolated from other CF's for that reason--I felt like I was looking into a futuristic mirror and didn't want to see it...but now I know that not knowing people with CF means losing support and personalized knowledge.

Sean continued, "patients with CF have become my lifeline. When CF takes things away from my life, others encourage me with humor, strength, resolve, love and grieving."

Some participants sought counselors to help normalize feelings, validate concerns, and appraise strengths. When Elaine started to see a pattern in her physical losses similar to a friend who recently died, she began to have suicidal thoughts. She believes her therapist has been most effective in working with her because he is blind. She states that he really knows how she feels because he has experienced a loss too. Elaine was also working on her intense fear of suffocation which she experienced daily.

With only 30% of her lung capacity since 1990, Elaine is acutely aware that her transplant needs could escalate at the sign of any infection or further lung loss.

Counselors also helped to share grief, direct problem-solving, and assess the need for referrals and medication. As with the general population, these chronically ill people had crises in their lives, but due to their unique circumstances were sometimes unable to cope with the stress through physical outlets or escape. Sean and his counselor explored the baggage that CF brought into relationships and how to avert crises before they happen.

Attending support groups: Support groups were another important way that these adults connected with others. Although most wanted to keep their CF a secret while growing up, in adulthood they welcomed the chance to share stories and experiences with one another. Most support group meetings were a combination of education and socialization. Contact with older members offered a hope that was more tangible and believable than platitudes of health care providers without first hand experience. Individuals complained, rejoiced, and commiserated with others who shared their disease. They compared medication, therapy, physical status and medical care. The groups offered information that made life a little easier. "Learning how others manage gives me perspective about myself that is invaluable," Mae acknowledged, "and I draw strength from others with CF because I'm not afraid to admit to them that I sometimes feel weak, both physically and mentally." The most important facet for some participants was to be able to poke fun at their own adversaries, allowing them to see the brighter side.

Although the support group was a connection used in the past, some support groups are no longer active because of the fear of acquiring new organisms. Some support groups, clinics, and hospitals have developed guidelines based on the high/low risk of cross infection. This situation compounds the problem that most CF adults are already drug resistant and many transplant centers are currently rejecting multi-resistant patients as well as those with certain new infections. The issue, therefore, goes beyond simply acquiring an exotic bacterium with its own host of problems to an issue of being accepted in the future for transplantation. For these reasons, many of the support groups and some social events are no longer offered. Although some adults are afraid to interact, for others the issue of cross-infection is just another barrier to overcome and the need to interact with others with CF outweighs the potential risks. As Sean said, "I'm not giving up my social life for an organism and I'm not giving up my life for a gene!"

Connecting on the Internet: One connection that has replaced the face to face support group for some is the

Internet. Cystic-L is an Internet support group. Established in 1994, this group has an ongoing "discussion" taking place through e-mail messages. In the past two years the Cystic-L has garnered over 500 members, with the bulk of them from North America, but with a growing cadre of Australians, Europeans, and South Africans. The Cystic-L offers practical experience and knowledge by people who are dealing with CF on a day to day basis. The importance of being able to "reach out" on the Internet is a tremendous help and support to newly diagnosed as well as previously diagnosed people.

The topics for Cystic-L support groups are amazingly similar to the topics of discussion for face to face support groups. The Cystic-L is used to share stories about complex medical issues, obnoxious health care personnel, and incompetent bureaucrats. It is also a place to share helpful hints about treatments and late-breaking news about research. Most importantly, cries of anguish are shared when the disease begins exacting its toll and cries of joy are heard when life returns to "normal." Indirectly, this link provides a reminder of the dark side of the disease when the person is on the upswing. And when the dark side threatens to overwhelm, the communication with those who understand the feelings helps to keep a balance.

Anthony Dugdale (1996), creator of the Cystic-L, described in the April issue of Network newsletter his feeling of the e-mail communication:

> An e-mail support group will always remain more distant, less whole than a more incarnate group. But being embodied isn't always the favorite characteristic of someone with CF--sometimes we would like to interact without our body getting in the way. It's so marvelous to see straight into the soul's health, without having to focus our eyes first on the body's health. That is what this discussion allows.

As in the above quote, the participants' connections were multidimensional. Vi struggled to control herself post-operatively, as she combined self, others, and spirit.

> It was the most horrible thing in the world with the tube in my throat and it wouldn't let me breathe. So my sister calmed me down and held my hand all night. That's the one time my religion came in handy. I prayed and prayed. I knew if I could keep thinking a prayer, that God wouldn't forsake me. That the constant hand was the touch of life!

The theme **Connecting Through Self and Others** expresses the way members of the adult community of CF have been sustained and lifted. They have learned awareness of their own bodies through a focus of physical fitness and spiritual connection. They have been spared some degree of heartache through sharing and to share some comfort by being together in some bodily or virtual sense. Their connections have propelled them to move beyond the moment and transcend with the possibilities of the future.

Transcending Beyond the Statistical Odds

Transcending is going across, rising above, or going beyond ordinary limits. The current generation of people with CF is the first to reach adulthood in large numbers. Now that many have surpassed the odds of living beyond an expected lifespan, the question becomes "I'm still here. What do I do now?" An almost palpable sigh of relief and wave of peace were expressed by participants as they explained their life after the expected time of death. In living beyond their expected life span, the participants explained that the burden of proof had been fulfilled and now they could hope for a future. "Once I reached my twenty first birthday, I figured I better make some plans," Windsor explained. Sean saw no need for hope if you have a guarantee, but "if you're not sure if you're going to get there, but you want to be there...that is hope." Uncertainty was Sean's trigger to experience hope.

Many of the survivors have developed an aggressiveness in pursuing health care needs, their lives and their happiness. Consequently, by their sheer existence, they are a beacon of hope, a hope that is both pragmatic and inspirational for those yet to come. When they are seen in a clinic waiting room or in a support group, parents with CF children marvel at "how good you look" or say "I never really believed it was possible." According to Mark, "in this business, being behind is a definite plus!"

In search of meaning for their lives, the following examples express how participants described making their moments meaningful. Sean described his involvement with a support group and CF newsletter:

> It gives me a sense of self-worth. I'm giving something back...I'm in tune with what I didn't have growing up, the voids in the CF and medical community...so in a sense I want to give myself--I want to give the community something back which I didn't have, give them more tools to work with...and it gives me a sense of self esteem.

Mark volunteered to undergo an experimental gene treatment that involves a lot of time and multiple bronchoscopies:

> There's a bigger picture than me in the scheme of things...I don't look at this selfishly for myself. I say if these experiments work, those coming up behind us won't have to experience what we went through...we'll (this generation) definitely play a pivotal role in what's going to happen. The bottom line is that we're expendable. We're not supposed to be here, so if things don't work out, it's not as great a loss. Our generation had nobody to do this with because we were not even expected to be here...so I can break the chain and set an example.

