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SPIRITUALITY AS EXPRESSED BY FAMILY CAREGIVERS OF INDIVIDUALS WITH CANCER: A DESCRIPTIVE STUDY

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SPIRITUALITY AS EXPRESSED BY FAMILY CAREGIVERS OF INDIVIDUALS WITH CANCER: A DESCRIPTIVE STUDY

By

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ABSTRACT

SPIRITUALITY AS EXPRESSED BY FAMILY CAREGIVERS OF INDIVIDUALS WITH CANCER: A DESCRIPTIVE STUDY

By

Linda J. Keilman

The purpose of this study is to describe the self-reported expressions of spirituality in a sample of family caregivers of individuals with cancer. Data utilized were collected among 278 primary family caregivers of individuals with cancer via telephone interviews and self-administered questionnaires. The Spiritual/Philosophical Subscale developed by Hammer and Marting (1988) was the instrument used to obtain information related to spirituality. Demographic data were recorded during the screening process and the intake phase of the funded longitudinal study. Descriptive and inferential statistics were employed to analyze data for this study.

Through this research, an increased understanding of the meaning and expression of spirituality may serve to add depth to the wholistic (bio-psycho-social-spiritual) approach by health care professionals interacting with caregivers of individuals with cancer.

DEDICATION

This thesis is dedicated to Robert and Delores Keilman, my parents. It is through their caring, love and remarkable example of living life wholistically that I have been able to follow my dreams and aspirations. It is through their teaching and guidance that I first became acquainted with the spiritual dimension and the hope it offers. Without their support and encouragement, this manuscript would not be possible.

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CHAPTER I

Introduction

It is generally accepted in the nursing profession that human beings are wholistic and can only be understood wholistically by assessing their bio-psycho-social-spiritual dimensions. Much research has been done and volumes of literature can be found to expand one's understanding of the bio-psycho-social dimensions. The spiritual dimension, however, has only infrequently been made the subject of empirical investigation.

The lack of literature related to the study of spirituality may be accounted for in several ways. First, it is difficult to measure a concept which is abstract and focuses on subjective thoughts and feelings. It may be difficult for people to express their inner-most beliefs and thoughts about the concept of spirituality. Researchers have found operationalization of the abstract concept of spirituality to be a difficult task.

Secondly, the scarcity of research may lie in the concept itself. What is spirituality? Scholars have not been able to agree upon a common definition for the concept. Religion, religiosity, coping, reactions to death and dying and terminal illness are often conceptually intertwined with spirituality.

Hammer and Marting (1988) developed a Coping Resources Inventory that measured individual resources in five domains, one being

the spiritual or philosophical. The Spiritual/Philosophical dimension, which is the definition that will be utilized throughout this paper, is defined as:

> The degree to which actions of individuals are guided by stable and consistent values derived from religious, familial, or cultural tradition or from personal philosophy. Such values might serve to define the meaning of potentially stressful events and to prescribe strategies for responding effectively. The content domain for this scale is broader than traditional western religious definitions of spirituality (p. 3).

This broad definition allows many different personal beliefs and values to be measured by use of a scale.

Vastyan (1986), defined spirituality as "that aspect of our human nature that strives for control" (p. 112). Further, Vastyan states that spirituality adds another dimension to existence when one is able to relinquish control and accept a passive openness. Spirituality, as defined by Dugan (1987), incorporates one's sense of internal "togetherness" or person integrity. When one is "fragmented," pain and suffering are usually present.

Peterson and Nelson (1987), define spiritual as referring to "the transcendental relationship between the person and a Higher Being, a quality that goes beyond a specific religious affiliation, that strives for reverence, awe and inspiration, and that gives answers about the infinite" (p. 35). Granstrom (1985) defines spirituality as involving "a personal quest to find meaning and purpose in life and a relationship to the Mystery/God and the rest of the universe" (p. 41). Granstrom further qualifies that formal religion may be a part of spirituality but it can mean much more.

Reed (1987) defines spirituality "in terms of personal views or behaviors that express a sense of relatedness to a transcendent dimension or to something greater than the self" (p. 336).

Spirituality is a broader and more wholistic concept than religion or religiosity, although a facet of spirituality is frequently manifested by religious behaviors. This study focuses on the expressions of spirituality.

Control, relationship with or belief in a Higher Being, meaning and purpose in life, personal views and coping are some of the dimensions that are defined in an examination of spirituality. Hammer and Marting (1988) discuss the dimension of a personal philosophy that provides potential meaning for stressful events. In this study, the personal philosophy dimension (spirituality) will be examined in describing how family caregivers adapt to providing care for individuals with cancer.

Spirituality and Health

Studies can be found in which the researcher describes the spiritual dimension of persons diagnosed with a terminal or chronic illness (Baldree, Murphy, & Powers, 1982; Granstrom, 1985; O'Brien, 1982; Owen-Still, 1985; Reed, 1987; Vastyan, 1986). Invariably, data analysis indicates a trend to a heightened interest in religion and the spiritual dimension of people at this point in life. The focus on spirituality in terms of impending death only, or for those left behind to deal with the death of a loved one, can easily be retrieved in the literature (Augustine & Kalish, 1975; Bascom,

1984; Dugan, 1987; Neugarten, 1979; Newman, 1979; Parse, 1981; Schaie, 1977). A premise of nursing practice centers on the belief that spirituality is present at all times in a person's life, not just at death.

Only a few studies were located that focus on spirituality as manifested at points in the lives of human being's when they are faced with a difficult life experience (Fehring, Brennan & Keller, 1987; Malcolm, 1987; Hall, 1986; Thomas, 1989). No research was located that examined the expression of spirituality by family caregivers. There is a great need for research to describe the role of human beings' spiritual dimension at various points in their existence and life experience.

Spirituality and Stress

The stress and strain experienced by families as they assume the role of caregiver has been abundantly addressed (Blank, Clark, Longman & Atwood, 1989; Burden, 1989; Montgomery, Gonyea & Hooyman, 1985; Oberst & Scott, 1988; Poulshock & Deimling, 1984; Zarit, Reever & Bach-Peterson, 1980). Family members, as they become caregivers, are under stress as they deal with changes in relationships, take on new roles and become acclimated to a new environment.

George and Gwyther (1984) have explored caregiver burden and well-being associated with caring for an impaired older adult. Rabins, Mace and Lucas (1982) have researched the emotional impact of caring for the chronically ill. Each of these researchers, as

well as others, documents that caregiving is a stressful experience for family caregivers. Clearly, research has shown family caregiving to be an all-consuming task, involving every aspect and dimension of the caregiver's life (Bunting, 1989; Deimling, Bass, Townsend & Noelker, 1989; Baillie, Norbeck & Barnes, 1988; Silliman & Sternberg, 1988; Birkel, 1987; Chenoweth & Spencer, 1986; Brody, 1985; Crossman, 1985; Poulshock & Deimling, 1985; George & Gwyther, 1984; Cantor, 1983; Soldo & Myllyluoma, 1983; Archbold, 1982; Clark & Rakowski, 1982; Archbold, 1980).

Stetz (1987) reported the experience of a family member with cancer created demands not previously experienced by most family members. When cancer is diagnosed, numerous and varied emotions are experienced not only the individual with cancer but by other family members as well (Peck, 1972). "Cancer represents severe insults to the psychological state of the patients and their families" (Krouse & Krouse, 1982, p. 97). In most instances, the diagnosis of cancer is unexpected and no time is allowed for future views of plans.

Through this research, the manifestation of spirituality at a point in time when family stress is extreme (the caregiving experience) may come to be more fully explained. An increased understanding of the meaning and expression of spirituality may serve to add depth to the wholistic approach by health care professionals interacting with caregivers of individuals with cancer. The findings from this research may also serve to help health care professionals and individuals understand that spirituality may

serve as a resource for hope and strength during the caregiving process.

The diagnosis of cancer creates a crisis situation for the family. The environment of the family is in a state of fluctuation and change. This state of change creates stress and strain and may hinder the family's ability to take on the role of caregiver in a positive manner. "Stress also limits or impedes a family's ability to be caregivers" (Hinds, 1985, p. 575). Even with the recognition by researchers of this extremely vulnerable and stressful situation, little research has been focused on the needs of the family caregiver, especially in the realm of the spiritual dimension. Leavitt (1984) defined this vulnerable status as "at risk" for deterioration in personal health and functioning and as inadaptive for the family unit. It is apparent to this researcher, that the spiritual dimension of family caregivers of individuals with cancer needs to be researched.

Statement of the Problem

The problem to be studied is a description of the expression of spirituality by family caregivers for individuals with cancer. The spiritual needs of family caregiver's can be recognized and understood and ways to provide for them can be developed and utilized.

Literature and research related to the concept of spirituality have been extremely limited in focus. There has been minimal research into the exploration of spirituality as a dimension of

human beings and their existence, making them unique (Burkhardt, 1989; Carson, 1989; Nagai-Jacobson & Burkhardt, 1989; Rew, 1989; Shelly & Fish, 1988; Brooke, 1987; Kennison, 1987; Lane, 1987). Little attention has been paid to the role played by spirituality in family caregiving. The focus of this study is to describe, from self-reports of family caregivers of individuals with cancer, expressions of spirituality.

Statement of the Question

The focus of this study is to address the following question: "What are the self-reported expressions of spirituality among family caregivers of individuals with cancer?"

Conceptual Definitions

Major concepts upon which this study is focused are spirituality, expressions of spirituality, family caregivers and individuals with cancer. The following conceptual definitions will be utilized throughout the study.

Spirituality: The degree to which a person's actions are guided by stable and consistent values derived from religious, familial or cultural tradition, or from personal philosophy (Hammer & Marting, 1988).

