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I am submitting herewith a dissertation written by Carol J. Smucker entitled "The Wonder of Meaning: A Phenomenological Understanding of Spiritual Distress." I have examined the final copy of this dissertation for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Doctor of Philosophy, with a major in Nursing.

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Associate Vice Chancellor
and Dean of The Graduate School

# THE WONDER OF MEANING:

# A PHENOMENOLOGICAL UNDERSTANDING OF SPIRITUAL DISTRESS

A Dissertation

Presented for the

Doctor of Philosophy Degree

The University of Tennessee, Knoxville

Carol J. Smucker

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To my mother,

Vivienne Eleanor Naden Crowell,

for her constant faith and abiding love.

## ACKNOWLEDGMENTS

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## ABSTRACT

The purpose of this study was to describe the phenomenon of spiritual distress as it is experienced by adults in the general population. This study focused on the key aspect of spiritual distress--concern about the meaning of life, death, and/or beliefs. Using phenomenological interview procedures, ten participants were asked to describe experiences of being concerned about the meaning of life, death, and/or their beliefs. All participants considered their beliefs to be very important, evaluated their health as good, and named a religious affiliation with which they identified.

A hermeneutical approach was used for data analysis. Data were analyzed within the dialogic process of a phenomenological research group in addition to the researcher's individual work. The thematic structure derived from the data describes the experiential themes of spiritual distress and their inter-relationships.

Participant narratives were grounded in the context of time. The thematic structure of the experience of spiritual distress was biphasic. The metaphor of the Web of Life, taken from the words of one participant, was used to describe both phases. Phase one was termed Breaking the Web, and occurred when an event broke the continuity of life. The three major themes and subthemes of this phase were: (1) Falling Apart (Pain, Instability), (2) Wondering (Questioning), and (3) Something Beyond (Feeling, Presence, Mystery). The second phase, during which participants found meaning in their experiences, was termed Rebuilding the Web. The four major themes and subthemes of this phase were: (1) Stability (Strength, Security), (2)

Change and Growth (Self, Beliefs), (3) Wondering (No Answers, Accepting Limits to Knowing), and (4) Something Beyond.

Findings were discussed in relation to nursing practice, education, and research. Implications of this research for the nursing diagnosis Spiritual Distress were addressed and suggestions were made for future research on spiritual distress.

And a man said, Speak to us of Self-Knowledge.
And he answered, saying:
Your hearts know in silence the secrets of the days and the nights.
But your ears thirst for the sound of your heart's knowledge. You would know in words that which you have always known in thought.
You would touch with your fingers the naked body of your dreams.

And it is well you should.
The hidden well-spring of your soul must needs rise and run murmuring to the sea;
And the treasure of your infinite depths would be revealed to your eyes.
But let there be no scales to weigh your unknown treasure;
And seek not the depths of your knowledge with staff or sounding line.
For self is a sea boundless and measureless.

Say not, "I have found the truth," but rather, "I have found a truth."
Say not, "I have found the path of the soul."
Say rather, "I have met the soul walking upon my path."
For the soul walks upon all paths.
The soul walks not upon a line, neither does it grow like a reed. The soul unfolds itself, like a lotus of countless petals.

Kahlil Gibran, The Prophet

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# CHAPTER I

## INTRODUCTION

> *As you ought not to attempt to cure the eyes without the head, or the head without the body so neither ought you to attempt to cure the body without the soul...for the part can never be well unless the whole is well. Plato*

Nursing education prepares practitioners to recognize and treat human responses to actual or potential health problems. These problems can be physical, psychological, social, or spiritual. The spiritual problems remain the most difficult for many nurses to recognize and treat (Burkhardt, 1989). For early nurses who were educated within religious orders, attending to spiritual needs may have been second nature. Often, hygiene and prayers were all these nurses had to offer those in their care.

There may be several reasons for the uncertainty nurses experience today in recognizing spiritual distress and giving spiritual care. One reason may be that most nurses are not educated in and do not practice in religious settings. Also, nurses have received limited content on spirituality in their nursing programs and research-based literature on spirituality is scarce. Additionally, care priorities revolve around technology, allowing little time for nurses to address needs other than the physical ones. Isabel Stewart, one of nursing's early leaders, wrote prophetically about nursing's current practice situation.

> The real essence of nursing, as of any fine art, lies not in the mechanical details of execution, nor yet in the dexterity of the performer, but in the creative imagination, the sensitive spirit, and the intelligent understanding lying back of these techniques and skills.

> Without these, nursing may become a highly skilled trade, but it cannot be a profession or a fine art. All the rituals and ceremonials which our modern worship of efficiency may devise, and all our elaborate scientific equipment will not save us if the intellectual and spiritual elements in our art are subordinated to the mechanical, and if the means come to be regarded as more important than ends (Stewart, 1929, as cited in Donahue, 1985, p. 467).

Prior to the 1970s and nursing's adoption of the holistic health paradigm, nurses were taught that spiritual care primarily related to a patient's religious practices (Piles, 1990). This perspective limited spiritual care to consideration of religious preferences and practices. Nursing literature after 1970 reflects an increased interest in the nurse's role in spiritual care as well as a broader definition of spirituality. Journal articles published during this time addressed meeting patients' spiritual needs (Ferszt, 1988; Forbis, 1988; Granstrom, 1985; Hover, 1986; Peterson, 1987; Sims, 1987) and nursing textbooks included sections on spiritual care (Beland & Passos, 1975; Sorensen & Luckmann, 1986). In 1976, a new category entitled Spirituality was added to the Cumulative Index of Nursing and Allied Health Literature (CINAHL).

## Clarification of Terms

The terms religion and spirituality are not used consistently in the literature. Generally, religion refers to a specific set of beliefs held in common by a group. Therefore, not all persons are religious; that is, they are not affiliated with a specific religious body. Spirituality, in its broadest sense, refers to "an aspect of any attempt to approach or attend to the invisible factors in life and to transcend the personal, concrete, finite particulars of this world" (Moore, 1992). Thus, all persons have

experienced spirituality when they have felt connected to an unseen reality or asked themselves questions such as "What is my relationship to the universe?", "What is the meaning of life?", and "What happens when I die?". These are called ultimate questions and refer to ideas of a transcendent reality. Tillich (1957), a philosopher, referred to this experience as the "centered movement of the whole personality toward something of ultimate meaning and significance" (p. 106). Mayer (1992), a British chaplain's assistant, writing about nursing's role in spiritual care, states that

> If spirituality is seen as embracing the whole of what it means to be human, then the essence of spiritual care is not doctrine or dogma but the fundamental human capacity to enter into the world of others and respond with feeling (p. 51).

This broadening of the idea of spirituality is evident throughout the nursing and psychology literature. Though some nurses (Karnes, 1991) may decry this change from a Judeo-Christian based spirituality to a more humanistic one, it seems mandated by our national multicultural diversity. Nurses increasingly care for persons form a variety of cultural, and thus, spiritual backgrounds.

Emblen (1992) has traced transitions in the definitions of religion and spirituality in the nursing literature published between 1963 and 1989. Generalized definitions of religion and spirituality were formed from the most common words found in the literature for these terms. Thus defined, religion is a: System (of) organized beliefs and worship (which the) person practices. The definition of spirituality is a: Personal life principle (which) animates transcendent quality (of) relationship (with God or god being).

The terms used in nursing literature during this period have included spiritual need, spiritual distress, spiritual pain, spiritual health, and spiritual integrity. The following are examples of the way definitions of these terms have changed. While a spiritual need was viewed in 1975 as something that interfered with a person's relationship to God, by 1982 it had broadened to include those variables that provided inspiration to transcend the material world. In 1980, spiritual distress was related to disruptions in spiritual practices and life situations that threatened one's belief system. Currently, Gordon (1989) conceptualizes it as a disruption in the life principle which pervades a person's entire being and which integrates and transcends biopsychosocial nature.

It should also be noted that all of the literature reviewed on spirituality referred to it as a life-giving force. Some religious and spiritual excesses, however, can be unhealthy; for instance, religious practices of self-flagellation, fasting, self-sacrifice, and acts motivated by drug-induced visions have resulted in suffering and death throughout history (James, 1902/1961). Moore (1992), a psychotherapist, believes that the "spirit gets stuffed into the symptomatic forms of cults and quackery" when it is not allowed a full range of expression. Currently, there is also a renewed interest in various types of spiritualism, which is not to be confused with spirituality.

Spiritualism is a religious practice in which the living attempt to communicate with the dead through the use of a medium. Jung (1933) characterized these forms of religion, which were having a revival during his time, as systems that are based

exclusively upon the manifestations of the unconscious, and their moral teachings "do not baulk at the shadow-side of life" (p. 207). Jung uses the term "shadow-side" to include what is unreasonable, senseless, and evil in human nature.

## Holistic Philosophy and Spirituality

Holism, the idea that a person is more than the sum of parts, has been a key concept in nursing. This philosophy is evident in the writings of nursing leaders from Nightingale in 1860 to Henderson in the 1960s to nursing's most recent theorists, such as Rogers, Orem, Neuman, and Roy. Although these theorists describe a human being in different terms, they all emphasize the integrated wholeness of the person (Chinn & Jacobs, 1987). While nursing conceptualizes the person as multidimensional (physiological, psychological, sociological, and spiritual) with each part having its own unique characteristics, all parts function together as a whole. A measure of well-being or health is how well these different parts are integrated.

Spirituality, similar to holism, is considered an integrative concept, one which emphasizes the unity or wholeness of the human person. Thus, research about spirituality rests upon a holistic philosophy. Ellerhorst-Ryan (1985) contends that nursing's holistic philosophy mandates research in spirituality. She expressed concern about a noticeable absence of the spiritual dimension in nursing theory and research. Nursing theorists, however, have not totally neglected the spiritual dimension. Neuman includes the spiritual as a variable in the client system (Fawcett, 1989); Watson (1979) identifies the spiritual as one of the environments nurses provide, support, protect, and/or correct in giving nursing care and more recently (1988) she

identified human needs that are spiritual; and Travelbee's theory (1971) focused on the spiritual aspect of illness and suffering. She described both general and specific ways of helping persons find meaning in illness. Other nursing theories which are holistic are those of Rogers (1970), Parse (1981), and Newman (1986). These theories emphasize not only the unity of persons but also their meaningful interactions with their environment. Reed (1992) refers to this unity as connectedness which occurs within a person and between a person and the environment. The term environment encompasses others, nature, and the transcendent dimension (God or a higher power). Nursing studies of spirituality which have supported this idea of connectedness will be discussed further in Chapter II. The idea of spirituality as an integrative force makes it an important topic for nursing research. However, the complexity of spirituality makes it difficult to study.

## Spiritual Distress and Health

Concern for clarifying the concept of spiritual distress ultimately relates to a concern for the health of patients. By Selye's (1974) definition, dis-stress is literally "bad stress." Selye defined stress as the body's nonspecific response to any demand made upon it and distress is damaging or unpleasant stress. Thus, any stress, whether pleasant or unpleasant, can have untoward effects on the body depending on the person's specific interpretation of that stress. What then, is spiritual distress? Seen as a unifying force (Barker, 1989; Burkhardt, 1991) spirituality is frequently cited for its role in personality integration, harmony, and sense of meaning. Thus, spiritual distress is likely to be experienced as personal disconnectedness (disharmony,

disintegrality). If perceived as distressful, and if the situation is not resolved, illness may result from the physiological stress response described by Selye. Remen (1988), a physician, believes that unrecognized spiritual distress may be at the root of much illness. Illness, of course, can also be the source of spiritual distress. It is at those times of stress that many people struggle with the meaning of their illness or traumatic life event.

Writing about women in distress, Ashurst and Hall (1989) see distress as "an experience by which we signify that all is not well with our world" (p. 9). They state that distress may be expressed in many different ways and indicates a state of "dis-ease" with our bodies, our environment, and with other people. Therefore, distress will manifest itself in physical or mental symptoms. These manifestations may be reflected in the current defining characteristics (signs and symptoms) of the diagnosis Spiritual Distress.

## Nursing Diagnosis: Spiritual Distress

The nursing diagnosis movement has stimulated an interest in the spiritual dimension of nursing (Fearing & Rantz, 1991) and has given impetus to research on spirituality. Nursing diagnosis is an important step in the nursing process. It is the use of nursing judgment; a link between information collection and care planning. Making a nursing diagnosis is a cognitive process that results in a product, the diagnostic label. The diagnostic language communicates to healthcare professionals the etiology, definition, and defining characteristics of the diagnostic concept. According to Gordon (1976),

> Nursing diagnoses, or clinical diagnoses made by professional nurses, describe actual or potential health problems which nurses by virtue of their education and experience are capable and licensed to treat (p. 1299).

The current diagnostic label of spiritual distress had its origins at the First National Classification Conference of the North American Nursing Diagnosis Association (NANDA) in 1973. The original four diagnostic categories created at that time related to an Alteration in Faith. At the NANDA conference in 1978 the diagnoses of Spiritual Concern, Spiritual Distress, and Spiritual Despair were added. Spiritual Distress (Distress of the Human Spirit) replaced these and became the only diagnosis in the Value-Belief pattern in 1980. The Value-Belief pattern is one of the eleven patterns of the Functional Health Patterns, an organizing framework for nursing diagnoses, created by Gordon (1982). Work continued on the development of diagnostic labels related to spiritual distress at the Fifth NANDA conference (Fehring & Rantz, 1991). Although a variety of labels of spiritual distress that had been formulated from an unpublished master's theses (Flesner, 1981) were considered (spiritual distress related to forgiveness, love, hope, truth, and meaning and purpose), the diagnostic framework was not changed. The current definition, etiologies/related factors, and the defining characteristics of spiritual distress are those that were developed at the Fourth NANDA conference in 1980.

Defining characteristics of a diagnostic category are the signs and symptoms associated with a specific health problem. Nurses are to choose a specific diagnostic label only when the critical defining signs and symptoms of that label are present (Gordon, 1982). For the diagnosis of Spiritual Distress, there are thirteen defining

characteristics (Hurley, 1986), with the first one considered to be the key defining characteristic. To label a patient's response as spiritual distress, this key defining characteristic must be present. The other characteristics do not necessarily need to be observed to make this diagnosis. The defining characteristics of the nursing diagnosis spiritual distress are:

- Expresses concern with meaning of life/death and/or belief system
- Anger toward God
- Questions meaning of suffering
- Verbalizes inner conflict about beliefs
- Verbalizes concern about relationship with deity
- Questions meaning of own existence
- Unable to participate in usual religious practices
- Seeks spiritual assistance
- Questions moral/ethical implications of therapeutic regimen
- Gallows humor
- Displacement of anger toward religious representatives
- Description of nightmares/sleep disturbances
- Alteration in behavior/mood evidenced by anger, crying, withdrawal, preoccupation, anxiety, hostility, apathy, etc.

Although NANDA now has a formal system for submitting diagnoses for review, diagnostic categories were originally considered based on the identification of common conditions nurses said they diagnosed and treated in their practice (Gordon,

1987). Credibility continues to be a problem in the acceptance and revision of categories because they are opinion based. Although research on diagnosis has increased since 1980, it falls short of what is needed. To address this concern, Gordon (1987) has said that research is needed to analyze each diagnostic set of manifestations and to describe the phenomenon further. She states that the current emphasis on cost and quality control in health care will influence research to increase diagnostic efficiency and validity.

## Research of Spiritual Distress

Only two studies have been done to evaluate the diagnosis of Spiritual Distress and the purpose of these studies was to validate the defining characteristics of the diagnosis. In the first of these, Weatherall and Creason (1987) identified cues of spiritual distress from the literature on spirituality, spiritual needs or care and religious needs or care as found in the Cumulative Index to Nursing and Allied Health Literature (CINAHL) and from the NANDA bibliography on spiritual distress (Kim, McFarland, & McLane, 1984). These cues from 34 nursing articles were compared with assessment data on spiritual distress obtained from 13 patient records. Results suggested that five characteristics were the most valid and clinically useful. The three that were NANDA characteristics were: "questions meaning of suffering," "verbalizes concern about relationship with deity," and "verbalizes inner conflict about beliefs." The other two, "hopelessness" and "cues having to do with relationships with others" have not been added to the list of defining characteristics. The study's usefulness was limited by the small sample size (N=13) and most likely

by the variability in the charting. Also, most charting is related to physical data with less emphasis on charting psychosocial data such as spiritual concerns.

The second study was a descriptive one by McHolm (1991). In a random sample, oncology nurses (N=97, 32% return rate) were asked to identify defining characteristics used in clinical practice when diagnosing spiritual distress from a list of 41 defining characteristics. A Likert scale validation system suggested by Fehring (1986) was used to rate characteristics. Characteristics with ratios greater than 0.75 were considered critical supporting characteristics.

It is interesting to note that only 28 (28.9%) of these nurses said that they used the nursing diagnosis of Spiritual Distress in their practice. The majority of critical defining characteristics identified were alterations of mood or affect. These included anxiety, fear, depression, helplessness, discouragement, and crying. The one critical defining characteristic that more specifically related to spiritual concerns was "cues that religious/spiritual needs are important." The nonspecific nature of these characteristics may be one reason nurses have difficulty differentiating spiritual from psychosocial distress. This difficulty among nurses was also found by Highfield and Cason (1983) in their study of the identification of spiritual needs.

Because more than 25% of the NANDA characteristics were not observed frequently enough to be considered usable indicators, McHolm suggested that the present list of characteristics may not be appropriate or sufficient to identify spiritual distress. One limitation of her study is its low return rate. Another serious limitation, which McHolm identified, is the confusion over the definition of spiritual

distress. McHolm states that "This lack of clarity has perhaps been a major restraining factor in the willingness of nurses to tackle the problems of dealing with spiritual aspects of practice" (p. 118). Creason (1988), in her critique of McHOlm's study, suggests that another problem is that the defining characteristics themselves are not defined. Creason (1988) sees this lack of agreement about nursing diagnosis definitions as a "serious obstacle to the development of a common practice and research base for nursing diagnoses" (p. 195).

These two studies highlight several important issues regarding research on spiritual distress. One of these is the continuing confusion over the definition of the term spiritual; another is that religious, spiritual, and psychosocial needs overlap. There has been no research done on spiritual distress using inductive methods, such as interviewing persons about their experience of such distress. Qualitative studies like this could be useful in developing a conceptual basis for the phenomenon and in theory building. Clearly, this work has yet to be done for the phenomenon of spiritual distress.

## Purpose of Study

The purpose of this study was to describe the phenomenon of spiritual distress as it is experienced by adults in the general population. This study focused on the key aspect of spiritual distress--concern about the meaning of life/death and/or beliefs. In addition to describing the main aspect of the phenomenon of spiritual distress, this study also sought to clarify the nursing diagnosis Spiritual Distress and evaluate the appropriateness and sufficiency of the defining characteristics for this diagnosis.

## Research Question

How do people describe the experience of spiritual distress (being concerned about the meaning of life/death and/or beliefs)?

## Research Perspective

A phenomenological approach was chosen as the most appropriate method to study the experience of spiritual distress. A basic assumption of phenomenology is that human experience is organized in some way and that the structure of this organization can be known through an analysis of the language used to describe experience. The structure of a phenomenon is the common understanding of the phenomenon that is present in various contexts. Phenomenology, as a research method, is based on a combination of existentialism and phenomenological ideas. an overview of the key elements of each of these philosophies will be given in the next section.

Until recently, quantitative methods have been used more frequently by nurse researchers. The emphasis of quantitative approaches is on objectivity and cause and effect. Phenomena are reduced to an essential set of quantitative dimensions that operate according to the laws and principles of mathematics (Thompson, Locander, & Pollio, 1989). Qualitative approaches, on the other hand, emphasize an understanding of phenomena through description. As a developing profession, nursing is still searching for the research methods that will best provide the knowledge needed for nursing care. To establish its credentials, nursing adopted the research methods of established disciplines, such as the natural sciences. Although these methods were

useful for answering many of nursing's research questions, the inner, or subjective, human experiences were not deemed an appropriate or available phenomenon for scientific study; they were not observable, and therefore, not measurable. Perhaps this quote from Giorgi, a phenomenological psychologist, still applies today:

> ...the mistaken notion that if one is interested in the whole person then it is not possible to be scientific is still too prevalent (1970, p. 12).

Because human experience consists of both the contextual world and awareness or consciousness in this world, a method needs to be used which allows these phenomena to be studied as one. The personal meaning of spiritual distress is grounded in human experience and traditional research methods have limited nursing's understanding of this important concept. Descriptive studies are required to elucidate the essential components of this concept. To include experience in the research of spiritual distress will provide an understanding of spiritual distress in terms of what it means for people.

Alternative research methods are currently being used in nursing and most of the social sciences to study human experience. Phenomenological research has become increasingly important in nursing (Cohen, 1987). According to Swanson-Kauffman and Schonwald (1988), phenomenology has had a "profound impact" (p. 97) on how nurses view the nature of human being-in-the-world. Within the last two decades, the increasing number of research studies in the nursing literature that report using qualitative methodologies for the study of nursing phenomena seems to reflect nursing's commitment to these types of methods.

## Origins of Existential and Phenomenological Thought

There are two classical schools of philosophic thought: Realism and Idealism (Parkinson, 1988). Existential and phenomenological philosophy are identified with Idealism while Realism is associated with the most prevalent scientific method, empiricism. The ideas of these two schools are complex and dynamic. The intent here is to merely point out the differences in the two schools as they relate to the development of the unique philosophies and methods relevant to this study.

The realists trusted or were "positive about" only the material world, the world of matter that one could "see" or know through the senses ("outside" the mind). The idealists trusted the knowledge that was present to or "in" the mind, or consciousness. Idealism reduces all physical phenomena to minds or mental phenomena (ideas) (Parkinson, 1988; Spiegelberg, 1975). The idealists believe that reality is essentially mental in character (Barbour, 1990), an idea that goes back as far as Plato. Although the mind is not matter, the idealists said that it is essential to matter and the understanding of matter (Masih, 1975).

The positivists, as those who employed the empirical method have been called, use research methods which attempt to hold the world static while they observe natural phenomena. The world is conceived as external; its nature is independent of persons and personal experience. The idealists, alternatively, seek to examine the world of human experience and the underlying essence of things (Masih, 1975). These phenomena are dynamic and continually being created by the interaction of subject and object.

The dualism of Descartes clearly distinguished between object and subject. Phenomenology, on the other hand, connects a person's "inside" and "outside" world. Heidegger's (1962) idea of Being-in-the-world, known as Dasein (German for personal existence or "here-being") permits no separation between a person and his or her world. Consciousness is at the same time an inner and outer awareness and experience. The world, therefore, does not exist without consciousness and consciousness reveals the world. In order to maintain objectivity, persons are often studied by researchers apart from the context of their world. However, phenomenology allows entities to be studied within their contexts.

***Existentialism***

Existential philosophy was founded by Kierkegaard (1813-1855), a devout Lutheran. Kierkegaard saw a need for philosophy to address the "concrete existence" of individuals and to attempt to bring out the fundamental themes with which humans struggle (Valle, King, & Halling, 1989). Existentialists came to define the self by its acts and deeds (Barry, 1980). Situated freedom is an important concept of existentialism. This is the freedom, and therefore obligation, that individuals have to make choices in situations, although this freedom is often limited by the constraints inherent in situations. In this sense, individuals and the world are said to co-constitute one another (Valle, King, & Halling, 1989).

Kierkegaard's religious beliefs are evident in his idea that the self needs to discern what action would be desired by God. For Kierkegaard, while the self was the focus of reality, it was a self whose function was not only in mental ways (or

consciousness) but also one that functioned by acting, willing, and deciding (Solomon, 1980). The existentialists were a diverse group and not all were religious; Nietzche (1844-1900) represented the existentialists who said the world existed without a God and that only the human will to power was real. Views that existentialists do hold in common are a concern for the individual, subjective experience, the importance of self, the need for personal freedom, and the reality of personal responsibility (Barry, 1980). Existentialism builds on and gives form to phenomenology's ideas of consciousness and Being.

***Phenomenology***

The German philosopher Husserl [1859-1938] was the originator of phenomenology. Basing his work on Descartes and Kant (Solomon, 1980), he developed a theory of consciousness which was concerned primarily with perception (Edie, 1987). Husserl's phenomenology represents an attempt to develop a rigorous and unbiased study of things as they appear (or "things in themselves") (Valle & King, 1978). Specific methods are used to understand human consciousness and experience as they are lived out in the world (Valle & King, 1978; Giorgi, 1971). Direct and immediate experience is termed the "life-world" (Lebenswelt), or the world of every-day experience as expressed in ordinary language. Within the dialogue between person and world, the life-world is co-created. Thus, the life-world is not a construction of consciousness (Husserl, 1964). Husserl considered the nature of one's immediate experience of the life-world a "pre-reflective," or prior to and foundational to reflective thought (Valle, King, & Halling, 1989).

Phenomenology is the study of phenomenon, or a thing as it appears in and to consciousness. Kant distinguished between phenomenon, the experience of a thing and noumenon, or the thing as it is. Kant believed only the phenomenon could be known (Barry, 1980).

For Husserl, the main concern was consciousness itself and the essences of experience. Essences are what make a thing "what it is" (Solomon, 1980). Phenomenology made possible the study of Being which historically had been considered in the realm of metaphysics. The philosophers of metaphysics had come to the conclusion that the ultimate reality could not be known. Thus, phenomenology opened the way for further study of consciousness by including the study of experience.

Being was the primary concern of Heidegger (1962) [1889-1976], a student of Husserl's, who is credited with combining existential philosophy and phenomenological methodology. The key elements of this method are a search to explain the essence, structure or form of both human experience and behavior, as revealed through descriptive techniques, including disciplined reflection (Valle, King, & Halling, 1989). The "structure" of a phenomenon is the common thread that runs through many diverse appearances of a phenomenon. The structure presents itself as meaning. Therefore, existential-phenomenology enables the disclosure of the nature of structure in the form of meaning. In this way, the pre-reflective life-world is manifested as psychological meaning through the level of reflective awareness (Valle, King, & Halling, 1989).

One of the main ideas of existential-phenomenology is that a person and the natural world are a unity; an interrelationship that is essential to consider when studying either people or the world. Each must be considered in the context of the other. The world is seen as essential to the meaning that persons form of their existence. Heidegger discovered similar ideas to his own in reading Zen literature. The similarity between Heidegger's ideas and Eastern thought was a concern with one's inner nature and with being real rather than what is real. In Being, there is a oneness of the subject with the object; the person and the experience are one (Barry, 1980). Therefore, knowledge of the world is through an understanding of a person's perception of living in the world.

Existentialism and phenomenology are considered movements and as such are continually changing (Solomon, 1980). While most of the critics of these movements agree that metaphysical issues can be talked about, the analytical school of philosophy still does not agree that statements about ultimate reality and Being are meaningful. The dissension of this group, however, has not deterred others from studying human experience using existential-phenomenological methods. The basic assumptions of existential-phenomenology which make it an appropriate choice for this study are: (1) people are viewed as a total indissoluble unity in interrelationship with the world, (2) a person's existence has meaning through the world, (3) a person's existence gives the world its meaning, and (4) this relationship is based on dialogue (Polkinhorne, 1989).

Spiritual distress, as a human experience, is a reality that has eluded philosophic analysis and scientific study. Existential-phenomenological philosophy and methods offer a means of exploring this dimension of life that appears to be a universal experience. This study's methodology depends upon the analysis of language, the result of a dialogue between the researcher and the research participant. A description of the specific phenomenological methodology used in this study will be provided in Chapter III.

## Significance of Study

Nurses continue to value both the art and the science of their profession. Giving spiritual care will always be more of a nursing art than a nursing science. New methods are being introduced in nursing research, undergirded by a holistic philosophy, that are designed to enable nursing to explore the spiritual dimension. Careful exploration of the spiritual distress experience has the potential (1) to provide a basis for further study of the spiritual in relation to health and (2) to guide nurses in identifying spiritual distress in their patients, and (3) to direct nurses in caring for patients who are spiritually distressed.

## Limitations

This study provides a description of the experience of being concerned about the meaning of life/death and/or beliefs as it was experienced by a sample of ten individuals with unique group characteristics. The results of this study cannot be generalized to other groups. However, the thematic description of this experience

may be beneficial to persons who have experienced being concerned about meaning or for those who have cared for persons with such experiences.

The experience of spiritual distress includes additional aspects besides being concerned about meaning. However, this study describes only one aspect of that experience. Phenomenological methods provide only a description of the themes and their relationships within the experience of spiritual distress, and do not attempt to explain these relationships. Finally, despite the researcher's efforts to validate themes with research group members, it is possible that a somewhat different interpretation of the data might be given by a different group of researchers.

## SUMMARY

This study was motivated by a need to clarify the concept of spiritual distress, so that nurses could better care for patients who are concerned about the meaning of life/death and/or their beliefs. Also, the nursing diagnosis Spiritual Distress needs further study to decrease confusion about its definition and key characteristics. A phenomenological method was chosen for this study because it is particularly useful for exploring and describing human experiences.

In the next chapter the relevant literature from psychology and nursing that provides the background for studying spiritual distress will be discussed. The research methodology will be described in Chapter III. The results of the data analysis will be presented in Chapter IV. In Chapter V these results will be discussed in relationship to nursing practice, education, and research.

# CHAPTER II

## LITERATURE REVIEW

### INTRODUCTION

In this chapter selected literature on the spirit, spiritual experience, spirituality and health, nursing theories regarding spirituality, meaning, and spiritual distress will be discussed. Writings of theorists, researchers, and practitioners in a variety of disciplines will be reviewed.

### SPIRIT

The spirit is traditionally believed to be a vital principle or animating force within living beings (American Heritage Dictionary, 1978). Derived from Middle English, Norman French and Latin, the roots of the word spirit mean breath, breath of a god, and inspiration. Associating the word spirit with breathing attributes to it characteristics of a life-giving force.

The word soul, while often used interchangeably with spirit, has a broader definition than spirit. It is thought that humans have believed in the existence of the soul since prehistoric times. Like spirit, the soul has also been associated with the breath as well as with water or the sea. Additionally, the soul has been located in various parts of the body. Philosophers and theologians have placed it in the blood, bones, bowels, brain, heart, or liver. It has been called by many names, including a fiery or smoky vapor, a shade, a collection of atoms, or a vital spark (Knox, 1989).

The definition of soul extends the idea of a central or integral part of something (a vital core) to include the faculties of thought, action, and emotion. For

the Greeks, the mind or reason was the highest part of the soul (Parkinson, 1988). Thus, soul has been identified with the mind, consciousness, and personality (May, 1940). The soul is conceptualized as an immaterial entity distinguished from but temporally coexistent with the body. The nature of the soul, whether it is material or non-material, has been debated for centuries.

All those who have tried to define spirit or soul have found it a difficult task. The soul is an elusive quality, one that is known more through experience and which loses something when translated into language. Moore (1992), a psychotherapist who draws from Jung's work, writes in the introduction to his book, Care of the Soul, "It is impossible to define precisely what the soul is. Definition is an intellectual enterprise anyway; the soul prefers to imagine." He believes that the soul is very much bound to life and revealed in attachment, love, community, as well as in inner communing and intimacy. Tradition, he says, tells us that the soul lies between understanding and unconsciousness, but that it needs an articulated world-view, a system of values, and a sense of relationship to the whole. It must also speak to immortality and death.

Jung (1933) writes that until the second half of the nineteenth century, the soul was universally believed to be a substance that had independent existence. After this time, psychology accepted the ideas and methods of scientific materialism. For this way of thinking, unless something could be visualized or touched it could not be real, scientific, or true. Consequently, Jung believed that psychology developed a "psychology without the soul" (p. 173).