Hope extends beyond the self to others with these participants. This phenomenon may be expected in older adults in the generativity phase, however it was interesting to see in this age group of 23-48 year olds. As youth, many had not planned for the future and as we spoke, I realized some participants still weren't planning for a future. Most seemed to believe if what's done today is right, things will take care of themselves in the future.

Transcending for these people was connecting with meaningful moments. The clock provides a technical measurement of how long each of us lives. Far more real than the ticking of time for these people is the way they open up the minutes and invest them with meaning. Meaning made life worth living.

The theme **Transcending Beyond the Statistical Odds** merged precious moments of now with anticipated rewards of the future. Participants focused on the gift and quality of life itself rather than the number of years left. This group recognized that the statistics were not their reality, thereby creating the meaning of life as the focus rather than the quantity of life. Transcending time and space was accomplished through acts that would impact future generations: by education, research, and political action.

Summary

The purpose of this study was to gain understanding of the meaning of hope for people who have lived beyond their expected life span. The findings are authenticated in the participants' descriptions and interpreted heuristically in accordance with van Manen's protocol analysis. Participants in this study, adults with Cystic Fibrosis who have outlived an expected life span, expressed the meaning of hope in this experience as **Fighting With Spirit and Energy**, **Connecting**

With Self and Others, and **Transcending Beyond the Statistical Odds** to accept the gift of life.

In Chapter VI, I will compare and contrast some of my findings with the findings in the extant literature. I will also discuss the implications of the research findings, limits to the study and recommendations for future development in nursing theory, nursing practice, and nursing research. I will conclude with a personal reaction to the research process.

CHAPTER VI

LITERATURE REFLECTIONS AND NURSING IMPLICATIONS

> We can't control life. The only thing we can control is how we respond to it. I shake my head that my life could be influenced so much by one bad protein on one damn gene out of billions. The pleasure of life is greater than the pain, so I endure. And I hope. 'Hope deferred makes the heart sick.' (Living Bible, 1971, p. 434.) Don't stop hoping. (Bill, study participant)

Investigating the phenomenon of hope when living beyond one's expected life span has not been previously addressed in the literature. This study opens up the possibility for future work both with the phenomena of hope and with this unique population. In this chapter I compare and contrast my findings with the extant literature. I discuss the unique and universal aspects of hope and explore the conclusions and implications of the research findings. I also make recommendations for future development in nursing theory, nursing practice, and nursing research, and conclude with a personal reaction to the research process. This framework also serves to validate the findings of this study.

Literature Reflections

In my study, adults with Cystic Fibrosis who have outlived an expected lifespan expressed the meaning of hope in this experience as **Fighting With Spirit and Energy**, **Connecting With Self and Others**, and **Transcending the**

Statistical Odds to accept the gift of life. The themes identified in this study share commonalities with the work of previous researchers, adding to the validity of this conceptualization of hope. While these findings essentially concur with previously identified findings, they add a new dimension of uniqueness.

The first theme--**Fighting with Spirit and Energy**--was described as lethal and healing energy with both body and mind embracing the battle. The association between hope and energy in the literature of nursing, philosophy, and psychology underscores the importance of this theme. In the interpretation of my dissertation, spirit was used to portray an attitude or will in the action of fighting. The participants revealed that this mental attitude contributed significantly to maintaining their health and hope.

Miller (1992) spoke of maintaining hope as a challenge for chronically ill people, despite a downward physical course. Chronic illness, by virtue of its unpredictable nature and concomitant losses, precipitates powerlessness. In my study, participants spoke of the work in fighting for power and strength. This energy was both lethal and healing, both physical and mental. Initially expressed as rebellious and unhelpful, the participants' energy was sometimes channeled by an epiphany or precipitous event causing a change in focus to positive fighting, exercise, and taking control of treatment and self.

May's (1953) existentialistic viewpoint explains that people are more joyful and able to act in the present when hope about a future event is evidenced. Nurses, through practice and research, have observed that hope energizes individuals to positively respond to alterations in health (Stoner, 1982; Hinds, 1989; Nowotany, 1989; and Herth, 1989). The participants in my research proudly spoke of their present status of being alive as hope itself, since they had already outlived the expected life span. Having survived against the odds fed into the expectation that life was a gift and would continue.

Herth (1990, 1993a, 1993b) offered three definitions of hope with a common theme of inner power and transcendence. In a qualitative descriptive study with terminally ill patients, Herth (1990) was directed toward an awareness and enrichment of 'being', rather than toward any specific expectations or goals. She maintained that hope was within a person's thought processes. The theme of **Fighting With Spirit and Energy** is internal but also manifested outwardly through self care, exercise, or good grades. The participants' energy came from within, although at times was fostered by outside forces. Marcel (1960) also referred to hope as an inner force essential for human survival. Hope energizes one toward life and away from hopelessness.

Several authors (Lynch, 1965; Stotland, 1969) have stated that hope is energized by the person's belief in his/her ability to accomplish something. In her study with older adults, Herth (1993a) discovered the inner power of hope enabled a brighter tomorrow. In my study, participants took a more existential view that to live each day to the fullest was the goal. This may reflect the sphere of generalized hope identified by Dufault and Martocchio (1985). Some expressed a fear that to look into the future and goal-set might be a self-fulfilling prophecy. Thus, immediate goals were envisioned by the participants such as work to be accomplished, exercise limits to be challenged, or love relationships to create, renew or sustain. Participants were often not able to identify goals much beyond the present and they reported that goal setting had not been a priority in the past. This raises a challenge to some previous conceptualizations of hope and suggests a new dimension for those who are living beyond an expected life span.

The literature strongly supports the theme of **Fighting With Spirit and Energy**. Morse and Doberneck (1995) in a concept analysis using qualitative methods identified the degree of threat to personal safety as the primary factor that contributes to the intensity of hope and serves as a motivating force. Their belief was that unless a threat is acknowledged and assessed, hope does not exist. With my study participants, however, hope emerged through an entire lifetime of threat to their being alive. My data point to a new understanding of hope as independent of a triggering event or specific focus.

The second theme--**Connecting with Self and Others**--addressed the connections that CF adults make with their own bodies through fitness programs, spiritual thinking, and extension of themselves to others. This theme compares favorably with the literature because a vast amount of hope research has focused on the contribution of social support to the maintenance of hope (Bruhn, 1984; Herth, 1989, 1990, 1993a; Miller, 1983, 1992). According to Lynch (1965), a philosopher and theologian, hope is a positive inner sense that calls for a response from the outside. Hope has meaning only as it relates to others in mutuality and is an escape from difficult circumstances.