Expressions of Spirituality: The measured self-reported responses to eleven questions in the Spiritual/Philosophical subscale.

Family Caregivers: A designated family member of significant other who provides emotional, psychological, spiritual or physical

assistance, support or supervision for an individual with cancer in the home.

Individual with Cancer: A human being diagnosed with a new or recurrent solid tumor who is 18 years of age or older and has designated a family member or significant other as their primary caregiver.

Assumptions of the Study

For the purpose of this study, the researcher makes the following assumptions:

1. Spirituality is a dimension of all human beings and can be expressed.
2. Family caregivers answer self-administered questions with thought and honesty and their true feelings or beliefs are reflected.
3. A scale can be utilized to capture and measure some aspect of spirituality.

Limitations of the Study

For the purpose of this study, the researcher identifies the following limitations:

1. Family caregivers who agreed to participate in the study may be different from family caregivers who chose not to participate. Because subjects are a non-random, convenience sample, research findings may not be generalized to the larger population of family caregivers.

2. Major variables such as level of depression and stage of cancer diagnosis which, according to literature, may have a profound effect on self-perceptions and research findings, are not included in this study.
3. The experience of family caregivers of young children with cancer are not included. In this study, the family member with cancer, in most instances, is an independently functioning individual eighteen years of age or older. The family caregiving experience may be systematically different for dependent children.
4. The environment is measured only from the perception of the family caregiver.
5. Data for this research were collected at one point in time. No measures of spirituality prior to this experience are available for these caregivers.

Overview of Chapters

This research study is presented in six chapters. Included in Chapter I are an introduction, background of the problem, statement of the problem, statement of the question, conceptual definitions and assumptions and limitations of the study.

Concepts and relevant nursing theory integrated into a conceptual framework are presented in Chapter II. The relationship of Martha Rogers' Science of Unitary Human Beings to spirituality is explored utilizing the specific concepts in this research study.

In Chapter III, pertinent literature relating to the research question is reviewed.

Source of subjects, human rights, description of the population, description of research methodology, instrument utilized, data collection and scoring procedures are presented in Chapter IV. The results of data analysis are presented in Chapter V. In Chapter VI, research findings are summarized and interpreted. Conclusions, recommendations and implications for professional practice are also presented in Chapter VI.

CHAPTER II

Conceptual Framework

Introduction

In this chapter, the conceptual framework for this study will be described and discussed. Martha Rogers' Science of Unitary Human Beings will serve as the organizing model for this researcher's conceptual framework of spirituality.

Rogers Abstract System

The conceptual framework provides a tool for examining the life of human beings within their environment and creates a foundation for development of significant research and application of the research findings to professional nursing practice (Rogers, 1970). Incorporating Martha Rogers' Science of Unitary Human Beings into a research framework provides a positive view of family caregiver's and their environment in general. According to Fitzpatrick (1988), Rogers' conceptual framework is compatible for basic theoretical research in that it:

> . . . appears to represent the most innovative and comprehensive conceptualization relevant to basic and applied nursing research. It has the best potential of uniting and advancing our discipline, both in terms of the scientific development, and our direct applications to professional practice (p. 16).

Assumptions

Martha Rogers' abstract system is based on five assumptions:

1. Human beings are a unified whole possessing unique integrity and manifesting characteristics that are more than and different from the sum of their parts. Human beings are unique in their individuality and, therefore, creative, dynamic and continually evolving. The emotional, pathological, social, and spiritual are manifestations of the whole person pattern and cannot be reduced (Cowling, 1989).
2. Human beings and their environment are constantly exchanging energy and matter in a flowing and interchanging manner. Human beings are an open system and inseparable from their environment. No definitive boundaries exist and the environment extends to infinity.
3. Human beings life process evolves irreversibly. "The life process is a becoming" (Rogers, 1970, p. 55). Change is negentropic and evolving toward increasing complexity and diversity. Change is always non-repetitive and innovative (Sarter, 1989).
4. Human beings life pattern and organization uniquely identifies them and reflects the innovative wholeness. An individual can influence her/his pattern and repattern by making decisions and choices in which aspects of the environment to interact with on a daily basis. With

choice, human beings can experience life as harmonious, rather than discordant. "Pattern and organization are fundamental attributes of all there is. They give unity to diversity and reflect a dynamic and creative universe" (Rogers, 1970, p. 65).

5. Human beings are characterized by the capacity for imagery, abstraction, language, thought, sensation and emotion. Human beings are unique and different from other living forms and are irreducible.

This researcher postulates that one primary difference between human beings and animal is the unique dimension of spirituality. "Religious rituals, art forms, and speculative philosophy attest to man's continuing search through time for the meaning of life and death" (Rogers, 1970, p. 68). Spirituality is a manifestation of human beings patterning (M. E. Rogers, personal communication, July 7, 1989).

These assumptions about Unitary Human Beings, as unique individuals, serve to lay a foundation for guiding the role of the nurse in practice and within the evolutionary process. These assumptions further accentuate the wholistic view of human beings as being comprised of bio-psycho-social-spiritual dimensions.

Building Blocks

Martha Rogers (1989), states that currently there exists no language available to human beings that allows for clear communication of her thoughts and beliefs into words. Several building

blocks integral to Rogers' abstract system have been defined: energy fields, universal open systems, pattern and four dimensionality. In addition, the concepts of environment, irreversible life process, continuous human being - environment interaction, nursing and health will be discussed.

Energy fields are the fundamental unit of the living (animate) and nonliving (inanimate) universe. These fields have no boundaries, are indivisible and extend to infinity (Falco & Lobo, 1985). According to Sarter (1988), "the energy field is four-dimensional, identified by its pattern, in a continuous motion or change and dynamic in nature" (p. 61). Energy fields are open and constantly exchanging energy and matter (Rogers, 1970). They are broad, dynamic, infinite and multiple. The interchange between energy fields exhibits pattern and organization which are observable properties of human behavior (Fawcett, 1989). According to Rogers, "persons do not have energy fields, they are infinite energy fields" (1989). "The field itself is identified by a constantly evolving pattern, yet the field is an irreducible whole and therefore endures throughout the infinite life process" (Sarter, 1989, p. 77).

Universal open systems are integral with one another and extend to infinity (Fitzpatrick & Whall, 1989). Rather than the view of a static, entropic universe, it is Rogers' belief that the universe is negentropic and characterized by increasing order and complexity with irreversible evolution (Malinski, 1986). Causality

is invalid in a universe of open systems. Open systems are characteristic of energy fields and are innovative, unpredictable and exhibit continuous flow.

Sarter (1988) explains pattern in the following manner:

> Pattern identifies and is unique to each energy field. All the characteristics and behaviors of any field are manifestations of pattern; it is these manifestations that are changing in the process of evolution. Pattern is perceived as a single wave; that is, it manifests and is apprehended as a whole. Since pattern is continually changing, the life process appears to be a dance of rhythmical waves vibrating at various frequencies. Pattern constitutes the essential nature of an energy field (p. 61).

Human beings and their environment interact continuously by patterning and repatterning in a mutual, continuous and simultaneous manner (Rogers, 1980, p. 333). According to Rogers (1989), it is the manifestation of pattern that can be seen, not pattern itself, which is an abstraction.

It is only through viewing human beings wholistically, within their unique environment, over time, that nursing professionals can accurately assess the individual and their special needs. It becomes apparent then that the spiritual dimension is an integral component of the nursing process. The spiritual dimension, added to the bio, psycho and social dimensions, makes up the whole of human beings.

Human and environmental fields are characterized by four-dimensionality which is defined as a nonlinear domain which is not derived from three-dimensionality (Rogers, 1989). There are no spatial or temporal attributes.

Concepts

The environment encompasses all that is outside the human being's energy field and extends to infinity. Boundaries are nonexistent. Rogers (1980) defines environment as "an irreducible, four-dimensional, negentropic energy field, identified by pattern and manifesting characteristics different from those of the parts and encompassing all that is other than any given human field" (p. 332). Environment is that which is external to human beings. Family caregivers enter the environment of individuals with cancer and interact with them. Family caregiver choose how they will react to the situation. With the spiritual dimension, hope, perseverance and determination may be the outcome. The spiritual dimension is within human being's, a creation of their uniqueness and sentience. It is an important dimension of the human beings evolving and becoming.

The unique, continuous human being - environment interaction is integral to Rogers abstract system. Human beings are a unified whole with the capacity to search for meaning in life and death and beyond. Human beings are sentient, thinking beings capable of questioning, feeling, creating and sensing the environment. Human beings are biological, psychological, social and spiritual. Human beings must be viewed as existing with all these dimensions or they are not viewed in their entirety. The interaction is unique, individualistic and creative, manifesting increasing diversity and complexity of field pattern characterized by non-repeating rhythmicities (Ferrence, 1986).

Irreversibility of life implies the passage of time, always forward in growing diversity. Human beings progress through time in one direction, ever growing, evolving and "becoming" through the life experience. "The life process evolves irreversibly and unidirectionally along the space-time continuum" (Rogers, 1970, p. 59). Rogers (1970) further states, "a human being is the expression of the totality of events present at that point in time" (p. 57). In a 1988 article, Rogers cautions against interpreting the direction of change in a linear fashion and has dropped the terminology of unidirectionality. Higher wave frequencies of patterning and increasing diversity in the evolutionary process of human beings are most often the outcome of interaction with the environment (Sarter, 1989). Rogers (1989), refers to growing diversity being representative of the complexity of wholeness which implies no steady state, no causality, no repetition and no homeostasis. "Unpredictability transcends probability" (Rogers, 1989).