Although Jung credits scientific empiricism with psychology's loss of interest in the soul, it is interesting to note that scientists, particularly physicists, are currently exploring metaphysical concepts in relationship to the material nature of the world (Bohm, 1980; Penrose, 1989). In fact, one of the great scientists of our time, Albert Einstein, believed that everyone who was seriously involved in scientific pursuits would become convinced that a spirit was evident within the laws of the universe. For science to be able to deal with the concepts of spirit, mind, and consciousness, a new theory may be needed (Penrose, 1989). Penrose, a mathematician, writing about computers, minds, and the laws of physics, states that the phenomenon of consciousness cannot be understood with our present theories. Similar to the inability of classical physics to describe certain aspects of the world which gave rise to quantum theory, present attempts to know the phenomenon of the spirit may give rise to new theories.

If the spirit cannot be defined, examined under a microscope, or its existence proved through philosophic argument, how can the spirit be known? Historically, it has been known through descriptions by those who have experienced it. The commonalities of these experiences have provided us with the definitions of spirit given above. Spiritual experiences have reassuring similarities across cultures and across the ages: that there is a transcendent order that will, if we allow it, guide and support us (Cunningham, 1992). Cunningham, a psychobiologist who writes frequently about the application of the spiritual to healing in his work with persons with cancer, emphasizes that the spirit is a dimension, not a thing, and that it is

known directly through intuition rather than through reason. Similar to Bohm's thinking about the implicate or unfolding nature of the universe, Cunningham suggests that spirit, like mind, is an informational concept that describes the pattern or organization of the cosmos as a whole. Bohm (1980) states that it may be this information, enfolded in brain cells, which enters consciousness. Mind, itself, is an informational concept, a description of the pattern of organized matter. In Cunningham's hierarchical model of human structures and their information correlates, spirit is incorporated into the level of the cosmos. While this model may not be "true," it represents the connections that many people experience between the cosmos and the self.

Although the spirit is considered a basic element of all traditional religions (Isherwood, 1971), it is conceptualized differently by Eastern and Western philosophies. Klivington (1992), a scientist, compared Western and Eastern ideas of spirit as he sought to define and clarify the ideas of spirit, mind, and brain for other scientists. He states that Western thinkers view the spirit more in a hierarchical relationship with the body, brain, and mind. In this view, the spirit is seen as an emergent property of the mind. Eastern thinkers, on the other hand, do not separate the physical, psychological, and spiritual worlds and consider the life of the inner spirit available to everyone (Barbour, 1990). Hinduism, for example, affirms the essential oneness of the human soul with God/cosmic spirit. In this belief God is not "above" or transcendent to humans or the material universe. Instead, God is present (immanent) in creation (Fisher & Luyster, 1991). The soul/spirit in Western thought

is considered superior to body/matter; Eastern thought views both of these dimensions as equal and inseparable (Kitagawa, 1987).

The concept of soul may be more difficult to accept for Western thinkers. A young Jewish woman, Etty Hillesum, whose diaries document her spiritual development during the war years in occupied Amsterdam, touched on the differences between the Western and Eastern concepts of the soul. The soul, she writes, "is that part of man that he is least aware of, particularly the West European, for I think that orientals 'live' their souls much more fully. We Westerners do not really know what to do with them; indeed we are ashamed of our souls as if they were something immoral" (1981, p. 240).

Griffiths, a Catholic monk who has lived in an Indian Hindu community, views the spirit as a means to knowledge of both the self and the divine mystery beyond the self. Through his writings, he has tried to unite Eastern and Western religious thinking about the spirit. Griffiths tries to articulate a framework based on a universal wisdom lost to the West with the rise of materialism. This universal thought originated in ancient times in India, China, the Arab world, and in Christianity, but was superseded by the dualistic concepts of Greek philosophy. Thus, the three major categories of world religions, (1) Judaism, Christianity, Islam; (2) Hinduism and Buddhism; and (3) Confucianism and Taoism, all have their roots in Eastern thought (Paden, 1992). Fisher and Luyster (1991) see contemporary western science beginning to return to the earlier concept of the interrelatedness of life in which the spiritual was a natural part of this wholeness.

Another way of thinking about the spirit, which is common to both Eastern and Western schools of thought, is to identify it with energy. Scientists are currently exploring the electromagnetic fields produced by energy released in the body. Klivington (1992) states that mind, often referred to as consciousness, may be a transducer of energy between the electromechanical energy of the brain and the energy of the spirit.

If the spirit is energy, it may be considered matter. Generally, though, spirit has been considered immaterial and inaccessible to sense perception. Sloan (1992), in his discussion of spirit in relationship to material and immaterial phenomena, compared the spirit to other immaterial aspects of life. The qualities of experience such as color, scent, and sound come to our awareness through sense experience, but the full experience of these, like spirit, also includes feelings and meanings. Similar to the qualities of ideas, concepts, meaning, intelligibility, thinking, and thought; spirit is conveyed in thinking as well as in feelings, relationships, aesthetic experiences, language and story.

## Studying Spiritual Experience

Although theologians and philosophers have written extensively about spiritual matters, their knowledge has not been built on research. The preponderance of empirical studies of spiritual experience have been done in psychology. Psychology has explored religious behavior using both qualitative and quantitative research methods. Religion has been and still is the predominant term used in psychology to identify a person's beliefs in and behavior toward a personal God. More current

definitions in the psychology literature often include existential beliefs in addition to religious behaviors. Other disciplines have also extended the definition of spirituality to include other elements of the transcendent experience in addition to specific religious beliefs and practices.

William James' Varieties of Religious Experience (1902/1961) is considered by Edie (1987) to be the first attempt to describe religious experience in an experiential sense. The book is based on the Gifford Lectures James gave in Scotland in 1901-2. For these lectures he systematically compiled and analyzed a variety of materials to show the essential structures of religious experience. Although this work is often criticized for its focus on the more extreme varieties of experience, it uniquely allowed the benefits of religious experience to be left to the perception of the followers rather than to the judgment of an outside observer. It was a qualitative study, using case studies and literature of historical figures to convey the essence of the experience in a person's own words. James was most interested in the meaning that these experiences had for people.

Although James did not have access to modern theories of personality, his ideas were similar to those of contemporary psychologists. He attributed religious development to physical needs, temperament and mental capacity, psychogenic interests and values, pursuit of rational explanation, and response to surrounding culture (Allport, 1950). James considered the writing of the lectures a religious act and an opportunity to legitimate religious faith (Wulff, 1991). One of the major themes of James' work was the differentiation of two types of temperamental

predispositions which perceive the world in different ways. Labeled the "healthy-minded" and the "sick soul," the former see everything in life as good, while the latter acknowledge and suffer for the evil in the world but find joy because of the immortal significance they attribute to it. Some of the criticisms of James' work are that he neglected normal experience, excluded institutional and historical factors, overestimated the role of feeling, and overemphasized pathology (Wulff, 1991). Despite these criticisms, Varieties has become a classic and a necessary starting point for other researchers who plan to study religious experience.

Following James' study, behaviorism was embraced by psychology, and religious experience was not studied seriously until mid-century, The majority of studies in the intervening years focused on religious behavior, such as church attendance, rather than on subjective religious experience (Bergin, 1983). While behaviorism predominated in the early part of this century in the study of religion, in the 1950s the concept of religion was put back within the broader framework of holistic personal experience (Brown, 1985).

Before proceeding with the discussion of the development of research on the spiritual dimension, it is important to note that religious experience has been viewed from two opposing directions. Researchers have either been religiously committed themselves and approached the study in a positive, health promoting light or have been non-believers who viewed religion from a negative, pathological stance. In a review of the early researchers in the psychology of religion (Beit-Hallahmi, 1985), it

is possible to see how personal beliefs and attitudes toward religion influenced theory development.

Freud, an avowed atheist, saw religion as little more than a neurosis, a projection of a child's relationship with his or her parents (Fisher & Luyster, 1991). He also explained religion in sexual terms (Eerdman, 1982; Jung, 1933). In his book The Future of an Illusion (1927), Freud considered religion a form of wish fulfillment, a desire to be rescued from helplessness.

Fromm, like Freud, was a Jewish psychoanalyst who early in his life gave up all religious practice. However, he continued to be influenced by the humanistic principles and values of the Jewish scriptions. He came to define religion as "any system of thought and action shared by a group" (1950, p. 21) that provides meaning and something to worship. Humanistic religion emphasizes the individual's strengths of thinking and feeling rather than relying on some authority (Wulff, 1991). Fromm believed that a humanistic, religious attitude of concern for the soul and the powers of love and reason were common to the teachings of the founders of all the great religions (Allen & Bachelder, 1985). In his writings about psychoanalysis and religion, Fromm (1950) identified the elements of religious experience as a concern with the fulfillment of the task which life sets before us, and an attitude of oneness with self, others, and the universe.

Allport (1950), building on the work of James, described the religious development in the mature adult in light of personality theories. Countering the prevalent negative attitude by psychoanalysts toward religion, Allport asserted that

personal religious development could continue throughout a lifetime toward achievement of a well-integrated personality. Religion, he stated, develops through a combination of a person's needs, cognition, values, and mean-seeking, and also as a social response. Allport suggested that the mature individual who is not disposed to developing religiously would instead develop a philosophy of life. This philosophy, or religion, would serve as an integrative agent for the personality thus playing a key role in health. Allport is well known for distinguishing between the immature and mature religious person; in his later work, he used the terms extrinsic and intrinsic rather than immature and mature. A person described as intrinsically religious would "live" their religion, while a person with an extrinsic religious orientation would tend to use religion as a means rather than an end in itself (Allport & Ross, 1967). This distinction between intrinsic and extrinsic religiosity has helped to explain apparently inconsistent findings in many studies of religious experience (Gartner, Larson, & Allen, 1991).

In a 1958 symposium, members of the disciplines of psychology and religion concluded that it was time to study the functioning of religion "in both its healthy and pathological manifestations" (Feifel, 1958, p. 565). Another change in the research approach was to broaden the definition of religion to include not only institutional membership and behavior but also individual religious experience.

Hardy's (1979) research on religious experience was motivated by James' work and Maslow's study of peak experiences among self-actualized adults (1964). It consisted of an analysis of 4,000 written accounts of religious experience. Hardy

pointed out that research had neglected to study religious feeling systematically. His study led to a classification of religious experience. These various types of spiritual awareness were described as: sensory or quasi-sensory experiences: visual, auditory, touch, smell; extra-sensory perception; dream experiences; behavioral changes; cognitive or affective elements; how the experiences developed; dynamic patterns in experience; and the antecedents and consequences of experience. He concluded that the most characteristic feature of a religious experience was the feeling of transcendental reality (i.e., that there is a spiritual reality that appears to be beyond the conscious self with which a person can have communion in one way or another).

The work of Batson and Ventis (1982) was an attempt to develop a social psychology of religion, and focused on the effects of religion on a person's life. Like many psychologists interested in researching religious experience, they come from a Western religious (Christian) background. As social psychologists they were also interested in how the social environment affects an individual's religious experience. Batson and Ventis were particularly concerned about distinguishing between the mature (flexible) and immature (rigid) personalities of the intrinsically religious person. They identified three types of religious orientation known as external, internal, and interactional. The religious behavior of a person with an external orientation is primarily motivated by the social expectations and rewards of personal religion. A person with an internal orientation finds that religion meets internal needs for security, strength, and direction. An interactional orientation is characterized by a person who remains open to new religious ideas and continues to search for answers.

The hallmark of a mature religious orientation would be a person who remains reflective and critical rather than rigid and unquestioning. Current research has identified the interactional orientation primarily in adolescents.

Fowler's (1981) qualitative research on faith development consisted of interviews with hundreds of men, women, and children of all ages who were asked to describe their religious experiences. The data formed the basis of his theory of faith development. This theory is a developmental stage theory which is congruent with the psychological developmental theories of Piaget (cognitive), Erikson (psychologic), and Kohlberg (moral). In Fowler's theory, faith is seen as a dynamic, patterned process providing meaning to life. Faith is experienced as a natural part of living and is not necessarily religious; it is a response to the transcendent. Similar to Erikson and Piaget, Fowler focused on health and looked for patterns in behavior.

Characteristic of the developmental theories upon which Fowler based his theory, the faith stages build on each other; one stage must be accomplished before moving onto the next. This movement begins when "problems" cannot be solved with the methods available in the present stage. These structures take shape through a process of sequentially forming concepts, images, and words. Each of these processes are configured in increasingly complex ways as one moves through the various stages.

Briefly, the following are descriptions of each stage:

(1) Intuitive Projective: faith is made up of images rather than by logical thinking.

(2) Mythic-Literal: the world is ordered through logical thinking.

(3) Synthetic-Conventional: a variety of self-images are merged through cognition to form a coherent identity.

(4) Individuative-Reflective: the ability to critically reflect on one's beliefs and values.

(5) Conjunctive: an appreciation of a variety of religious traditions and the acceptance of multiple interpretations of reality.

(6) Universalizing Faith: a feeling of oneness with the power of being.

More recently, Fowler has presented the stages in non-hierarchical terms; instead, he imagines them as a spiraling process which takes a person more deeply into the mystery of life (Brennan, 1990). One inadequacy that Fowler saw in his theory was the limited understanding of the relationships between faith's structure and content. To learn about the interplay between these two components, Fowler urged that a person's unique faith experiences be investigated. Another criticism of Fowler's theory is its emphasis on the cognitive aspects of religious experience while neglecting the emotional content. "Staging" a person's faith is not meant to judge the worth of the person; it serves as a way to better understand the interrelated patterns of faith.

## Spirituality and Health

There is currently no single recognized definition of spiritual health (Bensley, 1991). Several researchers are currently working on the concept of spiritual well-being. Since the 1970's, Moberg, a sociologist, has been refining this concept, and

more recently Paloutizian and Ellison (1982) have built on Moberg's ideas. Although the concept of spiritual well-being overlaps with religiosity, these terms are not synonymous. Spiritual well-being includes both spiritual and existential components. These two components are based on Moberg's conception of religion's two basic orientations. One orientation is the vertical (to God; conceptualized primarily in terms of a Christian framework), and the other is the horizontal (reaching out to others; a sense of life purpose and satisfaction).

The current interest in studying spiritual well-being and other aspects of spirituality is multidisciplinary. New research tools are being developed and tested to measure these concepts. However, the differences in conceptual definitions have made it difficult to compare results across studies. The majority of the research in spirituality has been done using quantitative methods. Only a few qualitative studies have been done in this area. Although descriptive studies are often discredited because of their "subjective" nature, Vandenberg (1991) has pointed out that there are limitations to the quantitative approach to studying religious phenomena. He thinks it is more appropriate to acknowledge the limited ability of science and technology to answer questions related to meaning, value, and being, rather than to criticize religious thinking for its non-logical characteristics.

Current research in spirituality using qualitative methods is an attempt to develop a theoretical basis for future research in this area. Two recent qualitative studies done by nurses (Barker, 1989; Burkhardt, 1991) explored the experiences of spirituality among Appalachian women. In both studies, Appalachian women's

experience of spirituality consisted of meaningful harmonious relationships with self, others, nature, and God or some Higher Power. The findings of these two studies were consistent with the current literature on women and the meaning they find in life through relationships (Anderson & Hopkins, 1991; Gilligan, 1982; Ochs, 1983; Randour, 1987). Research has primarily investigated the relationships between religious behaviors and aspects of mental and physical health. Bergin's (1983) meta-analysis of studies on religiosity and mental health showed that religion was significantly and positively related to subjective well-being in adults, but that it accounted for only 2-6% of the variance in well-being. A more recent review of 200 empirical studies by Gartner, Larson, and Allen (1991) led to the conclusion that study results on the relationship between religion and well-being have been mixed, although the positive relationship has a slight edge. It appears that the determination of a clearer relationship between spirituality and health will depend upon the development of conceptual clarity.

As discussed earlier, psychologists have both criticized and praised religion for its effect on a person's psychological health, with each one's viewpoint varying with individual religious perspectives. Those psychologists favoring the benefits of religion have described its health-promoting components. Frequently cited is its role in personality integration, harmony, and a sense of meaning. These psychologists state that a critical part of the healthy personality includes having purpose and meaning in life (Frankl, 1946/1959; Fromm, 1950; Jourard, 1974; May, 1940).

Meaningfulness is also considered the most crucial element of the three dimensions of Antonovsky's (1987) health model.

Bohm (1980), a physicist who writes on the wholeness of the universe and its implications for human life, speaks convincingly about human integrality. Bohm contrasts Western and Eastern ideas of health. While the West measures health according to external standards, the East views the immeasurable (internal) as the primary reality. Harmony, or inter-connectedness, is also a frequent theme in Eastern thought. In a nursing study by Hungelmann, Kenkel-Rossi, Klassen, and Stollenwerk (1985), who used a grounded theory approach, a basic social process called "harmonious interconnectedness" was identified as the indicator of spiritual well-being.

The studies of spirituality among Appalachian women mentioned earlier (Barker, 1989; Burkhardt, 1991) also defined spirituality as a force in these women's lives that related to harmony, interconnectedness, and meaning. The definitions of spirituality that emerged from these two studies follow:

> The unifying force that shapes and gives meaning to the pattern of one's self becoming. This force is expressed in one's being, in one's knowing, and in one's doing, and is experienced within the context of caring connections with Self, Others, Nature, and God or Higher Power. (Burkhardt, 1991, p.176)

> The force related to harmony, interconnectedness, and meaning. (Barker, p. 125)

Although there is no conclusive evidence that spirituality is related to well-being, spirituality is consistently associated with the ideas of integration, harmony, and a sense of meaning.

## Nursing Theories and Spirituality

Nursing's historical interest in the spiritual domain can be traced back to not only the religious orders from which nursing began, but also to the founder of modern nursing, Florence Nightingale. Before discussing the nursing theories which address spirituality, the role that spirituality played in Nightingale's life and thinking about nursing will be considered.

Nightingale, a deeply spiritual person, viewed personal spirituality as a necessary element in nursing's work. These ideas are seen in her Notes On Nursing (1860/1946), written to the non-professional nurse, the woman who cared for others within her home:

> And remember every nurse should be...strictly sober and honest; but more than this, she must be a religious and devoted woman; she must have a respect for her own calling, because God's precious gift of life is often literally placed in her hands...(pp. 125-6).

Although she rejected organized religion as a basis of nursing practice, she recognizes that meeting the needs of the spirit was critical to health (Maggs, 1988).

In 1837, at age 16, Florence felt called to God's service (Brown, 1988). Due to family opposition, it wasn't until her 30s that Florence was able to act on this call by serving others as a nurse. Throughout her nursing career, Florence considered acting on her faith more important than attending to doctrine (Cook, 1942). Although her early ties were with the Anglican Church of England, she read broadly in the literature of Catholicism and mysticism. She was also influenced by her father's interest in Unitarianism. Homebound in her later life due to ill health, she was not

formally tied to any specific religion, but discoursed with persons who held a variety of religious viewpoints (Cook, 1942).

> At one and the same time mystic and practical administrator, Miss Nightingale had two soul-sides; but each was a reflection of the other. Her religion was her work; and her work was her religion. She read the Mystics, not to lull her active faculties into contemplative ecstasy, but to consecrate them to more perfect service. (Cook, 1942, pp. 240-1).

It is clear from Nightingale's life and writings that she considered a religious faith important to nursing care, with the emphasis not on specific religious beliefs but on a caring based on an appreciation and respect for God's gracious gift of life.

Although having a broad knowledge of a variety of religious beliefs led her to acknowledge the importance of faith to daily life, Wiederquist (1992) suggests that Nightingale struggled with her spiritual beliefs throughout her life. According to Wiederquist, the core of Nightingale's spiritual distress was her belief in the Unitarian doctrine of salvation. Salvation, for those adhering to Unitarianism, could be obtained only by character perfection. Unable to realize this perfection, Nightingale did not experience a sense of forgiveness or salvation. When she was not able to perfect or "save" the world, despite her herculean efforts at reform, she considered it a personal failure. This example from Nightingale's life shows that religious beliefs can also be a source of distress as well as a source of well-being.

Travelbee's theory (1971) is the only nursing theory in which the spiritual domain is the major focus of the theory. The theory's basic assumption is that "illness and suffering are spiritual encounters as well as emotional-physical experiences" (p. 61). Travelbee presents specific nursing interventions that may be

used to assist persons to find meaning in their illness. The nursing role provides the opportunity for nurses to relate at a personal level with patients, and it is within this relationship that interventions such as Travelbee's can be used. Travelbee states that the basic spiritual problem in illness is an inability to accept suffering as a reality of being human. The most effective interventions, according to Travelbee, include: addressing this problem in an indirect way through parables, putting the problem in the third person, and sharing a similar personal experience. Travelbee also identifies the behaviors that are typically present when a patient is struggling to find meaning. These are very similar to some of the current defining characteristics of the nursing diagnosis Spiritual Distress (e.g., anger, self-pity, depression, fear, and anxiety).

Several other nursing theorists include the spiritual in their theories in various ways. For Neuman (1982), the spiritual is one of five core variables of the client system. Watson (1985/1988) incorporates the spiritual in her ideas about caring, the nature of the person, and the goals of nursing. Paterson and Zderad (1976/1988) frame an understanding of human nature within the conflict between the spiritual and material aspects of the self. With the increased interest in spirituality by nursing, some theorists are including a spiritual aspect in their theories as they revise them, such as Roy did in her Adaptation Model (1988) by incorporating the spiritual into the self concept mode. Although Newman (1986) does not speak of spirituality <u>per se</u>, her theory of <u>Health as Expanding Consciousness</u> is similar to other models of spiritual development in this chapter. The highest state of consciousness within her model is an absolute consciousness or unconditional love, terms often used to refer to God.

## Meaning

Meaning, as discussed in previous sections of this chapter, has been consistently associated with spirituality. The search for meaning is a search for understanding the world about us and is a significant and universal human motive (Frankl, 1978). Comparing persons of ancient and modern times, Jung (1933) explained that both would give similar explanations for natural occurrences. The only difference between the two would be the assumptions on which the explanations were based. While in ancient times a person would relate to an event to what we call the supernatural, a person today would attribute it to natural causes. Another difference between past and current beliefs about the world is that, in early times, the psychic and objective were one. Today's emphasis on natural causation distinguishes between what is subjective and psychic and that which is objective and "natural." In the past, disease was assumed to be caused by spirits or witchcraft, whereas today's conclusion is that illness has a natural cause. Jung attributes our reluctance to acknowledge unseen forces in life to our hard work to gain rational consciousness. To admit once again the influence of such forces would seem to be taking a step backwards in time.

Another purpose that meaning serves is to provide a way to deal with chance occurrences in nature. Throughout history, humans have always viewed non-predictability, i.e., chance, as threatening. In the past, chance was explained by a belief in unseen forces; today, it remains simply chance. An advantage to believing in unseen forces was that it allowed measures to be taken to placate these forces.

While people today may have a different interpretation of natural events than did their ancestors, they still have a need to interpret, to explain, and to provide a framework of meaning around events in their lives. Finding meaning in life is not an easy task. Jung states that many of his patients came to him for help because they could find no meaning in life and part of his therapy was helping people find meaning by getting in touch with their inner nature. When they were able to do this, Jung believed it was the spirit within the psyche that was being manifest, a collective unconscious or universal spirit that was accessible through the individual psyche.

The search for meaning and purpose in life has been the focus of various psychological theories and therapies. Phenomenologists, especially Husserl, are credited with inspiring some of these theories and therapies through their use of the phenomenological method to study the nature of human existence (Denne & Thompson, 1991). Phenomenology, the study of things as they appear in human experience, seeks an understanding of human consciousness and experience. More recently, Merleau-Ponty (1962), a French philosopher within the existential phenomenological movement, has emphasized that the human being is "condemned to meaning." Both Husserl and Merleau-Ponty emphasized the critical role that meaning plays in the construction of reality. Their viewpoint was that "reality" was constructed by the meaning attached to experience (Batson & Ventis, 1982).

Having meaning is often tied to having a purpose for one's life. Heidegger (1927/1962), a student of Husserl's, who was mentioned earlier, states that this is because having meaning is future-oriented, in that it seeks fulfillment of future goals.

The existentialists, philosophers who see the reality of human life as a combination of behavior and experience (objective and subjective), view meanings as unique individual constructions rather than social creations.

Frankl (1946/1959), like Jung, whose therapeutic technique (logotherapy) reflects religious beliefs, argues that human discover meanings that exist independent of and prior to the thinking of individuals and societies. Using this transcendent approach, he encouraged clients to incorporate this transcendent meaning in their attitude and behavior to give meaning to their own life circumstances. Frankl's therapy is based on his survival of imprisonment in a World War II concentration camp. He attributes survival, his own and others', to maintaining a sense of meaning, purpose, and hope in the direst of circumstances.

Denne and Thompson (1991) conclude from their review of the literature on meaning that theorists differ over "whether meaning and purpose in life is conceptual, emotional, or goal-oriented; whether it needs to be discovered or created by the human mind; and whether it needs to be sought in the self or the world" (p. 112). These authors also report that research has found that interpersonal relationships are the most frequently mentioned source of meaning for all age groups. Other important sources of meaning are service toward others, living true to one's beliefs, and personal growth that includes goal attainment.

Denne and Thompson found little empirical work on existential meaning. Their phenomenological study of the experience of transition from meaninglessness to meaning and purpose in life concluded that there are two major sorts of meaning.

One type of meaning is ego-centered and results from doing something in life. The other type seems to be more fundamental and results from finding joy in the processes of life itself. This latter type is possible when the mind, body, and emotions are integrated into a higher-order unity. These authors state that there is a need for further study into the nature of both the meaning and purpose of life as each is experienced as either/or thoughts and emotional experiences.

In a phenomenological nursing study which explored the meaningful life experiences of the elderly (Trice, 1990), findings suggest a connection between the spiritual and meaning in life. For these elderly individuals (N=11), a meaningful life experience involved: a concern for others, a perception of being needed by others, an emotional feeling of positiveness, and an action. Eight of the research participants indicated that God or a higher being or church were either a part of, or directed or provided the context for meaningful experiences.

Baumeister (1991) states that meaning seems to serve two basic functions in people's lives. It allows them to predict events by seeing patterns in the environment and it enables them to control themselves. This control includes regulating one's internal emotional states, facilitating decision making, and guiding actions. Antonovsky (1987) views meaning as the key component of his health model. He describes this as a sense of meaningfulness in a situation which serves to motivate and strengthen the other core components of comprehensibility and manageability. From his description of the meaningfulness component, Antonovsky seems to be speaking of meaning and purpose in life as that which makes life worth living.

## Spiritual Distress

From all the literature reviewed, it appears that developing meaning in life is essential to living and is related to the other functions of spirituality; harmony, integrality, and connectedness. When meaning temporarily eludes us, what is the result? Could this be called existential or spiritual distress? How might it be recognized? What patterns of thought, behavior, and emotion would be present? These are some of the questions that this study is concerned about. Other scholars and researchers have also searched for answers to these questions.

Kierkegaard (1962) wrote that a lack of meaning or purpose is a result of becoming disconnected from personal values and will often appear as a spiritual crisis reflected in a feeling of dread or boredom. O'Brien (1982) developed seven nursing diagnoses related to spiritual integrity from data she gathered for developing a spiritual assessment guide. Participants in her study were chronically ill hemodialysis clients. These seven diagnoses are common human experiences and are similar to the current list of defining characteristics of the diagnosis Spiritual Distress. The diagnoses and the aspects of spirituality they reference are:

1. spiritual pain (altered transcendent relationships, values, and beliefs)
2. spiritual alienation (loneliness)
3. spiritual anxiety (fear of the unknown)
4. spiritual guilt (expressions of regret)
5. spiritual anger (toward God or an undefinable source)
6. spiritual loss (loss of meaning and purpose)

7. spiritual despair (loss of hope)

Dugan (1987/88), in his essay series on the art of caring in nursing, addressed the role that the human spirit plays in stress management for both the nurse and the patient. He states that the following three types of losses are indicators of spiritual distress: (1) loss of meaning, (2) loss of hope, and (3) loss of human contact (isolation). These experiences of spiritual distress may then be manifested in the non-verbal and symbolic language of emotions, intuitions, and the images of dream, myth, song, and ritual, as well as physically in somatic symptoms.

Ochs (1983), in her book Women and Spirituality, defines spirituality as a "coming into relationship with reality." It is a process that includes motion, change, and growth. This process may involve letting go of a certain way of being and of experiencing the confusing nowhere-in-between before forming a new relationship with reality. The process is similar to that described by Bridges (1980) during transitional periods in life. Current research in adult development views transition as a natural process of disorientation and reorientation toward personal growth (Denne & Thompson, 1991). The process begins when events disengage us from familiar contexts. The literature suggested various dimensions to the experience of spiritual distress and these ideas provided impetus for the development of the present study. Because the human experience of spiritual distress has not yet been studied in nursing using qualitative methods, there is still a need to explore the meaning of this phenomenon. This study builds on previous nursing studies related to the diagnosis of

Spiritual Distress and spirituality. Specifically, this study seeks to further clarify the key defining characteristics of spiritual distress.

## SUMMARY

The terms spirit and soul have been defined as essential aspects of human life. The experience of spirituality is essentially an inner, subjective, and sometimes unconscious process. Spirituality provides meaning and purpose to life. When this domain is disrupted, a person can be said to be in spiritual distress. The manifestations of spiritual distress may be subtle, reflected primarily in nonverbal behavior. Spiritual distress also may be expressed in verbal statements of anger, loss of meaning or hope, and the need to reconnect to self, others, the environment, or God. Spiritual distress is clearly a legitimate concern of nurses in all areas of clinical practice.

# CHAPTER III

## METHODOLOGY

### INTRODUCTION

In this study, the methodology of existential-phenomenology was used to yield a description of the experience of spiritual distress, a phenomenon characterized by concern about the meaning of life, death, and/or beliefs. This research method has evolved primarily from Gestalt psychology and clinical practice in psychology and involves a thematic analysis of dialogues between the researcher and a relatively small set of research participants (Thompson, Locander, & Pollio, 1989). The purpose of this type of research is to provide a clear, precise, and systematic description of the constituent meaning of some domain of human life (Polkinghorne, 1989).

Ten adults (five men and five women) were asked to participate in the present project. Each participant was interviewed, and the resulting audio recorded interviews were transcribed verbatim (See Appendices E and F for two complete transcripts). These transcripts were analyzed by the researcher with the assistance of a phenomenological research group. The present chapter includes a description of the study design, ethical measures, and data analysis. Additionally, issues of reliability and validity in qualitative research will be discussed.

### PARTICIPANTS

Phenomenology uses theoretical sampling. This involves finding research participants who have experienced the phenomenon under consideration. For this study, participants were sought who:

1. Had experienced spiritual distress (i.e., being concerned about the meaning of life, death, and/or beliefs).
2. Were able and willing to articulate the experience.
3. Felt free enough to express inner feelings.
4. Were adults (persons older than age 18) and not nurses.

Persons 18 years old or younger were not used for this study because it was thought that the majority of this group would be less likely than adults to have an established philosophy of life or belief system or have experienced events in their life that caused them to be concerned about the meaning of life, death, and/or their beliefs. Nurses were not used in this study because of the likelihood that their familiarity with the nursing diagnosis of Spiritual Distress might bias their description of personal experiences related to this domain. Both men and women were asked to take part in this study so that any differences between genders in the experiencing of spiritual distress might be understood.

Sample size for this study was ten: five women and five men. Qualitative samples are relatively small in comparison to quantitative samples because the volume of data to analyze quickly becomes difficult to manage. Ten persons from the researcher's church, neighborhood, and community were asked to take part in this study. One person declined who had recently been diagnosed with cancer and was undergoing chemotherapy. Another person was asked to take part in the study to replace this person. The researcher had known nine of the participants for three years. The tenth participant and the researcher had talked only during brief periods

for several months prior to the study. Over time, the researcher became aware of events in these persons' lives that suggested that they might have experienced spiritual distress. Because a trusting relationship had been established with these people, it was thought that they might be: (1) more likely to agree to take part in the study and (2) more willing to share their thoughts and feelings about spiritual distress at a deeper level than they would with a stranger.