Marcel's (1960) intersubjectivity concept of hope for another is embedded in the **Connecting With Others** portion of my theme. Participants using counselors, support groups and people on the Internet all displayed the need to interact with and be understood by others. This bonding assured that they were not alone in the battle. On the other hand, these connections made them aware of their own deteriorating health and the death of others with Cystic Fibrosis. In fact, they were surviving while confronting their own mortality. In the transplant literature, the importance of the support of successful patients has been described and

Lange (1978) noted that patients seek success stories from others in similar circumstances.

Another scholar whose research is supportive of my findings is Dufault (1981). She defined the affiliative dimension of hope as a sense of connectedness with others and involvement beyond self, including intimacy and attachment, mutuality and sharing, and other-directed social interaction and relationships. Sustaining relationships and interconnectedness with others was described also by Herth (1993). She suggested that these relationships can be linked with clinical nursing interventions to foster and maintain hope.

Watson's (1988) theory of human caring places a high value on the subjective-internal world of the patient and how the person (patient and nurse) is perceiving health-illness conditions. The nurse is viewed as a co-participant in the caring process. Two human carative factors described by Watson, sensitivity to self and others and helping-trusting in the human care relationship, directly relate to the theme of co-participation and the importance of **Connecting With Self and Others**. When human care is evidenced in the relationship, these factors serve to enhance the internal hope of the individual. The high value on the nurse-person relationship is blended with these two carative factors to guide the nurse in establishing meaningful relationships.

In summary, the literature supports the theme of **Connecting With Self and Others** as a key component of hope. Other researchers validate that self-knowledge, decision making power and persistence all help maintain a positive attitude. Connecting with others through the sharing of mutual experiences and having someone to call upon in time of need is important to clients as verbalized by participants in my study.

These participants stay connected through support groups and the Internet, which are unique methods in the context of reaching out for hope. Nothing was found in the literature about the supportive nature of Internet sharing, but personal observations certainly confirm this facet of our technology.

The most closely aligned validation for support groups related to deriving a sense of hope was demonstrated in an action research study at the Denver Nursing Project in Human Caring (Neil, 1993). Although this was not a formal support group, the project group consisted of men living with AIDS. Four themes were reported as sources of hope for HIV clients. All themes centered around connectedness: with a higher power, with someone or something, with nature, or with self through memories. As part of the research, the men were asked to create a visual representation of hope. The resulting poster created an aesthetic and meaningful depiction of hope while the experience of working together allowed further connections.

The third theme--**Transcending Beyond the Statistical Odds**--is the most unique finding of this study and the least explored in the literature. This theme expresses the participants' focus on the meaning of life rather than the number of years lived. Perhaps this theme can make the strongest contribution to new knowledge. Transcendence speaks of aesthetic knowing that allows one to move beyond the limits and circumstances of a particular moment, sense the meaning of the moment, and envision what is possible but not yet real (Chinn & Kramer, 1995).

The idea of transcendence parallels Ersek's (1992) conceptual modeling of hope as a process in her grounded theory study. An oncology nurse researcher, Ersek represented the process of hope with core categories of Dealing With It and Keeping It In Its Place. The first category, Dealing With It, involves steps that end with bringing closure when faced with a threat. After this point an individual manages the impact of a disease and its treatment by controlling one's response through various strategies such as taking a stance toward illness and treatment. The result of dealing with an alteration in health and its consequences and keeping the alteration in perspective is the opportunity to move on to hope. Ersek's theory of hope was heavily influenced by Stotland (1969) who stressed the development of a schema as a result of perceptions associated with the concept and the probability of successful actions.

The set-backs participants in my study experienced could be compared to Ersek's category of Dealing With It. The energy expended toward healing kept the individuals focused and the empowerment of control through knowledge influenced their perspective of hope. The perception that statistics didn't matter because they had already beaten the odds allowed them to ignore probabilities and set their own limits.

Marcel (1951) suggested that people can be guiding stars to one another. Indeed, several survivors of Cystic Fibrosis in my study served as models of hope for younger people or initiated teen and adult support groups. Miller's (1992) finding that hope gives meaning and purpose to life was demonstrated by my participants who shared with others through lectures and group discussions with parents of younger Cystic Fibrosis children.

The meaning of living beyond the life expectancy was explored in an unpublished grounded theory dissertation by Huebscher (1992) who studied the spontaneous remission of cancer and recommended that clinicians reevaluate how prognosis information is given. Huebscher's participants, called 'healees', transcended the implications of a cancer diagnosis and decided the odds were not good enough to accept the treatment. Huebscher's discovery of transcending, described by her healees, shows parallel elements to my findings. She described the healees as masters, taking control of their lives. She likened their ability to deal with diagnosis to elite athletes who excel and master their sport. Indeed, this would be similar to **Fighting With Spirit and Energy** as described and illustrated by the lives of my participants.

Caring process within Watson's (1988) Human Care theory requires knowledge of the other person, the meaning of the situation for him or her, and enabling actions that allow another to solve problems, grow, and transcend the here and now. The humanistic-altruistic system of values is associated with helping the other. This philosophy was expressed in my theme **Transcending the Statistical Odds** with participants who contribute to the sense of greater community and volunteer for research studies. Watson's carative factor, existential-phenomenological-spiritual forces, is actualized with the patient and is a circular process that potentiates transcendence and self-healing. Several of the quotations described previously illustrate the meaning of transcendence to my participants as they put their lives with CF into a larger perspective and consider the gift they could contribute.

In my review of the literature, many previously identified concepts from nursing, philosophy, and psychology have surfaced that validate my research findings. My concept analysis in Chapter II identified five critical attributes of hope from the literature, of which two were clearly found in the themes of my study: hope is energizing and motivating, and hope is internal and personal. The other critical attributes: hope is goal and future oriented and hope is variable with frequent changes, were not consistent with the themes for the adult CF population. In conclusion, in my study, adults with CF who have outlived an expected life span expressed the meaning of hope in this experience as **Fighting With Spirit and Energy, Connecting With Self and Others, and Transcending the Statistical Odds** to accept the gift of life. The philosophical and methodological foundations for the co-created meaning of hope paralleled Watson's carative factor of faith/hope (Watson, 1988). The literature supports the phenomenon of hope as expressed by these themes and the discussion further illuminates the essential meaning of the individual's lived experience. However, this study also provided new insights not found in the literature. The theme of **Transcending the Statistical Odds** was not observed in people who depended on a triggering event or focus for their hope.

Implications

This study compels nurses to reflect on what matters to individuals who live with hope beyond the expected life span. These participants collectively have concluded that it is counterproductive to set an actuarial time for death. Instead of looking for answers and expectations, nurses need to see the uniqueness of spirit and power of connections for people living beyond their expected life span. In light of this finding, my results emphasize implications for nursing theory development, nursing practice, and nursing research.