"The focus of nursing is human beings" (Rogers, 1970, p. 82). The goal of nursing is to promote the symphonic interaction between human beings and their environment. The hemodynamic principle of helicy reflects human being and environmental change as continuously innovative, rhythmically diverse and problematic. "The phenomena central to nursing's conceptual system is the life process in man" (Rogers, 1970, p. 83). Therefore, it is the nurse's responsibility to view human beings as uniquely individual and work with them to maintain their integrity and wholeness. It is also imperative for the nurse to strengthen the cohesion of the human

energy field and to assist, when needed, in directing and redirecting the pattern and organization of the human being - environment interaction for optimal health promotion, maintenance and wellness. This wholistic view thus represents the science of nursing as humanistic.

Nursing is both a science and an art. According to Rogers, the science of nursing studies the nature and direction of human development with the environment (Fawcett, 1985). The science of nursing is also the creative use of knowledge (Rogers, 1989). Creativity and wholism reflect the art of utilizing nursing knowledge in service to human beings. "The uniqueness of science lies in the phenomena of concern. The concern of nursing is assisting people in their environment" (Rogers, 1989). The overall service should reflect care and concern for the health and welfare of human beings and the environment in which they live.

The practice of nursing is the art (Rogers, 1989). Rogers (1989) further explains that the use of nursing knowledge in practice is for human well-being and human betterment.

Health was originally explained by Rogers as "an expression of the life process" (Rogers, 1970, p. 85). Currently, Rogers (1989) refers to health as human betterment. It is assumed that human beings will define it uniquely and maintain their maximum wellness. Maximum wellness, or state of health, is subjective and totally unique to each human being. Change is up to the individual and human beings have the propensity to create and achieve change (Rogers, 1989). "Health and illness, ease and dis-ease are

dichotomous notions arbitrarily defined, culturally infused and value-laden" (Rogers, 1970, p. 85). Health is a subjective component of each human being and pervades the bio-psycho-social-spiritual dimensions.

In this study, health will refer to spiritual health rather than psychological or biological. It is this researcher's belief that family caregivers are able to persist in their environment when faced with intense caregiving tasks because of this spiritual resource.

Understanding and believing the assumptions and building blocks basic to Rogers Science of Unitary Human Beings is imperative before application to spirituality can be achieved. In addition, there are several basic principles integral in understanding Rogers' abstract system. The three principles are integrality, resonancy and helicy.

Principles

Integrality is "the continuous, mutual human field and environmental field process" (Rogers, 1986, p. 6). Resonancy is the continuous change from lower to higher frequency and is characterized by increased diversity and innovation and is unpredictable (Rogers, 1989). Helicy concerns the nature and direction of change (Barrett, 1989). Figure 1 is a representative model of the assumptions, building blocks and principles.

In using Rogers' abstract system as a model for this study, it is important to remember that the focus of this research is to

ASSUMPTIONS

1. Unified whole greater than sum of parts.
2. Constant exchange of energy and matter.
3. Irreversibility.
4. Pattern identifies the human field.
5. Human beings are unique and individual.

BUILDING BLOCKS

1. Energy fields.
2. Universal open systems.
3. Pattern.
4. Four dimensionality.

PRINCIPLES OF HEMODYNAMICS

1. Resonancy
2. Helicy
3. Integrality

Figure 1. Components of Rogers' Abstract System.

describe the expression of spirituality by family caregivers of individuals with cancer. The environment of the family caregiver to be described is that which is created upon assuming the role of caregiver for the individual diagnosed with cancer. It is within this specific environmental experience that the description of spirituality will evolve.

Rogers views human beings as wholistic, ever evolving and capable of change. The wholistic view is assessing human beings as unique bio-psycho-social-spiritual individuals. The environment is evolved into and created when the human being takes on the role of a family caregiver. According to Rogers (1970):

> The environment is an open system with no boundaries and possessing its own wholeness. Man and his environment are coextensive with the universe and man is affected every day by a multitude of influences from his environment. Man knowingly makes choices. Through awareness of himself and his environment, he is an active participant in determining the patterning of his field and in reorganizing the environment in accord with his desires (p. 71).

In this study, taking on the role of family caregiver will be considered a conscious choice leading to change. This change will lead to the exchange of energy between the family caregiver and the individual with cancer. The life process will continue forward on an irreversible space-time continuum.

Relationship of Rogers Abstraction to this Study

A conceptual framework is an abstraction and represents the universe of human beings. The conceptual framework developed for

this study (Figure 2) addresses the human being as a bio-psycho-social-spiritual living entity.

The larger outer circle represents the human being (family caregiver) in relationship to the greater whole of the system (universe). Broken lines represent openness of the system and are representative of the concept of no boundaries. Arrows going in and out of the larger circle depict the flow and exchange of energy that constantly occurs between human being's and their environment.

The smaller broken lines inside the larger circle are interconnected to demonstrate the relationship of the four dimensions of every human being. They represent the components that serve to make up the greater whole. Without the presence of one of the dimensions, the human being would be fragmented and unwhole.

The environment is representative of the actual caregiving situation. The individual with cancer is present within this environment. The environment of the human being is everything outside of the larger circle in which the caregiver comes in contact.

The spiral represents the rhythmical nature of the process of life. Human beings are always moving forward. Variations in the spiral represent a slowing down at points of change or transition in one's life. However, even during periods of difficulty, human being's are moving forward in continuous interaction with their environment. The interactions (manifestations), pattern and repatterning, are unique and make a human being whole. At the time when the family member becomes a caregiver for an individual with cancer, a transition in the life process occurs.

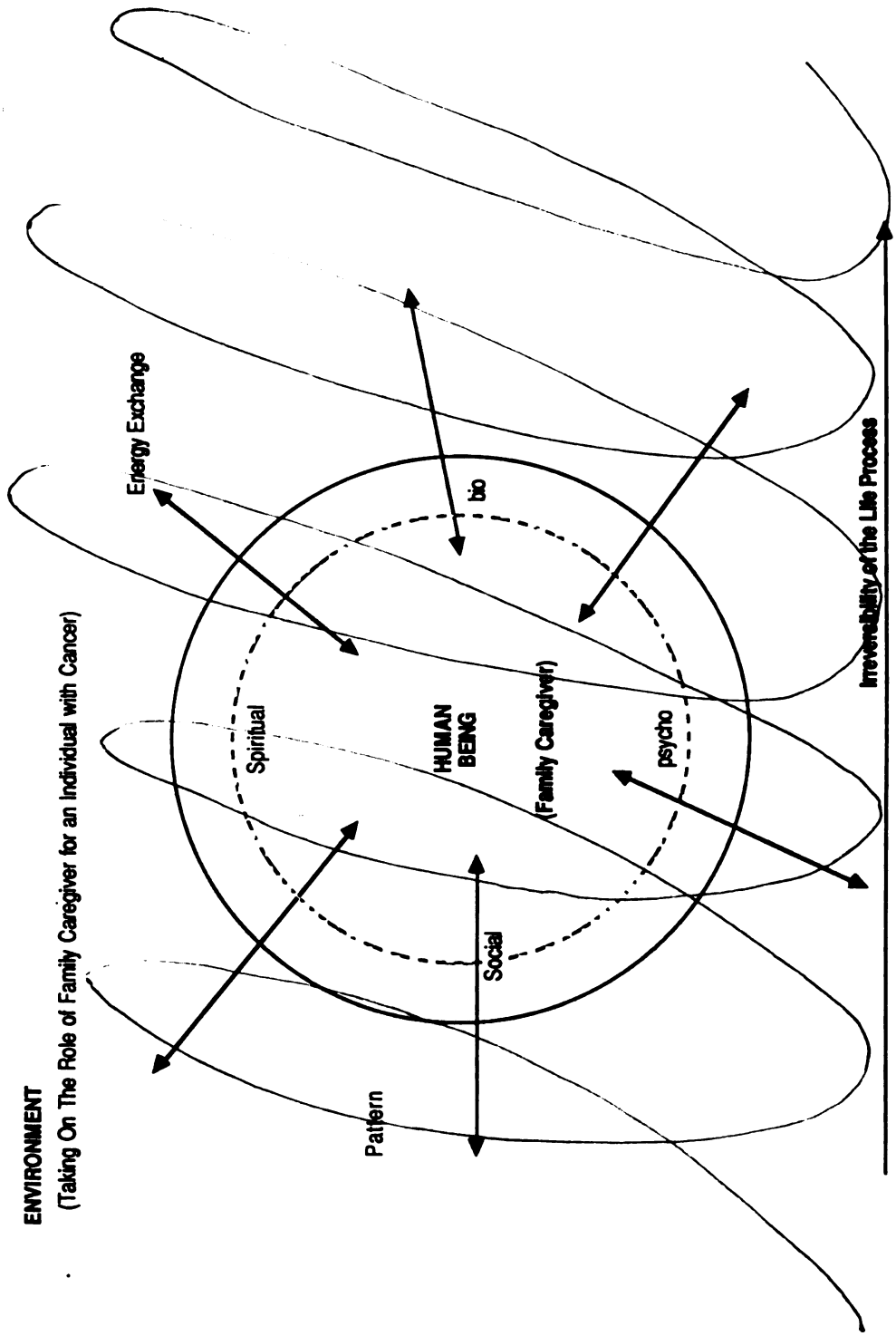

Figure 2. Conceptualization of Wholistic Human Being (Family Caregiver of an Individual with Cancer.)
(Based on Rogers' Abstract System)

Figure 2 represents the conceptual framework for spirituality, based on Rogers Science of Unitary Human Beings, which serves to guide this study. The purpose of this study is to describe the human dimension of spirituality within the environment of caregiving.