The following demographic data were collected: (1) gender, (2) age, (3) marital status, (4) education, (5) occupation, (6) religious affiliation, (7) importance of beliefs, and (8) perception of current health status (See Demographic Data Form in Appendix D). Demographic characteristics of the subjects are summarized in Table 1. With the exception of one person, all participants were highly educated, with most having earned graduate degrees. All had either a current affiliation or personal identification with a particular religious denomination or religion. All also perceived themselves to be in good health and all reported that their beliefs were very important to them.

## Ethical Measures

Approval was obtained prior to beginning this study form the College of Nursing human subjects review committee and the University of Tennessee Institutional Review Board. Before being interviewed, each participant was informed (orally and in written form) of the purpose of the study and informed consent was obtained for the interview and audiotaping. Each participant received a copy of the information and consent form. Completed forms were stored in a locked file at the researcher's

**Table 1.** Demographic Characteristics of the Ten Participants

| | Number of Participants |
|---|---|
| Gender | |
| Male | 5 |
| Female | 5 |
| Age | |
| 33 (Male) | 1 |
| 41 (Female) | 1 |
| 46 (Male) | 1 |
| 57 (Male, Female) | 2 |
| 61 (Female) | 2 |
| 64 (Male) | 2 |
| 66 (Female) | 1 |
| Marital Status | |
| Married | 8 |
| Divorced | 1 |
| Widowed | 1 |
| Education | |
| 10th grade | 1 |
| Bachelor's Degree | 1 |
| Master's Degree | 6 |
| Doctoral Degree | 2 |
| Occupation | |
| Minister | 1 |
| Librarian | 1 |
| Engineer | 1 |
| Accountant | 1 |
| Retired Teacher | 2 |
| Research Scientist | 1 |
| Landscape Architect | 1 |
| Retired Medical Technologist | 1 |
| Hairdresser | 1 |
| Religious Affiliation | |
| Presbyterian | 8 |
| Baptist | 1 |
| Christian | 1 |

**Table 1. (continued)**

| | Number of Participants |
|---|---|
| Importance of Beliefs | |
| Crucial | 1 |
| Essential | 1 |
| Very very important | 1 |
| Very important | 5 |
| Important | 1 |
| Highly | 1 |
| Perception of Current Health Status | |
| Excellent | 2 |
| Great | 1 |
| Very Good | 1 |
| Good | 6 |

home. (See Appendix A for Information and Consent Form). All participants chose pseudonyms by which their interviews were to be identified. A brief second follow-up interview took place either in person or by phone. Subjects were informed that they were under no obligation to take part in the study and that they could withdraw at any time without penalty. There were no anticipated physical or psychological risks involved in participating in this study.

It was anticipated that participants might experience a variety of emotions during the interview, and this turned out to be the case. At the end of the interviews, however, all participants said that taking part in the study had been beneficial to them in various ways. Some of the benefits that were mentioned are: (1) they had learned new things about themselves, (2) they had been able to talk about many experiences at one time, giving them a broader view of their lives than they had had before, and (3) that by reflecting on these experiences, their experiences had been given a greater meaning in their lives. The researcher was prepared to refer participants to counseling professionals if their reactions to the interviews were beyond her professional nursing ability to handle; this did not become necessary.

Participants were identified on tape and in the transcriptions only by their pseudonyms and no actual names were used with the quoted material that appears in these chapters. Tapes were transcribed verbatim by, and will remain in the possession of, the researcher. The audiotapes were used only by the researcher for transcription purposes. Transcripts and audiotapes were stored in a locked file at the researcher's home and all audiotapes will be erased at the end of the study.

Confidentiality statements were signed by research group members taking part in the data analysis. (See Appendix C for Confidentiality Statement).

## Phenomenological Interview

The phenomenological interview focused directly on the research phenomenon. The interview was unstructured and used open-ended questions so that predetermined categories of interpretation would not be imposed. It is not unusual in phenomenological interviews that the meaning of the phenomenon changes during the interview itself. Both the interviewer and interviewee may gain new insights, meanings, and discover new relations during the interview. In other words, the meaning of an experience is continually in the process of being constructed during the interview. In this regard, I asked one man at the end of his interview if he could see the connections I could between the type of work he does and his view of the world. He replied, "I was interested in hearing your...you could explain the connections in the work I do and my thoughts about the earlier part of our conversation. It...in fact...had never occurred to me."

Research participants were interviewed individually for approximately one hour at a location of their choice. Five participants were interviewed in their homes, four in their church, and one at his place of employment. Participants were asked to tell about a time in their life when they experienced concern about the meaning of life, death, and/or beliefs. The term "spiritual distress" was not a part of the interview question, although it did appear on the Information and Consent Form. It was not a part of the question for two reasons: first, it was thought that since the term is not a

familiar one, research participants would have difficulty answering the question; secondly, it seemed more appropriate to let the diagnostic label emerge from the analysis of the transcripts rather than to impose it at the outset. Questions other than the main research question were asked only to seek clarification or elaboration of participant responses that seemed relevant to the phenomenon of spiritual distress. Phenomenological questions were asked that led toward themes but avoided leading to specific meanings of these themes (Kvale, 1983). All interviews were transcribed verbatim by the researcher and participants received a copy of their transcript. These copies were given to them to review for transcription accuracy and for them to keep. One man asked to have a computer disc copy of his interview so that he could "clean up" the incomplete sentences before giving copies to his children. He wanted to share his reflections on his life experiences and beliefs with his children.

## Analysis of Interview Content

The basic data of the present set of interviews consisted of ten transcribed interviews in which participants described a variety of times in their lives that they experienced being concerned about the meaning of life, death, and/or their beliefs. Basic to phenomenological analysis is the assumption that a person's experiences are organized in some way, and that the structure of this organization can be analyzed thematically. The "structure" of a phenomenon is assumed to be concerned with the common understanding that is present in diverse appearances of the phenomenon and which is disclosed in the form of meaning (Valle, King, & Halling, 1989).

Qualitative data analysis is a reduction process in the sense that the data are transformed in an attempt to yield their fundamental structures. Reduction can also be thought of as a condensation process in which data nonessential to the phenomenon of spiritual distress are removed. These repetitions or digressions are known as noise (Kvale, 1983). The nonreductive structures or themes that are disclosed through this process unite the unchanging elements of an experience into a whole (Polkinghorne, 1989).

The interpretive framework (Pollio, 1993) that was used in this study is atheoretical and descriptive (See Figure 1). Within this framework, experiential patterns were described as they emerged from the dialogic context (Thompson, Locander, & Pollio, 1989). Often these patterns are not revealed unless they are viewed within the context of the text. This is similar to the patterns of human experience which emerge only as they are "lived."

A hermeneutical approach was used to interpret participants' experiences when research protocols were read and discussed within the phenomenological research group. This approach emphasizes that each part of the text is to be understood in relationship to the whole (Pollio, 1993). Divergent interpretations given by each member of a hermeneutic research group during this analysis were critical to understanding the meaning of each interview. Other important considerations in this type of analysis are: (1) describing the phenomenon from the participant's perspective (Thompson, Locander, & Pollio, 1989) and (2) discussing the text in terms of patterns, figure/ground structures and unreflected experiencing of the text.

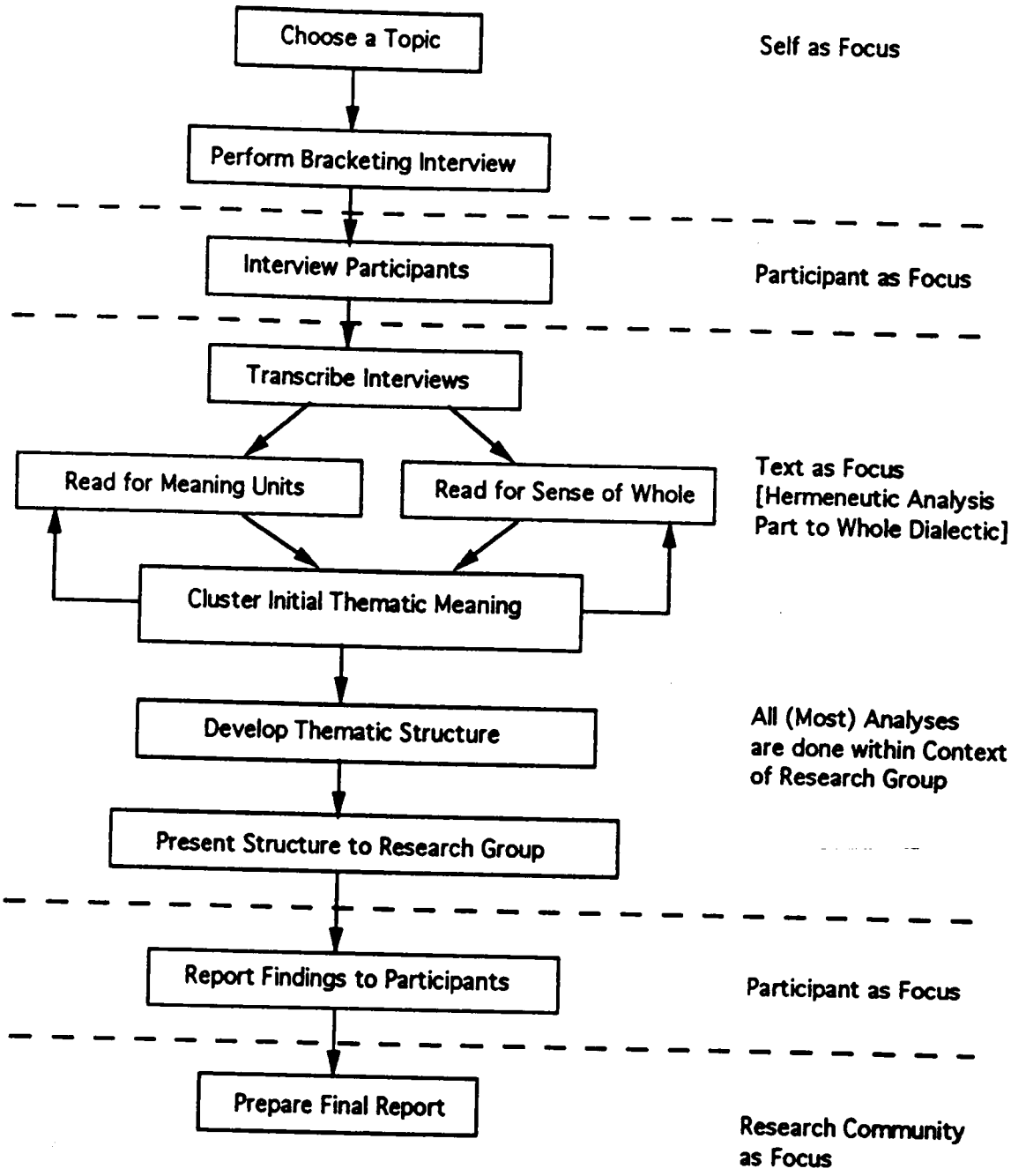



**Figure 1. Steps for Doing a Phenomenological Research Project**

In this study, the research group helped the researcher refine her style of phenomenological interviewing. The first two transcripts that were read within the research group setting were the first and second interviews of the study and during the course of dealing with this protocol, members of the research group suggested alternative questions that could have been used in the interview to allow the participant and not the researcher to clarify the meaning of a particular word or phrase. Members of the research group pointed out that the researcher was allowing the participant to deviate from talking about the phenomenon, and that she was often pursuing information not directly related to the phenomenon. The researcher used this advice in the remaining eight interviews. The last transcript read by the group was the seventh interview. Members commented on the researcher's improved interviewing style evident in this transcript.

***Bracketing***

Before proceeding with the present study, the researcher was interviewed by a fellow research group member using the same interview question used in the study. This was done to "bracket," or set aside, any preconceptions the researcher might have had about spiritual distress through an increased awareness of this experience. This type of interview represents an attempt to suspend or put aside one's preconceived ideas and biases regarding the meaning of the phenomenon (Valle, King & Halling, 1989) in order to remain open to new and unexpected aspects or meanings of the phenomena (Kvale, 1983).

The themes that emerged from the bracketing interview were similar to the categories that emerged from the complete set of ten interviews. These were: time, sudden or unexpected events, emotional responses, spiritual experience, questions/no answers, limit to knowing, change in thinking and acting, events fitting/not fitting within the natural order, gratefulness, personal response, acceptance, and wonder. Because of the importance of some of these categories to my own personal experience, it was evident in the first couple of interview protocols that I was attempting to have the participant focus on these categories more than on the research phenomenon. Thus, I had continually to be aware of bracketing throughout the ten interviews to keep from imposing personal interpretations onto the research data.

It is acknowledged by phenomenologists that bracketing is never complete, and must be an ongoing consideration throughout all interpretations of the text. The interpretation strives for consistency between the participant's world view and experience (Pollio, 1993). The two procedures suggested by Pollio (1993) to aid in successful bracketing were followed in this study. First, all interpretations used the participant's exact words, and two, some of the interpretation was conducted in a group setting. Critical questioning by members of the research group contributed to the adequacy of the description of each participant's experience. Adequacy of interpretation is also measured by the degree of support for each interpretation in the text and all interpretations were based on evidence directly from the text.

### *The Hermeneutic Circle*

Hermeneutics is defined as the science of understanding (Bouchard & Buerette, 1991). Historically, this process was often used by interpreters to understand the hidden meanings of religious texts, such as the Bible. Hermeneutic analysis seeks to understand the meaning of words through an analysis of text.

Under the influence of Heidegger and the phenomenological movement, hermeneutics became a central part of European philosophy in this century (Dreyfus, 1991). Applied to phenomenological interviews, hermeneutic analysis seeks an understanding of a reality that is not self-evident. This is done through a circular dialectic process called the hermeneutic circle (Bouchard & Guerette, 1991).

The hermeneutic circle corresponds to the Gestalt understanding of the relationship between the parts and the whole. During data analysis, the parts of the texts that are relative to the phenomenon are always interpreted in light of the whole text; therefore, the meaning of the part exists only within the context of the whole (Pollio, 1933). Reeder (1988) describes it this way:

> In addition, it is helpful for the interpreter to act like an artisan between the life of the languaged text and the life of the author; that is, in a back and forth motion, tacking like a sailor does a boat, toward the goal of understanding. Quite literally, the interpreter is to be suspended between the universal and particular aspects of the text (p. 202).

Other than this general dialectic between the part and the whole, there are no explicit rules for using this method. It is partially an intuitive process (Spiegelberg, 1985; Solomon, 1980), for which there are no rules and for which rational knowing is only part of the experience. Despite this, the logic of this method can be described

and may be said to involve three types of interpretation: group, idiographic, and nomothetic (Pollio, 1993). Group interpretation involves interactions between the interpretations of group members and the interpretations of the researcher which were made independent of the group. Idiographic interpretation is the identification of significant meanings, relations, and patterns within each interview. Nomothetic interpretation consists of naming the themes using participants' words from the protocols.

During group meetings the text was read aloud by group members. The group leader, an experienced phenomenologist, started and stopped this reading. The amount of text read and discussed at one time was based on the content of the text. A good stopping point was often when a topic changed within the text.

The discussion of a section of the text by group members focused on the meanings and relationships seen in the text. It is not necessary for the group to be involved in the interpretation of all the research transcripts. However, using the group at the beginning of text analysis was very helpful to the researcher to begin to organize and interpret the data. Later in the analysis process, the group was again involved in discussing and assisting the researcher to form and refine the thematic structure of the data. The thematic structuring involved setting forth tentative idiographic and nomothetic thematic descriptions.

Reading and rereading the texts both within the group as well as independently allowed the researcher to get a sense of the whole and to identify what are called meaning units. According to Lincoln and Guba (1985), a meaning unit is:

> ...the smallest piece of information about something that can stand by itself, that is, it must be interpretable in the absence of any additional information other than a broad understanding of the context in which the inquiry is carried out (p. 345).

These units are portions of the text which have a unitary character. This means that each unit yields an interpretation around a central idea. Patterns "emerge" through trying to understand the text from the participant's viewpoint; i.e., what is meant by "seeing" in existential-phenomenological terms. Reflecting on a previously unreflected experience reveals the pattern of the experience. To stay close to participant experience, meanings are expressed in words used by the participant rather than in abstract theoretical terms.

As a variety of similar meaning units clustered, a beginning thematic structure was formed and thematic descriptions were developed. Although generalizability is not the goal of analysis, interpretations were compared across interviews which allowed the experiential patterns to exhibit in diverse situations and highlighted the similarities between situations. This diversity may be present in as few as three to five interview transcripts (Pollio, 1993). In this study, experiential patterns became very evident after five interviews.

Pollio (1993) writes that the development of a thematic interpretation involves:

> ...a continuous process of going back and forth among various parts of the text in which earlier and later parts are continuously being rethematized in the light of new relations provided by an unfolding descriptive understanding of the text (p. 78).

The thematic structure consists of words and phrases that describe the relationship between meaning units. After doing this with the first interview, each new interview

was considered in this way, and the developing thematic structure was judged for its fit with the new data. The research group determined if these descriptions were supported by the data and if they related clearly to the participants' experiences. This process is similar to what is known as an external audit, a measure of the trustworthiness of the data, used by a variety of naturalistic researchers (Lincoln & Guba, 1987). In this study, however, this function was met within the group interpretative process rather than by an independent auditor external to the group. For example, the group questioned the representativeness of the Wondering Theme because two participants had said that this was not a part of their experience. The data were examined very closely to determine how these two participants' perspectives fit within the thematic structure. Their words were read and re-read to insure that this theme was appropriate; in the case of this theme it was decided that it was.

Although a hermeneutic circle literally has no end, the analyses came to an end when the patterns seen in the interviews made sense and a consistent unity of meaning was achieved across all of them (Kvale, 1983). A thematic structure was constructed which described experiential patterns and interrelationships among themes. The thematic structure is the goal of existential phenomenological interpretation (Pollio, 1993) and will be presented in the following chapter.

When the research group was satisfied that the thematic structure was an accurate representation of the phenomenon, a letter was mailed to each participant which included a description and drawing of the thematic structure (See Appendix G).

Participants were asked to compare the overall thematic structure with their own experiences as discussed in their interviews. Nine participants were contacted in person or by phone to discuss this thematic structure in relation to their own experiences. The researcher was unable to discuss the final thematic structure with one woman because she had not yet returned from her summer home. Eight of the participants were satisfied that the thematic structure represented their experiences. One man said that all but one thematic element represented his experience of distress. He said that the theme Something Beyond was not part of his experience of spiritual distress.

## Reliability and Validity

Reliability and validity issues are approached differently in qualitative research. The philosophy of existential-phenomenology guides the types of reliability and validity determination that are appropriate to this methodology (Reeder, 1988). The main concern in qualitative research is the accuracy and validity, or trustworthiness, of the data (Lincoln & Guba, 1985). The most important factor in achieving trustworthiness is the choice of a sound qualitative method and then its rigorous application during the research process. The following measures were taken to ensure the trustworthiness of this data.

### *Internal Validity: Credibility of Findings*

1. Prolonged engagement with the data
2. Results validated by participants
3. Presence of the essential structure in all protocols

4. Methodological rigor

5. Method appropriate to study purpose

***External Validity: Transferability of Data to Other Circumstances***

1. Thick description obtained (phenomenon full described)

***Reliability: Dependability***

1. Meaning persists through factual variations (Wertz, 1986)

2. Thematic structure formed through the research group interpretive process

***Objectivity: Confirmability***

1. Above measures used to assure that findings are supported by the data

2. Participants' own words used to name and illustrate themes

3. Phenomenon allowed to emerge from the data

4. Thematic structure formed through the research group interpretive process

## SUMMARY

An existential-phenomenology methodology was used in this study to yield a description of the experience of spiritual distress. Ten participants were interviewed about their experiences of being concerned about the meaning of life/death and/or their beliefs; the interviews were audiotape recorded and transcribed verbatim. Data were analyzed individually by the researcher and within a hermeneutic research group. The methodology was applied rigorously at all stages of the research process in order to meet reliability and validity criteria appropriate for qualitative studies. The thematic structure of the experience of spiritual distress and other findings of this study will be presented in the next chapter.

# CHAPTER IV

## RESULTS

### INTRODUCTION

The purpose of this study was to describe phenomenologically the experience of being concerned about the meaning of life/death and/or beliefs as it is experienced by adults in the general population. Because this concern about meaning is the key defining aspect of the nursing diagnosis Spiritual Distress, it was thought that the description would contain the experience of spiritual distress; this prediction was confirmed. As spiritual distress was the focus of the study, descriptions given by participants of times when they were concerned about meaning of life--but were not distressed--will be discussed only briefly before presenting the thematic structure of the experience of spiritual distress.

For this study, ten research participants were asked to describe experiences of being concerned about the meaning of life, death, and/or their beliefs. Interviews of these conversations were audiotape recorded and then transcribed verbatim. Participants were identified only by their chosen pseudonyms. A hermeneutical approach was used for data analysis as described in the previous chapter in order to yield a thematic description of the first person experience of spiritual distress.

Phenomenologically, the experience of spiritual distress presents itself as having two clear phases. The metaphor of the Web of Life, taken from the words of a participant, was used to describe both phases:

> And one does wonder on the death of a child...what (sighs)...that's very difficult...it's very difficult. Parents, you know, it's going to happen and one way or another they get less able and less enjoying of life and that isn't...it isn't the same...they break your web of life and you obviously have to rebuild around it and put the scar tissue around it to make it work and you...you kind of encapsulate them and all their memories in your life...in the way you operate. But it's...but a child...it's much harder. I find it that way. And it took a lot longer to get over that than the parents. (Jean)

From these words, the first phase of the experience of spiritual distress was termed Breaking the Web. This aspect of the phenomenon begins when an event suddenly or unexpectedly breaks into one's life. The second phase of spiritual distress follows the first and was named Rebuilding the Web. In this phase, the person comes to some acceptance of the event and is able to find meaning in it through positive actions in the world.

Figural to the phase of Breaking the Web (Figure 2) were the following themes (and subthemes):

(1) Falling Apart (Pain and Instability)

(2) Wondering (Questioning)

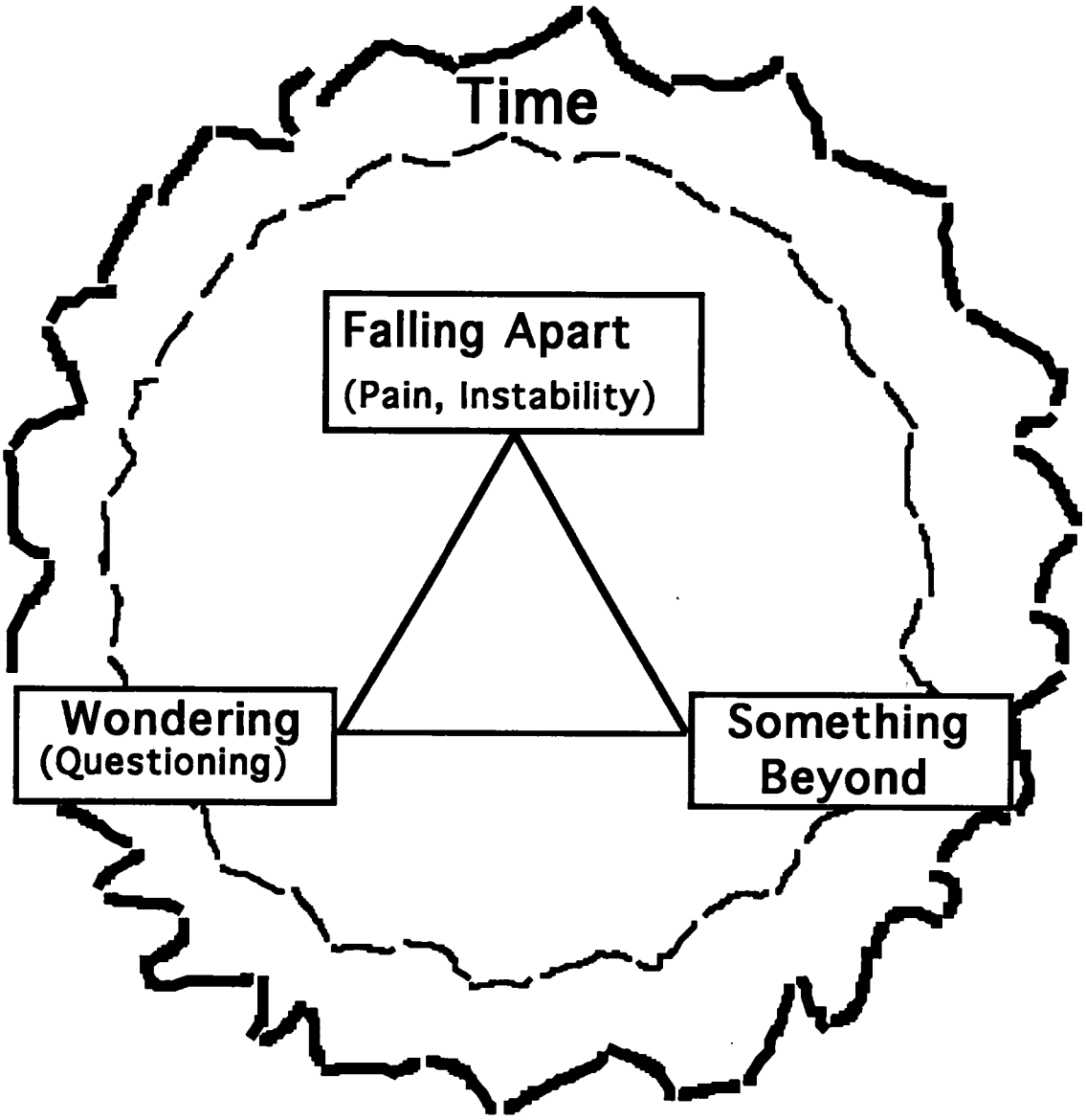
(3) Something Beyond (Feeling, Presence, Mystery)

The second phase, Rebuilding the Web (Figure 3), was described in terms of the themes and subthemes of:

(1) Stability (Strength and Security)

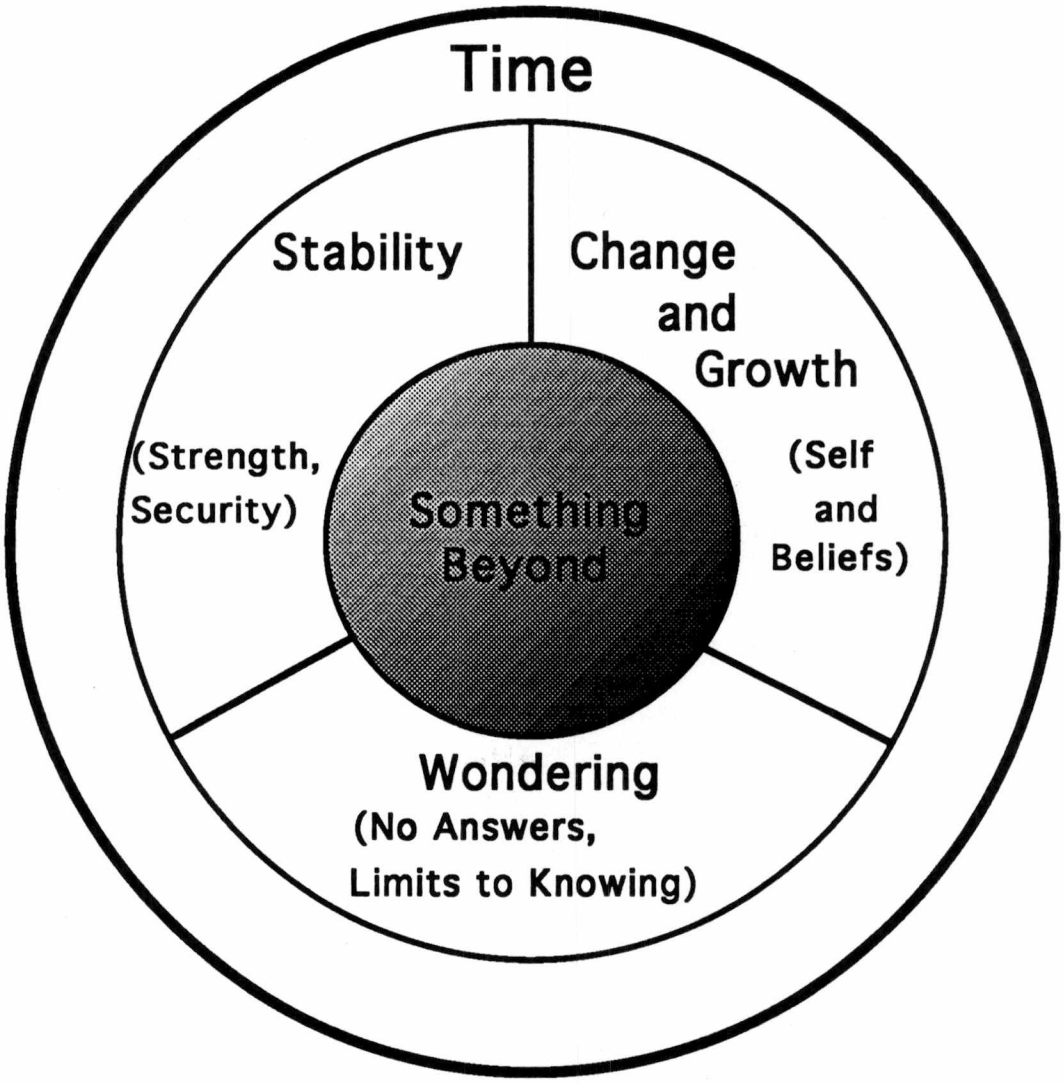
(2) Change and Growth (Self and Beliefs)

(3) Wondering (No Answers and Accepting Limits to Knowing)




Breaking the Web

**Figure 2. Phase 1: Breaking the Web**




# Rebuilding the Web

**Figure 3. Phase 2: Rebuilding the Web**

Although the two phases of the spiritual distress experience will be described separately, they are interrelated. The movement experienced by participants between phase one and phase two is considered a rebuilding process that occurs over time (Figure 4) and varies across individuals. There is a sense in which the restructuring is never fully completed. As was evident throughout the interviews, when a participant recalled and discussed an event that had once been distressful, there was a reexperiencing of the distressful elements to some degree. Coming to terms with some events may be a life-long process. Participants emphasized that it was not only time that restructured the web of life, but that hard work was also involved. This work included feeling the pain, seeking meaning through questioning, and experiencing "something beyond." While phase one represents spiritual distress, phase two is characterized by spiritual growth. Each phase is bounded by time, although the boundaries of phase one have been ruptured by some event which usually occurs suddenly and unexpectedly, ripping or tearing the fabric of life and interrupting the continuity of time. In phase two, Something Beyond becomes the central aspect which pulls the structure together again. Each of these aspects will be presented in this chapter and further discussed in Chapter V.