Nursing Theory Development

The meaning of hope in those living beyond their expected life span has implications for nursing theory development. Historically, nursing's views on human relating have assumed linearity of the nurse-patient relationship over time, proceduralized the experience and left the meaning of the rich human experience unarticulated. Through the sharing of individual stories, these participants have revealed the need to be heard as individuals, not as statistics. The experience of the adult outliving an expected lifespan has been given a voice.

This research has significance for the development of nursing theory and specifically for middle-range theory of hope in illness. According to Newman, Sime, & Corcoran-Perry (1991), nursing is the study of caring in the human health experience. My study described the meaning of the human health experience of hope in those participants who had outlived their expected life span. This new understanding helps to close the gap of knowledge in a technological era where scientific advances are continuously creating uncertain circumstances for people who expect premature mortality, despite steady increases in life expectancy.

Middle-range theory can advance the discipline of nursing by focusing on an identified phenomena of concern. Creating understanding about the hoping experience can illuminate the nursing paradigm and contribute to the advancement of nursing as a discipline. Further research could be conducted to discover a new typology of hope. The patterns of hope identified by Morse and Doberneck (1995) were based on four groups of participants: patients waiting for heart transplants, spinal cord-injured patients, breast cancer survivors, and breastfeeding working mothers. Including a population who has exceeded the expected life span could reveal an additional pattern that would advance the concept and enrich theory development.

Nursing Practice

No time would be considered a good time to have Cystic Fibrosis, but the future for the person with Cystic Fibrosis is brighter now than ever before. Several new therapies and drugs have become available in the past few years and more treatments are in the stages of testing. Eventually, gene therapy may be perfected and bring a cure. However, at this time, people who live with CF are working to survive and remain open to available future treatments.

The significance of this study to nursing practice lies in providing nurse clinicians with insight and understanding to increase sensitivity to the experience of hope as expressed by adults with Cystic Fibrosis. Although information gained through inductive methods is not generalizable, insight into the lived experience may assist nurses to be supportive in their caring role.

Another significant contribution of this study to nursing practice is that by allowing clients to discuss the hoping experience, the nurse begins to "build a bridge to the patient's lived experience of illness" (Benner & Wruble, 1989, p. 12). Although not a cure, understanding and concern are conveyed in the caring relationship. By discussing the experience of hope, a wall of isolation is removed from the patient's perception and the nurse begins to understand the meaning of hope to a person who has lived beyond the expected life span. Montgomery summarized, "When caregivers relate from the intention to connect rather than to do to a person, the communication can have a healing effect" (1993, p. 45).

Interpersonal relatedness was a common theme in the hope described by participants and in the literature. Nurse-client relationships are significant in the therapeutic process. Evidence of care and concern for the other may be essential to maintain hope. Nurses can not 'give' hope to another person, but by understanding the nature of hope nurses can develop ways to help people experience hope. The creative focus on human interrelationships is demonstrated according to Watson in the nurse-client relationship in which empathy and transpersonal caring predominate (Watson, 1985).

Although the health care environment demands outcome criteria and goal setting in all nurse planning, assisting the individual to focus on current projects and connections and less on the future outcomes may increase hope. Co-creating experiences through personal reflection can individualize the care and reinforce that the person is making progress but predictions can not be made. The nurse can invite self care and involvement by allowing autonomy about decisions such as oxygen therapy, timing of antibiotics, and placement on the transplant list. This decision making allows for a great feeling of empowerment, fulfillment and hope. Clients can be partners in their care and be allowed to control, as much as possible, the health plan and environment. Participants in my study were knowledgeable about their medications and treatments and shared strong ideas voiced through feelings and concerns. Nurses who are open to patients that express a firm belief in their knowledge base and who are assertive in the ways they want to be treated, can enhance the fighting spirit in those patients, thereby affirming their hope.

The nurse takes on a significant role of educator throughout the life span of a Cystic Fibrosis patient. In addition to medications, treatments, and illness, the nurse can share practical information about working environments and career and reproductive counseling. Based on my research, nurses are encouraged to provide information to Cystic Fibrosis patients about the specific effects of drug abuse, the danger of interaction with prescribed medications, and the suppression of the cough reflex with alcohol possibly leading to hemoptysis. In building trust and confidence in the nurse-patient relationship, an opportunity to see patients alone, as well as with their parents, may be necessary to allow the nurse to pursue individual client issues.

Nurses are in a unique position to help people search for meaning and hope in life. We also need to prepare for the time when recovery is not possible so that quality of life can be preserved. Participants remind us that the quality of life is the gift, not the quantity. While the findings of this study stimulate ideas for clinical nursing care, additional research obviously is needed.

Nursing Research

This phenomenological-hermeneutic study provides insight into the lived experience of hope for people who have outlived an expected life span with Cystic Fibrosis. Life span research also calls attention to the population who has lived beyond their expected prognosis. Some evidence exits that many people out live the probabilities and statistics. Research is needed with survivors of cancer, birth defects, and people who have been the recipients of innovative new treatments to examine how these people understand and experience prospects of the future and their meaning of hope.

Future inquiries about hope could include family members and their lived experience since they are often the caretakers, and in this case, the recipients of the original statistics. Stoner and Keampfer (1985) suggested that we need to determine what, how much, when, and how to provide information to patients and families. They found that those with the highest hope scores had no recall of life expectancy information. They questioned if hope influences the level of recall or if recalling the information makes the person less hopeful. Questions such as this need to be researched and nurses need to be aware of the personal and aesthetic ways of knowing as well as the empirical statistics.

Further research is also indicated to fully examine the meaning of hope for those who have outlived a life expectancy and the strategies used by these individuals. Support groups or one to one approaches with clients reaching out to one another could be evaluated in terms of hope. Participation in support groups is good evidence that we need connections. The examination of energy and its relationship to hope also needs further exploration. Although the nature and some of the characteristics of energy were revealed by the participants both physical and psychological energy were fluid and intermittent. Another study might look for hope connections as a slow sustaining energy.

Further exploration of hope that is not goal directed is also recommended. The development of hope scales might be revised and retested in light of this uniqueness in the newly identified population.

A call for action research is also prompted by this research. Many social issues emerged in this never-ending battle and psychological burdens were uncovered. Participants revealed particular difficulty with dating relationships and the timing of disclosure of their illness. Employment issues, access to health care, insurance coverage, and end of life decisions also emerged as grave concerns to the participants.