To relate this to family caregiving, the human being may not have experienced the individual with cancer in the home situation before. Caregiving is a tremendous new role and causes strain and fluctuation in the environment. If the family caregiver can take time to manage the change creatively, positively and wholistically, he/she will be able to repattern caring in to their environment and universe. The dimension of spirituality will assist the family caregiver to repattern their life and assimilate this new role into dynamic interactions.

In utilizing Rogers (1970) framework, human beings can be conceptualized as having the capacity to search for meaning in life and environmental situations that they encounter. Family caregivers are able to persist in carrying out tasks because of their inner source of strength, conviction and beliefs. The existence of the spiritual dimension, as well as the environment, plays a major role in the life process.

In this chapter, the assumptions, building blocks, concepts and principles of Martha Rogers' Science of Unitary Human Beings have been explained and their relationship to this study identified. Additionally, a conceptual framework has been proposed to guide the research of the concept of spirituality.

In Chapter III, a review of the literature pertinent to this research will be presented. In this chapter, literature relevant to the concepts of spirituality and family caregiving will be discussed.

CHAPTER III

Review of the Literature

Overview

The goal of this research is to describe expressions of spirituality by family caregivers for individuals with cancer. It will be the purpose of this literature review to address a brief background of the phenomenon of family caregiving, the stress of caregiving for individuals with cancer, spirituality and how the environment and spirituality are related. Present research and contributions currently in the literature will be presented to substantiate the research problem and provide background for the research question.

The Caregiving Phenomena

In an October 1988 National Survey of Caregivers (The American Association of Retired Persons and The Travelers Companies Foundation), it was revealed that approximately four out of five older adults avoided institutionalization because of personal care and financial assistance received from family members or friends. With the aging of baby boomers, this phenomenon will likely increase.

Dychtwald and Flower (1989), report that the senior boom, the birth dearth, and the aging of the baby boom are coming together to

create a demographic shift which they refer to as the Age Wave. This shift, according to Census Bureau projections, will result in a total of 35 million Americans over 65 by the turn of the century, accounting for approximately one-seventh of the population. The National Institute on Aging projects that by 2040 there will be 87 million Americans over the age of 65 (Dychtwald & Flower, 1989). This national aging trend will serve to increase the family caregiving phenomena.

At least 3.5 million Americans are chronically ill or disabled and need medical or support services for an extended period of time (Lopez, 1988). Families of individuals with chronic disease may have the potential for finding themselves in a caregiving role in the future related to several factors. Some of these factors include advances in modern technology, the ability to sustain life for longer periods of time, increased life span of human beings, hospital stays being reduced related to high cost, increased out-of-pocket expenditure for insurance benefits and increased usage of out-patient services for treatment. Policies are being created at the state and federal level that support family caregiving in the home (Bowers, 1987; Hatch, 1982; Townsend, 1981).

Historically, caregiving has been a role that the family has assumed for various reasons. Hirst and Metcalf (1986) define a caregiver as an individual who strives to fulfill the psychosocial and physiological needs of another person. Cantor (1983) states

that one of the precursors for assuming the role of caregiver is feeling close to the care-recipient.

According to Benner and Wrubel (1988), caring involves a certain level of involvement and is primary in setting up the condition of trust where help can be given and can also be received. Even when a good caring relationship exists, the toll of the role on the family caregiver can be high (Clark & Rakowski, 1983). Caregiving can be an all consuming task (Clark & Rakowski, 1983; Crossman, 1985; Deimling & Poulshock, 1985). Life satisfaction, level of perceived stress, personal freedom, career and personal relationships can be impacted when caregiving responsibilities are incorporated into the life process of the caregiver (Archbold, 1982; George & Gwyther, 1984).

The ability of family members to assume the additional responsibilities for care at home varies in relation to the ill individual's needs, the environment, and the caregiver needs and responsibilities. The family's ability to adapt to the caregiving role also depends upon resources available within the family unit and the larger social support system (Hinds, 1985). Support received from other family members' appears to be an important predictor of family members reactions to their caregiving role (Blank, Clark, Longwood & Atwood, 1989; Collins, Given, Given & King, 1988; Lewis, 1986; Hooyman, Gonyea & Montgomery, 1985; Johnson & Catalono, 1983; Horowitz, 1982; Goldstein, Regnery & Wellin, 1981; Archbold, 1980; Sanford, 1975).

The increasing phenomenon of family caregiving has been presented in this section. Numerous factors exist that can potentially have an effect on the care of the chronically ill and elderly family member in the home. The all-consuming aspect of the family caregiving role has also been discussed. The potential for stress that the caregiving role evokes will be discussed in the following section.

Caregiving and Stress

Caregivers are faced with major life restructuring and experience varying degrees of stress according to complex variables (Bunting, 1989). Competing demands on the caregiver include time, energy, attention and money; and these demands increase with the level of dependency of the care-recipient. This increasing demand often leads to caregiver stress, which is demonstrated by ill health, depression and other stress-related manifestations (Birkel & Jones, 1989; Moritz, Kasl & Berkman, 1989; Pruchno & Resch, 1989; Baillie, Norbeck & Barnes, 1988; Quayhagen & Quayhagen, 1988; Silliman & Sternberg, 1988; Birkel, 1987; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Brody, 1985; Cantor, 1983; Soldo & Myllyluoma, 1983; Archbold, 1980).

Caregiving is described as a burden, strain or stressor; an experience that produces negative psychological responses (Montgomery, 1985; Oberst & James, 1985; Poulshock & Deimling, 1984; Thompson & Doll, 1982; Zarit, Reever & Bach-Peterson, 1980). Caregiving may be burdensome and evoke a range of negative and

positive reactions, but it has been defined as a part of a set of normative responsibilities of family members (Brody, 1985). This responsibility may be fulfilled because of love and personal commitment on the part of the caregiver. Many families negotiate the caregiving situation before if occurs. Less strain is experienced and personal growth may be an outcome of planned caregiving situations (Brody, 1985). Even in a congenial, homeostatic situation however, the family changes in structure, and this structural shift can be a potential for stress. In summary, the family can be affected by interference with life-style, privacy, socialization, future plans, vacations, income and by the diversion of the primary caregiver's time from other family members.

The Environment of the Cancer Caregiver

Approximately two out of every three families in the United States are at risk for a family member developing cancer (American Cancer Society, 1987). The probability at birth of developing cancer before the age of seventy-five is approximately twenty percent in both men and women (Hinds, 1985). The prevalence of cancer in the population makes it one of the major chronic health problems in the United States. Therefore, the potential exists for family members to become caregivers of individuals with cancer.

The family cancer caregiving phenomenon is different from caring for persons with other debilitating and chronic illnesses (Northouse, 1984; Grove, Ilstrup & Ahmann, 1982; Stoler, 1982; Wellisch, 1981; Weisman, 1979). Public attitudes toward cancer are

such that the diagnosis induces in many persons a foreboding greater than that of other diseases carrying equally serious or worse prognosis (Greer & Silberfarb, 1982).

Cancer evokes feelings of impending doom, devastation, fear of the future and eventual death (Northouse, 1984; Lewis, 1982; Krant & Johnston, 1978; MacVicar, 1975; Mastrovito, 1972). Cancer as a diagnosis creates an immediate burden through emotional and psychological distress (Greer & Silberfarb, 1982).

The entire family is impacted when one of the members is diagnosed with cancer (Oberst & Scott, 1988; Welch-McCaffrey, 1988; Hinds, 1985; Oberst & James, 1985). Emotional distress is an understandable and realistic response in the family member and the individual with cancer related to the unpredictable nature of the disease and the resulting stresses (Miller & Nygren, 1978).

Families play an important role in assessing the needs and providing the home care necessary for the individual with cancer. Family members provide a wide range of care including physical, emotional and spiritual. The type of care provided changes with length of time since diagnosis, progression of disease and amount of disability. For example, the family caregiver may only provide emotional or spiritual support for an ambulatory individual with cancer or may be called upon to provide around the clock, total physical care for a family member in the terminal stages of the disease.

Illness in one family member affects the entire family system (Lewis, 1986; Northouse, 1984; Cassileth & Hamilton, 1979; Bowen,

1976; Minuchin, 1974). "Cancer is a chronic disease that is accompanied by physical, psychologic, emotional, and social problems that patients, family, and friends must cope with so they can go on living" (Blumberg, Ahmed, Flaherty, Lewis & Shea, 1981, p. 3). The research question for this study implies that spirituality may serve as one way of coping through the cancer caregiving phenomena.

Spirituality

Numerous definitions have been proposed for the concept of spirituality and range from a belief in a Higher Being to a sense of inner peace, well-being and tranquility (Brooke, 1987; Dugan, 1987; Peterson & Nelson, 1987; Reed, 1987; Vastyan, 1986; Granstrom, 1985; Harmon, 1985; Kenner, Guzzetta & Dossey, 1985; Egan, 1984; Ryan, 1984; Colliton, 1981; Barshinger, 1979; May, 1974). Specific definitions have been reported in Chapter I of this manuscript (Hammer & Marting, 1988; Dugan, 1987; Peterson & Nelson, 1987; Reed, 1987; Vastyan, 1986; Granstrom, 1985).

Additionally, various terminology has been used interchangeably to describe spirituality. Some of the terms utilized are spiritual distress, spiritual needs, spiritual concerns, and spiritual well-being (Ellerhorst-Ryan, 1988).

Pumphrey (1982) states "spirituality is rooted in a matrix of meaning and purpose arising from what is termed by some a worldview, by others a philosophy, and by still others, a specific theology" (p. 203). This statement is compatible with the definition of spiritual/philosophical proposed by Hammer and Marting (1988)

and utilized in this research. Spirituality is that which the person defines for her or himself and can be acquired through various avenues of life including family, education, religion, culture and a personal belief system (philosophy). This view is also compatible with Martha Rogers abstract system and belief that spirituality is a manifestation of pattern and unique to each human being (1989).