It is important to point out that many of the events that participants talked about for this study were not considered by them to be times when they were experiencing spiritual distress, and these events did not contain the thematic structural characteristics of phase one: Breaking the Web. Although these events were

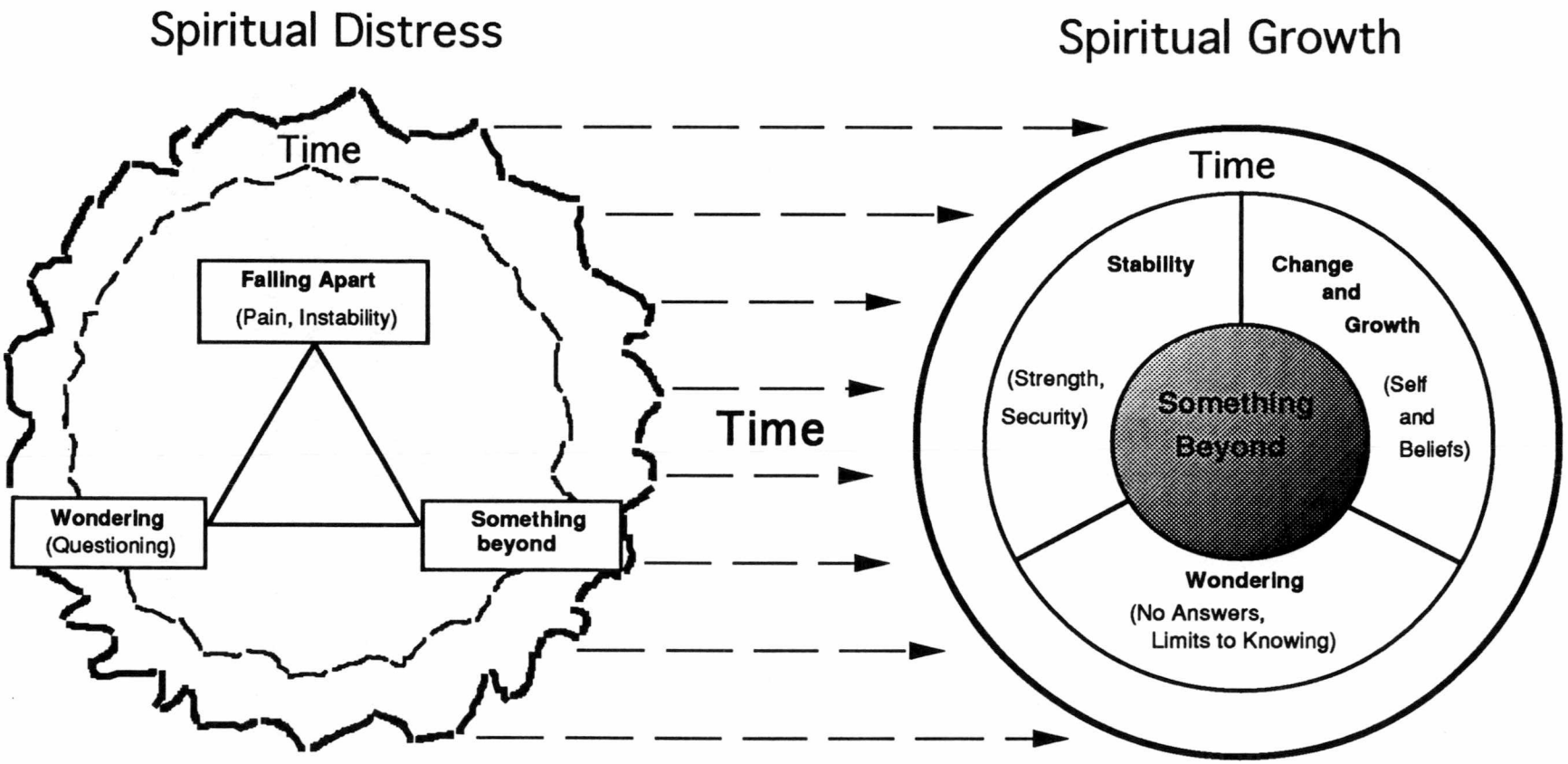



**Figure 4. The Process of Rebuilding the Web**

distressful emotionally, they did not contain the instability and intense questioning of the spiritual distress experience. Of the 54 events mentioned in this study (Table 2), 34 were considered by participants as not being spiritually distressful, although the types of events (deaths, illness, divorce, etc.) were similar. Whether an event was experienced as distressful seemed to depend on the participant's perception of the event. Events which were perceived as occurring within the natural order of things or those which "fit" or made sense were not considered distressful. These different responses to events can be seen in the following illustrations in which a parent's death may or may not be a time of spiritual distress or trigger a concern about the meaning of the event:

> My mother died rather suddenly. I don't remember terribly much dealing with it (meaning) then. My father's illness with his very brilliant mind basically coming unstuck with not being able to cope. But again, I don't think I really dealt with death or the meaning of death or anything else. Or my father-in-law, which was, you know, it was a relief by the time it happened because the last year had not been wonderful. (Jean)

> Oh, it was terrible. It was absolutely...my father...I...my mother called in the middle of the night and I remember that call and I remember sitting up the rest of the night thinking, you know, that I'll just...how terrible (tears). (Greg)

> Oh, very definitely. Because he died very suddenly and I didn't get to say good-bye. I was planning to visit him and I hadn't seen him in awhile and I don't think I will ever get over that because we were very close and ...see...just speaking of him makes me sad (crying). (Greg)

Many of the times that participants described as ones in which they thought about the meaning of life were times which involved learning about the world in the course of growing up, in school, or as part of their work:

Table 2. Events discussed by participants which involved being concerned about meaning. Events perceived as distressful by participants are marked with an asterisk (*). Names are pseudonyms selected by participants.

**Participant/Event**

Mark
* 3 month-old daughter died of Sudden Infant Death Syndrome
* Death of father (Mark was age 15)
Visit to Haiti
World events

Beth
Process of mother dying
Mother developed a dementia
Mother-in-law suffered a stroke
Daughter diagnosed as diabetic at age 4
* Meeting of church elders

B.J.
* Sister's serious illness
* Husband's dying of leukemia
Lifelong concern about meaning
Life "coincidences"

Beth #2
* Daughter diagnosed with spinal meningitis at age 9 months
Mentally retarded brother and uncle
First husband hit and killed by car
Brother killed on job at age 29
Divorce from second husband

Ace
Graduate school courses
* Religious discussion with atheist
Cardiac problems and bypass surgery
Pilot during Korean War
Continuous search for meaning
Feelings of parent toward children

Greg
* Divorce
* Step-mother experience
World travels
* Father's death
* Aunt's death (when Greg was a child)
Life-long concern about meaning
Mother's death

Frank
* Births of daughters
* Orphan children singing in Vietnam
Career change

Clyde
* Encounters with people who "have no sense of meaning beyond their immediate gratification and well-being"
* When it looks like Christianity is not functioning very well
Paradoxes in life
Life-long concern about meaning
Going away to college
Political events
* Hurting others unintentionally
Death of Parents

Jean
* Niece hit and killed by truck at age 8
Colleagues killed in plane crash
* Father's illness and death
* Husband's injury (broken neck) in car accident
Career change
Experiencing Extra-sensory perception (ESP)
Friend dying of cancer
Mother's and parents-in-law's deaths

A.Q. Biddle
Life-long concern about meaning
Research discoveries
Interest in sciences
* Car accident and hospitalization for broken neck
Introspection following accident

> I remember at various stages of my life...and I was quite intellectual and I'd read all the philosophers. I read all these things. (Greg)

> I've always had that interest in...I was very interested in evolution and fossils and geology. I just felt that was my duty in a sense. That's why I was here to try and figure out better...deeper. (A.Q. Biddle)

> But I was really interested in philosophical kinds of questions. Like the first one I remember asking myself was "Why am I me?" And I was very young then. But I wouldn't have dreamed of talking about that with anybody. I grew up thinking that was a taboo sort of thing. (B.J.)

> When I took some philosophy courses in college I first began to think about the meaning of life and the purposes. (A. Q. Biddle)

For participants in this study, once they began thinking about the meaning of life, it became a life-long pursuit, as one man said:

> Just constantly. Just constantly. I just bounce back and forth from one book to another and that's as much as part of the mystery of the meaning of life as anything. Chase through all those different books. That's a tremendous excitement for me right now. (Ace)

Another man considers thinking about meaning as a normal developmental process:

> In fact I'm in to the point that that's a natural part of maturing is to reexamine and question everything that you've been brought up with. You come back pretty close to where you started. But you have to work it out for yourself. (Clyde)

Positive emotions were experienced at these times of thinking about meaning, and participants expressed feelings of awe or wonder at the mystery of life or the order and structure of the universe. One man, a research scientist, expressed it this way:

> I still wonder at the...at the amazing universe and the creatures on earth...the fragile little planet...what we can do about trying to save it to make it better...save people...and those things. (A. Q. Biddle)

From these descriptions, thinking about meaning in life seemed to be an essential part of making sense out of one's world and was not necessarily distressful. Being concerned about meaning involved questioning and wondering, good feelings, and sometimes the sense that one was "understanding a little corner of God's plan," as one man described it. These responses to thinking about meaning are similar to those of the rebuilding phase of the experience of spiritual distress which will be described later in this chapter.

Both phases of the spiritual distress experience were grounded in the context of time. Examples of these temporal aspects will be presented prior to describing the thematic structure of the central event itself. For each theme and subtheme the most representative examples from the various protocols will be used in order to provide the reader with a deeper understanding of the themes.

## Time as Ground

The experience of being concerned about the meaning of life, death, and/or beliefs takes place within the context of time. Examples of time as ground were present throughout all transcripts in various ways. For instance, the specific date was sometimes given for a traumatic event which broke into time or specific times were mentioned by participants as reference points for <u>when</u> they became concerned about the meaning of life. There was also the sense of time passing when participants talked about the changes that had taken place over time. Some examples of such references to time follow:

> But certainly one significant point at which I was concerned with this was when my niece was killed in a ...was run over by a truck. On April 30. (Jean)

Because the year of this event was not given, the interviewer asked if the death had happened this year, to which the person replied, "No. It was 20 years ago."

Participants became very emotional when giving specific dates. It seemed that referring to time in this way reevoked the emotions that had been present at the time of the event. This man began his interview this way:

> On March 29, 1988 my wife and I awoke one morning and discovered that our three month old daughter had died during the night of Sudden Infant Death Syndrome. And that incident caused me to reevaluate my belief system and God and caused me to examine further my hope and desire that there was an afterlife and/or for me to be reassured that there would be a reconnection after death. Because it seemed if death was a stopping point then there wasn't much meaning to life because of the pain and the agony that separation and death causes in a relationship (sighs). So that's the basic incident. (Mark)

The matter-of-fact description of the event was abrupt and startling and seemed to reflect how the event must have been experienced by the couple at the time. After these first sentences were said, this man cleared his throat, and stopped speaking. It was then that I sensed that he could not continue speaking. Perhaps by retelling the event in this way he had tried to protect himself from the depth of painful emotions he knew would come in the retelling.

Other participants contrasted the way that they had thought about life before and after a certain event. The event appeared to have stimulated or forced their thinking about meaning to a deeper level. For one woman, it was when her sister was diagnosed with a life-threatening illness:

> ...up until that time I'd thought a lot about prayer and the Bible and all spiritual matters had been a big concern of mine all my life and I often thought, that, you know, well, prayer is just something you do and you don't expect too much. Not directly--on reflection you see things--but I thought, there is some incredible something out there that comes to people's aid when they need it. (B.J.)

Participants vividly described the way that time was interrupted by life events which broke in suddenly or unexpectedly. This was very characteristic of times when people died, as in the following examples:

> ...it was a surprise that it came into my life...It was a great surprise that death would enter my life the way it did. (Mark)

> I was totally unprepared emotionally...for my maturity rate to handle something like that because of the suddenness. (Mark)

> Apparently this hardening of the arteries just caused him to have a sudden stroke. We were always taking care of mother. She was the sick one and he died very, very suddenly. It was just unbelievable, you know. Accidents happen and death happens very quickly and you never forget that. How suddenly things change. (Greg)

> That was an accident too. He was killed on the job. So we were not prepared for any of it. It happened...right then. (Beth #2)

This characteristic of time was also experienced in the more everyday circumstances of work and graduate school for one man:

> All of a sudden an idea comes or a design comes...and you didn't do it. But there it is all of a sudden. (Ace)

> So I can't say that there was any point of any period other than I associate my time at (college) as being a time when all of a sudden I started thinking and I started reading a whole lot of different kinds of things. (Ace)

In such incidents, participants reported experiencing a break in the continuity of time and life. This break was particularly noticeable throughout one woman's interview. She talked about her mother dying as a result of a car accident:

> She was 91 and had been in excellent health all her life and then experienced--this was five years ago--she experienced gall bladder problems and had an operation and partially recovered from that but then she and I were in an automobile accident and the seatbelt pressed against her chest and bruised her heart and she went into a slow progressive heart failure. (Beth)

When Beth's four year old daughter was diagnosed with diabetes there was a similar sense of a break in the continuity of life.

> Our youngest daughter was diagnosed when she was...on her fourth birthday. Just the fact that ...I guess that this sweet little girl should not be in perfect health.

One final example of time is presented in a very dramatic illustration of a participant being aware of time passing when he was trapped in his car during a recent accident:

> Even when I knew that I had broken my neck--I was a little concerned about that. Well, I knew that I was having trouble breathing and I knew I couldn't move my arms. I remember looking at my watch and watching it go 'round and thinking, Well, what can you do? And I said, What you do is what you've always done--you take what God gives you and you do the best with it. That's <u>your</u> responsibility. That's all you have to do and you're told that if you ask for help you'll get it and I did. (A. Q. Biddle)

Participants discussed time in various ways in both phases of the experience of spiritual distress. It was difficult to visually represent in a figure the two different dimensions of time that participants talked about experiencing during both phases. One dimension was the time that humans are aware of on a daily basis as measured in units of time, such as hours, days, weeks, or years. The other dimension was experienced when the feeling of Something Beyond was present: a feeling of time without bounds. Participants talked about these two dimensions of time as occurring together.

## Phase One: Breaking the Web

The thematic structure of this phase of the spiritual distress experience contains three themes and several subthemes. The three themes are Falling Apart, Wondering, and Something Beyond. The theme Falling Apart contains the subthemes of Instability and Pain in addition to Falling Apart. The theme of Wondering, in addition to sequences labeled as "Something Beyond," also includes the subthemes of Feeling, Presence, and Mystery. Although the three major themes together with their related subthemes will be presented individually, they must be taken together to adequately define the total experience of spiritual distress.

Although all themes were present to a greater or lesser degree during descriptions of spiritual distress, the time when each theme became focal varied across individuals. As the following example shows, some participants indicated that immediately after a devastating event occurred in their lives they were not thinking about the meaning of the event; their primary focus was on survival:

> So, initially, the first couple days following the death...there really wasn't a whole lot of thinking going on, at all period. And there wasn't questions coming up. It was just a matter of emotional and physical survival...remember to eat, get enough sleep, apply some skills to help you with your crying, have someone help you make the important decisions. (Mark)

One woman experienced this period as one of not feeling or numbness:

> I can remember for several days she was in the coronary care or cardiac care unit of the hospital and someone there said to me that she should have very limited visitation and I was a little numb, I guess, at that point, and I didn't realize that that didn't mean me. (Beth)

Many of the events that people talked about were tragic and/or emotional times in their lives. These times often concerned the deaths of loved ones; a child, parents, a sibling, an aunt, dear friends or colleagues. Other serious events involved the illness or near-fatal injuries to self or others. The news of catastrophic world events or the awareness of the paradoxical elements of nature could also result in distressful feelings. Church meetings, or other meetings involving discussions with people who held different views than one's own, could arouse these emotions. As discussed earlier, the wide diversity of experiences in which spiritual distress occurred makes it clear that a prediction of spiritual distress cannot be based on the type of event alone. (See Table 2 for a listing of events by participants.)

In the following section each of the structural components of Breaking the Web, beginning with Falling Apart, will be presented. Falling Apart is a feeling component which is often the first to be experienced when persons become aware of an event that causes them to focus on the meaning of life.

***Theme 1: Falling Apart***

A broad range of feelings was elicited by distressful events (See Table 3). Rarely was the same word used by any two people to describe their feelings; despite differences, however, feeling words clustered into three main groups. These categories were termed Falling Apart, Pain, and Instability; each of these was a word used by participants to describe their feelings.

**Table 3.** Feeling Words

| Falling Apart | Pain | Instability |
|---|---|---|
| devastating | hurt | trouble hanging on |
| unstuck | awful | floundering |
| separation | agony | without direction |
| lonely | terrible | take pavement away |
| breakdown | unpleasant | quicksand |
| crash | uncomfortable | get shaky |
| hit by bomb | unhappy | churning |
| abandonment | sad | turning |
| structures falling apart | frustration | moving |
| basket case | angry | out of control |
| | frightening | out of balance |
| | terrifying | wander about |
| | threatening | adrift |
| | scared | out on a limb |
| | fear | salmon swimming |
| | anxious | upstream |
| | intimidated | hang on to |
| | dread | |
| | immobilizing | |
| | guilt | |
| | resentful | |

**Falling Apart**

The words Falling Apart communicate a sense of disconnectedness, separateness, coming apart, and sometimes total destruction. Often, the words used to describe this theme were very vivid.

> When you really have to accept defeat--and it is defeat. It is mind-boggling, emotionally you crash. (Greg)

> It's like being in a war. When you're hit by the bomb and it just sort of explodes. (Greg)

> The structure's falling apart. (Frank)

> A devastating occurrence for all of us. (Jean)

> I was a basket case. (B.J.)

For some, Falling Apart was described as an experience of being apart from others or God--a feeling of loneliness or abandonment.

> So there's a lot of loneliness as a teenager--abandonment. Where I didn't really feel that as an adult when my child died. I never felt abandoned by God when my daughter died. I felt abandoned by God when I was a teenager. (Mark)

> That was the dark night of the soul for me and I thought...well, now's the time for God to pull a miracle here and show up (laughs), you know, like other people see lights and things, now's the time for him to show up and take over here. But God did not show up and I was a wreck. (B. J.)

**Pain**

Words grouped in this category represented different levels of pain, ranging from being uncomfortable to hurt or in agony:

> I guess the churning feeling...it's so uncomfortable. It's just...I want to yell..."Stop it!" or something. It's... "Get me beyond this," you know. (Frank)

> I was ready for the pain to be over with very quickly--like that. I want the pain to be over and I want my grieving to be over and I want to go all through this grieving process and be at the other end by the end of the week please. I just wasn't any fun. (Mark)

The feelings of being anxious or fearful were also included in this category, as the following examples show:

> I think the very first time that I got really concerned was when my sister became ill. She got idiopathic hemolytic anemia and I, being a medical technologist, knew that that was a very serious matter and nobody else really understood that. And so I got very anxious about her prognosis. (B.J.)

> There were times when she would have those relapses and I remember going right back into that awful feeling of dread and fear...fear, anxiety. (B.J.)

> It's bad. It's just immobilizing fear. Anxiety and not being able to put it aside. Not being able to lay that down. It's a burden to carry. (B.J.)

Another painful feeling that was present in the majority of interviews was guilt or remorse. Some people mentioned more than one situation that caused them to feel guilty. In these instances, participants talked about the pain they experienced when they felt that they had violated a personal code of behavior. Their pain seemed to be a reflection of the real or imagined pain that they felt they had caused others.

> And sometimes when I start feeling sorry for myself, that's usually when the questions arise. That's when I feel guilty and then I'll hug her or something and then I'll cry a little bit and then once that's over with then I get into my daily routine again. It doesn't happen too often anymore. (Beth #2)

> I felt guilty about not spending as much time with my oldest daughter. (Beth #2)

> If I violated them (family values) I always felt tremendously guilty. (Ace)

> I felt very sad and quite guilty that I hadn't been with her during that time. (Beth)

> But I don't do as much as I ought to or as deeply as I should (practice faith). Interested in my own career and things like that much more than I should have been. (A.Q. Biddle)

Pain was evident not only in the words people used to describe how they felt during these times of distress, but also during the interview itself. Most of the women were able to describe their emotions using feeling words and cried openly. However, two women showed or described little emotion during the interview despite the very tragic events that had happened in their lives. At the end of one interview, the researcher asked if emotion was present at the time of the events. This woman stated:

> I do my crying on the Interstate (laughs). I do cry, it's Okay. In fact, as I've talked about some of these things I wasn't sure I was going to get through a couple of them (laughs). Because it came close...and there are, obviously, raw parts of all of this still out there. (Jean)

For the other woman, when I discussed this observation with her several months later, she was very surprised that she had not talked about her feelings because she said she is "a very emotional person." Reflecting on her interview, she concluded that the day she was interviewed she was feeling very positive. On positive or "up" days she intentionally chooses not to relive the experiences with all their painful emotions. If she had been interviewed on one of her "down" days she thought that she would have talked about the events in great detail and expressed many emotions.

The men in this study had a more difficulty talking about and showing their emotions. The researcher came to realize, after it had happened several times, that when men stopped talking, cleared their throats, or lowered their voices, their emotions were very close to the surface. At these times, the researcher acknowledged

the difficulty of talking about emotional events, and waited before continuing the interview. Some men then attempted to put words to their feelings whereas others were not able to continue and changed the subject.

What one man said is representative of the difficulty that the men in this study had in talking about their feelings.

> And this was the curious thing and I don't know why. We've tried to (talk) about it in...at least tried to talk about it in our group...talk about happy emotional close loving kind of emotional times. Bad times or mean times, I can talk about anything. But talk about closeness to somebody. I'm the same way in a movie. You know...death and a lot of that stuff and other kinds of pain don't bother me, but the human goodness that you see in a movie...sometimes I just start bawl'n. (Ace)

As we have seen from these examples, diverse feelings are associated with spiritual distress. For the most part, these feelings are painful and unpleasant.

**Instability**

While there were a variety of very descriptive words used within this category; all conveyed a sense of becoming unstable, losing control or hold of something, or being insecure. The first example below of instability occurred during one man's experience of discussing religion with another man who considered himself an atheist. As a result of this encounter, the participant "lost" the faith that he said he had "taken on" as a church member. He described this faith as "shallow" and as "just one of these David Koresh kind of things."

> But also that he was a total atheist and a very intellectual and knowledgeable atheist at that. And he didn't try to knock out my underpinnings, but he just being who he was and some of my relevant questions that he just totally shot any sense of religion or faith or in the traditional sense that I had. I mean it just completely blew it. (Ace)

Other selections from the protocols depict the instability experienced during this phase of spiritual distress:

> You know one day you're the wife of a professional man and the next day you're really adrift. I just remember the very feeling...that I had to hang on to some feeling of a center post because of the fact that I had these two small children who looked up to me. I was the only thing they had to, you know, hang on to. (Greg)

> You and I both realize when we go through life and we're thinking about these things that so often we're out of balance. It doesn't take much to trigger it off. (Greg)

> Things are out of control...things are...I can...things are shifting. I can see that they're shifting...or have shifted. In the case of the memory of the children singing it's the memory that has initiated the change more so than when the event was actually happening. (Frank)

> It feels good, but then again it's kind of scary dealing with something that you don't feel very often. You know, when feelings are stirred. I think it's something that...it's something you can't control so you're...sort of the fear of things being out of control. (Frank)

> I had a friend one time who said to me, "You know, you put yourself out on a limb so far that God has to help you." And I never forgot that expression because I literally was out on a limb and I went to live with my parents that summer. It was the worst summer--in terms of anxiety--I ever had in my entire life. (Greg)

These examples have shown that when a person talks about spiritual distress many feelings are experienced. These feelings are represented by the words Falling Apart, Pain, and Instability. Although some people said that they experienced these feelings as a part of questioning the meaning of an event, questioning usually occurred <u>after</u> feelings.

***Theme 2: Wondering***

Wondering was the word used by several people to indicate a period of questioning and trying to understand or make sense out of what was happening to them. Many people asked "why" questions. Some participants found that asking questions was an inevitable and even healthy thing to do in times of crisis. Many of the questions these participants asked addressed a deity:

> It causes me to question God's sanity in a sense. What's go'n on God? Can't you intervene? You did it in the Old Testament. You did it in the New Testament. Where are you right now? (Mark)

> Although there was a period of questioning, a short, even at short times questioning the existence of God whether, you know, questioning the why question was a big part of the search, you know. Why should God kill a baby, you know, these questions come through your head. (Mark)

> Everybody I've talked to has at least asked the why question. And if you're asking a question, you've got to ask it of somebody or some direction which in the why question means you're going out of yourself to find an answer. (Mark)

> When my daughter was diagnosed with spinal meningitis when she was nine months old. I think that was the first time that I ever, spiritually, that was the first time that I ever questioned why something like that had to happen. It left her completely helpless, mentally retarded, and physically handicapped. (Beth #2)

> I grew up with a mentally retarded brother and...I even asked "Why did I have to have one when I already had a brother...that my parents had...to deal with this again?" (Beth #2)

In the search to find a reason for an event, some people asked if they were the cause.

> Sometimes I wonder if I've done something to deserve things that's happened in my life like that. And if I have, I don't know why. But I have wondered that. (Beth #2)

> It caused me to...ask that why question again. That why being 15 why do I have to go without a dad? I'm a good guy. I didn't do anything wrong. Why am I being punished for that? Those were some of the questions. (Mark)

Holding certain religious beliefs can also be a source of stress, as these examples show:

> I have a real problem with this. If the God is a loving God, why does He allow so many horrible things to happen in this world? (Greg)

One man who questioned God's sanity (see quote on previous page) also struggled with the contradiction between God's omnipotence and his failure to act in this case:

> It's that separation of being all powerful and all knowing and within there there's a lot of great questions go'n on in my own beliefs. (Mark)

What this person said seemed to summarize all the statements about questions:

> And it's the question of What does it mean? It's the same kind of questions that occurred to me when I was in Vietnam during the war. The children...sang Christmas carols and that meant a great deal to me in What's it all about? (Frank)

Sometimes, even whether there is meaning in life is under question.

> Well, the question of What is the meaning of life? sort of assumes that life has a meaning and sometimes I question that. (Frank)

Questions arise when one is aware of both the order and disorder present in the natural world.

> My feeling is there's so much order and structure. That magnificent, intricate system that's been put together that there has to be an intelligence behind it. Just doesn't tell you anything what you're supposed to make out of it and here we are--Why?--there's not a clue. (Clyde)

> The evidence that we see in this world is absolutely contradictory. We see nature with immense order and structure and grandeur and beauty and at the same time tornados and hurricanes and earthquakes and forest fires and pestilence and plague and starvation...just absolutely contradictory from the scientific perspective. It's not given to understand the nature of creation. We're stuck with accepting it and having the faith that it makes some sense. (Clyde)

Two participants said that they had chosen not to make questioning a part of their experiences. They were aware of the possibility of questioning, but that for different reasons, had decided it was not an option for them.

> No. I didn't blame God for anything. I have never...that I am aware of...blamed God for a problem. I just feel He's there to call on to help you through a problem. (Beth)

Another woman (Jean), who said she was a very practical person, made several statements about questioning. These statements helped to explain why questioning is rarely a part of her response in a crisis:

> I don't think there is a lot to be gained by that. I think you're probably...it's inefficient use of mental energy (laughs)...or emotional energy. I don't think there is anything to be gained by spinning one's wheels either in guilt or why did this have to happen? I don't indulge in that.
>
> Flanders and Swan had a book about children and it was something about the poem on the front of it about if you're an ant and how would you possibly have a concept of a person, you know...it was that...therefore, why should I presume I could have a concept of God? In the same huge just inconceivable leap forward and that kind of stuck with me and of these things because, you know, how can I know? It's beyond what I can conceive of.
>
> Now if you can ask questions and therefore learn...as I dealt with, for instance, not doing something with (husband) or my father as well as I could. It is worth spending time thinking about that whether it's painful or not, so that...and talking with other people about that because we can learn from that. But beyond that, once you've got that done you need to move on. Do whatever else you need to do.

The word <u>wonder</u> was chosen as the title of the present research project for two reasons; first, because it was a word that frequently appeared in the protocols and second, because it conveys a sense of puzzlement, doubt, and curiosity. These meanings fit both phases of the spiritual distress experience. First, through asking

questions or wondering, a person attempts to figure out a rationale for the puzzling and disruptive event, and questions are directed at either the self or to something or someone beyond the self. In the second phase, questioning appears to continue at a lesser intensity even when answers are not forthcoming.

Although all participants indicated a belief in God, God's actions and presence were not beyond questioning. Questioning God seemed to lead participants to experience God in new ways during times of distress. Crises were described as making people open to experiencing God emotionally rather than on the basis of rational thought or argument. Participants identified this feeling of God's presence through the use of the words "Something Beyond."

***Theme 3: Something Beyond***

When people talked about Something Beyond, they referred to that experience as a feeling, presence, or a mystery. These differences were not always clear-cut, and no attempt was made to categorize statements in this way. As will be seen in the following excerpts, God and Something Beyond often were talked about at the same time and held one or more of the above characteristics. Experiencing Something Beyond did not occur in all distress situations described by participants. Sometimes, experiencing Something Beyond was seen only when reflecting on the meaning of an event, not during the event itself.

For one man, becoming confident that there was Something Beyond was a very gradual process over many years. For others, experiencing Something Beyond was

present in the midst of the experience. In the following examples, participants experienced Something Beyond as communication:

> Well, you're talking about the birth of a child. The question was "What is it that you know?" And knowing that...I'm not going to...I don't know...what is it she knows even with a...I was getting the communication of there being somehow knowledge or wisdom there. (Frank)

> I suppose I am trying to talk...and it's not even to someone. It's to something beyond what I can understand. But I am trying to communicate what it is with a certain amount of confidence that something can be done should whatever this other dimension is... (Jean)

Other participants talked about the universality of "God issues" and the feeling that there is a helpful transcendent dimension available to humans.

> There are some God issues that everybody struggles with. I'm convinced everybody struggles with that issue as to the existence of a Supreme Being or God or whatever label you want to put on it. But there's a sense in all of us that there's something beyond who we are. (Mark)

> But I thought, I mean, there is some incredible something out there that comes to people's aid when they need it and I didn't sense that in my dark night. There's something that prompted her to come to me at that particular time. And whatever, however that message is done. I think God has a role he plays in that. (B.J.)

> Even though I have had the feeling there is something out there...I have a lot closer real life experience that I can...convinced of this I'm not sure what it is and I think that, as I've said earlier at the beginning that other...lots of people have experienced this and the way to communicate these kinds of experiences has been as we've done through religion. (Jean)

All participants had some experience in a church from childhood on, although several said attendance was infrequent and of little consequence at the time. All participants said that they did have a basic belief structure, which in some instances seemed to be more about morality than religion. However, it was this basic structure

that some participants said was helpful to fall back on during times of instability and stress:

> It seems to me a person needs that...in the background. Because if you have a crisis, then, these things that you have studied and associated with help get through this hump. If you don't have anything, then I don't know what you do. I really don't know what you would do. You'd have nothing to fall back on. (Greg)

> For me it felt very healthy cause in a sense I've never really let go of my belief system even though I question whether, you know, does God really exist? I would always balance that off with my belief system--well, of course He does--so I would be in a dialogue with myself... (Mark)

Some participants reported being quite involved throughout their lives in all aspects of church life and had a broad knowledge of their religious beliefs. Even these participants talked about the inadequacy of their knowledge of God to comfort them during times of stress. The seven participants who used the specific term Something Beyond indicated that they had come to experience it more through feelings than through thinking.

> Just a look of wisdom. It had to go beyond anything that makes any kind of sense. There has to be something greater than what we can see or explain or touch. If there's meaning, it has to be beyond any of that...because of what we see and touch and hear and experience in a rational, conscious way...so much of it's bad. If, you know, that good has to triumph over evil then from what I can see or tell to you rationally, evil's winning. So, if there's any good, it has to be beyond the rational conscious. (Frank)

> And all that reading and all that wondering was an exercise of my intellect. Facing the illness and the death is a matter of the spirit and of feeling and there was a sense in me of unfairness and unjustness on God's part and what kind of a God would single us out and other people that I'd remembered and what about the miracles? (B.J.)