Lastly, a need exists for research with people awaiting transplants and those who have had transplants. One participant who already had a transplant spoke of the adjustments to her life after recovery. After the discovery of the gene in 1989, a surge of anticipation emerged which has now quieted. In 1992, participants in my study on growing up with a chronic illness frequently hoped for a cure or a transplant. Now, only three years later no one spoke of a cure within their lifetime. Several participants spoke of observing the large number of people who died while awaiting transplant, expressing that for these people hopes for a cure died with them. This switch in goals from cure to palliation in the past three years would be another area for study. We need to know the meaning of new medical discoveries to individuals living with fragile physical conditions. Rapid change in science does not provide time for individuals to adapt to new findings and technologies.

The loss of hope and narrowing of expectations and goals for life is believed to lower the quality of life (Haase, et al., 1992; Stoner & Keampfer, 1985). Defining hope in the usual ways is problematic for people who have lived beyond their expected tomorrow. Hope, studied at the time of a crisis, differs from hope in the generalized sense of day to day living. This area presents many questions to be explored through research. Indeed, these participants need the hope that research brings.

Personal Reflections

This caring inquiry has been an extremely rewarding and fulfilling experience for me. These individuals revealed their challenging daily lives and extreme courage to me through their stories and true presence with me. By immersing myself into their world, thinking about and integrating their experience into my life and my nursing practice, a new understanding and many new values about living beyond the life span with hope have emerged for me. These participants have enjoyed life for life's sake, not because they think their life span is shorter than anyone else's. Hope offers no promise of immortality, only proof of our uniqueness and the opportunity to experience full growth and meaning in life. This experience has taught me that it would be a terrible thing to miss out on living by worrying about dying!

Summary and Conclusions

This phenomenological-hermeneutical dissertation was an exploration of the meaning of hope for people who have lived beyond their expected life span. Hope, a universal phenomenon, is an expectation that something better is to come and serves as a guide to action for the hoping person. Although numerous hope studies have focused on people adjusting to a diagnosis or learning to live with a disease, the critical issue of people living longer than expected remains unstudied. The research question was: What is the meaning of hope to people who have lived beyond their expected life span?

Chapter I of this dissertation introduced the study and phenomenon of interest. The specific aims of the study and the researcher's perspectives were delineated. The purpose of this study was to describe and interpret the meaning of hope in people who have beaten the odds of statistics. Chronic illness and life expectancy information was highlighted. Also included was an overview of investigating the lived experience and the significance of this research.

In Chapter II, I reviewed the hope literature in the disciplines of psychology, theology, and philosophy. My concept analysis delineated the critical attributes of hope, and I presented my personal definition of hope: a positive emotion toward future life events involving voluntary, flexible goal setting that has personal meaning to the individual. The theoretical framework of hope within the health/illness context and hope in the stress/coping model was reviewed. A critical analysis of some hope literature in nursing is included in table format. Through the literature review, multiple investigations of hope were uncovered but hope without a triggering event in the chronically ill has not been studied.

Chapter III includes the framework and methodology for the hermeneutic-phenomenological design as informed by van

Manen and influenced by Watson and Parse. Through sixteen phenomenological in-depth interviews, the meaning of hope was co-created. Participants were volunteers over twenty-one years of age who had been diagnosed with Cystic Fibrosis since infancy or early childhood.

The sixteen participants were introduced through narrative stories in Chapter IV. These stories captured the essence of the hope experience and gave a snapshot view of each person. Phenomenological-hermeneutic analysis of interview data and stories shared by the sixteen participants led to identification and interpretation of themes. While the unique was preserved in the stories, the hermeneutical themes that expressed the meaning of hope for the individual who lived beyond an expected life span were: **Fighting With Spirit and Energy, Connecting With Self and Others, and Transcending Beyond the Statistical Odds** to accept the gift of life. Fighting with spirit encompassed lethal and healing energy using mind and body in the battle. Connections were discovered through exercising, volunteering, attending support groups, using counselors, and communicating on the Internet. Transcending was lived by volunteers who served as research participants and as examples for younger people with CF.

In Chapter VI, I compared and contrasted my findings with the extant literature and discussed the unique and universal aspects of hope. Reflection with the literature on hope revealed the fighting and connecting themes have much in common with other researcher's findings. The unique findings for my participants included: a threat or triggering point was not a specific focus for hope, and the use of support groups and the Internet had not been mentioned in previous hope studies. I explored the conclusions and implications of the research findings and recommended future development in nursing theory for those who have outlived an expected life span. In nursing practice, co-participation relationships are encouraged in order to allow the client to stay in control and become a partner in self-care. Research is indicated with survivors to explore the meaning of new medical discoveries to individuals living with fragile physical conditions.

REFERENCES

Achterberg, J. (1991). Woman as healer. Boston: Shambhala.

Benner, P. (1985). Quality of life: A phenomenological perspective on explanation, prediction, and understanding in nursing science. Advances in Nursing Science, 8(1), 1-14.

Benner P. & Wruble, J. (1989). The primacy of caring: Stress and coping in health and illness. Menlo, CA: Addison-Wesley Publishing Company.

Bloom, J., & Spiegel, D. (1984). The effect of two dimensions of social support on the psychological well-being and social functioning of women with advanced breast cancer. Social Science and Medicine, 19, 831-837.

Brown, P. (1989). The concept of hope: Implications for care of the critically ill. Critical Care Nurse, 9, 97-105.

Bruhn, J. (1984). Therapeutic value of hope. Southern Medical Journal, 77(2), 215-219.

Burke, W. & Aitken, M. L. (1994). The aging cystic fibrosis patient: Presentations and problems. Seminars in Respiratory and Critical Care Medicine, 5(5), 383-390.

Carson, V., Soeken, K. & Grimm, P. M. (1988). Hope and its relationship to spiritual well-being. Journal of Psychology and Theology, 16, 159-167.

Chinn, P. L. & Kramer, M. K. (1995). Theory and nursing - a systematic approach. Baltimore, MD: Mosby-Year Book, Inc.

Collins, F. S. (1992). Cystic fibrosis molecular biology and therapeutic implications. Science, 256, 774-779.

Corbin, J. M. & Strauss, A. (1988). Unending work and care: managing chronic illness at home. San Francisco: Jossey-Bass Publishers.

Cousins, N. (1989). Head first: the biology of hope. New York: E. P. Dutton.

Dilthey, W. (1900). The rise of hermeneutics. Translated by Thomas Hall. In P. Connecton (Ed.), Critical Sociology (104-116). New York: Penquin Books.

Dufault, K. J. (1981). Hope of elderly persons with cancer (Doctoral dissertation, Case Western Reserve University, 1981). Dissertation Abstracts International, 42, 1820B

Dufault, K. & Martocchio, B. (1985). Hope: It's spheres and dimensions. Nursing Clinics of North America, 2, 379-391.

Dugdale, A. (1996). Virtual community. Network, 4(4), 5.