Lay literature has addressed the concept of spirituality utilizing varied approaches. The search for meaning of life, overcoming inner struggle, body/mind connection, peace, hope, psychosocial aspects of health, meditation, imagery, death and dying, self-acceptance, self-healing, positive reinforcement, love, stress, coping and similar topics have been discussed in relation to spirituality and personal philosophy and are accepted by the general public (Borysenko, 1988; Siegel, 1986, 1989; Hay, 1984; Spingarn, 1982; Cousins, 1979, 1984; Weisman, 1979; Simonton, Simonton & Creighton, 1978; Sontag, 1978; Pelletier, 1977; Selye, 1976; Thomas, 1974, 1979; Kubler-Ross, 1969, 1978; Frankl, 1963). The concept of spirituality has only recently become the focus of valid research by health care professionals.

Several scales have been developed that measure aspects of spirituality including well-being, distress, needs and coping (Moberg, 1984; Paloutzian & Ellison, 1982; McCorkle & Benoliel, 1981; Stoll, 1979; Martin, Burrows, & Pomilio, 1976; Hess, 1969). The scale most consistent with this author's understanding and belief related to the concept of spirituality is the

Spiritual/Philosophical Subscale developed by Hammer and Marting (1988) as one domain in the Coping Resources Inventory (CRI).

The CRI was developed to focus on the strengths and resources available to individuals in coping with stressful events. Understanding personal resources and how those resources influence coping strategies was the major reason the instrument was developed. Hammer and Marting were interested in determining whether the spiritual/philosophical values and beliefs of an individual would be important in assisting them in meeting and coping with stressful events.

In interpretation of the CRI, Hammer and Marting (1988) stated that:

> Professionals can suggest to individuals that high resources may help to lessen some of the negative psychological and physical impact of stressors. Sometimes just identifying the fact that they have some relatively high resources can be a useful intervention. This not only increases self-esteem, but also provides a starting point for selecting coping strategies in specific situations. Professionals can also identify the low resources and explore with individuals ways of improving these areas (p. 5).

It is this researcher's belief that spirituality is a high resource for family caregivers of individuals with cancer and they can self-report their expression of spirituality via use of a questionnaire. The caregiving role and the diagnosis of cancer both create stress, and resources are needed for individuals to cope. One of the avenues of coping available to caregivers is that of the spiritual dimension. Spirituality can help family caregivers to perceive their environment as less stressful.

Literature and research related to the concept of spirituality have been limited in focus. There has been minimal research into the exploration of spirituality as a dimension of human beings and their existence, making them unique. The concept of spirituality is often intertwined with other concepts including religion, and religious beliefs, practices and preferences (Ellerhorst-Ryan, 1988). No research was located which had focused on caregivers' expression of spirituality. The patient is most generally the subject of research. More research needs to be conducted into how family caregivers are able to function in their role and how they express their spirituality.

The Environment and Spirituality

Sodestrom and Martinson (1987) state:

> . . . patients use spiritual beliefs and practices as coping actions to obtain peace, strength, or direction in the stressful situations their illness creates. Religious faith (as a coping strategy) may even lessen the negative impact of cancer and sustain the patient during illness (p. 41).

In the research done by Sodestrom and Martinson (1987), 25 hospitalized patients diagnosed with cancer were used to describe spiritual coping strategies. A one-time interview was conducted using an adaptation of McCorkle and Benoliel's (1981) Spiritual Coping Interview. Hospital nurses' awareness of their patients spiritual coping strategies were also measured. Data indicated that patients use a variety of spiritual activities such as prayer, Bible reading, sacraments, religious music, religious objects and speaking with spiritual leaders to help them cope. Nurses were

able to identify only a few of the spiritual activities and some of the spiritual resource persons.

Vastyan (1986), an Episcopal priest involved in medical education, describes the spiritual phenomena that becomes apparent during health crisis. The spiritual context of the health crisis is defined as "one of those highly significant times in human life that mark a turning point, one that inevitably involves change, one in which judgement and choice can be crucial" (p. 110). Vastyan considers the diagnosis of cancer a health crisis in which spiritual phenomena become evident. The diagnosis, or the fear of cancer, sanctions the sick role in which an individual does not have to have control or power. Vastyan (1986) states that spirituality requires acceptance and not control.

Dugan (1987) discussed spiritual support in his article and addressed the inability of many caregivers, families and professionals to allow patients to discuss their deepest feelings. Dugan states that the ability to provide emotional and spiritual support is closely related. Spiritual pain, or suffering, is described as, "a loss of one's sense of internal 'togetherness'" (p. 27). The goal of therapeutic dialogue should be to allow for release of emotional or spiritual pain.

Crisis, as a release of the spiritual dimension, was the focus of Ryan's (1984) article.

> . . . a crisis can clarify and intensify spiritual beliefs. A sense of God's love and presence even in suffering, a belief in the ultimate victory of good

> over evil, an ability to tolerate the unknown and mysterious aspects of life - these may strengthen an individual in a way that mitigates the impact of crisis (p. 1258).

The importance of individuality and personal experience were stressed.

Granstrom (1985) paints a vivid picture of how cancer victims visualize their spiritual life. "It is helpful to imagine that an individual's spiritual life is like a 500-piece puzzle. It is the task of each individual to put the puzzle together to the best of his or her ability" (p. 43). Each individual determines for her or himself what their meaning and purpose is and how to attain it.

According to Sodestrom and Martinson (1987), "coping implies successful adaptation to stressful situations by behaving and thinking a specific way to decrease perceived threats and their associated stress" (p. 41). These two researchers designated religious faith and/or spirituality as a coping strategy which could include prayer, participation in communion rites, reading the Bible and talking with clergy.

Hammer and Marting (1988) also hypothesized that spiritual/philosophical values "might serve to define the meaning of potentially stressful events and to prescribe strategies for responding effectively" (p. 3). If the caregiving role and cancer experience of a family member with cancer are stressful for the caregiver, spirituality may serve as a coping resource and thus help to alleviate the stress of the situation.

As discussed in Chapter II, the environment of the caregiver, for this study, will be the role of caregiver for a family member or significant other with cancer. Literature has documented the caregiving role to be stressful. If caregivers have a sense of personal spirituality, perhaps this is one of the ways in which they are able to maintain their caregiver role and decrease their levels of stress. Further, related to the fact that most major research into the realm of spirituality has focused on the chronically ill person, it is necessary to look at how other persons (family caregivers), touched and affected by the cancer experience, utilize their sense of spirituality as a coping resource.

Lastly, while spirituality has long been an interest to the general and religious sectors of society, valid research by professionals is scant. Work is needed to factor out the components of spirituality (well-being, distress, religion, etc.) and define the concept in such a way that every individual participating in a research study will be able to 'fit' within the terminology used.

Spirituality exists separate from religion and religiosity. Many instruments currently exist which utilize the terminology of God and ask about religious participation. To continue in this procedure will negate the dimension of spirituality as unique for every human being. Thus, the decision to conduct a descriptive study to determine if spirituality is a dimension that can be expressed, through utilization of a research tool, by family caregivers of individuals with cancer. It is a goal of this study to create a foundation of descriptive and statistical information for

future research into the dimension of spirituality of human beings in the family caregiving experience.

Summary

The content of Chapter III has included a brief review of the caregiving phenomenon, caregiving and stress, the environment of the cancer caregiver, spirituality and the environment and spirituality. The focus in Chapter IV is a comprehensive outline of the study methodology and planned procedures.

CHAPTER IV

Methodology and Procedure

Overview

This study was designed to describe spirituality as expressed by family caregivers of individuals with cancer. Data for this secondary study were collected as part of a grant from the National Center for Nursing Research, #R01-AG01915-01 "Family Homecare for Cancer - A Community Based Model" conducted by B.A. Given, Principal Investigator. The purpose of the original longitudinal grant was to study individuals with solid tumors and their family caregivers to determine the effectiveness of care provided by families, home care and community agencies. The goal of the funded study was to describe the needs for, the receipt of, and the outcomes of care provided to individuals with cancer (solid tumor) by families from formal health care systems (physician offices and home care agencies) located in community based settings.

The study design for the funded project was a longitudinal sample of 367 family caregivers of individuals with cancer. Data collected on 278 subjects at the intake phase of the original study were utilized for this research.

In this chapter, the criteria for selection of the original sample along with data collection procedures, instrument selection, and human rights protection are presented. These descriptions are

identical to those used in the original research project, unless otherwise stated. In addition, the concept under study is operationally defined. In the conclusion of this chapter is a discussion of the methods of statistical analysis.

Research Question

This study was directed at answering the following research question: "What are the self-reported expressions of spirituality among family caregivers of individuals with cancer?"

Sample

Twenty-three community-based agencies in the lower region of Michigan were utilized as contact sources for distributing information to prospective research participants. Health care professionals employed by these agencies selected clients who might be eligible for the research study based on the following inclusion criteria:

1. Individual with a solid tumor 18 years of age or older.
2. Family member or significant other who had been designated as the primary caregiver by the individual with cancer.
3. The individual with cancer had to be currently receiving some form of cancer therapy (hormonal, radiation or chemotherapy).

The ideal target population of this study consists of primary family caregivers of individuals over the age of 18 diagnosed with a solid tumor. Because the available sample was not a random

selection of the ideal target population, the results of the study cannot be generalized, in a statistical sense, to all family caregivers of individuals with cancer. In the strictest sense, findings from this research only describe the study sample.