Two female participants who used the term God exclusively to refer to Something Beyond spoke of an awareness of and a confidence in God's presence:

> I guess my most poignant memory is I had God's support and God was very close to me. (Beth)

> I have a little plaque in my bedroom. It says "Don't worry about tomorrow. God is already there." So that's what I think He's telling me most of the time. Live...worry about today. If you have to worry at all--do it today--and get through today and He'll be there tomorrow to help me through the next day. That's why I take it one day at a time. (Beth #2)

One man said that he did not experience God or Something Beyond in the experience that he talked about as spiritual distress. His faith had been shaken and rebuilding it was a gradual process over many years. He reported that part of this process of reestablishing confidence in his beliefs concerned a renewed ability to experience Something Beyond. As an artist, he experienced "Something Beyond" during the creative process, and as a parent, in his feelings for his children.

Some participants noted that the experience of Something Beyond seemed to come from being more open or emotionally vulnerable. Other participants reported that trying to reach Something Beyond was an act of despair. In the next two examples, such despair is apparent as a woman (Jean) talks about asking for a "sign" that her husband would live following a car accident in which his neck was broken:

> I don't understand what it is, but I was in bed one night, I guess and I just decided I really had to try and get through and it must have been that second week and fairly regularly thereafter and a few times since then even since he's been home.

> Periodically, through this whole thing. I had never particularly prayed before and yet I found myself on my knees at my bed after coming home, saying, I've got to get through. I've got to see all this. I kept trying to see through all of it to whatever...whatever it is I think I believe is out there that I don't understand. And it would be amazing what I would be routinely worried about, something would come through, you know.

From these "answers to prayer," this participant reported that she had a better understanding of her beliefs.

> And, you know, time after time things that came from all the teaching in the Bible would come back to me that, you know, OK, you know, I understand that a little better now because I'm experiencing it in real life.

## SUMMARY

The thematic structure of the first phase of spiritual distress, Breaking the Web, included the themes of Falling Apart, Wondering, and Something Beyond. Life events that break the web of life often evoke feelings of falling apart, instability, and questions combined with a sense that there is something beyond the self. The experience of Something Beyond is sensed as a feeling, a presence, and a mystery that is present during times of need. Participants reported that it cannot be explained, and that they viewed it as a "mystery."

The second phase of spiritual distress was characterized by participants as a time of Rebuilding the Web of Life. It follows the Break in the Web and is characterized by a sense of stability. During this time, the event that caused the break has been incorporated into life. Participants talked about rebuilding their lives in terms of putting the pieces of their lives back together. This reconnecting included (a) coming to terms with the knowledge that there were no answers to many of their questions, and (b) the feeling that there was "Something Beyond" which would meet their needs and be with them if such events occurred again. All participants discussed the ways that they had found meaning in their suffering through helping others in similar circumstances.

## PHASE TWO: REBUILDING THE WEB

This phase begins when people start rebuilding the tear in the fabric of their life that was experienced during times of spiritual distress. In addition to the woman whose words were used to name this phase, another woman used the word rebuild when talking about ideas from a book she had been reading after her husband's death:

> And he said: Well, your anxiety and his fear has turned to sorrow. And sorrow is better because fear is always diminishing. It's always bad...and you can't...but sorrow can be enriching. And then he said: It's like the man who's the tornado's coming and he's fearful for losing his house and then he does lose his house. Well, the fear is gone, the anxiety is gone, the sorrow is there, but he can rebuild the house and that's kind of the situation I found myself in. (B.J.)

The phase of rebuilding was described as involving a change in feelings and beliefs about the self and the world; in general, participants perceived these changes as positive. The major themes defining the rebuilding phase are: (1) Stability (Strength and Security), (2) Change and Growth (Self and Beliefs), (3) Wondering (No Answers and Accepting Limits to Knowing), and (4) Something Beyond. For most participants, choosing to rebuild appeared to follow a time of distress naturally. This association seemed to imply that phase one had meaning for them because they chose to move into a new phase. One woman confirmed this when I talked to her later about the thematic structure. She said that healing was hard work, and did not result merely from the passage of time. In phase two, participants worked to incorporate into their lives all that they had learned from their suffering during the time when they experienced the web as broken.

***Theme 1: Stability***

In phase one of spiritual distress people spoke of feeling unstable, hurt, and as if things were coming apart or falling apart. In the second phase, however, they talked about things becoming stable, stronger, and more secure. Some of the references that participants made to feelings of stability during this period are as follows:

> My everyday life is...it's...I feel in control of what's going on most of the time. I feel like the situation's stable and so on so I don't feel the need to have to control anything because it's basically in control and stable. (Frank)

> I'm sure that if there is a God and if there is a loving God I'm sure His intention is to keep...is to promote peace and a balance. Christian Science, I think, often talks about this...a balance of everything is very important. And I'd like to see this. I think that would be a very good goal for all of us to try and work on. Whether it's a balance in our life...a balance in nature...you and I both realize when we go through life and we're thinking about these things that so often we're out of balance. It doesn't take much to trigger it off. (Greg)

> As for me, I've come to the conclusion that just because I try to be good, God isn't going to protect me from anything. The most I can hope for is an assurance that whatever happens, God is there and then I'll have the necessary support that I need to see me through and that has happened since then. (B.J.)

**Strength**

Participants used the word strength to refer to changes in themselves and their beliefs.

> The death of my daughter caused me to even feel better about a person's doubts because it was very healthy. Is just how I really felt about it that it was good and that it made me a stronger Christian to be able to question, you know, as mush as I can look God in the face to question--do you exist and why does this happen to people for no reason? (Mark)

> His illness made us stronger, better people. And here's what his death gave me. The courage to face my own death and living without him has made

> me a person in my own right as I never was before. I am seldom afraid now and never as fearful as I was about losing him. (B.J.)

**Security**

The experience of security in this phase was not the same kind of security that participants had experienced before their world had fallen apart. No longer did they have a false sense of security. No matter how "good" they were, they now knew that this did not protect them from being hurt.

> I believe that there's a lot of chance in life and I think God set it up that way. I do. For awhile, before my daughter died there was this false sense of security in the world, that bad things just happen to other people and that chance is happening to somebody else, not to me and that God's got a good grip on my life. So, if there was one thing that really changed for me was not really my view that chance happened, but that all of a sudden I was included in how I viewed the world. (Mark)

> For me a faith to kind of live by is that no one is safe in the sense of knowing what's going to happen or being Okay all the time or not having to suffer or not having to deal with unpleasant things and solve many problems. And I am never going to be absolutely sure that I have chosen the right solution or the right thing. But what I am secure in is that I will be okay. I mean my needs will be met. (B.J.)

> And I guess somehow this book and these discussions and this searching and everything allows the outside things to come in instead of being a threat they are a stimulus. They are an exciting experience. (So there's a lot less fear, I guess, in your life now than there was before.) Yeah. Yeah. A lot more security. A whole lot of comfort. They're (beliefs) your whole substance. I don't see how people get by without (them). (Ace)
> (The sentence in parentheses is a statement made by the researcher.)

***Change and Growth***

Participants talked about change and growth at the same time as they talked about what it was like in the midst of spiritual distress. They said that as time passed, they became more aware of this process (and its benefits) and consciously chose to pursue

it. Some people talked about looking back on their life and seeing some sort of pattern as expressed in these ways by one woman (Greg):

> It's totally funny but it seems strange that your life does have a path and sometimes it pays to be patient so and you look back and say--wasn't that an interesting turn in the road?
>
> I don't feel...when I was a child I felt...I don't feel that personal God that I was made to feel that was there. I don't feel that now. But I do feel that there is a pattern...that's all I can say.

All participants gave examples of the ways that they had chosen to give meaning to the distressful events in their lives. There seemed to be a great sense of responsibility to help other people in similar circumstances out of what they had learned by surviving an event.

In the following responses it can be seen that the changes and growth that occurred in self and beliefs overlap:

> Oh yeah, I mean, but that was twenty years ago. One would hope I had grown spiritually and in all other ways. (Jean)
>
> Life would go on very well without me. (And that has changed for you?) Yeah. Well, I think so. It's not so important. I hope that I can live long enough for...that I can help (son) and get finished with good things. (A.Q. Biddle)
>
> I think all these different things in my life have made me a more outgoing person. Made me do things that I wouldn't ordinarily have done and really kind of changed my personality. I like myself a lot better now than I did when I was twenty or twenty-five. (Beth #2)
>
> I wanted everything settled. I wanted to put that away. I didn't want to think about that anymore but it's never settled. I mean there's always something new that comes up and I mean I thank God for that. I mean I'm growing as a reason (laughs). (B.J.)
>
> I was the one that said we had to have the divorce. I could not continue this way and that's a growing situation. Terrible hard on you and I think the

> stress really caused the cancer. But as a result of that, you do grow. I think that's an important point. (Greg)

> I think that maybe I'm a better mother to my other two children because of the handicapped child. I think it helped my children, having her around also. I know that growing up with my handicapped brother I think helped me for having my own child handicapped and in other's lives when they face the same crisis. And that's been a very rewarding experience that has resulted from a tragedy. (Beth #2)

> I keep thinking and reflecting and realize more and more that I'm a better person for what I've suffered. That I'm deeper and more in tune with how God has managed the Universe. (B.J.)

Some participants talked about the specific ways in which their religious beliefs had changed. They often felt a new dimension of feeling had been added to faith that further confirmed what they had learned on the basis of rational thought. Overall, changes seemed to deepen their faith, to provide a new understanding of faith, and/or introduce one to a new reality about faith that had not been present before.

> So it (thinking about beliefs) didn't really begin, I suppose until after we almost lost him that week. That was right scary and it was probably somewhere along in there that I really got thoroughly frightened. And I was alone, to some extent at that point, and had time to think about it. I don't understand what it is, but I was in bed one night, I guess, and I just decided I really had to try and get through and it must have been that second week and fairly regularly thereafter and a few times since then even since he's been home. And I finally have a much better perception of it (monks and nuns praying). I really can understand it. I'm to the point where I probably take it a whole lot more seriously now (intercessory prayer). (Jean)

> I know I felt really very close to God and that I would have that strength to make the right decision as she was dying. And that was one of the...I mean that was probably the most poignant memory is I had God's support and God was very close to me. (Beth)

> ...that in the face of crisis and tragedy and pain and death that all these promises were still true for me and that just showed me a different side of Christianity that I had never really experienced before. (Mark)

> And all that talking and all that wondering was an exercise of my intellect. Facing the illness and the death is a matter of the spirit and of feeling. And there was a sense in me of unfairness and unjustness on God's part and what kind of God would single us out and other people that I'd remembered and what about the miracles? In order for me to move forward spiritually, I had to put into words what I was feeling, not what I'd been thinking about all those years--even though my thoughts weren't too far off of the mark. (B.J.)

Each person in this study could identify the positive things that had come out of what initially looked like a negative circumstance. These individuals had chosen to take some action that would turn bad into good for themselves and others. They talked about their actions within the framework of responsibility. There was a sense that they almost felt compelled to respond in a positive way; that is was required to balance the good that they had received in life.

> I've tried to help several close friends through that process since my mother died and I've had relatives of those people tell me that I was very attuned to how to go through that with another person. (Beth)

> I've chosen to take this crisis and make it a very positive thing in my life in the sense of allowing me to intervene in other's lives when they face the same crisis. And that's been a very rewarding experience that has resulted from a tragedy. (Mark)

> The only thing that makes any sense is--what do you do while you're here? That's where I put Christianity in this whole mess. The message...this is what you're supposed to do. It seems to me...my poor knowledge of the Bible...that you try to help other people. (Clyde)

> He was trying to hold my hand and I wrenched my hand free...I've just been mortified because Dad wanted to hold my hand...and I blew it. I've told a lot of people about it and I've said...at least it may save someone else from doing the same dumb thing. (Jean)

> I think that's what life's all about. I think this matter of responsibility--giving your children values and making them feel as they achieve...then you feel that you can go on. (Greg)

> I had called the hospital and said that I would be...that I had been trained to visit newly diagnosed families in the hospital...and that I'd be happy to do that here... (Beth)

> You know, both of these experiences have come out with a positive end. With the children singing, my own commitment to being a part of the community of faith. The children singing kind of thing was a coming to terms with the community and the world around me. With the birth of the children...I guess more of an internal thing, a recommitment...to importance that I do need people who care about me and for whom I can care and nourish and provide for and I feel that somebody can provide for and nourish and care for me too. (Frank)

A sense of gratefulness appeared to be a part of change and growth for these participants. They were grateful for the way their lives had unfolded, despite all the difficult times that had come their way. Some examples of feeling grateful follow:

> I'm very grateful and I'm very privileged and I'm very hopeful that I have a little longer to enjoy it...to see the sun come up. I do believe that in the end if there's nothing...it's all right. It's been a wonderful way to live, you know, productive...and joyful...and I've been blessed with many blessings. (A.Q. Biddle)

> I feel the only prayer that I can say is...acknowledge the excitement of the opportunity to be at least this conscious of my chance to pursue the Oneness. I consider myself fortunate that somehow those parts of the total universe have evolved through me are gravitating that way (his creativity and artistry) instead of going and killing somebody or something like that. So I'm grateful for that. (Ace)

***Theme 3: Wondering***

Wondering during the initial phase involved the asking of many questions; most of these were about the "whys" of the event. Why me? Why this? Why now? In the second, or rebuilding phase wondering was described as more of a sense of awe at the mystery of life. Although questioning continues, there is an acceptance that there need not be any answers. There also is a realization of the limits to human knowing.

Rather than expressing frustration at this turn of events, participants reported reaching a new level of faith and trust.

The following responses indicated not only that wondering or questioning was a part of the rebuilding phase, but also that participants considered it to be a vital part of life:

> Yes, and I hope I do (continue questioning). Because when I quit questioning that then I think I've really become insensitive to it. If I quit questioning God and asking him, you know, what's really going on here? When I quit asking that, then I've really distanced myself and really quit caring. My questioning is a result or a demonstration of even I do care. (Mark)

> I know that (I'm not going to get an answer) before I even ask the question (laughs). But it doesn't keep me from wondering why. I don't know. I know it's even silly to ask that but...it just seems to be normal. (Beth #2)

> I'm sure that there is a pattern to something and I don't know what that pattern is yet. Hopefully, maybe, I'll get some sense of understanding at some point in my life. I certainly will keep seeking it because I think it's worth the search to try to understand. (Greg)

For some, there is the hope of a life after death, a place where there may be answers.

> I still don't have an answer, and it's been 22 years now. I still wonder. I didn't just wonder it then, you know. I've wondered it probably everyday since then. It's just that it's something that I have to deal with on a daily basis just like I deal with taking care of her. I always thought that God has the reasons and someday I'll know what it is. I don't know when, but maybe someday that I will. (Beth #2)

> If I get to heaven I want to look in the Book and see how a lot of terrible things work. I would think that would be...it's incredible. (Later in the protocol he said the following.) I'm not ready to commit suicide because I think it would be much better to be with God and find out all the answers. I don't think that's responsible. (A.Q. Biddle)

## No Answers

Participants discussed the conclusion that they came to over time that many of their questions about life would not be answered:

> There really are no answers in the area of death for me. (Mark)

> There aren't a whole lot of things that will make sense in life. There aren't answers to everything...there aren't answers to a lot of things. But I liked answers. I liked answers that were right and wrong. I wanted black ad white. Well, I've discovered that that is not possible and that's the part for me to deal with in terms of my belief system and the Bible and all of that because I didn't like all those inconsistencies that I kept running up against. (B.J.)

> I still don't have the answers (laughs). I've realized throughout the years that there are no answers for it, but...Well, I still wonder why that it had to happen and why it had to happen to me. (Beth #2)

> I don't have the answers. But I still continually search for these answers, hoping in some small way. Then...when my time comes, I want to feel that I have accomplished something and that's all we can do. (Greg)

In spite of the human need to continue questioning, there was also an acceptance that came with the awareness that there are limits to knowing.

## Limits to Knowing

This theme is related to the perception that faith is more than rational knowing. Participants concluded that the ways of God are unfathomable and, in the end, one must stand in awe and wonder at the great mystery that is life.

> You have to be accepting. I mean it's not given to understand the nature of the creation. We're stuck with accepting it and having the faith that it makes some sense. I guess there's some unity to the think--some coherence for better or worse. (Clyde)

> A guy who's a physical chemist says "The significance and joy in my science comes in those occasional moments of discovering something new and saying to myself--So that's how God did it! My goal is to understand a

> little corner of God's plan." I think that's real. I think one of the functions of science and the beauty of it is to understand the incredible beauty and symmetry and some fantastic things that are involved in all the atomic structure, physics, chemistry, and biology. (A.Q. Biddle)

> I do consider the meaning of life a real mystery. I wouldn't quantify and say that it was an unanswerable mystery. But I don't know that in my time or our time we'll ever solve the mystery. I get comfort in the excitement of the mystery, I guess, as much as anything. (Ace)

> I very definitely feel that there is a God who has orchestrated this and in some way all have to leave it to Him. (Greg)

> The important thing is it's absolutely meaningless to envision what a heaven might be like, an afterlife...beyond the statement that you have to have faith and trust that it all makes sense because it just can't go any further. It's just sheer speculation. (Clyde)

> Well, most everything is just a finality to it though, so you have to accept it. There's nothing else you can do. (Clyde)

***Theme 4: Something Beyond***

The experience of Something Beyond, which had been described by nine of the participants during the Breaking phase, was discussed by all ten of the participants as being present in the Rebuilding phase. The man who did not experience Something Beyond in his time of distress said that it took him twenty years to rebuild <u>his</u> faith, and not one that he just took on from others. This is what he says about his beliefs today:

> It's a feeling of great excitement that it's (life) such a mystery, that it's magnitude is such that it's almost inconceivable. You're just kind of in awe. If I ever said there was any purpose in the total evolution, it is our response to that subliminal or unconscious or conscious gravitation towards that Oneness. (Ace)

Other participants talked about their current spiritual beliefs in the following ways:

> Even though I have had the feeling there is something out there I have a lot closer real life experience that I am convinced of this...I'm not sure what it is. Lots of people have experienced this and the way to communicate these kinds of experiences has been as we've done through religion. (Jean)

> A man from an Oriental country that I basically don't understand. And he had an enormous effect on the world...and the Bible says loves me. I found that's probably true. But it's still hard to understand. But, also, I think maybe that's not such an important situation. You just miss the strength and peace that come from knowing that, I guess. (A.Q. Biddle)

> They (crisis events) almost forced me into a closeness with God at those times. But I do feel that my life...that religion is your life...it isn't something apart from it. (Beth)

> Both of these experiences have come out with a positive end. With the children singing, my own commitment to being a part of the community of faith. (Frank)

> And all those questions that I asked myself about judgment and I think that the outcome to that judgment is that we will see Him as He is. And we will see us as we are and that is what judgment is. ...I'd like to know more about it but I'm not frightened of it in any way because I think I'll still be me pretty much the way I am and I'm gonna see myself, and that might not be too easy (laughs) but, I mean, everybody does it so I guess I console myself with that. And I think I'll be loved. I'll be loved. (B.J.)

> I probably never would have gotten through it (crisis) if I hadn't had my faith. (Beth #2)

> I think that believing that God exists helps you to live without answers to your questions. (Mark)

The ways that participants discussed Something Beyond in the rebuilding phase indicated that it was a central aspect of this phase.

## SUMMARY

The two phases of spiritual distress, Breaking the Web and Rebuilding the Web, described two interrelated experiences. Breaking the Web was described when people become aware of some event that broke into their lives, often suddenly and

unexpectedly. Immediately there was a diversity of feelings; of hurting, of feeling unstable, and of devastation. In the midst of pain there also was a sense of something beyond that will provide comfort and support. The Breaking phase is one of intense questions and wondering--sincere doubt and puzzlement about the ways of the world and of God.

In the Rebuilding phase the wondering continues, but with the sense that there will not always be answers. With an acknowledgement of a limit to rational knowing comes an acceptance and a renewed sense of wonder at the mystery of life. Feelings that were reported as occurring during this time were of stability, strength, and security. There were also feelings of excitement at the perfectness and pattern of things in the world, including one's life. Beliefs in God, or in Something Beyond, were reported as at the core of the Rebuilding phase. Overall, participants expressed a sense of gratefulness for all of life, and responded by using their new knowledge about the world to benefit others.

# CHAPTER V

## DISCUSSION

### INTRODUCTION

A general discussion of the results of this study will be followed by a discussion of the thematic structure of the experience of spiritual distress. Results will be related to previous studies, and implications for nursing practice, nursing education, and nursing research will be addressed. Finally, suggestions will be made for further refinement and validation of the nursing diagnosis of Spiritual Distress.

### DISCUSSION OF FINDINGS

The purpose of the present study was two-fold:

1. To describe the experience of being concerned about the meaning of life/death and/or beliefs among adults in the general population.
2. To describe the experience of spiritual distress in order to evaluate the nursing diagnosis Spiritual Distress for appropriateness and sufficiency of its definition and defining characteristics.

These purposes were met through the rigorous application of phenomenological interview and analysis methods. Ten adults were interviewed and an analysis of the transcribed interviews provided a description of 54 experiences. In 34 of these experiences, participants were concerned about meaning but were not spiritually distressed, while in 20 of the experiences participants experienced spiritual distress. The diversity of events mentioned by participants suggests that spiritual distress cannot be predicted from the type of event. For some participants, what made the

event distressful was the arousal of emotions, while for others it was the sudden loss of people through death or the struggle to make sense out of what was happening. The results of this study reinforced that being in a crisis situation does not necessarily catapult a person into thinking about the meaning of life. In my work as a parish nurse I remember being astounded that a man I was visiting in the hospital, who was recovering from a cardiac arrest on the golf course, never talked about what that experience meant to him. Similarly, one man in this study said that times of serious illness or the sad times in life were not occasions for him to be concerned about the meaning of life. His illness (cardiac problem requiring bypass surgery) had come on so suddenly that there was no time to think about those things, and, when the problem had been resolved, he was just relieved it was over. He said that he thought about the meaning of life during quiet times by himself or during happy times.

Another participant (Frank) also experienced thinking about meaning during pleasant events; the births of his two daughters and a time in Vietnam when he heard orphaned children singing Christmas carols. Looking at what made these happy events stressful is helpful in understanding what may be distressful in non-crisis situations. For example, the births of his daughters were happy times, but ones of such intense emotions that they were frightening to him. His emotions were "stirred" to the point that he feared he might lose control. He said that being in control was important to him because it made him feel like the situation was under control and stable:

> Well, it's both...it feels good, but then again it's ...it's kind of scary dealing with something that you don't feel very often. You know, when

> feelings are stirred. I think it's something that you can't control so you're...sort of the fear of things being out of control.

His other experience was in Vietnam when children from an orphanage sang Christmas carols across the base's perimeter fence amidst the sounds of war. Again, it was, on the surface, a pleasant experience within what he described as the relatively secure and stable environment of the military base. But because he was emotionally moved in a way that rarely happened, it was disturbing to him. This movement of emotions in addition to the potential for a turn of events were both frightening to him:

> With those children...it's how...Why is this happening? How could they respond and act and bring such a thing of beauty in the midst of all the ugliness? I guess, in a sense, the frightening thing about that is that if something so beautiful can come out of ugliness, can beautiful things turn ugly too? I mean, it seems reasonable to think that if one can happen, surely the other can too and...I guess that's scary.

For those experiences participants described as spiritually distressful, the structure of this experience had two phases. While separated for purposes of description, they are interrelated and interconnected parts of a process of rebuilding life following a tear in life's fabric. This tear in the fabric of life which characterized the first phase of the experience of spiritual distress began when an event broke into time and altered the continuity of a person's life. Although there were a wide range of events of this type described by participants, the event often was one that occurred suddenly or unexpectedly, did not fit within the natural order of things or did not make sense, and was often tragic and emotional. During this phase, the person experienced feelings of falling apart, instability, and/or painful emotions which, for some people, were mitigated by a sense of something beyond the self that provided

comfort and support. Throughout this phase there often was intense wondering that involved trying to understand or make sense of what was happening.

The second phase, in which the person attempts to rebuild his or her life, begins within the first phase as the person begins to cope with the situation in terms of skills that worked in the past or draws upon new ones. Resources for support are sought from friends, family, and religious and/or spiritual beliefs. Initially, all energy is focused on survival, and there is little time to question the meaning and significance of the event. When some stability has been achieved, and the person has time in which to think, information is sought to put the pieces of life back together.

During the rebuilding process, the web in rewoven, thereby encapsulating the break, and making the web intact and functional once again. This is reflected in the themes of stability, strength, and security that participants talked about in phase two. These themes are similar to those of the resolution phase described by participants of Seidner's (1988) study of the phenomenon of "Falling Apart." His participants reported making reconnections with familiar people, places, and things and reestablishing control of themselves and their lives. In the present study, many participants were not able to make reconnections with people because of the separation that death had caused. They had to reconnect the pieces of their lives by incorporating the event into a new structure of meaning that they formed.

Participants reported being aware of the change and growth that had taken place in themselves and in their beliefs. Some participants remarked on the pattern that they could now see as they viewed their life from the present perspective. Wondering

in this phase still involved a type of questioning, although at a lesser intensity than in phase one. Unlike the first phase, however, there was now no expectation of an answer. Instead, there was an acceptance that answers would not come as a result of rational thinking. Rather than yielding frustration, such a limitation seemed to make participants aware of other ways of knowing, which some referred to as mystery.

Participants in this study had not become bitter because of the things that had happened to them. Instead, they expressed a sense of gratefulness for life's blessings. Similar to Frankl's (1959) attitude during his imprisonment in concentration camps, they had chosen to see their experiences in a positive light. Choosing one's attitude in any given set of circumstances, Frankl said, is the one human freedom that cannot be taken away from a person. Participants discussed a sense of responsibility following these distressful experiences and the need to help others who were or might in the future experience a similar crisis. This new mode of being is similar to the self-transcendent commitment that Frankl talked about in relation to logotherapy; that meaning can be found through creative actions in the world.

## Thematic Structure of the Experience of Spiritual Distress

### *Phase One: Breaking the Web*

#### Theme 1: Falling Apart

Falling Apart was a phase used by participants to describe aspects of the way in which they experienced the first phase; that of breaking the web. Various words were used to indicate that either they or their world were coming apart. One participant actually talked about "structures falling apart." In comparing this theme with a

previous phenomenological study of the experience of "Falling Apart" (Seidner, 1987), there are many similarities. In this earlier study, Seidner interviewed 12 adults whose ages ranged from 23-44. All were well educated; eight participants were graduate students. The themes Seidner found to characterize experiences of falling apart were: (1) Crying/Pain, (2) Losing/Lost, (3) Alterations in Time, and (4) Feeling Being Out of Control. The setting of Falling Apart was the threatened or actual loss of the familiar world of people, place, and relationships and participants spoke of familiar meanings being gone and an alteration in the continuity of time.

Typical experiences discussed by participants were divorce, a marital argument, a new job, and the death of a close friend. Even a change in a familiar room was described by one person as yielding an experience of falling apart. The diversity of experiences discussed in Seidner's study appeared as broad as those in the present study.

In the Falling Apart of spiritual distress, participants experienced these same themes, although time seemed better represented as a contextual ground rather than as a theme. Participants in both studies perceived similar alterations in the continuity of time. Similar words were used in both studies to describe feelings of hanging on, questioning faith, being isolated, disconnected, and disoriented. The congruence between these findings is interesting and adds a measure of validity to each study.

**Theme 2: Wondering**

Wondering was the part of the distress experience that involved trying to understand or make sense out of what was happening; the event that had disrupted

participants' lives. A vital part of this wondering was a time of asking questions. Questions were asked of God, the self, and about the "why" of the event. Questioning was at an intense level and involved various emotions, such as anger or guilt. If an event that evoked this questioning was extremely traumatic or tragic, a period of not thinking and not feeling preceded questioning.

Before participants could move on to the next phase of rebuilding, they indicated that they had to come to some acceptance that there would not be answers to all their questions and that there were limits to their knowing. Participants talked of the work that they had to do to find meaning in what had happened to them.

Forming new meanings is similar to Bridges's (1980) work on the transitions adults make in life. This process involves letting go of a certain way of being and of experiencing the confusing nowhere-in-between before making a new beginning. Current research in adult development views transition as a natural process of disorientation and reorientation toward personal growth (Denne & Thompson, 1991). The process begins, as in spiritual distress, when events disengage us from familiar contexts. The journey to a larger meaning often involves asking "Why?".

During this time of wondering, participants also reported questioning their religious beliefs, similar to Batson's and Ventis's (1982) interactional religious orientation in which a person is open to new religious ideas, continues to search for answers, and is reflective and critical about religious beliefs. Questioning involves a reformation of a person's cognitive structures that are involved in constructing

meaning. It is this transformation of structures that Fowler (1981) states is a part of moving to a higher level of faith.

While it was evident that participants were trying to form new meanings in this phase, none of them spoke of their lives as being meaningless. Struggling to find meaning in a particular event did not mean being without meaning in life for this group. Although these participants felt free to question their religious beliefs, only one man lacked a sense that there was a spiritual dimension providing meaning during this chaotic period.

**Theme 3: Something Beyond**

Nine of the participants discussed experiencing the spiritual dimension during phase one. Two participants used the word God exclusively while nine participants referred to "something beyond." Something beyond was experienced as a feeling; a loving, comforting, and supportive presence; and a mystery. One man did not experience any of these feelings in his time of distress. The other participants talked of "knowing" that there was something beyond because of their feelings at this time. This knowledge confirmed and validated what they have previously believed about God and gave them something to hang on to or fall back on during this difficult time. This feeling seemed to sustain them in their pain and questioning and direct them forward to new meaning.

***Phase Two: Rebuilding the Web***

**Theme 1: Stability**

Words that participants used to describe this theme were stability, strength, and security. While phase one was one of instability, participants in this phase reported (a) feeling like their life was now stable, (b) they were in control of their life situation and of their emotions, (c) they felt a measure of security, and (d) their faith had become "stronger." The security they now felt was not a false security. They now knew that the would not be protected from painful events because they were "good." But they felt secure in their new knowledge that the spiritual dimension would provide for their needs during such difficult times.

**Theme 2: Change and Growth**

Change and growth occurred in the self and beliefs. Participants noted many ways that they had changed and become "better" people. They talked about becoming more able in many areas of life and having a clearer self-identity. Defining the self in a new way has been identified as a part of transitional processes (Bridges, 1980). Participants reported that this process of growth occurred over time but could not be attributed only to the passage of time. They said that finding meaning was hard work and involved feeling the pain. Batson and Ventis (1982) speak of this change as a transformation process; a part of the mature religious perspective. For transformation to take place, cognitive structures need to be flexible and adaptable as an old reality is transcended. It is often a personal crisis that brings about the most dramatic personality growth. This description of transformation corresponds closely to study

participants' accounts of their experiences of growth and change. Growth and change for them was not a state, but rather a continually evolving process across a lifetime.

Nursing theorists Rogers (1970), Newman (1986), and Parse (1981), include this idea of evolution in their theories in terms of expanding consciousness. Schorr and Schroeder (1989) compare this idea to Prigogine's theory of dissipative structures, which are physical systems driven away from stability to regain it at a higher level of organization. This movement seems comparable to the change and growth reported by participants in the present study. These three theorists emphasize the interaction between the person and environment. As this interaction increases in complexity over the life-span, a person's consciousness, or informational capacity, is thought to expand, becoming more complex and diverse, but with greater unity or wholeness.

**Theme 3: Wondering**

The wondering in this phase is at a different level than in the first phase. It is more a wonder or awe at the universe and the pattern of events that participants can identify in their lives. For many of the participants, there is still a questioning, an asking "Why?", but it is at a lesser intensity. Even though they know that there will not be an answer to this question, they talk about it as a common human behavior, an ongoing attempt to make sense out of the event that will be life-long. Some participants expressed the belief that they would get answers to their questions from God after death.