Elborn, J. S., Shale, D. J. & Britton J. R. (1991). Cystic fibrosis: current survival and population estimates to the year 2000. Thorax, 46, 881-885.

Engel, G. (1968). A life setting conducive to illness. The giving-up given-up complex. Annals of Internal Medicine, 69, 293-300.

Ersek, M. (1992). The process of maintaining hope in adults undergoing bone marrow transplantation for leukemia. Oncology Nursing Forum, 19, 883-889.

Farran, C. J.& McCann, J. (1989). Longitudinal analysis of hope in community-based older adults. Archives of Psychiatric Nursing, 5, 272-276.

Farran, C. J., Salloway, J. C., Clark, D. C. Measurement of hope in a community-based older population. Western Journal of Nursing Research, 12(1), 42-59.

Farran, C. J., Wilken, C. & Popovich, J. M. (1992). Clinical assessment of hope. Issues in Mental Health Nursing, 13, 129-138.

Fiel, S. B., FitzSimmons, S. & Schidlow, D. (1994). Evolving demographics of cystic fibrosis. Seminars in Respiratory and Critical Care Medicine, 15(5), 349-355.

FitzSimmons, S. (1993). The changing epidemiology of cystic fibrosis. Journal of Pediatrics, 122, 1-9.

FitzSimmons, S. (1995). Cystic Fibrosis Foundation Patient Registry, 1995. Annual Data Report.

Foote, A. W., Piazza, D., Holcombe, J., Paul, P., & Daffin, P. (1990). Hope, self esteem and social support in persons with multiple sclerosis. Journal of Neuroscience in Nursing, 3, 155-159.

Frankl, V. E. (1962). Man's search for meaning. New York: Simon Delta.

Frankl, V. E. (1984). Man's search for meaning. Boston: Washington Square Press.

Fromm, E. (1968). The revolution of hope-toward a humanized technology. New York: Harper & Row.

Gadamer, H-G. (1975). Truth and method. New York: Seabury Press.

Gadamer, H-G. (1976). Philosophical hermeneutics. (D. Linge Trans.). Berkley: University of California Press.

Gordon, J. (1988). Give me one wish. New York: W. W. Norton & Co.

Haase, J. E., Britt, T., Coward, D. D., Leidy, N. K., Penn, P. E. (1992). Simultaneous concept analysis of spiritual perspective, hope, acceptance, and self transcendence. Image: Journal of Nursing Scholarship, 24, 141-147.

Hagedorn, M. I. (1993). A way of life: A new beginning each day. The family's lived experience of childhood chronic illness. Unpublished doctoral dissertation, University of Colorado.

Hall, B. A. (1990). The struggle of the diagnosed terminally ill person to maintain hope. Nursing Science Quarterly, 3, 177-184.

Hanson, J. (1990). Exporting health--and hope. RN, 9, 25-26.

Herth, K. A. (1989). The relationship between the level of hope and level of coping response and other variables in patients with cancer. Oncology Nursing Forum, 1, 67-72.

Herth, K. A. (1990). Fostering hope in terminally-ill people. Journal of Advanced Nursing, 15 (11), 1250-1259.

Herth, K. A. (1991). Development and refinement of an instrument to measure hope. Scholarly Inquiry for Nursing Practice: An International Journal, 1, 39-52.

Herth, K. A. (1992). Abbreviated instrument to measure hope: Development and psychometric evaluation. Scholarly Inquiry for Nursing Practice, 5, 39-51.

Herth, K. (1993a). Hope in older adults in community and institutional settings. Issues in Mental Health Nursing, 14, 139-156.

Herth, K. (1993b). Hope in the family caregiver of terminally ill people. Journal of Advanced Nursing, 18, 538-548.

Hickey, S. S. (1986). Enabling hope. Cancer Nursing, 3, 133-137.

Hinds, P. S. (1988). Adolescent hopefulness in illness and health. Advances in Nursing Science, 10(3), 79-88.

Hinds, P. S. (1989). Method triangulation to index change in clinical phenomena. Western Journal of Nursing Research, 4, 440-447.

Hinds, P. S. & Martin, J. (1988). Hopefulness and the self-sustaining process in adolescents with cancer. Nursing Research, 37, (6), 336-340.

Huebscher, R. R. (1992). Spontaneous remission of cancer. Unpublished doctoral dissertation, University of Colorado.

Jalowiec, A. Murphy, S., & Powers, M. (1984). Psychometric assessment of the Jalowiec coping scale. Nursing Research, 33 (3), 157-161.

Katz, R. C., & Lowe, L. B. (1989). The will to live as perceived by nurses and physicians. Issues in Mental Health Nursing, 1, 15-22.

Keller, S., Guzman, C., & Culen, L. (1985). Psychological intervention for adults with cystic fibrosis. Patient Education and Counseling, 7, 263-273.

Kim, T. S. (1989). Hope as a mode of coping in amyotrophic lateral sclerosis. Journal of Neuroscience Nursing, 21(6), 342-347.

Kierkegaard, S. A., (1848). The aesthetic works, Part II. Point of View. Torch Book edition. Walter Lowry, Ed. New York: Harper & Row.

Klopfer, B. (1957). Psychological variables in human cancer. Journal of projective techniques, 21, 331-340.

Kuebler-Ross, E. (1969). On death and dying. New York: MacMillan.

Ladd, G. T. (1915). What may I hope? New York: Longmans, Green.

Lange, S. P. (1978). Hope. In C. Carson & B. Blackwell (Eds.), Behavioral concepts and nursing interventions (171-190). Toronto, Canada: J. B. Lippincott.

Lazarus, R. S. (1966). Psychological stress and coping process. New York: McGraw-Hill.

Lazarus, R. S., Kanner, A. D., & Folkman, S. (1980). Emotions: A cognitive-phenomenological analysis. In R. Plutchik & H. Kellerman (Eds.), Emotion: Theory, research, and experience (189-217). New York: Academics.

Lazarus, R. S. (1991) Emotion and adaptation. New York: Oxford University Press.

Leininger, M. (1985). Qualitative research methods in nursing. Orlando, Fla: Grune & Stratton.

Living Bible. (1971). Proverbs 13:12. Wheaton, Illinois: Tyndale House Publishers, Inc.

Lynch, W. F. (1965). Images of hope. Baltimore, MD.: Helicon.

Marcel, G. (1951). Sketch of a phenomenology and a metaphysic of hope. In Homo Viator. Chicago: Henry Regency Company, 10-57.

Marcel, G. (1962). Homo viator: Introduction to a metaphysic of hope. New York: Harper & Row.

Marx, J. (1992). Gene therapy for CF Advances. Research News, January 17, 1992, 289.