Recruitment

Community-agency health care professionals were asked to distribute informational letters and stamped return postcards to interested subjects. Letters included the description and purpose of the study, potential benefits, and the length of time and involvement required for participation. A toll-free telephone number and the names of research team members were also included in the letters for those seeking additional information. Interested caregivers/individuals with cancer returned postcards to the research office.

Follow-up on all postcards was conducted by members of the research staff. A screening questionnaire was administered to the designated caregiver over the telephone to determine eligibility for the study. During this initial contact with the research team, the purpose and goals of the study were described again and questions answered. Those subjects meeting inclusion criteria were entered into the study, assigned an identification number and entered into the caseload of a research interviewer. The first formal contact was during the intake phase of the study, which consisted of a telephone interview (approximately 45 to 60 minutes in

length) and mailed self-administered booklets for both the family caregiver and the individual with cancer.

Characteristics of Sample

Three hundred and sixty-seven family caregivers of individuals with cancer were entered into the funded longitudinal study. The data for this specific research were obtained from 278 family caregivers who completed the intake phase of the study.

Methods of Data Collection

Sociodemographic data were compiled from the screening instrument, interviewer telephone conversation at intake (Wave I) and the caregivers' mailed self-administered questionnaire. Verbal consent was received during screening, and written consent forms were mailed to the caregiver/individual with cancer and returned with the self-administered booklets.

The original grant was funded for two years. The caregiver/patient contacts were over a twelve month period and consisted of five contacts with participants every three months. At the time of this writing, the research is still in progress.

Operationalization of the Concept

For the purpose of this study, spirituality was defined as the degree to which a person's actions are guided by stable and consistent values derived from religious, familial or cultural tradition, or from personal philosophy (Hammer & Marting, 1988). In this study, spirituality was measured by using scores from the

Spiritual/Philosophical subscale from the Coping Resources Inventory (Hammer & Marting, 1988).

On each of the eleven items in the subscale, subjects were given four Likert-type response options ranging from "never to rarely" to "always or almost always". The highest possible score for this scale is 33 (all 11 questions answered with "always or almost always"). Scores closer to 33 are indicative of spirituality being an important resource for the individual.

To better understand this subscale and its associated statistical properties, it is necessary to describe the Coping Resources Inventory developed by Hammer and Marting (1988). The next section of this chapter will describe the research instrument.

The Coping Resources Inventory Research Instrument

The Coping Resources Inventory (CRI) was developed to focus on the strengths and resources available to individuals in coping with stress. Hammer and Marting (1988) postulated that understanding the personal resources of individuals and how these resources influence coping strategies would be helpful in designing interventions and prevention programs.

Hammer and Marting (1988) define coping resources as:

> those resources inherent in individuals that enable them to handle stressors more effectively, to experience fewer or less intense symptoms upon exposure to a stressor, or to recover faster from exposure (p. 2).

This definition is distinct from coping strategies terminology which refer to reactions that individuals have after experiencing a stressor or when in a stressful event. The coping resource domains

that were utilized in the 60-item instrument included Cognitive, Social, Emotional, Physical and Spiritual/Philosophical. Scale scores are the sum of the responses to each item after reversal of six items that are negatively worded. A Total Resource score is achieved by summation of the five scale scores. The higher and scale score, the higher the resource (Hammer & Marting, 1988). Only the Spiritual/Philosophical subscale was utilized in this research study. The eleven specific items/questions from the Spiritual/Philosophical subscale are reported in Table 1.

In development, the CRI was administered to n=>850 subjects. The statistical results for the Spiritual/Philosophical subscale are reported in Table 2.

Specific demographics for the sample groups in Table 2 are not available. However, Hammer and Marting (1988) reported means on 22 forty to forty-nine year old individuals as 34.36 with a standard deviation of 5.85. Twelve individuals over the age of fifty had a mean score of 36.75 and standard deviation of 5.83. These statistics are similar to those analyzed by this researcher in a study that is described later in this chapter.

Reliability and Validity of Spiritual/Philosophical Subscale

Reliability, in the sense of internal consistency of an instrument, refers to the extent to which all items of the instrument are equally good indicators of a concept or attribute in question (Polit & Hungler, 1987). Cronbach's alpha is one of the most useful statistical techniques in measures of internal consistency.

Table 1

Items from the Spiritual/Philosophical Subscale (Hammer & Marting, 1988).

1.	I accept the mysteries of life and death.
2.	I can make sense out of my world.
3.	I believe in a power greater than myself.
4.	Certain traditions play an important part in my life.
5.	I know what is important in life.
6.	I attend church or religious meetings.
7.	I pray or meditate.
8.	I seek to grow spiritually.
9.	I take time to reflect on my life.
10.	My values and beliefs help me to meet daily challenges.
11.	I accept the problems that I cannot change.

*See Appendix D for copyright information.

Table 2

Statistical Results of the Spiritual/Philosophical Subscale: Sample Size (N), Mean (M), Standard Deviation (SD), Standard Error of the Mean (SEM), Confidence Interval (CI), N = > 850 (Hammer & Marting, 1988).

N	M	SD	SEM	95% CI
327[a]	31.26	5.94	0.33	30.62 - 31.90
491[b]	32.48	6.17	0.34	31.81 - 33.15
843[c,d]	32.02	6.10	0.34	31.36 - 32.68
21[e]	37.86	3.75	NA[f]	NA

[a]Males

[b]Females

[c]Total males and females

[d]Missing data account for difference in male/female total

[e]Bereaved Caregivers of family members with Alzheimer's disease

[f]NA = data not available

Alpha coefficient values among items range from 0.00 to 1.00 if all item-total correlations are positive. The higher the coefficient, the higher the degree of internal consistency (Polit & Hungler, 1987). In Hammer and Marting's (1988) sample of 749 individuals, the Spiritual/Philosophical subscale analysis for Cronbach's alpha was reported as .80 or a high level of internal consistency.

A second meaning of reliability refers to reproducibility of results. The less the scores of an instrument are influenced by error, the greater reliability of the instrument. A measure is reliable to the extent that repeated application of the instrument produces the same results.

The Spiritual/Philosophical subscale item-to-item corrected correlation range was from .34 - .67 with a mean score of .42 as reported by Hammer and Marting (1988) on a sample of 749 individuals.

The Spiritual/Philosophical subscale was also utilized in another independent sample of family caregivers of physically-impaired elderly, ("Caregiver Responses to Managing Elderly Patients at Home" #NIA-IROHAG06584-01). This was a three-year grant from the National Institute of Aging to Co-Principal Investigators, Dr. Charles W. Given (College of Human Medicine) and Dr. Barbara A. Given (College of Nursing) at Michigan State University to study responses of caregivers managing elderly family members at home (Appendix A). Data was analyzed from this study, by this researcher, to further study the statistical properties of the Spiritual/Philosophical subscale on a sample of family caregivers.

The sociodemographic data analyzed in the family caregivers of physically-impaired elderly study characterize the sample and assist in describing the study. The mean age of family caregivers of physically-impaired elderly was 62.3 with a standard deviation of 11.5 and range of 27 to 64 years. The majority of caregivers were female (n=172, 84.7%), Caucasian (n=190, 93.6%), married (n=163, 80.3%) and had at least a high school education (n=159, 78.4%). The duration of caregiving ranged from 1 to 61 years with a mean of 6.86 years and standard deviation of 7.0. One hundred and eight spouses were being cared for (n=108, 53.2%).

Spirituality data analyzed on family caregivers (n=203) of physically-impaired elderly revealed an alpha of .82, a mean scale score of 34.45 and average correlations among scale items were .31. These statistics are comparable to the results Hammer and Marting (1988) obtained in development of the CRI. Table 3 is a summary of the statistics obtained from analysis of the Spiritual/Philosophical data at the Wave V (12 month contact) of this study. This data helps to clarify, for this sample, that family caregivers of physically-impaired elderly are able to self-report their expressions of spirituality. Furthermore, the Spiritual/Philosophical subscale statistical characteristics for the family caregivers of physically-impaired elderly study, serve to build a statistical foundation for possible reproducibility and support of the findings in the cancer caregiver study. Results of the current research study are compared to the findings from the elderly caregiver study in Chapter V.

Table 3

Spiritual/Philosophical Subscale Characteristics for A Sample of Family Caregivers of Physically-Impaired Elderly, N = 203.

Alpha	.82
Mean Scale Score	34.45
Standard Deviation Scale Score	5.89
Average Correlations among Scale Items	.31
Range	18-44
Possible Range	11-44
Skewness	-.43
Kurtosis	-.45

Validity

Validity refers to the degree to which an instrument or scale measures the concept or entity it is intended to measure (Phillips, 1982). Items in a scale are examined to determine: 1) that the whole range of the construct is covered by the items; 2) that no particular aspect of the construct is given undue weight; 3) all items are concerned with the construct under study (Wilson, 1985). According to Woods and Catanzaro (1988), a measure can be reliable but not valid, but a valid instrument must be reliable.

Hammer and Marting (1988) reported the range of validity from .61 for the Spiritual/Philosophical subscale to .80 for the Physical subscale. The statistical results were determined after administering the CRI to 108 junior high school students in conjunction with the Stress Test for Children (Elkind, 1981) and the Personal Stress Symptom Assessment (Numeroff, 1983). Hierarchial multiple regression analysis and other statistical techniques were employed to determine validity (Hammer & Marting, 1988). Further research with varied populations and age groups needs to be conducted in the future to establish additional statistical properties for the Spiritual/Philosophical subscale.

Descriptive Variables

According to Roberts and Burke (1989), a variable is simply a concept that has a measurable range of attributes. In this study, the sociodemographic data of age, gender, race, marital status, relationship to the individual with cancer, living arrangements,

education, monthly income, duration of caregiving and religious preference were obtained. These items were utilized as descriptive variables, and no attempt was made to control for the effects of these variables on caregivers expression of spirituality. The sociodemographic data for this research will be utilized only for the purpose of characterizing the family caregivers of individuals with cancer who participated in the study.