**Theme 4: Something Beyond**

Participants expressed a continuing and strengthened belief that there was something beyond themselves and this present world with which they could communicate and which would meet their needs. Their belief in something beyond seemed to be the force vital to the rebuilding process during which a meaningful structure of life was reformed and made functional. It is not possible to know from these findings where in the rebuilding process spiritual distress became spiritual growth. As evidenced by the emotion experienced in the retelling of these events, there is a sense in which a person is always vulnerable to reexperiencing some level of spiritual distress at a later time. However, at some point in the rebuilding process, growth predominates over the distress. Perhaps this is the time which one woman referred to as formation of the "scar." While the distress may always be present to some degree in this scar, the structure's new strength and stability allow the wound to be reexperienced without rebreaking the web.

## Nursing Diagnosis: Spiritual Distress

One purpose of this study was to clarify the concept of spiritual distress and to validate and/or modify the current defining characteristics of the nursing diagnosis of Spiritual Distress. From the results of this study a new title, "Spiritual Distress: Potential for Growth," is suggested for the diagnosis. The new title includes the spiritual and personal growth participants talked about in the rebuilding phase. A new definition of spiritual distress is also proposed. The current NANDA definition of spiritual distress is "a disruption in the life principle which pervades a person's entire

being and which integrates and transcends biopsychosocial nature" (Hurley, 1986, p. 543). This definition suggests a disruption, break, confusion, or disorder of the person's spirit. The new definition of spiritual distress that is being suggested is: "an uncomfortable experience of spiritual and/or existential struggle within which there is potential for growth." This researcher also suggests that the following defining characteristics be added to the present list, based on the findings of this study:

1. Verbalizes feelings of falling apart, pain, and/or instability.
2. Verbalizes feelings of something beyond.
3. Chooses to make a positive response physically, emotionally, socially, or spiritually to crisis.
4. Accepts limits to knowing.

The current defining characteristics adequately encompass the dimension of questioning that was so important to participants of this study. The present study validates the inclusion of psychosocial behaviors as defining characteristics. This overlap with the psychosocial has been seen as a difficulty in studies of spiritual distress (Highfield & Cason, 1983; McHolm, 1991). Because spiritual experience is more of an internal process, it is visible more often through the expression of emotional behavior. These behaviors may be the first indications of a patient's distress. It is important that the nurse validate assessments of distress with patients. Emotional distress could indicate a wide variety of problems, not only spiritual distress.

Of the current defining characteristics, the majority were validated in this study. The characteristic "Unable to participate in usual religious practices" is probably an antecedent to the diagnosis, and it is recommended that it be removed from the list. Although "Gallows humor" and "Displacement of anger toward religious representatives" were not discussed by participants in this study, these have been observed often enough in this researcher's clinical experience to suggest retention of these pending further research of the diagnosis.

Additional characteristics of spiritual distress that have been identified by others in the literature were presented in Chapter II. Authors such as O'Brien (1982) and Dugan (1987/88) bring to our attention that being concerned about meaning in life is only one aspect of spiritual distress, although an important, and perhaps central, one. It is necessary to explore the other aspects of spiritual distress suggested in the literature before the concept of spiritual distress can be fully described. It seems especially important to research the connection between relationships and spiritual distress; relationships to self, others, nature, and God were found to play an important role in spirituality in both Barker's (1989) and Burkhardt's (1991) studies of women's spirituality.

Moberg's (1979) theoretical dimensions of spiritual well-being (religious and existential), which are the two dimensions measured on Paloutzian's and Ellison's Spiritual Well-Being tool (1982), may not adequately capture the concept of spiritual well-being. This present study suggests that questioning and critically examining beliefs as well as accepting limits to knowing may also characterized spiritual well-

being. The former idea is also maintained by Batson and Ventis (1982). Furthermore, Moberg's conceptualization of spiritual well-being and the Spiritual Well-Being instrument emphasize the person's relationship to God in a manner that may not be relevant to non-Christians. The items on this instrument are phrased in terms of a personal relationship to God which is more characteristic of a Christian perspective.

The characteristics of the rebuilding phase of spiritual distress found in this study may be a result of the uniqueness of the present sample. This was a group of ten healthy people who were functioning in a highly integrative manner. All have purpose in life and are living out their values and beliefs. In addition, religious and/or spiritual beliefs are very important to this group. Many nurses encounter people at times of crisis who are not functioning in a healthy manner, and not all people have spiritual resources to draw upon in times of crisis. How these people might describe spiritual distress at such times might be quite different from the way a healthy group reflected on their past experiences of distress. However, it is the belief of this researcher that there is a lot to be gained by studying health and healthy populations. It is evident that studies on illness and disease predominate and that health and the healthy are underresearched areas. Perhaps it would have been more beneficial for researchers to have thoroughly studied health before studying illness.

Present results indicate that spiritual distress can be an opportunity for growth and change; that is, the distress and its resulting "scar" can be transformed into something meaningful. The individual experiencing distress may initiate this

transformation or may need some assistance in the process. In either case, the experience does not need to be "cured" or "solved" by the nurse. The nurse, in fact, may be peripheral to the healing process. If a patient remains "stuck" in distress, the nurse may be able to play a role in getting the person moving toward a meaningful future. Because the perspective of the current nursing diagnostic framework is one of treating problems, study results regarding the potential growth inherent in the distress experience may not be construed by NANDA as an appropriate addition to the diagnosis at this point.

## Implications for Nursing

### *Nursing Practice*

#### Assessment of Spiritual Distress

Spiritual distress is not a common term, so it was not surprising that participants in this study were unfamiliar with it when they saw the term on their information and consent form. In the course of the interviews, only two participants recognized their own experience as one of spiritual distress or spiritual crisis.

> But I had a spiritual crisis again when he was sick. When (husband) got sick, there was a part of me that didn't want to believe that all that work and all that goodness wouldn't protect me and him from an illness that would most probably and did end in his death. And he was good too and did all that was expected of him in serving and being God's man, so to speak. So what kind of a reward could we expect for at least trying hard and if God is in the reward and punishment business then why pick us when there are far worse out there...and far better too (laughs) who also have to suffer? (B.J.)

> I suppose it is spiritual distress that I was experiencing. When you first said that I thought...aaahhh...I'm not in spiritual distress. But then of course that's what it was. He had six really bad weeks and then he had

> another six weeks...And, you know, just working through all of this. (Jean)

Thus, it is unlikely for a person to recognize their distress as spiritual in nature. Participants were aware, though, of trying to make sense of things, to fit the pieces together, or to understand why something was happening to them. They were aware of many feelings which were often quite distressful. Emotions were close to the surface and overflowed in tears during the interviews, even though the events to which they referred had occurred up to twenty or more years ago.

From these findings, it is likely that the first indication a nurse may have that a patient is in spiritual distress is when the patient verbalizes feelings or acts in an emotional way. Dugan (1987/88) points out that the spirit speaks through the partly conscious and partly unconscious phenomena of emotions and dreams. The nurse must be very observant of non-verbal behavior and listen carefully to what is often symbolic language. If the nurse is comfortable being with the patient at these times, and indicates a willingness to listen, the patient may describe his or her feelings as indicated in these participant's statements:

> And I might not be inclined to tell her unless she established some trust and I don't know exactly how you do that 'cause I've seen enough nurses to know that some nurses could and others would never get it done but depending on how I felt about the nurse, yeah. But that's you know, getting pretty close to stuff you don't talk to strangers about. You're always putting yourself at risk when you expose yourself too. (Clyde)

> A lot of my personal struggle is mental. I'm a very inward and introverted type of thought processing person and so a lot of my struggles do happen inside of me and rarely do they ever get vocalized. (So how would people know then that you were struggling?) Oh, they don't! Not even my wife. My wife rarely knows when I'm struggling with issues of

> that magnitude. (You don't usually tell people that you're struggling.) No. Not unless they ask. It's not something that I offer people. (Mark)

If patients are in the first phase of spiritual distress, they may report feeling hurt, sad, scared, anxious; they may also report feeling out of balance, out of control, falling apart, unstable, or coming unstuck:

> You start to cry, I suppose. That's certainly part of it. And have more trouble...my unstuck is probably...I can still cope...pretty well. I'm as you have said...I am very practical...quite pragmatic. You would know in my office. I was not feeling very good those couple days. I don't look right. Function, I can, but, you know, I'm not that great a poker player and I look pretty unhappy. I think probably that...the other thing, you know...it('s) probably body language. You just don't have...obviously, the bounce goes out of one's step and all those kinds of things. (Jean)

At the height of the crisis when emotions are intense, patients may try to protect themselves from these emotions by maintaining objectivity, keeping busy, and trying not to think as one participant (Jean) did:

> But also I kept myself in many ways kind of objective to the whole thing and I dealt with what was I going to do? I kind of kept somewhat aloof. I went everyday. I talked to the people. I couldn't really communicate. He wasn't Dad. He really couldn't communicate. And I don't know if it hurt so much or what, anyway...I kept myself emotionally far away.
>
> What I discovered was if you keep busy and keep doing things and you keep focused on doing something, it will get you through and sitting, doing nothing, doesn't work well for me. It's whatever you need to think about is too painful then you go do something you can deal with.
>
> She went to turn him and he shut off and had a respiratory arrest right then. Afterwards, oh, several weeks afterwards, one of the nurses told me blow by blow what had happened...which was not great. And so I went in...and I didn't think, you know, I just purposely didn't...I couldn't do anything about it.

Dialogue was mentioned as being the thing that was most helpful to participants when they experienced their world as falling apart:

> After the fact, if there's a setting...support group setting or a group setting where I am allowed to verbalize my struggles...that is a place where I vocalized struggles. (Mark)

> Well, it took me three years to really cry real hard over my dad dying so I knew I was very susceptible to keeping stuff in and not dealing with it. She helped me, the counselor helped me, to ask me the right questions. (Mark)

> He (minister) helped me talk about the situation, how serious it was. So that helped me a lot. Plus it gave me more courage to, I don't know why, but it just gave me courage to face up to what was going on. (B.J.)

> And she felt better--obviously better and I did too just, you know, talking about it again (surprise evident in voice). (B.J.)

> One of my best friends is in (a) similar situation and so I have a lot of time that I discuss things with her. She and I keep the phone hot most (of) the time. Her children's father was killed and she raised her two children like I did. And my sister-in-law, also, when my brother was killed. She had to raise her three girls. So I have a lot of people that have the same type situations. (Beth #2)

> But time, talking about it, thinking about it, certainly helps. I find that even until fairly recently I still had trouble with (niece's) death (20 years ago). (Jean)

The importance of dialogue is present in the classical Biblical example of Job's suffering. It is interesting to note that Job asked many of the same questions that were asked by present participants. It was through dialogue with his family, friends, and God that Job came to an understanding of his suffering. Dialogue is also one of the most important ways that nurses can help people through spiritual distress. As mentioned before, to dialogue with patients, nurses must attend to developing trusting relationships. It is this trusting relationship to which Jourard (1971) referred when he spoke about the effects of confirming behavior. When a patient senses care and

concern from the nurse, it reinforces that person's sense of self, energizes their spirit, and promotes self-healing.

One indication that patients may be in spiritual distress is verbalization of questions (as illustrated in the previous chapter). There may be many "why" questions, and these questions may be concerned with either religious or philosophical issues. Often, such questions indicate that there is a conflict between beliefs and the nature of the distressful event. Nurses can tell their patients that questioning--even of God--is a natural endeavor; part of being human and trying to make sense out of the world. Elie Wiesel (1988), writing about his concentration camp experiences during World War II, quotes his religious teacher in reference to questioning God:

> "Man raises himself toward God by the questions he asks Him," he was fond of repeating. "That is the true dialogue. Man questions God and God answers. But we don't understand His answers. We can't understand them. Because they come from the depths of the soul, and they stay there until death. You will find the true answers, Eliezer, only within yourself!" "And why do you pray, Moche?" I asked him. "I pray to the God within me that He will give me the strength to ask Him the right questions" (p. 15).

Thus, the assessment of a person experiencing spiritual distress requires that the nurse listen carefully to the words used by patients to describe their experiences and the questions that they raise to make sense out of their experience. The nurse must also attend to nonverbal behavior and even symbolic language in which the patient attempts to talk about a spiritual experience or something beyond.

**Nursing Intervention in Spiritual Distress**

To be able to move through the distress, participants indicated that it was necessary, at some point, to dwell with the pain and experience it. Here is one participant's reflection on this:

> But I'm not sure that human beings are really capable of gripping that knowledge (of life and death and there aren't answers to everything) in a non-crisis situation. I haven't fully researched this in my mind yet but I'm almost convinced that it takes a crisis situation--divorce, job loss, death--to really open up yourself to be vulnerable enough to deal with these issues. It takes some pain and some instability. It takes your life to be turned, to become unstable in some way and to know that you don't have it all sewn up in a nice little box and it takes something to rip away that little container that we think we have everything all secure in in order to help us really wrestle with the real issues. (Mark)

Words such as instability and falling apart indicate a need for support. The nurse can ask the person to think of things that they used to support themselves in the past. In this context, patients may very naturally talk about religious beliefs and practices that they draw on in times of crises, as the following example suggests:

> I think they (beliefs) were very crucial. They allowed me a lot of stability as far as my emotional health. They...it allowed me...a place to turn. Cause I had my God to turn to with my pain and my questioning and my agony and even though at times it was very lonely for me I never really felt alone because I knew that I had a place to turn. A lot of people don't have that place to turn. (Mark)

Nurses should ask their patients to indicate the specific ways in which they can help them gather supportive resources within the healthcare setting. Dugan (1987/88) suggests that the role of the nurse is to facilitate a connection between the person and his or her own internal resources of meaning and self-acceptance. Prayer may be one way to facilitate this. If prayer is important to a person, the nurse can ask the patient

how he or she usually prays and if the person wants the nurse to pray. The importance of prayer to people who are in crisis was affirmed in my parish nurse work. Often, people said that they were too ill and did not have the strength to pray and welcomed someone praying on their behalf. When I made rounds to patients the evening before their surgeries and asked if they would like me to pray, no one refused. Prayers can be brief and simple, including patient requests or reciting with someone their favorite prayer. Sometimes, as in the following example, patients who are suffering may accept any type of prayer on their behalf:

> I was very grateful for what things happened when I was very frightened and anxious. We prayed and I wasn't anymore. That nurse who was a Baptist. She told me that she asked Jesus to put a fence around the anxiety and he did. And I would have laughed at her as, you know, someone who is so naive that would just say "Jesus, put a fence around this." (A.Q. Biddle)

In giving spiritual care, the nurse must be sensitive to and respectful of a patient's cultural and spiritual beliefs. Giving spiritual care from a particular religious perspective, as in the above example, could be offensive to some patients. It would be best for the nurse to (a) ask patients to suggest ways for the nurse to assist with spiritual needs or (b) obtain permission from the patient to respond to their spiritual needs from one's own spiritual perspective.

Establishing a trusting nurse-patient relationship should be the first step in providing a safe environment in which patients can talk about personal experiences and beliefs. During her interview, one participant said that she felt "pretty safe" in telling me about her beliefs, but that "I know a lot of people would be very disturbed if I were to say exactly what I believed about certain things. I mean I would have to

watch my language carefully and I'm not into getting into a big debate and causing a big rift or something like that." She said a safe group to talk about these things would be one in which she "wouldn't be judged too harshly if I did believe (a certain way."

Participants stated that recalling experiences over time and in the interview process itself made the experiences become more meaningful:

> I think at the time that is...was going on I didn't...I didn't give it a whole lot of thought, but it's a memory that...that stayed with me more than any other experience I had while in the Navy. I think as time went on...that memory staying with me...the importance of it to me...grew. I think now the memory's probably more meaningful to me than the event was when it was actually happening...going on. (Frank)

This may be the beneficial aspect of the interventions of reminiscence and life history review as currently used with older adults (Haight & Burnside, 1993; Kovach, 1991; Stevens-Ratchford, 1993). Haight and Burnside distinguish between reminiscence and life review. They consider reminiscence a basically pleasant psychosocial activity of remembering, while the life history review is an intentional therapeutic intervention which encourages a person to work through painful memories to achieve a personal integrity. Life history review helps persons to reframe, or find meaning in past events.

Frank, whose quote was used above, attributed the change that he was aware of in himself to the remembering of the event:

> Things are out of control. Things are shifting. I can see that they're shifting...or have shifted. In the case of the memory of the children singing it's the memory that has initiated the change more so than when the event was actually happening. Yeah...there was some feeling...there's some scariness there. And, you know, it's not that anything's changing

> for the bad. You know, both of these experiences I think have...have come out with a positive end. So, you know, that's not what might happen. It's not so much what scares me. I guess it's just there's something happening (chuckles).

(The complete transcript of this interview can be found in Appendix D).

Making meaning in life is an ongoing process, as shown in the Vietnam War vignette described above. This man saw more meaning now in the event than when it originally occurred. An event, in this sense, is never really "over with." Like the image of the scar, it is always a part of life. When as event can be brought within present awareness, there is the possibility that remembering will re-configure the event.

Forming meaning in life involves integrating events into an understandable pattern, a meaningful whole (McGuire, 1981). Several participants remarked that they could see a pattern or path to their lives. The participants in this study have successfully integrated a diverse number of sad and happy events into their webs of life. They see their beliefs as continually evolving and it seems as if their meaning structures have a flexibility and openness to them. Batson and Ventis (1982) talk about this in terms of a mature religious perspective. One man talked about the benefits he has discovered by broadening his own belief system:

> If I were a nurse and deal with people and exposed to people as I see them and in the way so many people are so they limit themselves so much in what they will allow themselves to think or believe or anything else. It puts you in a frightening world. I mean I would be intimidated and frightened. I can think of a lot of friends in this. They just...you can't say conservative or liberal because you can find them in any aspect of conservatism or liberalism or fundamentalism or...I don't know...existential...or any aspect. If they're narrowed in on only one thing and that's the only thing that's comfortable with life would be just

> frightening if you throw something at them that doesn't fall within the framework of that. And I guess somehow this book and these discussions and this searching and everything allows the outside things to come in. Instead of being a threat they are a stimulus. They are an exciting experience. Let's go out and let's go pursue that (laughs). (Ace)

The results of this study may help the nurse to know when patients are struggling with finding meaning. The nurse's role in this struggle is to encourage the patient to be aware of feelings, be open to new ways of thinking, to not be afraid of the questions, and to look ahead to the new meaning that is possible as a result of the event.

If the nurse identifies that the patient is experiencing spiritual distress and the nurse sees no indication of rebuilding present, he or she may decide to intervene and suggest ways for the patient to begin this process. If, on the other hand, the patient already shows signs of beginning this process, the nurse does not need to intervene, but to support the individual as the process continues. What is most important to be learned from this study is that thinking about the meaning of events is not necessarily a problem. It would be more helpful for the nurse and patient to see spiritual distress as an opportunity for growth and change. Of course, when the patient is not able to move out of phase one, spiritual distress is a problem that could be detrimental to a person's health.

One of nursing's roles has always been to create a healing environment. An environment that is conducive to finding meaning may be one that allows the patient some time in solitude. Steeves and Kahn (1987), in a study of the experience of meaning in suffering, describe a phenomenon that has been extensively observed by

nurses in hospice settings. Individuals who were considered to be coping with their illness talked about various types of transcendent experiences they were having in which they experienced their situation changed and their suffering temporarily lifted. Examples of these everyday experiences were working in the garden, listening to music, and walking the dog. Individuals who were having a difficult time dealing with their suffering and not coping, were not having transcendent experiences or "experiences of meaning." During transcendent experiences, patients were able to access something more important than self. These authors viewed such transcendent experiences as beneficial to a patient's well-being and suggested that patients need times of solitude. Nurses can create an atmosphere for these helpful phenomena to occur. One man in my study emphasized that he thought about meaning more often when he was happy, by himself, and had time to think.

A few participants talked about dealing with the crisis by keeping a journal or through music. Music was helpful as a mental distraction and as an emotional connection or release:

> I realized I could not play the violin if I wasn't concentrating on the music and that relieved the stress because I could concentrate. (B.J.)

> There's something about the emotional stuff in music that I could sing something and get the sense of it and feel it...I got a deeper meaning of what it was in my body when I sang. (B.J.)

> For a very long time I could not sing hymns in the church. I would just explode in tears. Music to me is a very moving thing. I'm not a passive person and people couldn't understand why was this woman at church was crying like that, you know, but that's the way I am, you see...music does that to me. (Greg)

One woman's use of the word "scar" in reference to the break in the web of life caused by a parent's death evokes a helpful image which is applicable to the experience of spiritual distress. When an event breaks into life, a person is wounded. There is an injury into which scar tissue grows, and the wound will be present to that person in the form of a scar for the rest of life. Just as it is important to have looked at a surgical scar to incorporate that event into one's life, looking at an event can teach us "...that there is meaning to life, difficult though that meaning may be to fathom--a much deeper meaning than we had thought possible before we became survivors" (Bettelheim, 1979, p. 150).

People who have been touched by life are not the same as they were before they were wounded. No longer is there that naivete about life. No longer do they feel that they will be protected from hurt because of their faith or goodness or right actions. They realize that they are indeed a part of the randomness of the universe. But most of all they have come to a larger understanding of their world and their place in it. They feel more a part of humanity and feel an obligation to care for others in that humanity. They have a new type of security and stability and a greater sense of being loved than they ever had before. They may be convinced that there is indeed Something Beyond that gives them tangible comfort or that relates to them personally. For those who are able to experience Something Beyond, this may provide the necessary support needed between the Break in the Web with its Falling Apart and the Rebuilding in which a re-formation of being-in-the-world takes place.

## SUMMARY

This discussion has focused on how the nurse can care for people in spiritual distress. Healing involves more than the physical; it involves integrating the physical, social, intellectual, and emotional levels of a person. The spirit has been conceptualized as a force which integrates these levels; therefore, it is important that the spirit be considered in caring for patients. As a vital process, the spirit needs to be nourished, and many nurses need to become aware of their role as spirit nourishers. Donley (1991) urges nurses to reclaim their "mission," or nursing role in spiritual care. This role involves a compassionate presence, meaning giving, and alleviation of suffering.

### *Nursing Education*

Teaching nursing students about spirituality falls within teaching about value-belief patterns (Gordon, 1987). It continues to be important that nurses learn about specific religious beliefs and practices so that their care will be given with respect to the person's belief structure. In addition to providing learning that addresses specific religions, knowledge is also needed about spirituality and its role in health and healing. Nursing acknowledges that religious and spiritual dimensions are a significant aspect of human experience. Because nursing values these dimensions, it has a responsibility to educate its current and future practitioners accordingly. This study has shown that values and beliefs are manifested in one's thinking, emotions, and actions. Teaching, then, about beliefs and values should include a focus on how these are manifested in human life.

Another important aspect of helping nurses to interact with their patients on a spiritual level is to include in their education a unit which focuses on values clarification. The curriculum could include journaling or other types of learning experiences which help students understand their own value-belief system. Before they can assist patients in spiritual growth, nurses must first be aware of their own foundations and the areas that they need to develop to have a healthy spirituality. Although not all students will value spirituality, they need to realize that they and the persons in their care will have some structure of beliefs about the world that will come into play in health care situations. If nurses have a broad understanding of (1) how values and beliefs are formed, (2) their importance to humans, (3) the implications of conflicts between these systems for health, and (4) ways to ameliorate these conflicts and their emotional manifestation, then they may be more confident to serve as a resource during times of spiritual distress.

***Nursing Research***

In this study, a phenomenological approach was selected to describe the human experience of being concerned about meaning, a crucial element of spiritual distress. Prior to this study, the phenomenon of spiritual distress had not been explored using qualitative methodology. This methodology was chosen because of its ability to clarify lived experiences. The breadth and depth of this study's findings have furthered the task of understanding the experience of spiritual distress and clarifying the concept for others. Ten participants have told us in their own words what it was like for them to be in spiritual distress. We know that this experience involves two

phases, each with a structure or pattern that can be identified by the words, words that nurses probably hear every day from their patients. With this new knowledge of the spiritual distress experience, nurses may be able to better "tune in" to spiritual concerns and to work with their patients as they attempt to rebuild their lives around a disruptive event.

A primary concern of nurses is how to facilitate the formation of healthy living patterns through interpersonal interactions with patients. Even the nurse who has had an experience similar to a patient's cannot know what that experience is like for the other person, because each person gives experience its own unique meaning. By using phenomenological methods of interviewing, a broad variety of human experiences can become known to the nurse through the use of structured techniques of analysis. Interpretation of human experiences leads to the identification of common themes or patterns in human experience, and it is these patterns of behavior that nurses look for in their patients.

Qualitative methodology offers great potential to nursing to explore, describe, and understand human beings and their ways of living in the world. Certainly, nursing must have a balance between qualitative and quantitative methodologies. Their respective use must be determined by the type of nursing questions asked. One method is not necessarily "better" than the other. When looking for answers to research questions, nurses must consider the method that holds the most potential for getting the answers that will be most useful for the questions being ask.

Spirituality is an underresearched area in nursing. It is an area that has potentially powerful implications for health and healing. Qualitative research seems uniquely suited to this beginning exploration of an area that is not readily amenable to quantitative research methods.

## Suggestions for Further Research

In this study phenomenological methodology was used to describe the experience of spiritual distress in ten adults from the general population. Five of them were men; five were women. All were Caucasian, middle-class, and either were affiliated with or identified with a specific denomination or faith perspective. All perceived their health to be good and placed a great importance on their beliefs. Their ages ranged from 33-66. Thematic structures described the two phases of the spiritual distress experience as Breaking the Web of Life and Rebuilding the Web of Life.

This study is one of only a few that have been done in nursing on the nursing diagnosis of Spiritual Distress. There is still much ground to be covered. To see if the same or similar thematic structure would emerge from asking a different group of individuals the same phenomenological question, future studies might include persons: (1) in younger and older age groups, (2) of other races, (3) with more diverse religious views, or (4) who have no denominational allegiances or interest. Interviews could be conducted with specific populations who were experiencing various types of events that might precipitate spiritual and/or existential struggle, such as acute or chronic illness, recent bereavement, or natural disasters. Patients in

various health care settings or patients who have been formally diagnosed as spiritually distressed could be selected as participants.

In addition to further phenomenological studies, other types of studies could be done using grounded theory or ethnographic research techniques. One method that has been used to clarify interrelated concepts could be used to clarify the concept of spiritual distress. Haase and her colleagues developed a method of simultaneous concept analysis (SCA) to clarify the interrelated concepts of spiritual perspective, hope, acceptance, and self-transcendence (Haase, Britt, Coward, Leidy, & Penn, 1992). As a part of this method, a process model was created with which to guide further analysis and theory development work.

As the phenomenon of spiritual distress becomes conceptually differentiated and theoretically grounded, quantitative studies could be conducted using instruments developed from the conceptual base provided by qualitative studies. This conceptual base could also lead to the development of tools specifically designed to assess spiritual distress. Based on both qualitative and quantitative research, the future nurse will know both when to intervene and which interventions are likely to be most helpful when their patient is spiritually distressed. It is hoped that this study will encourage nurses to further research not only spiritual distress but spirituality in general in relation to the nurse's role and the role of the spirit in health and healing. Such studies will help to provide the nurse with the knowledge needed to relate confidently to the spiritual needs of patients.

## CONCLUSION

The title for this study, The Wonder of Meaning, represents the heart of the study. As discussed earlier, the word wonder has two meanings that fit well with this study. Wonder as in "to be curious about, a puzzlement, or doubt" and wonder as in "to be in awe of." Wonder, in both senses, is connected with meaning. To find meaning in life is both to wonder and be in wonder.

Ten participants were asked to talk about a time in their life when they were concerned about the meaning of life, death, or beliefs. These times varied from everyday curiosity about the world to being devastated by the death of a loved one. What determined whether one of these experiences would be considered distressful was not whether the event was positive or negative, but whether it was experienced in terms of Falling Apart and Wondering. Although the feeling of Something Beyond was often experienced at these times, it is not present to all people in spiritual distress.

The second phase of spiritual distress, called Rebuilding, consisted of the feelings of Stability, Wondering, and Change and Growth. There is evidence that the second phase gave meaning to the first phase. Some persons may be stuck in phase one, either because they have not come to terms with the reality of there not being answers to everything and/or have not been able to experience something beyond. Growth may be possible only when pain is acknowledged, when one is open to the transcendent dimension, and when limits to knowing are accepted (Trice, 1990).

This quote from Ashurst's and Hall's book on Understanding Women in Distress (1989, p. 10) seems a fitting conclusion to this study. If we replace the word "therapist" with the word "nurse":

> The nurse is like a sherpa or mountain guide who knows something of the terrain and is more familiar with it than the person he or she is guiding. The sherpa cannot, however, take the steps for the traveller or stop him from experiencing some further pain on the way: but can, by his or her presence, support and reassure and take away the loneliness and terror of the journey.

It is hoped that this study will help the nurse to be a good guide for patients experiencing spiritual distress.

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# APPENDICES

## APPENDIX A

## INFORMATION AND CONSENT FORM

I am conducting my doctoral research in nursing. The purpose of my research is to explore and describe the ways people experience spiritual distress. For this study spiritual distress is being defined as a concern about the meaning of either life, death, or beliefs.

The study consists of two parts:

First, you will be interviewed for approximately an hour. The interview will be audiotape recorded. A demographic data sheet will be given to you to fill out.

Second, a short follow-up meeting will be necessary to discuss my analysis findings with you. Your feedback will be an essential part of the research process. There are no anticipated physical or psychological risks involved in this study. The knowledge gained from your participation will help nurses care for persons experiencing spiritual distress.

Confidentiality will be maintained in the following ways. Only pseudonyms (an imaginary name of your choice) will be used to identify the audiotapes and transcripts. I will personally transcribe all interviews. A university research group will be reading the interview transcripts as a part of the research process. Confidentiality statements will be signed by group members. Transcripts will remain in the possession of the researcher. Transcripts and audiotapes will be stored in a locked file at the researcher's home. Audiotapes will be erased at the end of the study.

Participation in this study is voluntary. Refusal to participate will involve no penalty. You are also free to withdraw your consent at any time without penalty. If you have further questions about this study, do not hesitate to call me.

Carol J. Smucker, R.N., M.A.
Nursing Doctoral Student
University of Tennessee-Knoxville
Home Phone: 984-4079

I have read the above information and consent form and I agree to participate in this research.

_____ _____

Signature Date

# APPENDIX B

## INTERVIEW PROTOCOL

Phenomenological Question: I'd like you to think about a time in your life when you were concerned about (or trying to understand) the meaning of either life, death, or your beliefs. Tell me what that experience was like for you.

Questions other than the main research question will be asked only to seek clarification or elaboration of the participant's responses such as: "Tell me more about..." or "You said...could you elaborate on that?"

# APPENDIX C

## CONFIDENTIALITY STATEMENT

As a member of the research group of either Dr. Howard Pollio or Dr. Kathleen DeMarrais, I pledge to maintain confidentiality of all data discussed in these groups from the transcripts of Carol J. Smucker's nursing dissertation research study entitled "Spiritual Distress: A Phenomenological Study".

**Signatures**

Researcher _____ Date _____

Research Group Member_____ Date_____

# APPENDIX D

## DEMOGRAPHIC DATA FORM

PSEUDONYM _____

GENDER _____

AGE _____

MARITAL STATUS _____

EDUCATION _____

OCCUPATION _____

RELIGIOUS AFFILIATION _____

IMPORTANCE OF BELIEFS _____

PERCEPTION OF CURRENT HEALTH STATUS _____

_____

## APPENDIX E

## FOLLOW-UP LETTER TO PARTICIPANTS

TO: Research Participants
FROM: Carol Smucker
DATE: 9/23/93
RE: Thematic Structuring of the experience of being concerned about the meaning of life/death, and/or beliefs (Spiritual Distress)

First I want to thank you for talking with me about some very emotional times in our lives. I was emotionally moved to hear your stories and excited to learn of the ways that you had dealt with some very difficult circumstances. Your stories give much food for thought for nurses encountering people in the midst of suffering. Based on what you have told me, there is much hope that nurses can give to people--good does come out of the bad--if people are willing to experience the pain and work through it.