May, R. (1953). Man's search for himself. New York: W. W. Norton.

Mayeroff, M. (1971). On Caring. New York: Harper & Row.

McCloskey, J. & Bulechek, G. (1993). The NIC taxonomy structure. Image: Journal of Nursing Scholarship, 25 (3), 187-192.

Meleis, A. I. (1986). Theory development and domain concepts. In Moccia, P. (ed). New approaches to theory development. New York: National League for Nursing. pp. 3-21.

Menninger, K. (1942). Love against hate. New York: Harcourt, Brace.

Menninger, K. (1963). The vital balance. New York: Viking.

Mickley, J. R., Soeken, K., & Belcher, A. (1992). Spiritual well-being, religiousness and hope among women with breast cancer. Image: Journal of Nursing Scholarship, 24(4), 267-272.

Miller, J. F. (1983). Coping with chronic illness: overcoming powerlessness. Philadelphia: F. A. Davis.

Miller, J. F. (1992). Coping with chronic illness: Overcoming powerlessness. Second Edition. Philadelphia: F. A. Davis Company.

Miller, J. F. (1989). Hope-inspiring strategies of the critically ill. Applied Nursing Research, 2, (1), 23-29.

Miller J. F. & Powers, M. J. (1988). Development of an instrument to measure hope. Nursing Research, 1, 6-10.

Moltmann, J. (1971). Hope and planning. New York: Harper & Row.

Montgomery, C. L. (1993). Healing through communication. Newbury Park: Sage Publications.

Morse J. M. & Doberneck, B. (1995). Delineating the concept of hope. Image: Journal of Nursing Scholarship, 27(4), 277-285.

Morse, J. M. & Johnson, J. L. (Eds.). (1991). The illness experience: Dimensions of suffering. Newbury Park, Ca: Sage.

Munhall, P., & Oiler, C. (1986). Nursing research: a qualitative perspective. Norwlak, CT: Appleton-Century-Crofts.

Naisbitt, J. & Aburdene, P. (1990). Megatrends Two Thousand. San Diego: Morrow.

Neil, R. M. (1993). Hope poster: Denver nursing project. Presented at International conference on caring, Portland, Oregon.

Newman, M. A. (1989). The spirit of nursing. Holistic Nursing Practice, 3(3), 1-6.

Newman, M. A. (1990). Newman's theory of health as praxis. *Nursing Science Quarterly*, *3*(1), 37-41.

Newman, M., Sime, A., & Corcoran-Perry, S. (1991). The focus of the discipline of nursing. *Advances in Nursing Science*, *14*,(1), 1-6.

Nowotny, M. L. (1989). Assessment of hope in patients with cancer: Development of an instrument. *Oncology Nursing Forum*, *2*, 57-61.

Nowotny, M. L. (1991). Every tomorrow, a vision of hope. *Journal of psychosocial oncology*, *9*(3), 117-126.

Obayuwana, A. O. & Carter, A. L. (1982). The anatomy of hope. *Journal of the National Medical Association*, *74*, 229-234.

Owen, D. C. (1989). Nurse's perspectives on the meaning of hope in patients with cancer: A qualitative study. *Oncology Nursing Forum*, *1*, 75-79.

Parse, R. R. (1981). *Man-living-health: A theory of nursing.* New York: Wiley.

Parse, R. (1987). *Nursing science: Major paradigms, theories, and critiques.* Philadelphia: W. B. Saunders Company.

Parse, R. R. (1990). Parse's research methodology with an illustration of the lived experience of hope. *Nursing Science Quarterly*, *3*, (1), 9-17.

Parse, R. R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly,* *5*, 35-42.

Pearlin, L. S. & Aneshensel, C. (1986). Coping and social support: their functions and applications. In L. Aiken & D. Mechanic (Eds.), *Application of Social Science to Clinical Medicine and Health Policy.* New Brunswick, NJ: Rutgers University Press, 417-437.

Pitzele, S. K. (1986). *We are not alone: Learning to live with chronic illness.* New York: Workman Publishing.

Raleigh, E. D. (1992). Sources of hope in chronic illness. *Oncology Nursing Forum*, *19*(3), 443-448.

Ray, M. (1990a). Critical reflective analysis of Parse's and Newman's research methodologies. *Nursing Science Quarterly*, *3*(1), 44-46.

Ray, M. (1990b). Phenomenological methods for nursing research. In Chaska, N. L. (Ed.) The Nursing Profession: Turning Points. (173-179). St. Louis: C. V. Mosby Company.

Ray, M. (1991). Caring inquiry: The esthetic process in the way of compassion. In D. Gaut & M. Leininger (Eds.), The Compassionate Healer. (181-189). New York: National League for Nursing Press.

Ray, M. A. (1994). The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. In J. M. Morse (Ed.), Critical Issues in qualitative research methods (pp. 117-133). Thousand Oaks, CA: Sage.

Rutledge, A. (1930). The flower of hope. New York: Fleming H. Revell Company.

Schactel, E. (1959). Metamorphosis. New York: Basic Books.

Schaffeld, M. M. (1991). Sean kept hoping against hope...fighting for cystic fibrosis. Nursing 91, 21(9), 60-62.

Scheier, M. F. & Carver, C. S. (1985). Optimism, coping, and health: Assessment and implications of generalized outcome expectancies. Health Psychology, 3, 219-247.

Scheier, M. F. & Carver, C. S. (1987). Dispositional optimism and physical well-being: the influence of generalized outcome expectancies on health. Journal of Personality, 55, 169-210.

Scheier, M. F., Weintraub, J. K., & Carver, C. S. (1986). Coping with stress: Divergent strategies of optimists and pessimists. Journal of Personality and social psychology, 6, 1257-1264.

Shubin, S. (1990). Offer families hope...or help let them go? A story of Anna, a brain injured patient. Nursing, 3, 44-49.

Siegel, B. S. (1986). Love, medicine, and miracles. New York: Harper & Row.

Simonton, O. C., Mathews-Simonton, S. & Creighton, J. L. (1978). Getting well again. New York: Bantam Books.

Smith, M. (1990). The lived experience of hope in families of the critically-ill. [Audiotape 258-12]. San Diego, CA.

Smith, M. C. (1991). Existential-Phenomenological foundations in nursing: A discussion of differences. Nursing Science Quarterly, 4, (1), 5-6.

Stanley, T. (1978). The lived experience of hope: The isolation of discreet descriptive elements common to the experience of hope in healthy young adults. Unpublished doctoral dissertation. The Catholic University of America, Washington, DC.

Stephenson, C. (1991). The concept of hope revisited for nursing. Journal of Advanced Nursing, 16, (12), 1456-1461.