Human Subjects Protection

Family Homecare for Cancer-Funded Longitudinal Study

The rights of the respondents were protected through adherence to standard criteria set forth by the Michigan State University Committee on Research Involving Human Subjects. All potential subjects were initially given an informational letter describing the study, benefits, assured participants of anonymity and confidentiality and requested family caregivers to return the self-addressed, stamped postcard if they were interested in participating.

An interviewer from the research team contacted those individuals returning a post card and administered a screening questionnaire. During the telephone conversation, the study was again described and questions answered. If family caregivers remained interested, they were entered into the funded longitudinal study. At this time, each subject was assigned an identification number and assigned by number to a research interviewer. Interviewers were responsible for contacting subjects assigned to their caseload

and set up a time for the intake interview. Upon this contact, packets of information were sent to each subject which included an informational letter and a consent form. The consent form provided a brief explanation of the research, the purpose of the study, the use of the results, and assurances of anonymity and confidentiality (Appendix B). Confidentiality and anonymity were assured through the use of case numbers on the instruments used for data collection and analysis.

This researcher was employed as the Data Collection Coordinator and Community-Agency Liaison for the funded longitudinal study. Because the data were coded into the computer before conduction of this research, specific individuals could not be linked with the data. Approval from the University Committee on Research Involving Human Subjects was received for this study to conduct analysis related to the expression of spirituality by family caregivers of individuals with cancer (Appendix C). Further risks to the subjects were not identified for this study.

Statistical Analysis of the Data

Data obtained from the intake phase of the one-year longitudinal research study were examined for this research. The sociodemographic data utilized for analysis were obtained during screening and the intake phase.

Descriptive statistics were used to characterize the sample of research participants in terms of sociodemographic attributes which included age, gender, race, marital status, relationship to

individual with cancer, living arrangements, level of education, income, duration of caregiving, and religious preference. Descriptive statistical analysis allows for presentation and summary of quantitative attributes of research participants in a specific sample (Polit & Hungler, 1987). Means, standard deviations and ranges were calculated for age and duration of caregiving. Race, gender, education, income, religious preference, marital status, relationship to individual with cancer and living arrangements are reported as frequency distributions. In Chapter V, summary tables of the sociodemographic and descriptive variables are presented.

The subjects' responses to the Spiritual/Philosophical subscale in this study are reported by the mean, standard deviation, ranges, alpha, average correlations among scale items, frequency and rank order. Scale characteristics are compared for the elderly caregiver study and the cancer caregiver study.

Summary

In this chapter, the methodology for this research was described and discussed. The research question, sample characteristics, operational definition of the variable under study, study procedure, human subjects protection and data analysis procedures were the specific topics addressed. In Chapter V an analysis of the data and findings relevant to the research question are presented.

CHAPTER V

Data Presentation and Analysis

Overview

A description and analysis of the sample and an interpretation of the research findings are discussed in this chapter. Selected sociodemographic and informational data are presented to describe the sample of family caregivers of individuals with cancer. Data relevant to the self-reported expressions of spirituality by family caregivers are also presented along with analysis of findings.

Sample Characteristics

The sample for which data were available and analyzed for this study consisted of 278 family caregivers of individuals with cancer. These caregivers represent a convenience sample solicited for voluntary participation via community-based health care agencies. Completed screening data, initial intake interviews and self-administered questionnaires on 278 participants in a larger sample of 367 family caregivers of individuals with cancer make up the data utilized for analysis in this research study.

Descriptive Variables

The descriptive variables addressed in this study include: age, gender, race, marital status, relationship to individual with

cancer, living arrangements, education, income, duration of caregiving and religious preference. Distributions related to the descriptive variables in this study are outlined in a series of tables. All of the variables are calculated on a sample size of 278 family caregivers. A brief synopsis of the descriptive variable frequency and per cent follows each table.

Descriptive statistics are "those statistics that organize and summarize numerical data gathered from samples" (Nieswiadomy, 1987, p. 283). The frequency and percentage will be utilized to describe the sample.

The mean age of this sample of family caregivers of individuals with cancer was 55.12 years with a standard deviation of 12.43. The range was from 20 to 81 years of age. The majority of caregivers (64.4%) were female and 96.0% (n=267) were Caucasian. Further description of the age, gender and race of the sample can be found in Table 4.

Ninety one percent (n=253) of the family caregivers were married. The widow/widower category made up 2.9 per cent (n=8) of the sample while nine (3.2%) were divorced and one was separated (.4%). Refer to Table 5 for additional information on marital status, caregiver relationship to the individual with cancer and living arrangements.

The majority (n=219, 78.8%) of individuals requiring care were spouses. In the parent category, there were 23 (8.3%) mothers and 2.9 percent (n=8) fathers. There were n=4 daughters (1.4%) in the child category; sons were not represented. Siblings were

Table 4

Frequency and Per Cent of Caregivers by Age, Gender and Race, N = 278.

Variable	Frequency	Per Cent
Age		
15-24	2	.7
25-34	17	6.1
35-44	44	15.8
45-54	51	18.3
55-64	99	35.6
65-74	54	19.4
75-84	11	4.0
Gender		
Male	99	35.6
Female	179	64.4
Race		
Caucasian	267	96.0
Black	6	2.2
Oriental/Asian	1	.4
Other	4	1.4

Table 5

Frequency and Per Cent of Caregivers by Marital Status, Relationship to Individual with Cancer and Living Arrangements, N=278.

Variable	Frequency	Per Cent
Marital Status		
Single	7	2.5
Married	253	91.0
Divorced	9	3.2
Widowed	8	2.9
Separated	1	.4
Family Relationship of Individual with Cancer to Caregiver		
Spouse	219	78.8
Parent	31	11.2
Child	4	1.4
Sibling	4	1.4
Other	20	7.2
Caregiver and Individual Live in Same Household		
Yes	241	86.7
No	37	13.3

representative of three sisters (1.1%) and one brother (.4%). The relationships contained within the other category included: four aunts (1.4%), eight friends/neighbors (2.9%), two mothers-in-law (.7%), one father-in-law (.4%), one brother-in-law (.4%) and four others (1.4%) consisting of cousins, and nonspecific relationships.

Two hundred and forty one (86.7%) caregivers and individuals with cancer lived in the same household. Thirty-seven (13.3%) of the family caregivers lived in their own homes.

Most of the family caregivers in this sample were well educated with only forty (14.4%) not graduating from high school. Twenty three of these caregivers (8.3%) possessed a master or doctoral degree. Table 6 contains additional statistical information on education.

The mean income (spouse and non-spouse caregivers combined) was $846.23 monthly with a standard deviation of $550.77. This monthly income calculates out to a mean yearly income of $10,154.76. The missing data could be accounted for by the difficulty many caregivers had in answering the question spontaneously during the in-depth telephone interviews conducted at the intake (one month) phase. Another factor may be that since the majority of family caregivers were female, perhaps they were not immediately aware of the exact income the family received on a monthly basis. Monthly income for this sample of family caregiver's of individuals with cancer is presented in Table 6.

The mean length of caregiving was 2 years or 24.29 months with a standard deviation of 3 years and 9 months (45.27 months).

Table 6

Frequency and Per Cent of Caregivers by Education and Income, N=278.

Variable	Frequency	Per Cent
Highest Level of Education Completed		
Grade School of Less	9	3.2
Some High School	31	11.2
High School Graduate	99	35.6
Some College	87	31.3
College Graduate	29	10.4
Grad/Prof Degree	23	8.3
Monthly Income (Dollars)		
200-500	83	28.8
501-800	101	36.4
801-1100	17	6.1
1101-1400	0	0.0
1401-1700	12	4.3
>1701	54	19.4
Missing	11	5.0

The minimum amount of time involved in the caregiving role was one month (n=12, 4%), and the maximum amount of time was twenty four years (n=1). Upon further examination of this caregiver's interview booklet, the individual with cancer had several bouts with various diagnoses of cancer over the years, including colon and lymphoma. The frequency and percent of the duration of years in the caregiver role is presented in Table 7.

Religious preference was an optional question with n=277 caregivers volunteering to answer. The majority reported Protestant (61.5%) as religion of choice, while no religious preference was reported by 7.9% (n=22). When questioned in relation to use of minister or religious services in the past three months, 75 (27.2%) caregivers answered "yes" while 201 (72.8%) answered "no". One hundred twenty six (45.7%) caregivers reported they had not attended a religious service in the past month. Table 8 contains further description of caregiver religious preference.

Fifty three percent of the caregiver sample (n=147) reported they felt someone helped them spiritually. Spiritual help from family and friends was received by 45.2% (n=66) caregivers, while n=80 caregivers (54.8%) felt they were helped spiritually by others.

Interpretation of Descriptive Variables

The typical family caregiver in this study was a married, Caucasian female (64.4%) between the age of 49 and 65 (47%) who was most likely caring for a spouse or parent. The majority lived in

Table 7

Frequency and Per Cent of Caregivers by Duration of Caregiving, N=278.

Variable	Frequency	Per Cent
Duration of Years in Caregiver Role		
1 year and less	168	62.0
1-3 years	69	25.0
3-5 yeas	17	5.0
5-9 years	9	3.0
10 years or more	15	5.0

Table 8

Frequency and Per Cent of Caregivers by Religious Preference, N=277.