The enclosed diagrams illustrate the thematic structure of the experience of being concerned about meaning derived from an analysis of your words. The experience has two phases. The first, called Breaking the Web (as in web of life) has three themes. These are: Falling Apart, Something Beyond, and Wondering. The second phase is Rebuilding the Web and its themes are: Stability, Growth and Change, and Wondering. Each theme has its subthemes. Falling Apart includes pain and instability; Something Beyond is experienced as a feeling, presence, and mystery; and Wondering involved questioning and trying to understand. In phase two, Stability includes strength and security; Change and Growth involve both the self and beliefs; and Wondering in this phase is more a realization that there are not answers and an acceptance that there are limits to knowing and often a sense of wonder or mystery. I have found evidence of all themes in all ten interviews. And this is where your input is needed for me to conclude my study. I will be calling you within the next week to talk with you about this thematic structure. Have your transcript handy so that we can refer to it together. What I am interested in knowing at this point is whether or not the structures of the experience are truly representative of your experiences that you have told me about. You do not have to agree with me! The structures can be changed. I have been able to find in every transcript examples of all structures and the research group that has been helping me interpret your experiences is satisfied with the structures. However, you are the ones who had the experiences, and you must be satisfied too!

I look forward to talking briefly with all of you about my results. Thanks again for all your help. Interviewing all of you has been a growing experience for me and I hope for you too.

Sincerely,

Carol J. Smucker

## APPENDIX F

## SAMPLE TRANSCRIPT: FRANK

C: I'm interested in having you talk about what it was like to be concerned about the meaning of life, death, or your beliefs. What that experience was like for you. If you can think back to a time in your life when you thought about those things and tell me about that experience.

F: The most immediate occasion that comes to mind is at the birth of my first daughter. I attended the birth, you know, I was there with my wife when it happened and I was...after the baby was washed and so on it was put in my arms to hold while they finished dressing my wife and all and it was...I guess the question kept running through my mind 'Well, what does this little creature know?'. And I think the reason the question occurred to me was that she was...the baby was quiet and she was just...had her eyes open and quiet and seemed very alert and was looking straight at me. When I say looking--knowing probably her vision wasn't really developed in any meaningful way--nevertheless, there seemed to be some sort of understanding...or knowledge...or something that seemed to be on the look on her face and that left an impression on me and much the same kind of experience happened with our second child for me that was recalled and the second child...she was quiet and alert and just...I felt she was looking at me...very deeply.

C: So it was a real personal experience.

F: Well yes, yes indeed.

C: Somehow, your question about what does she know was related to you. Can you talk about that a little bit further?

F: Well, at the...about everything that rationally I could figure out, you know...she would know nothing. I mean, she'd just come into the world (chuckles)...What could she know? So, therefore, the question--'What does she know?' And if she knows...a newborn child knows anything then it sort of says to me there is a meaning to life. On the other hand, if a newborn truly is completely ignorant...knows nothing...then the question comes up...'Does life have meaning?'...because, you know, that newborn child is part of life and, you know, I don't think knowing is just a rational consciousness, although it's the way we usually understand the term. I think in our deepest thoughts, if we're really truthful we know that knowledge goes beyond just...just rational consciousness.

C: So, like you kind of saw reflected in the child's eyes, a knowledge that perhaps wasn't even conscious, or intellectual...

F: Well, it couldn't be. I mean...it's something (Laughs)... C: MmHm, right. But that perhaps that child had experienced something before she came into the world and you saw that reflected on the child's face.

F: MmHm, right. And, it's the question of 'What does it mean?'. It's the same kind of questions that occur...or occurred to me when...when I was in Vietnam during the war. It was Christmas Eve and I was...I was off-duty and...I...I was just sitting on the steps of the barracks where I was quartered and it was right along the perimeter of the base where I was stationed and it was...the base I was on was inside a suburb of...of Danang...and so there were, you know, the community was right up around it...right up to the...right up to the fence around the perimeter of the base and our barracks was right there and so it was really just a fence like you would have at your back-door neighbor and there was next door to where we were a little school there that was...an orphanage, actually, that was operated by a ...a group of French nuns and the children that were there were orphans...and on Christmas Eve they gathered there along the fence and sang Christmas carols and...that...a...that meant a great deal to me in 'What's it all about?'. And here are these children...their lives have been wrecked by war...Here I was...here we were...several of us American military personnel there hearing them. Here we were for God only knows what reason and yet something...something good and beautiful was happening in spite of the sounds of war that were going off in the hills beyond us there. And at... you know, at the time that...being Christmas Eve of course it was a time of celebration. The downtown portion of the city was just across the...a wide river from where we were located so we could see in the distance which...you know, which was regarded generally as a beautiful thing. And yet...even farther back in the distance we could still hear the sounds of the ugly fireworks of war. So, you know, there it was, peace and war going on at the same time. And in situations like that I think questions about...the meaningfulness or meaninglessness, whatever...of life...comes to mind.

C: It was kind of...there were a lot of contrasts in that situation...

F: Yeah...strong contrasts really.

C: What does it feel like when you have two things that seem on the surface, so dissimilar?

F: I think at the time that is..was going on I didn't...I didn't give it a whole lot of thought, but it's a memory that...that stayed with me more than any other experience I had while I was there...or even in my whole experience in the Navy. I think as time went on...that memory staying with me...the importance of it to me...grew. I think now the memory's probably more meaningful to me than the event was when it was actually happening...going on.

C: It's been an event, then, that you've reflected back on...

F: Yeah. I have reflected on it a lot.

C: ...perhaps has more meaning today than when it actually occurred.

F: It does.

C: So today, reexperiencing that experience, then how does that make you feel?

F: Well it...I guess the feeling...Well, the question of 'What is the meaning of life?' sort of assumes that life has a meaning and sometimes I question that. And I think meaninglessness is probably the big problem rather than what is the meaning...is there any meaning at all?..and I guess...in the first case...I'm pretty much a pessimist. That there's really not very much meaning going on out there or even in here and when...in the few times and places and with the few people that it does happen...I think you really have to hang on to it and treasure that and i do think it's something that happens so rarely...and maybe for not enough people that that...those times and to those people that it does happen to it's something that really needs to be remembered and treasured and celebrated.

C: And so, in those two events--the birth of both of your daughters and your time on Christmas Eve, those were two events that you would consider that had a lot of meaning for you.

F: Yeah. Right. And perhaps for somebody else in those same situations it, you know, it wouldn't...it wouldn't have any resonance, but...

C: So if you could compare and contrast the times in your life where you felt meaning and the times in your life where you felt things were without meaning...what's it feel like in those two different situations?

F: Uh...well, the times where I've...where there's been meaning well I've felt something...and...(chuckles)--I guess most (can't hear next word) of us resist it well--it's hard to describe feeling and sort of hard to describe not feeling too...feeling's something it's hard for me to talk about...
C: Yeah, it is for a lot of men, I know.

F: ...and I'm no exception (clears throat).

C: So, it's hard to put into words, but you have...you can feel it in your body.

F: Yeah, yeah.

C: You know that the emotion's there, but to put it into words is hard.

F: Yeah, I can...there's something going on...that's right, exactly.

C: It's almost at so deep a level that...almost like it shouldn't be put into words, it should just be felt. I mean, that's enough in itself, to acknowledge that it is a feeling that moves you and that it moves you when you feel that.

F: Right. But I...but at the same time...I ...I do think it's important to put it into words if the words can be found to do it. I...some people are successful about it I guess...in ordinary communication, it's more likely women than men. But...

C: Would you say it feels good?

F: What, the expression of feelings?..or..having the feelings?

C: Right..feeling it...actually feeling it. Does it feel good to you when you feel that or is it positive or negative or are positive or negative even relevant to the feelings?

F: Well...it's both...it feels good, but then again it's...it's kind of scary dealing with something that you don't feel very often. You know, when feelings are stirred. I think it's something that...it's something you can't control so you're...sort of the fear of things being out of control and...

C: Is there any experience you experience in everyday life that would be close...close to what you feel at those times?...that you could name?

F: In everyday life?

C: UhHuh.

F: No. Not...my everyday life is...you know, it's I feel in control of what's going on most of the time so...the feelings and affection that I have...like, you know, I love my wife and my family and so on but...I guess...knowing that they're there and so on I feel like the situation's stable and so on so I...there's no...I don't feel the need to have to control anything because it's basically in control and stable...so I'd say that to say...while I don't think I'm unfeeling particularly...I don't feel stirred all the time in terms of my feelings...so...

C: So at these very significant moments that you talked about...then...is the feeling of being unstable and kind of...the fear of being out of control..is that...?

F: Things are out of control...things are...I can...things are shifting...I can see that they're shifting...or have shifted. In the case of the memory of...of the children singing...the...it's the memory that has initiated the change more so than when the event was actually happening. Yeah...there was some feeling...there's some scariness there and...

C: And it seems to be related to feeling out of control?

F: Yeah. Yeah. And, you know, it's not that anything's changing for the bad. You know, both of these experiences I think have...have come out with a positive end. So, you know, that's not what might happen. It's not so much what scares me. I guess it's just there's something happening (chuckles) and...just...

C: And you said it's also a time of...you ask questions.

F: Yeah, right.

C: In both of those situations you've asked questions?

F: I've asked questions, right.

C: And what were some of the questions?

F: Well, with my daughters--'What does she know?'. If she knows anything...then there's a meaning in life. What is it? With those children..It's how...Why is this happening? How could they respond and act and bring such a thing of beauty in the midst of all the ugliness? I guess, in a sense, the frightening thing about that is that if something so beautiful can come out of ugliness, can beautiful things turn ugly too? I mean, it seems reasonable to think that if one can happen, surely the other can too and...I guess that's scary.

C: And you said there's been something that's come out of reflecting on these experiences. Some end point. What's that been?

F: Well, with the children singing, my own commitment to being a part of the community of faith. It is...is...it's...what I've brought away from that experience. In some feeble way, maybe that's helping out, you know, to be a force for peace and not a force for war. With my children...similar issues are there as well, I guess, in a more personal sense. The children singing kind of thing was a coming to terms with the community and the world around me. With the birth of the children...it was...I guess more of an internal thing, a recommitment...to importance that I do need people who care about me and for whom I can care and nourish and provide for and I feel that somebody can provide for and nourish and care for me too.

C: When your daughters were born you said that part of feeling that there was meaning in that situation seems to revolve around knowledge--knowing things--you felt the infants had a look of knowing...

F: And that was the question that came to mind...'What do you know?'

C: And what kind of knowledge do you think that would be....knowledge of what?

F: Beats me (both laugh).

C: Just a look of wisdom, maybe, on their faces.

F: Just a look of wisdom. It had to go beyond anything that makes any kind of sense. It's real hard for me to say anymore than that just by the nature of the situation.

C: An experience in which you see meaning then is beyond rationality, in a sense, then.

F: Yeah. Yes, it has to be. There has to be something greater than what we can see of explain or touch. If there's meaning, it has to be beyond any of that...because of what we see and touch and hear and experience in a rational, conscious way...so much of it's bad. If, you know, that good has to triumph over evil then...then, from what I can see or tell to you rationally, evil's winning (chuckles). So, if there's any good, it has to be beyond the rational conscious.

C: And so at that time...at those times you kind of felt like you were in touch with that other

dimension or had an assurance of that other dimension.

F: MmHm, right. A sense of blessedness...and to be touched and to have been part of it.

C: You said it was also kind of scary. What do you mean by scary?

F: The control part of it. I like structure and things running smoothly. That gives me security and a feeling that I can...that I can act and do. Just knowing that things are in control and that I have a sense of it...I know for other people that's not true at all (chuckles), you know. Structure they find stifling and anticreative. But not for me.

C: But that's the way you are, right?

F: Right.

C: So then how does it feel when you're scared? These are tough questions, I know. It's trying to get beneath what words mean and what feelings mean...

F: The churning...the churning inside...shaking, sweating...I mean (chuckles)..these are all things that just happen to me. Just an unpleasant feeling.

C: Would they be similar to when you feel out of control..or when you feel things are out of control?

F: MmHm. Yeah. I guess that churning feeling...it's so uncomfortable it's just...I just want to yell.."Stop it!", or something...it's..."Get me beyond this!", you know.

C: When things are churning...then would you say perhaps, there wasn't a structure or an order in a sense that things were out of order or out of structure? Would that be the same as churning?

F: Right. UhHuh, yes. The structure's falling apart.

C: So somehow in those two events you described there seems to be some order or structure.

F: Yeah. But, O.K...With the birth of the children, for example, this is something that A. and I wanted and, you know, I trusted her and our lives were where we wanted to be. We were doing in our careers about what we wanted to be doing and where we saw ourselves going. So, you know, things seemed reasonably in control. In the case...in the Navy thing...in the children singing...well, I was in a structured environment...the military, I mean, it was there (chuckles) and even though I was in a place of danger, you know, in a way I still felt a sense of security in an external sense, even though I could hear war going on. It...it, you know, it might have been stupid and evil and all those things. I'll grant that. As far as stability..I had..I still had a feeling of that...of that going on at least...as far as my own physical security was concerned.

C: Can you think of any other times in your life when you thought about the meaning of life,

death or your beliefs?

F: (Long pause). I guess at points...it's something that wasn't experienced...that was really measurable as being an event I could recall and say it began here and ended thus and so, but...I suppose a lot of it had to do after I got through the military service what kind of career was I going to follow. I did a lot of deciding what I was going to do. I attended Law school. I decided, you know, I just didn't want that and got out of that...went back and worked in family business for awhile. Moved from that...working...as an officer in Savings and Loan Co. and this searching for well what was it that I really wanted to do in terms of a career and finally facing the fact that I enjoy books (chuckles) and enjoy doing things in order and being a librarian is really up my alley and making the decision to put my career...as it was going...just set all that aside and go back to graduate school, which I did full-time. To do that, A. had to leave her job...so there was, you know, I guess in a very practical sense, there was a lot of well--what am I going to do? And there were times when I didn't feel things were too much in control. So, but...it turned out alright.

C: So that was a real time of searching for you.

F: Yeah. And this went on for a period of several years. And I don't...I'm open to the possibility that it could happen again...although I don't see it happening again at this point, you know, it could happen again, I guess.

C: So in that experience, did you feel some of the same things you felt in the other experiences when you were thinking about meaning?

F: Yeah. I don't think I had any...I can't recall any particular event where I felt any particular sense of breakdown or turning or...some decision being made where all other possibilities were cut off except perhaps for the idea that, well, I will go to graduate school and that...in a sense, because that involved A. ...more so than me. I mean, I feel that she had...she had the tough decision to make in a way, more so than I did...in practical terms. But, you know, as far as some acute occurrence like the children singing I can't, you know, point out a time or place...

C: It was spread out...

F: Right.

C: ...over a period of time.

F: Yeah, yeah. It was a long process.

C: So you may have had times in that process where you might have felt things were insecure or unstable or you had questions but perhaps it wasn't that intense maybe as the two other experiences over a period of time.

F: And there were periods of time in that...I think particularly when I was in banking...where those kinds of questions never occurred to me at all, you know. Things were going along

fairly well, thank you very much. So...

C: Then what kept them from going all very well. What was the turning point during those years that made you change direction?

F: Well, with law school, I was just unhappy. I just did not want to do that. With the banking thing, I fell in love (laughs) and the...A., at that point, had accepted a call to be an associate pastor at a church in C. and either we didn't get married or I would leave my job and go with her. I mean, that was just...those were the choices and the...love won the day. I...left my job...and in a sense...I had been in this particular position I'd been in for several years. It was a good time to make a move professionally. Business was depressed, you know, things were sort of in a deep depression. This was 1982. And so there really wasn't much going on through the whole industry at that particular time and so it was...it wasn't all that difficult to quit my job and to take a chance on picking up something in C.

C: What did you do in C.?

F: (Laughs) Well...it was a period of recession...at the same time..and A. being in the oil patch at the time that I made the decision things were going well in the energy industry and I had put out a few feelers and it seemed like the job situation was pretty good in A. However, by the time we did in fact marry and we moved up there several months later the economy had gone bust there so I experienced a period of unemployment of almost a year and that was hard to live with. Everything was new and things were sort of not as I had been living them. I was married, so I was dealing...that was a new situation. Being far away in another country and coping with that was..was something, you know, that was stressful. Not knowing anybody there, having moved from a community where most of the people I knew I was also related to was, you know, that was stressful although I'd had experience with that because I had, you know, I'd been away to school, I was in college, and I'd been in the Navy, so...I mean that part of it I could...I handled pretty well just because I'd had experience already. But being without work and the feeling that because I couldn't get a paying job...that I couldn't do anything..I think that's a real problem that unemployed people have to face. I think I've gained some understanding and insight of people who don't have work and the problems they face psychologically. I guess that's something I brought away from that experience. It's hard.

C: During that time, was it a search for meaning in any way? Or did you think about the meaning of life? Was that a part of that experience or not?

F: No, not in a deeper sense. I was dealing with more immediate problems like...I want a job...I want a paycheck (laughing) and it was those...those...which I guess...there's some meaning in that for a living if not for life itself, you know...that was a...those were questions that were before me constantly.

C: So you did find a job then after a year?
F: Yeah.

C: And then, what did you do?

F: It...well...I was working in a financial institution (name of the institution?--can't hear) It...I...I didn't particularly enjoy the job. It was a problem with the management and the conduct of the business. It wasn't a question of ethics, it was simply a question of how we did things and I wasn't too pleased with what I had. But it certainly solved the immediate problem of...

C: A paycheck.

F: ..of a paycheck and a sense of doing something that is useful and that provided a little structure for my life.

C: Then what was the next change in your career?

F: Going to graduate school.

C: So that was right after the time in C.?

F: UhHuh. Right. And we left...we left C. ...my coming...for me to come to graduate school and A. left not...not knowing exactly what she was going to be doing. So...I think it was kind of scary in a way, you know. I had decided on a direction that I was going...so...I don't think I was experiencing as much fear and discomfort as A. was. There were things going on with her personally that I wasn't...that I wasn't feeling except by...by going through it with her. So...I don't think I was asking the question...the meaning as she was.

C: So during the time in C. you realized what it was you really wanted to do in life.

F: Yeah. I came to terms with it.

C: What was really most important. You decided if you were going to do that then you had to go back to school.

F: Right, yes, it was definitely a career thing. And...I went into it in a big way to find out, you know. I got professional counseling and all that sort of thing so I made a really directed commitment to finding out and how to deal with it.

C: So it had been a number of years since you had gotten out of the service between getting out of the service and making the decision what you really wanted to do. How many years did that span?

F: That would have been a span of 10 or 11 years. Pretty good while.

C: So when you did make that final decision--what did that feel like? When you knew what you wanted to do?

F: Oh, I was pleased. I was ready to go after it and looking forward to the new experience.

C: There wasn't a time and a date when you said--'This is what I'm going to do' and it was

terribly exciting to you. It just kind of transpired over a period of years.

F: Yeah...it just grew...it just grew...it just sort of grew up there somehow.

C: You must have been really tuned in to your thoughts and your feeling to know what you were doing didn't...I guess...meet your deepest needs to what you wanted to do in life.

F: Right, yes, oh yeah.

C: You knew something wasn't quite right.

F: I know something wasn't quite right. That I...couldn't see myself going on this way for the rest of my life and, you know, that I had to look closely at something that I could see myself going on for the rest of my life...assuming my life was a respectable period of time.

C: So what you do now really seems to have meaning for you? Quite a lot of meaning in what you do?

F: I do...which isn't to say I don't feel frustrations about it. But...yes...I'm one of these people that rather look forward to Monday to go back to work and I think for a lot of people that's hard to come by. I really don't...I don't dread the job. There are tasks and people I dread dealing with but the work itself I look forward to.

C: What is it about your work that you like best?

F: What is it about the work that I like best?

C: What gives your job meaning....what makes it meaningful to you?

F: I like the part about tracking down information. It's sort of...it's working a puzzle...figuring things out. It's trying to...well, I guess it starts with someone expressing a need for some sort of information and finding out whatever it is they're asking for, finding out what it is they really need. Most of the time people ask for something...at least from a librarian, they will ask you for what they think you can find rather than what it is they want to know and so finding out what it is they want to know as opposed to what they think you can find out and, you know, once knowing that, I can generally, figure out...if not the answer to the question, at least the direction they can take to find the answer to their problem and most of the time the direction is all I can provide because I'm no nuclear physicist by any stretch of the imagination. So I enjoy that and I enjoy...well. just seeing how...say, for instance, that field of knowledge...sort of how it's put together and searching and finding answers to things even though I may not really understand what the answer is. It's the search and finding it and I guess...just the structure of the information in the world of knowledge is what I like. I enjoy doing it and I don't think I've ever thought of it as giving meaning to my life but in and of itself but it's something I like doing and that does provide satisfaction and I guess give a sense of meaning and purpose I guess is a better word than meaning for life...that is...day to day...day in, day out.

C: It seems like you could...the way you talk about your job. It seems like you could apply that to how your life's been too. It seems like...how you talked about your job is how you talked about these experiences of finding meaning in your life. I see some relationships, anyway, between the two. That you're searching for knowledge in your job. And you're looking for the knowledge that you can get out of those events. You like structure and order. You seem to have searched for some structure and order in those events and that you may not actually know the direction you're going when you're looking for answers--I can see that in those situations too. And that there are guideposts, kind of, along the way to help you know things. Do you see any similarity between those? Do you see the similarities I'm seeing?

F: I see the similarities you're seeing. Yeah.

C: And that it's not all head knowledge. You don't get answers from just intellectual means. That there's some other dimension that provides some knowledge.

F: And in my work it doesn't have to be knowledge that I can understand. As I pointed out, what I know about nuclear physics I could put in a thimble. But, you know, it's the quest...the searching for...

C: Would you say that's the same as when you're looking for meaning in events...the quest...maybe?

F: Yeah, right. Well...you're talking about the birth of a child, you know..the question was 'What is it that you know?' and knowing that...I'm not going to...I don't know...what is it she knows even with a ...I was getting the communication of there being somehow knowledge or wisdom there.

C: And so you have questions, but you don't always necessarily find the answer to the questions or you don't find the answers that you think you're going to find.

F: Or...if I find the answer...I don't know what the answer means...it's gibberish (Laughs).

C: Well, I think I have a pretty good sense of what it feels like and what the experience is like for you when you have thought about these things. Do you have anything else to add?

F: No. I was interested in hearing your...you could explain the connections in the work I do and my thoughts about the earlier part of our conversation. It...in fact...had never occurred to me so it's...

C: Give you something new to think about.

F: Give me something new to think about.

C: Well, thank you very much for taking part.

F: You're welcome. Enjoyed it.

C: I appreciate it.

## APPENDIX G

## SAMPLE TRANSCRIPT: BJ

C: This is an interview with B.J. and I'd like her to think about a time in her life when she experienced being concerned either about the meaning of life, death, or her beliefs.

BJ: I think the very first time that I got really concerned was when my sister became ill. I was about...in my early 30s and she was over 35 I think and she got idiopathic hemolytic anemia and I, being a medical technologist, knew that that was a very serious matter and nobody else really understood that and so I got very anxious about her...her prognosis and she fortunately recovered very quickly with the transfusion and I was able to deny all that and to put that aside until 2 years later when she had a relapse and then I really had an emotional crisis with that and what was interesting in light of, you know, that she has lived and is still living (Laughs).

C: Is still alive, huh?

BJ: Yeah. But at that time there was not...nobody understood that disease very well and I had...I had not looked it up even though I had...knew about..about it as a medical technologist, I had never..never seen anybody that had it and so after she relapsed and I was home alone--my husband was out of town--I looked it up and I discovered that it was worse than I had even expected and I ...that was the dark night of the soul for me and I thought...well, now's the time for God to pull a miracle here and show up (Laughs), you know, like other people see lights and things, now's the time for him to show up and take over here. But God did not show up and I was a wreck. I had two children and I managed to cope with their daily life but when my husband...

C: (can't hear response) (Laughs)

BJ:...would come home I would absent myself from the family and I was scared to answer the phone. I was really in a great crisis over that and my faith didn't seem to help me. I didn't think I had any at that point and we had a brand new pastor that had come to our church--I really didn't know him well--and my husband took it upon himself to call him and ask him to come and visit me and so out of the blue he showed up and he helped me. He helped me...

C: How did he help you?

BJ: Well, he helped me talk about the situation, how serious it was. He helped me with the children in that I was trying to protect everybody from knowing and he helped me with that and told me that that was not a very possible thing to do and it wasn't even a very wise thing to do because the children know that somethn's wrong with mother and if they don't know what it is they're going to be more frightened than if they do know what it is and so it is better for them to see mother deal with a crisis in her life and maybe fall apart if that's the way she has to be (Laughs) but then put herself back together again and that this is what the way life is that we have things that happen to us and we fall apart and then we put ourselves back together and he thought that was a important lesson for my children to learn and that I was a model for that as bad off as I was.

C: Uh huh, right.

BJ: And so that helped me a lot. Plus it gave me more courage to...I don't know why...but it just gave me courage to face up to what was going on and so I went to see her. She was in the hospital. I went to see her and I went and talked to the pathologist in the hospital about a transfusion--what would happen if, you know, because she couldn't be transfused again and with these antibodies or you don't know..I mean..so I went and talked to him about that and he told me what they had done so far. That they were able to cross-match her on a one to ten dilution. I actually went to see her family doctor to talk a little bit and I did talk to her about my concern. Not that she was going to die, we didn't bring up the word death, but I was very concerned about that situation, about the transfusion. We put it on that level, not on the deeper level, but we were able to discuss what was going on and then she gradually got better.

C: Did she have family?

BJ: Yeah, and then what helped me a lot, too, was that after she recovered--her husband also had a health problem and they decided to get their affairs in order and they asked my husband and me to take care of their children should they both die so that was an action that put a lot of my concerns, you know, at rest--in a sense (Laughs).

C: Gave you new concerns too, huh?

BJ: Yeah. New concerns, yeah. But...and that's a brief overview of that but I really...Another thing that came up as a result of that and I've talked about this a few times. But there was a neighbor that lived near me and she was very very close-mouthed. She never told anything about herself or her life. She was very pleasant, very nice. She took care of...one of my children when I worked...I mean she just...but...her husband had diabetes. She never mentioned it, you know...there were things going on in her family she just always was...

C: It just wasn't her way.

BJ: No. She didn't share anything. She was very laid back, though, and calm, supposedly. I put that in quotes, but right after this happened to me and I hadn't gone to her...She came to see me, which was quite unusual, and she began...she told me she had to talk to somebody about this problem that she had and it was her sister...who had...who had recently discovered she had cancer and she really didn't have a treatable kind and not long to live and here was this woman worrying about her parents, trying to protect everybody just the same...I mean she was in just the same boat I was.

C: And she knew that you were dealing with your sister?

BJ: No, she did not.

C: No, she didn't know that. Oh.

BJ: She did not. This was so close to the time that I was dealing with her that I hadn't talked about it. I would have if I had seen her. I wouldn't go seek her out though because she was

so reticent, I wouldn't want to do that, but anyway, she came and told me the whole story and there was more to it than that even and my first response was "Well you'd better call the priest". She was Catholic and she said "Oh, he's no good at all", you know (Laughs) and I'm dealing with a very similar situation here and this is what, my minister came, and this is what we talked about and this is how...how we, you know, and she felt better--obviously better and I did too just, you know, talking about it again (surprise evident in voice) I mean...

C: You didn't think you were going to be able to use your...

BJ: No and I thought...

C: ...experience that soon.

BJ: No. And I thought, I mean, up until that time I'd thought a lot about prayer and the Bible and all spiritual matters had been a big concern of mine all my life and I often thought, that, you know, well prayer is just something you do (Laughs) and you don't expect too much (continues laughing) and, you know, not directly--on reflection you see things--but I thought, I mean, there is some incredible something out there that comes to people's aid when they need it and I didn't...I didn't sense that in my dark night.

C: What was your...so you were praying during this experience.

BJ: Yeah. In my dark night. Yes. And I was praying all the time. I was kind of having a dialogue with God all the time that about the typical old bargaining stuff...I was pretty young then...(Laughs)...anything..anything...I was willing to do anything, my part, whatever, that was going to be. Take some responsibility. But I wasn't thinking in terms of a real spiritual presence manipulating us and I still have trouble with, you know, there's something that prompted her to come to me at that particular time, I mean, and whatever, however that message is done. I think God has a pur...role in that...he plays in that but as far as calling all the shots and having this planned all ahead of time I can't buy into that because that takes away the free will thing, I mean, I have to believe that if I'm dealing with something and if I say, yes, one thing will happen and if I say, no, another thing will happen and so that is...that is still something that isn't completely answered. I don't bother with that much anymore, I mean I'm content to let it be.

C: You don't let it bother you.

BJ: No, I'm content to let that be. But...but it's happened other times in my life in smaller instances than that but bigger ones too maybe.

C: So then when this happened to your sister, this is really the first time in your life where you'd kind of given serious thought to what...

BJ: To death.

C: To death, uh huh.

BJ: Plus..uh huh..yeah...really was.

C: Mmhmm. And prayer had been a part of your life before that experience.

BJ: Oh yeah. But it was a shallow kind of...Let me tell you...I have done Bible study and everything out the ears since I was a kid

C: Right, uh huh.

BJ: but in real life...in early on in my life I was able to bring back a lot of things in my head but as far as relating that to my life I didn't do that very well or very often and I will say that I pondered lots of questions and...but that was holy ground off here someplace and I was in this real world over here someplace and somehow I was able to separate that and be in this different department (Laughs), you know, and I don't think I'm unusual in that but that's the way I was. But I was really interested in philosophical kinds of questions. Like the first one I remember asking myself was 'Why am I me?' And I was very young then. I...but I wouldn't have dreamed of talking about that with anybody.

C: It was very personal...

BJ: Yeah. And any kind of question like that wasn't treated very warmly in my...

C: Environment that you were in.

BJ: No, it wasn't. I mean it was put off...it was put aside. Well that's, you know, so I didn't...I mean I grew up thinking that was a taboo sort of thing.

C: So you questioned, but you kept it to yourself.

BJ: MmHm. Yeah, I did. But I liked answers. I went into this field of medical technology. I liked answers that were right and wrong. I wanted black and white. Well, I've discovered that that is not possible and that's the part for me to deal with in terms of my belief system and the Bible and all of that because I didn't like all those inconsistencies that I kept running up against and so ...but I think that experience was probably preparation for my husband's death because...

C: That's more recent?

BJ: That's more recent, yeah, and see my sister survived all that. But not to say that she didn't have a lot of times when we were very frightened and they know a lot more about it now than they did then and...

C: You said, initially, when she was first diagnosed you didn't read...you didn't go to read about it at that point but you had knowledge about it...

BJ: I knew that it was bad.

C: ...from your education.

BJ: I didn't want to read...

C:...and so you didn't want to pursue it any further because you knew the end result was probably not a happy one.

BJ: That's right. And what I did was...I have a very...a way of...I talked to her and she told me everything she knew and then she said "Talk to this doctor." She was in an excellent hospital. It was a group practice in a rural area and they had a lot of excellent doctors from New York City and everything that were doing residency there and it just...one of those incredible coincidences (Laughs) that I happen to think God has a hand in somehow or other. They had a wonderful hematologist there and he was able to do...to spot this and to talk about it and to instruct her other doctor later on about how to treat her and so I went and talked to him and I was able to hear what he had to say because he didn't talk about her prognosis. He talked about the specific things that were going on--the liver function tests and all the things that were related to blood that I would...that I could understand and everything. He talked about those in very concrete terms and I could handle that and but I just didn't ask that question "What if?"