Stoner M. H. & Keampfer, S. H. (1985). Recalled life expectancy information, phase of illness, and hope in cancer patients. Research in Nursing and Health, 8, 269-274.

Stoner, M. H. (1988). Measuring hope. In M. Frank-Stromberg (Ed.), Instruments for clinical nursing research, (pp. 133-140). Norwalk, CT: Appleton & Lange.

Stoner, M. H. (1982). Hope and cancer patients. Unpublished doctoral dissertation, University of Colorado.

Stotland, E. (1969). The psychology of hope: An integration of experimental, clinical, and social approaches. San Francisco: Jossey Bass.

Swanson, K. M. (1991). Empirical development of a middle range theory of caring. Nursing Research, 40, 161-166.

Tillich, P. (1959). The meaning of death. New York: McGraw-Hill.

Tracy, J. (1992a). Congratulations! It's been no picnic: The story of growing up with cystic fibrosis. Unpublished manuscript. University of Colorado.

Tracy, J. P. (1992b). Hope: An Analysis of the Concept. Unpublished paper.

van Manen M. (1984). Practicing phenomenological writing. Phenomenology and Pedagogy: A Human Science Journal, 2(1), 36-69.

van Manen, M. (1990). Researching lived experience. London, Ontario: The Althouse Press.

Walker, L. O. & Avant, K. C. (1988). Strategies for theory construction in nursing. East Norwalk, CT: Appleton & Lange.

Watson, J. (1985). Nursing: Human science and human care. A theory of nursing. New York: National League for Nursing.

Watson, J. (1988). Nursing: Human Science and Human Care. A Theory of nursing. New York: National League for Nursing.

Watson, J. (1989). Watson's philosophy and theory of human caring in nursing. In J. Riehl-Siska (Ed.), Conceptual Models for Nursing Practice, pp. 219-236, 3rd. Ed. Norwalk, CT: Appleton and Lange.

Webster's encyclopedic unabridged dictionary of the English language. (1989). New York: Portland House.

APPENDIX A

COLORADO MULTIPLE INSTITUTIONAL REVIEW BOARD SUBJECT CONSENT

COLORADO MULTIPLE INSTITUTIONAL REVIEW BOARD
SUBJECT CONSENT

Project Title:
THE MEANING OF HOPE FOR ADULTS WHO HAVE OUTLIVED AN EXPECTED LIFE SPAN

December 20, 1994

PROJECT DESCRIPTION:

You are being asked to take part in a study about the meaning of hope and expectations for your future as an adult survivor of Cystic Fibrosis. I am interested in hearing your personal feelings, thoughts, opinions, and stories. The results of this study will be summarized and presented in a dissertation for a Ph.D. degree in nursing at the University of Colorado Health Science Center in Denver, Colorado. The findings will also be presented at professional meetings or published in professional or lay journals.

PROCEDURES:

If you agree to participate in this study, you will be asked to tell your story about living with Cystic Fibrosis in an interview at a time and place convenient to you. The interview will last approximately 60 minutes and will be audiotaped.

DISCOMFORTS, RISKS, AND BENEFITS:

There are no direct benefits to you for participating in this study. No funding is available for the study, and you will not be paid to participate. Although there are no anticipated risks involved in participating in this research, discussion about these issues may uncover feelings you were not aware of and may make you uncomfortable. If you become fatigued we will take breaks to allow you to rest, or you may stop the interview and reschedule at a later date. You are free to withdraw from the research at any time.

CONFIDENTIALITY:

Any information you tell me will be kept in the strictest confidence and tapes will be kept in a locked file cabinet in the office of the investigator. The audio tapes will be transcribed word for word and you will be identified only by an assigned name. Your name and any other information that may identify you will not be used in any written reports or oral presentations.

INVITATION FOR QUESTIONS:

I understand that, should I have any questions or concerns, or if I would like to speak to someo s study I may call the researcher, **Janet Tracy** [redacted]). If I have any questions or concerns about my person in this research study, I may call the John Moorhead, Ph.D., Associate Dean for Research Affairs at the University of Colorad[redacted]

AUTHORIZATION:

I have read the above and I agree to participate in this research study. I understand that I may elect to withdraw at any time. Any questions I have had about my participation in this research have been answered to my complete satisfaction. I will get a copy of this consent form.

Name of Participant (print):________________________________
Address: ____
Telephone:_________________

Signature of Participant:______________________________
Date:_________

Signature of Researcher:_______________________________
Date:_________

APPENDIX B

SAMPLE TRANSCRIPT

Extracted from transcript interview with Sean, July, 1995

One of the things I'm interested in is people who've grown up like yourself with their parents or possibly themselves being told you're not going to make it to a certain age and 20 seems to be when they dropped off in terms of talking about ages - you're 36.

Validate beyond life span

Gonna be.

Going to be 36, OK. So I'm wondering what the meaning of hope is - how you would define hope for yourself?

(Throat clearing) How would I define hope? Well, hope is, hope is the absence of guarantees, like if you have a guarantee that I will get there tomorrow, then that's - then you don't need hope, but hope is you're not sure if you're going to get there, but you want to be there (throat clearing).

Hope

uncertainty is a part of hope.

So things that you really want, things or places wherever that you want to be?

Hm-hm.

What are your hopes?

Well, I hope to live as long as I can. I hope to live as happily as I can. I hope to continue - and my life has been blessed in so many different ways. I hope to continue to have the relationships that I have with people and I hope to continue enjoying life as I have (throat clearing), with all the bumps and dips that go along, having friendships, having relationships, being

Hopes
① long life
② happy
③ relationships
④ enjoy life

able to help people, having people help me. For example, this mobile home has come about to a large degree through the goodness of other people who have helped me out. This mobile home was given to me by a mobile home park free and then different things fell in together, and my sisters helped decorate it and so I came to the realization one day if I didn't have CF to some degree I wouldn't know that I was loved so much.

others helped support.

what CF has given me.

That's sounds beautiful.

So that's kind of neat (throat clearing).

Now is it mostly about the mobile home?

Well, you think about it, it comes to (throat clearing) - it comes into view maybe at that particular time, but throughout my life there have been a lot of people that have loved me and I don't know where I'd be without that (throat clearing), so I mean if you're a person who's totally independent, not needing of somebody, self-sufficient, self-reliant, you don't need anybody, you're just your own king, your own master, you can go along and that's it, but when you start meeting other people and you start receiving the help, you realize how much people can be wonderful and loving and caring and so it's kind of neat to have --

feels support -

what CF has given me

- connections

So you think that if you didn't have CF you might not know that?

APPENDIX C

PRELIMINARY THEMES

Preliminary Themes

- Measuring reference points for better self care
- Garnering strength and energy through knowledge, bonding, and attitude.
- Accenting the positives while acknowledging the existence of negatives.