C: And maybe you didn't. Could it have been you didn't question because she was in good hands?

BJ: Well, that was part of it but I wasn't prepared for the answer. I think denial. I don't think I consciously didn't ask it maybe. I just was handling what I could handle.

C: At that time.

BJ: At that time, yeah.

C: But then the second time. Then when she started having problems again...then you pursued it.

BJ: Yeah, I pursued it. I had to. I couldn't deny it I guess, any longer. It kept popping up in my mind--I need to know more, I need to know more.

C: And then how did that doctor talk to you?

BJ: Well, he wasn't there when I called upon him and but when I was around, I don't know if I ever talked to him directly or not, but from him we understood that he had talked to the original hematologist that he was going to treat the case as, you know, what do I want to say...conservatively as possible...not try to do any big thing. Let her body's recovery system work. But I've thought a lot about that kind of natural thing. I mean...God put us together in a way that we'd have a way that heals us. We'd have a built-in mechanism--our immune system and all these things that we don't understand we keep understanding more and better, but nevertheless, we have that in us and somehow I felt like we could trust that in her case.

C: So then it kind of gave you an assurance.

BJ: MmHm. It did.

C: So that you didn't have all the answers but there....you had some kind of new knowledge at this point that you could trust but you really couldn't put your finger on but then related

back to your religious beliefs?

BJ: Yeah. There's one other thing I was thinking about after I talked to you the other day. I told you I had this debate going on. I still do that all the time. I have this kind of religious debate, Biblical debate, a lot (chuckles) and I remember dealing with very fundamental questions. Nobody raised them in a group like--Mary's virginity question and very obvious questions that, you know, nobody said it and so I wouldn't say it either because I was such a good girl and I...this minister that came to visit me..He was a wonderful man and he could take care of himself, believe me, but..and he would have been the only one I would have felt safe enough to ask these questions with...but I wouldn't ask them because I was afraid it would cause division in that group or the church or I wanted everything to go swell, you know, and I just wasn't gonna to do that and yet I had those on my mind a lot. I think many people do. I don't think I'm alone on that.
C: Sure, no, you're not.
BJ: And then I sort of resolved them...in this debate somehow--and I don't ever, you know, write it down--say and come to a conclusion...but one thing about that particular question came up when Phil Donahue had one of his first talk shows was from Dayton, Ohio and I lived in the Pittsburgh area and they carried his show on public television. It wasn't, maybe live, I don't know, but it was the same time show he had Bishop Pike on there.

C: Oh, that would be very interesting.

BJ:...and Bishop Pike was a very interesting person and I had read a lot about his book, We Have These Treasures, but I hadn't read it yet, but I knew what he had said about our Bible, faith, and how we put it in this jar and put the lid on it. We don't let God get out of this jar. And that had really made a big impression on me. Even though I knew he was persona non grata in lots of religious circles I traveled in. Nevertheless, I had...I found myself in agreement with many things that he'd said and so, anyway, he was talking about how the ministers and the priests--they get together and they have one set of standards of what they believe but when they're talking to their parishioners they talk entirely different way. It's like a hypocritical thing and he said "Why don't we just be honest about it and just tell it like it is and tell people, you know, how we got the Bible and why it's, you know, the same things that I had been dealing with and some woman called up and she said that if they took away Mary's virginity that would be the end of her religious faith and I sat there and I thought--Boy, what a wonderful faith we've got here (Laughs) because, I mean, if they took...and then I realized for the first time in my life they could take, it didn't matter, to me whether she was or wasn't, you know, and I'm never gonna know and she's never gonna know, anyway, but it really was kind of a revelation that day that I had settled that so well for myself that I was able to respond to her in the way that I did.

C: Right. Depending on what group you were in and what those people...

BJ: ...and how safe I feel.

C: What do you mean by safe?

BJ: I feel pretty safe with you (Laughs).

C: And what do you mean by safe? When you say safe. Yeah, right.

BJ: Well, I know a lot of people would be very disturbed if I were to say exactly what I believed about certain things. I mean I would have to watch my language carefully and I'm not into getting into a big debate and causing a big rift or something like that.

C: So safe would be a group where you wouldn't...

BJ: I wouldn't be judged too harshly if I did believe...

C: You wouldn't be judged and people wouldn't be too emotionally upset. Maybe because they hold more liberal beliefs.

BJ: Yeah...more strict beliefs than I do and I've had that happen to me everywhere I've been.

C: And you said with your sister, then, when her illness reoccured that was an emotional crisis for you.

BJ: That was and I was able to work my way through that crisis and it helped a lot because she got better (Laughs).

C: Right. It worked out O.K. Maybe if she hadn't then...

BJ: Well, and there were times when she would have those relapses and I remember going right back into that awful feeling of dread and fear...fear, anxiety.

C: That's what I was going to ask you. Can you describe that emotional crisis. What it was like for you.

BJ: It's bad. Yeah. It's just immobilizing fear, I guess, is the only way I can say it--anxiety and not being able to put it aside. Not being able to lay that down. It's a burden to carry. Later on when...after my husband died...well, while he was living even, I realized how burdensome that anxiety was. Even knowing something's that bad is better than not knowing what's going to happen in my life--I don't know how other people are, but for me...if I don't know, I can't cope as well as if I know because if I know then there's maybe...maybe there's something that I can do. That's kind of the way I am. And I remember reading, after he died, I started doing some classes at (college) in Human Services on Death and Dying and Grief and Loss and support group...making a support group of a class and talking about that issue and I was reading...it just happened...coincidentally, I guess (Laughing).

C: Again.

BJ: Again--this incredible thing that I was reading Cry The Beloved Country and it wasn't the first time I'd read it but it was a long time after I'd read it the first time and I had really not remembered much about it. And there was this man in there that everything bad happened that could happen and he had a friend that was really a stranger to him but that was kind of seeing him through things and finally they got to sort of the end of the line and he's talking about this and he said...Well, your anxiety and his fear has turned to sorrow and sorrow is better because fear is always diminishing. It's always bad...and you can't...but sorrow can be enriching and then he said it's like the man whose the tornado's coming and he's fearful for losing his house and then he does lose his house. Well, the fear is gone, the anxiety is gone,

the sorrow is there, but he can rebuild the house and that's kind of the situation I found myself in. That...

C: That you kind of have to work through the fears or let the fears go...

BJ: Yeah. And I hadn't thought about it in terms of her so much but when he got sick and I was dealing with this over again I got into that dread, fear, awful immobilizing kind of thing that I couldn't concentrate--things like that--so I had to learn how to deal with that kind of stress.

C: And what were some of your fears at that time?

BJ: Well, my fear of his was that he was going to die because he had leukemia and it was not a kind that was responding well to treatment and I mean his prognosis was bad and that's all there was to it. And so..and I mean I was a part of the team, as you will. I mean I went in to...the doctors at (hospital) were very unusual at that time. That they were more open about what was going on with people. They didn't keep any secrets and they just had a social worker that had just started working on the cancer unit when he got sick and so and they were interested...and they were interested in me participating. Bob was very interested in me participating because he didn't understand the language and he had a lot more trust in my knowledge than it deserved (Laughs). My knowledge didn't deserve all that trust. But he was sure that I would take care of him in that sense.

C: That you would find out the information that he needed and explain it to him.

BJ: That I would find out, yes. That I would sort through it all and I would and if I wasn't satisfied with the treatment I would know right away that we had to do something different and he trusted me in that and so that made it nice for me that the doctors trusted me to be with it all the time too. That was very good. But I had a spiritual crisis again when he was sick.

C: And what was the nature of that?

BJ: Well...maybe...I brought my journal because I...first entry in my journal was way over here in the middle somewhere...I don't know why but any...

C: You kept a journal while your husband was ill?

BJ: I did. But this isn't it. This was after I had reflected on the illness that I wrote these things down. But this was the spiritual crisis and I talked about it and I could tell you about it but it's in...

C: Well, great, yeah, if you have your exact words from that time, that's wonderful.

BJ: Yeah, O.K. This...there is so much in the Bible about punishment. Some bad things were interpreted to mean that God punished those who did wrong and rewarded those who did good. Of course there are many examples where that didn't happen and Job is outstanding. Nevertheless, the theme of that is engrained in many of us and a certain level it was in me. While studying for Kerygma it was there again. Sometimes God made a promise that was

unconditional or seemed so and sometimes it depended on behavior and even the Presbyterians of old had the notion that to prosper was to show the world a faith and trust in God and in being good. That was how the world knew that you were elect, so to speak. So somewhere, I too, on an emotional or gut-level went about my church life and my spiritual life on that premise. Not in an intellectual way but doing what I thought was the right thing, doing the devotions at home and for circle and being the choir director and oh, I won't go through all the things I did and then raising my kids the way I did and Sunday School and sacrificing a lot of T.V. so that they wouldn't see bad stuff and all those things that I did...that when (husband) got sick, there was a part of me that didn't want to believe that all that work and all that goodness wouldn't protect me and him from an illness that would most probably and did end in his death. And he was good too and did all that was expected of him in serving and being God's man, so to speak. So what kind of a reward could we expect for at least trying hard and if God is in the reward and punishment business then why pick us when there are far worse out there?..and far better too (Laughs) who also have to suffer. So I read a lot about suffering and I've seen a lot of people sick and dying who didn't deserve it anymore than we did. So when I'd hear, "Well, why me?", I'd also wonder "Well, why not me?" and all that reading and all that talking and all that wondering was an exercise of my intellect. Facing the illness and the death is a matter of the spirit and of feeling and there was a sense in me of unfairness and unjustness on God's part and what kind of a God would single us out and other people that I'd remembered and what about the miracles. Lots of them happened to other people. Why couldn't or wouldn't God pull one off for me and my husband and if we had the "right", like I said, in quotes, faith and enough faith, a mustard seed--even--of faith, why, we could get a miracle, couldn't we? And how much faith could I have in a miracle for (husband) when so few people were getting them. People with leukemia didn't seem to be on that receiving end of miracles and my experience was bad in that area (Laughs). Well, I could hope for a miracle and I could believe that a miracle did happen but I couldn't stretch so far as to believe that one would happen for us. It might. But while hope was there so was anxiety and fear as a necessity to prepare for death and for life as a widow and there is the crux of my spiritual crisis. In order for me to move forward spiritually, I had to put into words what I was feeling, not what I'd been thinking about all those years--even though my thoughts weren't too far off of the mark. I was feeling that God was unfair and unjust. That God was fickle and that He doesn't keep His promises and that He doesn't answer prayer, as far as I was concerned. And who needs a God like that?

C: Right. So that way..the way that you had thought of God.

BJ: So that was the way...that was what was my trouble right then. And it was hard for me to admit right then that I was even feeling that way and I never did say them aloud to anybody because I was too good and spiritual (Laughs).

C: And that goes back to again to the way that you grew up.

BJ: Yeah, yeah. I was too good to own up to that so it was better to keep on talking the way I thought about things cause that wasn't lying either, you know, cause I was thinking all those things. Now, how did I get out of that place and into another place is the biggie--How do I do that? And I think...I think that...I think well (Laughs)...that's one of the things...

C: Thinking is important to you.

BJ: Yeah. Thinking is something I do best and studying and being scholarly and all that stuff. So I had to think about that experience, my own experience, I had to think it all again--over and over many times and what it taught me about what God does and doesn't do or what he or she can or can't do. And I just put it down in just such a simple thing, there's more to it, but this is what I decided at that point. That God designed the universe. He designed the universe according to His plan, including us. We're born and we all are going to die and it was even possible that I could meet my death before (husband) met his. No one knows the day or the hour. The circumstances of our death are not necessarily of God's design. The illness may not even be because...as I mentioned before...God puts healing power in us and defense mechanism and cancer cells come and are zapped and some of them aren't. But something goes wrong. Somewhere along the line. And that's what happened and we don't have all the answers about what went wrong and when and what might have been done to change any of that or what medical science or mental powers or spiritual powers can be brought to bear to cause some miracle to happen. For now, all I can say is--we all die and we did what we did...what we could do to heal (husband) and he died and healing is not necessarily curing, so he may have been healed by having died, I don't know. As for me (Laughs), (this is hard)...

C: Well, I can appreciate you being willing to share. It's beautiful. I'm choked up just listening to you (Laughs).

BJ: As for me, I've come to the conclusion that just because I try to be good, God isn't going to protect me from anything. The most I can hope for is an assurance that whatever happens, God is there and then I'll have the necessary support that I need to see me through and that has happened since then...that has happened
and so...Here's a day that I was so anxious about (husband) and I wrote about it again in the journal too. But I remember the day so well because he was good and I'll just read it to you because I can't tell it this good. "The day I was so anxious about (husband) he was reasonably well at work. I was waiting at home on the porch. Waiting for his car to turn the corner. Today he's coming home. He's not going to die today. And then it hit me that I was so anxious and I'd been praying so hard for God to make him well and I was worrying constantly that He wouldn't do that and he wouldn't be well that I couldn't enjoy the time that I had that was left and I realized I needed a rest from pain and worry and I was given a day that was lovely, a day when his numbers all were good and he was feeling O.K. enough to have gone to work and he'd soon be coming home to me and he felt good enough to eat and to hug and kiss and make love and sleep and yet I was miserable and I knew right then that what I needed was peace. I needed peace of mind and a hope that was realistic and a confidence that whatever happened I'd take care of it at that time. That was the bottom line."

C: That was kind of a turning point, then...for you.

BJ: Uh huh. And I'll just read the end of this. "I keep thinking and reflecting and realize more and more that I'm a better person for what I've suffered. That I'm deeper and more in tune with how God has managed the universe." And what I had there, I think, is a Buddist idea. I wrote more about this later, but I needed to get into the present tense and make my life minute by minute, hour by hour. This is hard for me. And I got better at it when the circumstances were such that I had to be better at it...

C: Forced you into it...kind of.

BJ: Yeah. But I get worse again.

C: It's hard to stay there. Uh huh.

BJ: Yeah. See and I used to put myself and him in God's hands and then I'd do it again and again and again and again and again (Laughs).

C: Hard to release control, I guess.

BJ: Hard to give up...give up that control. And so....but that was the spiritual crisis.

C: Well, you've described it very well.

BJ: And I know other people go through it. They don't think...I've talked to other people in support groups. They don't think their belief is strong enough. They don't think they've been good enough. All the same thing.

C: You've been active in the support group here. And I don't know, did you start it?

BJ: No. This one I stepped in when I was asked. We started one here that wasn't very successful that I had a real part in starting. Then the second one (name) wanted to start and she asked me if I'd help and I said I would. So, since then, I've been very much involved in it. But I went back to school after (husband) died and I got this degree in Human Services was my major and I did a placement at UT Hospital. I did an independent study on grief. I did support groups with her...with (name) there and that program just when my husband got sick and later developed into the Psychosocial Clinic which is now gone.

C: So then you ended up working with this person.

BJ: I did. I worked with this person and it helped me a lot. It really helped me a lot. But one thing my husband said to her the very first day that we met her was after we knew he had the leukemia and after we...he had...had...he had an operation...it presented in his spine...he had to have an operation on his spine. but it was aleukemic at the time so there wasn't any treatment going on. And it wasn't all removed from his spine either but he was recovering and then when his blood count went up we had to go in to get treatment and we met her for the first time and I cried...you know, I mean my emotions right there on the surface and in talking with her and he and I sat and she said something to him about...well, she knew where I was (Laughs) but she didn't...

C: That was obvious.

BJ:...know exactly where he was. He said to her "I've got one day. Hell, (name), that's all anybody's got." And so he was already at that point that it took me a long time to get to.

C: Maybe his personality was different and he dealt with things differently?

BJ: Well, he'd had more illnesses too.

C: Oh, O.K.

BJ: He'd had polio when he was little and he'd had other illnesses that I think...

C: So maybe he had already struggled with those questions.

BJ: Uh huh. And he was not a talker. To talk over and so it was hard for...I had a hard time with that because I wanted to talk about his death and get myself into a place where I could take advantage of him while he was living and his concern for me and it was very hard to talk about it because I thought that if I did he would think--knowing all the things I know--that I had given up hope for his life and this was a very serious matter and I still wanted to talk about it but I didn't know how I could talk about it without making him think that I had given up on him and Boy--I didn't want him to think that for an instant. I did want to be realistic and that's what I said in my journal. Hope is not just a little carrot dangling out there. Hope is got to be that you have in spite of all that you know. It's got to be a realistic hope. You just can't be a positive thinker or I can't. I'm only speaking for me, but I cannot see how anybody can--to be honest with you--you...denial just goes so far and you have to be realistic.

C: So, Joyce, was that her name?

BJ: Yeah.

C: Was she able then to facilitate you and your husband talking about these things?

BJ: Well, we didn't need her facilitation. Because what came about was that we had to plan for my future and we could talk about money things, that was neutral. We could talk about money. So we talked about money. And we got on that level that when you got down to that and you can talk about insurance--Well, if you died before you're 55--this is what's going to happen. If you die after you're 55, this is what's going to happen and the word...the magic word was 'dead' at that meeting and then we could talk about it. Isn't that amazing? As much as we loved each other and wanted to and he really wanted to talk about it too and we had decisions to make about it because we thought we would finish up our business and then something would come along and lo and behold there was a decision that we hadn't talked about and then one time he was very bad and they were talking about taking him to ICU and I hadn't really leveled with him that they told me that if he went down there, chances are he wouldn't get out anyway and of course I wouldn't be able to stay with him and I had stayed with him 24 hours a day for most of the time he was in the hospital. Whenever he was in, I stayed there.

C: You were there.

BJ: And everybody liked me to be there...

C: Oh, yeah.

BJ: Because...it wasn't even very convenient for them com'n in and out 'cause our rooms were very small. We were in a different area then than they are now. Second floor where the labs are now, but, anyway, they told me many times, the few times I wasn't there that he was a lot more comfortable with me there and he wasn't one to say "I want you to come". But we had to work out things. I had to say to him--"I'm so nervous today I can't stand it.

I've got to go with you today." But he didn't necessarily want me to because he wanted to drive himself to work and come home and that meant I...but if I said that, he'd agree to it and then if he absolutely did not and wanted something of me, he had to learn to say "Look, you've got to keep your butt home today." (Laughs) "I'm going to work today."

C: So you really had to learn to talk to each other.

BJ: So I had to learn how to talk and then I had to learn how to deal with that when I wasn't there. It seemed like things were worse than if I was there and so that's when I wasn't there I started playing the violin again and (name) daughter was--she was working on her doctorate degree and she used to play the violin. So she used to come down and play with me. We played duets and we had a record for the accompaniment so we could play with music and we had...and that I mean I realized I could not play the violin if I wasn't concentrating on the music and that relieved that stress because I could concentrate...

C: It could take your mind off...

BJ:...that's about the only thing I could concentrate on 'cause I could do housework or almost anything and not be thinking about it. So that helped me a lot.

C: So, otherwise it was always going through your mind.

BJ: Uh huh. I just couldn't concentrate. I was a basket case.

C: You were just really anxious. You said when your sister was sick that you had beliefs but they weren't adequate to deal with what you had to deal with.

BJ: Well, what I had was down deep I had a faith that everything was going to be O.K....I knew that God was there but I had a lot of problems with the belief system. Did I believe that, you know, Jesus was the only son? What about all these other people? What about Mahatma Ghandi? What about Ghandi--what he said? And all the things he said about...and what about Albert Schwietzer? I would have had to deal with all these people that weren't Christian in the sense that very literal sense and deal with them in a way that I could feel that I was going to stay O.K. 'cause I thought I was O.K. But if I got too much into the creeds and everything there's always something in them I can't believe it...I mean...I'd like to believe like Billy Graham, maybe. But I can't do it. I just--my mind won't let me do it.

C: So that's been true for you always...

BJ: Always, always, always.

C: ...since you were little. You've always been struggling with that.

BJ: Struggling with these little things. I...wanting things black or white and not being able to stand being in the gray area and not being settled about it and I wasn't afraid of hell. I mean, that was not a part of it at all because somehow I knew I wasn't going to be kept out of the kingdom on a technical difficulty I was having (Laughing) with my mind. And God gave me that mind so...

C: So it was more you had a certain...you were in the church...you were expected to be a certain way, think a certain way and being good was important to you and so being good translated to believing some of these things and acting a certain way.

BJ: Yeah, yeah, yeah, yeah. So then...yeah...but I had to separate them actually and I don't know when I was able to do it but faith is not what you believe...really...I mean those are two different things and when I was thinking about I didn't have enough faith in her instance...I was talking about what I was believing...what I was able to believe and what I wasn't able to believe and in that sense...No (Laughs). But...faith...I really have that. I just needed to get in touch with that. But it took me a long time to separate. I mean...you can't be young and involved in so many things and I constantly was reading a lot...I mean I was always searching for...

C: And you've read about other religious faiths.

BJ: Uh huh, uh huh and other people and how can I reconcile all those things with such exclusiveness that the Bible has in it?

C: So you've always been interested in learning...real broad knowledge base and all and what other people believe and then compared them with your belief and sometimes they're not the same and so then that's what you've kind of...kind of struggled with.

BJ: I have. But I've come to kind of an accommodation and I put down in...I cut this out not long ago I was reading this book The Search For God At Harvard. The theology class is studying it and he's a Jew writing from his Jewish perspective and he's quoting what Ghandi had to say and I had read quite a bit what Ghandi had to say about religion and Christianity and so on but this was this little capsule that really helped me so much and this is what Ghandi is saying: "It is idle to talk of winning souls for God. Is God so helpless that he cannot win souls for Himself?" And then he goes on to say "Conversion is a pointless exercise. All religions are branches of the same mighty tree. But I must not change over from one branch to another for the sake of expediency. By doing so I cut the branch on which I am sitting." And I say for me to be a Christian is what I am and so I'm not going to cut the branch on which I'm sitting. But neither, I mean, I've got an open mind, you know, about other religions but I don't let my brains fall out either when I'm...while I'm sitting on my branch and while I'm looking at other things. But I don't need to settle everything either and that is one thing that has helped..you know, is very helpful.

C: That in the past...did you want to settle?

BJ: I wanted everything settled. I wanted to put that away. I didn't want to think about that anymore but it's never settled. I mean there's always something new that comes up and I mean I thank God for that. I mean I'm growing as a reason (Laughs).

C: So you see that as something positive then.

BJ: Oh, yeah, I do, I do. And then he goes on, the author who's the Jew, said that there's one section of all religions are true (that book that Ghandi wrote that disturbs me) and he goes on to say that with all his (next word?) and all he writes about the Old Testament. He says, "Between the Old and New Testaments there is a fundamental difference. And while the Old

contains some very deep truth, I am unable to pay the same honors I pay to the New Testament and/or pay the same honors to the Old Testament I pay to the New Testament. I regard the latter as an extension of the teaching of the Old and in some matters a rejection of the Old." And the author, the Jewish author, did not like that statement of Ghandi. But he said he was talking about--I'll just read you this other little bit--"..nor do I regard the New as the last word of God. Religious ideas, like everything else, are subject to the same law of evolution that governs everything in this universe. Only God is changeless and as His message is received through the imperfect human medium it is always liable to suffer distortion in proportion as the medium is pure or otherwise...pure or otherwise."

C: So this really spoke to how you were feeling...

BJ: Yeah, it did.

C: About your kind of new way of believing.

BJ: MmHm. "I will therefore respectfully urge my Christian friends and well-wishers to take me as I am. I am convinced, I know, that God will act. As of now, not what we label ourselves, but what we are, what we do with Him, deed is everything, at least without deed is nothing, with Him, doing is believing." So that touched me at that level of...I don't need to settle most points.

C: You wrote on the demographic form that beliefs were very important to you, right? Can you briefly summarize what your beliefs are today?

BJ: Well. My beliefs are evolving like I mean as I learn and grow and I guess as far as a...

C: Which ones are most important to you today to live by?

BJ: To live by.

C: You had said that your beliefs had been kind of head knowledge before...

BJ: Yeah. Well, yeah, I think that...

C: ...and then you had kind of talked about faith as being a little bit different..more experience based.

BJ:...for me a faith to kind of live by is that no one is safe in the sense of knowing what's going to happen or being O.K. all the time or not having to suffer or not having to deal with unpleasant things and solve many problems and I am never absolutely sure. I may pray for guidance. I do. I am never going to be absolutely sure that I have chosen the right solution or the right thing. But what I have...what I am secure in is that I will be O.K. in some...I mean I...whatever happens will happen and I will be allright and I...

C: What's it mean to be allright or O.K. then? And how...

BJ: I mean my needs will be met. There will be someone there that ...that I will be able to rely upon. I mean, God has met my needs in the past. I have enough trust in that and I was

new to this area and nobody owed me any kind of paybacks for any wonderful things I'd done in the past (Laughs) or anything I didn't...I was just the neediest person that ever...ever happened and here I am, you know, having survived.

C: So you trust more.

BJ: Yeah.

C: So you trust in God more but a God that you see...

BJ: It's a bigger God.

C: You define as a little broader than you did when you were younger.

BJ: Yeah. It's a bigger God, I think. I have something in here that maybe tells you where I am at. Well, when I wrote this...that isn't it...This is more about that same day crisis but I said another thing that day about where I am now...I said that maybe I would have him that day, maybe I would have him another and another, kind of like I'd written before but however many days I had there would never be enough days and so I discovered I only had that moment that's what I talked about before so I won't go into that again. But I was in a place where I couldn't enjoy the beauty of nature and yet I only had that moment to enjoy that and was I ever going to and I couldn't see any meaning for me without him at that time and what did that mean? You know, that was kind of the...

C: Mmhm. What are the consequences of that?

BJ: Yeah. What are the consequences of that? and so this is much later. And I said "As I reflect on that day, which is much like the day I.." and today, much like today's day outside, "there is meaning in my life without him. I can appreciate the beauty of nature and I do--even more perhaps than I ever did and I wanted more days with him and I wish he were here now but they were enough and when I say that I mean that looking back--we were married almost 29 years--if I look back from today and we'd been married 30 years that would not have made a significant difference. But that year, at that time, would have made a very significant difference. Whether his quality of life would have been good or not good, it would have made a significant difference at that time, but now--we had enough days--we had enough days. And I had the opportunity to love someone til death parted us and I was loved til death parted us and the love is there and our life together changed me and gave me my womanhood and it changed him and his illness made us stronger better people and here's what his death gave me--the courage to face my own death and living without him has made me a person in my own right as I never was before. I am seldom afraid now and never as fearful as I was about losing him and sorrow is better than fear (Laughs).

C: So it's really evident that you really have grown through these struggles.

BJ: I have, I have, I have.

C: And it's been positive for you.

BJ: It has. I didn't think it would be. But...

C: So now you know if you have another similar experience...

BJ: I know that I'm not going to know ahead of time what to do. I know that I'm going to have to live through that experience and that--it's going to be very very hard. But I know it's possible and I know there's no other way (Laughs).

C: No choice.

BJ: There's no other way out.

C: But you do have a choice about how you can be in that circumstance that makes a difference, I guess.

BJ: Mmhm, yeah. And I'll tell you one other thing that has helped me. I was a choir director for a long time and I was always singing anyway in choirs and there's something about the emotional stuff in music that I could sing something and get the sense of it and feel it and not believe it in my head because I couldn't believe that in my head but I got a deeper meaning of what it was in my body when I sang.

C: So like there's almost a different way to communicate with the spiritual. That the only way is not through your mind.

BJ: There's a different way. Yes, Yes. It's not through my head. Definitely. And. But words are very very powerful. And once I became responsible for the words that the choir was singing I suddenly realized--What is this song that I used to think was so wonderful? It's trite...it's not theologically right. It's just a lot of bull. We can't sing that, you know, and so, there I am, into how powerful these words are. When I think about my own faith coming from...many times coming from them...going against my head and I think, you know, one thing that I picked for a New Year and the words were "I stood at the gate of the year...or I said to the man as I stood at the gate of the year. Give me a light that I might walk safely into the unknown and then the man said--Well, put your hand in the hands of God and He'll be...He is safer than a light or brighter than a light or something and safer in the unknown and that was so true for me.

C: It was kind of a letting go I guess...a letting go of your control maybe and trusting and resting in God's.

BJ: Yeah. A letting go. You've put it right in the right spot. Letting go. Yeah. And I mean I never even talk about my own simple prone to err nature but singing "Create in me a clean heart" is a lot easier and a lot more contrite when I think of my heart needing cleansing.

C: So music for you has been another way to communicate and experience your relationship to God.

BJ: Mmhm, mmhm. In a big sense. A very big sense.

C: So it's probably maybe, a relief, to know that it doesn't have to be all head knowledge, that it can be heart knowledge, too.

BJ: Mmhm, yeah, yeah, yeah.

C: So I think that summarizes it very well. Unless you have something else to add..I really...

BJ: I really don't.

C: I really appreciate you talking with me about it.

BJ: I did think about it though because I've talked about these same things with other people before but not all at one time...

C: To put it all together.

BJ: Yeah.

C: And I will give you a transcript of this so you will have it to read and make sure that I transcribed it all correctly.

BJ: Oh, that will be nice!

C: And then when I finished...

(Tape turned back on)

BJ: I promised to scatter his ashes at our cottage on a very nice day and it always...in the morning when it was calm and so on and so forth and so after it took me 2 years after...

C:...to be able to do that.

BJ: ...to be able to do it. Now I will admit that some of the days weren't right, you know, and at some point in time I didn't have a boat or canoe or something, but most of it I think was my reluctance to say goodbye.

C: It would be just like a body going into the grave.

BJ: Yeah. But I was reluctant, that was the last thing that there was for me to do and I think, emotionally, I wasn't ready but I blamed it on other things (Laughs) and they were true to a certain extent. But anyway, I picked something to...from a Bible passage to read while I was doing that.

C: You did it all by yourself?

BJ: Well, my daughter went with me. She paddled the canoe and I wrote..I wrote a poem and I'm not going to share it. It's not because it's so personal but it's just I don't like it. But anyway--we scattered the ashes and I picked words from First John 3:1-3 and it says "See what love the Father has given us that we should be called the children of God and that is what we are. The reason the world does not know us is that it did not know Him. Beloved, we are God's children now. What we will be has not yet been revealed. What we do know is this. When He is revealed we will be like Him for we will see Him as He is." And all

those questions that I asked myself about judgment and I think that the outcome to that judgment is that we will see Him as He is. And we will see us as we are and that is what judgment is.

C: So, there's no fear.

BJ: So there's no fear about that there. But...

C: And there's the hope that there is a life after this life.

BJ: But, I mean, I think that this life is eternal life too. I
mean, I don't think of heaven as a place that you go when you die, necessarily. We're going on living ...living this spiritual life is going on and I'd like to know more about it but I'm not frightened of it in any way because I think I'll still be me pretty much the way I am and I'm gonna see, you know, myself, and that might not be too easy (Laughs) but, I mean, everybody does it so I guess I console myself with that.

C: So there's a lot of hope and a lot of trust.

BJ: Yeah. And I think I'll be loved. I'll be loved.

# VITA

Carol Jean Smucker was born in Carthage, Missouri on December 17, 1944. She attended primary and secondary schools in Zion, Elgin, and Wheaton, Illinois. She graduated from Wheaton Community High School in June, 1963. In August, 1966 she received a diploma in nursing from West Suburban Hospital School of Nursing in Oak Park, Illinois. She married David Eugene Smucker in Wheaton, Illinois on June 17, 1967. They have three children: LynAnne, Mark David, and Christine Joy. She received her undergraduate education at the University of Illinois, Urbana-Champaign and Marycrest College, Davenport, Iowa. The Bachelor of Science in Nursing degree was awarded in May, 1979 from Marycrest College. In August, 1986, Carol received a Master of Arts in Nursing degree from the University of Iowa, Iowa City, Iowa.

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