Variable	Frequency	Per Cent
Religious Preference		
Protestant	171	61.5
Catholic	69	24.8
Jewish	0	0.0
Other	16	5.8
None	22	7.9

the same household (86.7%) with the individual diagnosed with cancer and had been functioning in their caregiver role for approximately 36 months or less (87%). Sixty two percent (n=171) of the individuals with cancer had been diagnosed since January of 1987. The mean number of house of daily care provided by the caregivers was 3.81 with a standard deviation of 5.18.

The majority of caregivers had a high school education with some college (66.9%) and an average yearly family (spouse caregiver) income between $10,000 and $24,999 (35.4%). However, there were 39 caregivers (20%) who had a family income of $50,000 or more. One hundred and thirty one (47%) caregivers were employed either part or full time outside the home.

The descriptive variables and informational data have been presented. These data help to describe the sample of family caregivers of individuals with cancer participating in this research study. In the next section of this chapter, the concept under study, the expression of spirituality, will be described.

Analysis of Spiritual/Philosophical Data

The Spiritual/Philosophical subscale was contained within a mailed self-administered booklet at the intake phase of the federally funded longitudinal study. Two hundred and seventy eight family caregivers of individuals with cancer returned the completed self-administered booklet to the research office.

Those participants returning self-administered questionnaires filled out the booklet in the privacy of their home. The

Spiritual/Philosophical subscale consists of 11 short items, and responses are on a 4-point Likert scale. Respondents were instructed to circle the answer they felt most likely described their feeling/belief about each specific item. Response choices were: "Never or rarely" (0), "sometimes" (1), "often" (2) and "always or almost always" (3). The section was not labeled Spiritual/Philosophical, so caregivers were not aware of the specific concept under study.

It is interesting to note the comparison of the Spiritual/Philosophical scale score characteristics for this sample with the results of Hammer and Marting's (1988) analysis and the caregivers of physically-impaired elderly study described in Chapter IV. Value responses for Hammer & Marting (1988) and the elderly study ranged from 1 to 4 as compared to the cancer study with value responses ranging from 0 to 3. This difference accounts for the variance in analysis of the scale score characteristics. Table 9 represents the comparison.

In Table 10, the central tendency and distribution for the Spiritual/Philosophical subscale compiled from the returned self-administered questionnaires for this study is described. This description is a measure of the mean and standard deviation of each item within the scale.

According to Nieswiadomy (1987):

> Measures of central tendency are statistics that describe the average, typical, or most common value for

Table 9

Comparison of Spiritual/Philosophical Scale Score Characteristics for Three Samples.

	Hammer & Marting	Elderly Caregiver Study	Cancer Caregiver Study
Alpha	.80 (n=749)	.82 (n=203)	.86 (n=278)
Mean Scale Score	34.36	34.45	22.12
Standard Deviation Scale Score	5.85	5.89	6.26
Range	NA[1]	18-44	5-33
Possible Range	11-44	11-44	0-33

[1]NA = data not available.

Table 10

Central Tendency and Distribution for Spiritual/Philosophical Subscale: Item Mean and Standard Deviation (SD) for Cancer Caregivers, N=278.

#	Specific Item	Mean	SD
1.	I accept the mysteries of life and death.	2.16	.91
2.	I can make sense out of my world.	1.96	.86
3.	I believe in a power greater than myself.	2.60	.74
4.	Certain traditions play an important part in my life.	1.89	.86
5.	I know what is important in life.	2.40	.73
6.	I attend church or religious meetings.	1.48	1.81
7.	I pray or meditate.	1.88	.94
8.	I seek to grow spiritually.	1.77	1.01
9.	I take time to reflect on my life.	1.67	.76
10.	My values and beliefs help me to meet daily challenges.	2.29	.74
11.	I accept problems that I cannot change.	2.13	.86

Values

0 = Never or Rarely

1 = Sometimes

2 = Often

3 = Always or Almost Always

> a group of data. Central refers to the middle or average value, and tendency refers to the general trend of the numbers to cluster in a certain way. A measure or central tendency summarizes a frequency distribution by the use of a single number (p. 289).

The mean represents the arithmetical average of all scores (Woods & Catanzaro, 1988). This measure of central tendency is also the average of each specific item and is one of the most widely used measures of statistical significance (Wilson, 1985).

The standard deviation is a useful statistic to employ when one is interested in determining what the average deviation about the mean of a distribution is. In other words, the standard deviation allows one to see how individual scores differ from one another.

Interpretation of Central Tendency and Distribution

Given the coding scheme, the lowest possible answer on each item is zero and the highest, three. Therefore, the midpoint for each item would be 1.5. This caregiver sample falls above the midpoint in all items with the exception of number six ("I attend church or religious meetings"). This is consistent with the 45.3% negative responses to the question related to attending a religious service during the past month. If caregiving is an all consuming task (Clark & Rakowski, 1983; Crossman, 1985; Deimling & Poulshock, 1985) then it would make sense that individuals are not able, or do not have the time, to attend religious services.

The average mean for the Spiritual/Philosophical subscale is 2.02. Five items are above this mean and indicate responses that fall between "often" and "always or almost always." On a scale of zero to three, a great number of the 278 family caregiver's answered "always or almost always" to three questions on the Spiritual/Philosophical subscale resulting in means of 2.60, 2.40 and 2.29 respectively. These three areas reflect the strength of beliefs in this sample of family caregivers. Beliefs, values and knowing what is important in life may be some of the abstract critical elements/dimensions existing in family caregiver's lives that assist them in carrying out their caregiving role.

The highest mean score (2.60) was on the question, "I believe in a power greater than myself." This finding is consistent with definitions of spirituality that encompass belief in a Higher Being. "I know what is important in life" had a mean score of 2.40 which may correlate with the personal philosophy component of Hammer and Marting's (1988) definition of spiritual/philosophical. Additionally, "My values and beliefs help me to meet daily challenges," had a mean score of 2.29. This may reflect the cultural tradition portion of the larger description of spiritual/philosophical as proposed by Hammer and Marting (1988).

To understand more fully how each item in the subscale correlates, it is helpful to look at the item-total scale characteristics to get a broader view. The correlations are the association of the item-score for all family caregivers with the total scores, excluding that item for the family caregivers. In Table 11, each

Table 11

Item-Total Correlation and Scale Mean/Alpha if Deleted for Each Item in Spiritual/Philosophical Subscale, N=278.

Item #	Item-Total Correlation	Scale Mean If Item Deleted	Alpha If Item Deleted
1	.53	20.07	.85
2	.45	20.27	.85
3	.56	19.63	.84
4	.43	20.34	.85
5	.56	19.84	.85
6	.49	20.75	.85
7	.66	20.35	.84
8	.71	20.46	.83
9	.55	20.56	.85
10	.67	19.95	.84
11	.50	20.11	.85

Alpha Coefficient for 11 items = .86

item is analyzed to determine what the scale mean and alpha would be if the specific item were deleted. The scale mean is calculated by adding the total scale scores for all individuals and then dividing the sum total of all scores by the sample number to determine the average. In this study, the total sample number is 278.

Analysis for Research Question

The focus of this study was to determine: "What are the self-reported expressions of spirituality among family caregivers of individuals with cancer?" It is evident from the analysis of data that family caregivers of individuals with cancer are able to report expressions of spirituality. Furthermore, each of the eleven items in the scale seems to be correlated with one another and thus reflects a similar measure.

The Spiritual/Philosophical subscale had a coefficient alpha of .86. According to Knapp (1985), reliability estimates the internal consistency or homogeneity of a measure made up of several items utilizing Cronbach's alpha. The alpha reported in Hammer and Martings' (1988) research was .80 for the Spiritual/Philosophical subscale. In the Elderly Caregiver Study conducted at Michigan State University, the reported alpha was .82. This comparison of alphas would suggest that the Spiritual/Philosophical subscale, developed by Hammer and Marting (1988), appears to have consistent results. However, the subscale needs to be further tested, over time, on the same sample to verify consistency, stability, and repeatability of the instrument.

Item correlational procedures are generally used to measure the degree of reliability (Nieswiadomy, 1987). All item-total correlations in the Spiritual/Philosophical subscale are positive. However, in a general sense, only correlation coefficient correlations above .70 are considered acceptable (Nieswiadomy, 1987; Polit & Hungler, 1983; Fox, 1982). Only question number eight ("I seek to grow spiritually") has an item-total correlation of greater than .70 (.71). Further research and utilization of this instrument need to be conducted over various samples to establish solid validity and to explain the concept of spirituality in more depth. Furthermore, as the scale is administered to varied samples, the goal would be to improve the inter-item correlations so that the researcher could be sure that the items are measuring the same concept.

Result of Item-Total Characteristics

If participants answered all 11 items with a response of "never or rarely", the possible score would be 0. All 11 item answers of "always or almost always" would reflect a highest possible score of 33. Therefore, the possible range of scores on the Spiritual/Philosophical subscale, for this sample of family caregivers, is 0 to 33. The actual range of scale scores for this sample is 5 to 33 with a mean of 22.12 and a standard deviation of 6.26. These statistics represent a relatively high expression of spirituality falling at an extreme high "sometimes" response. According to Hammer and Marting (1988) this score would represent a

high personal resource in the spiritual/philosophical domain and imply a great potential for effective coping.

Face validity for the Spiritual/Philosophical subscale would appear to be present. On the surface, this instrument appears to be measuring the broad concept of spirituality as defined by Hammer and Marting (1988). In development of this instrument, the researchers used experts in the field of coping resources to help determine validity. No content experts were utilized in this research study to determine validity. "The validity of an instrument concerns its ability to gather the data that it is intended to gather" (Nieswiadomy, 1987, p. 200). Construct validity was established for this scale by the researchers in administering the instrument to varied groups of people (Hammer & Marting, 1988).

Another statistic that gives valuable information about a scale is the frequency distribution. The frequency reported in this study indicates the number of responses for each of four values in the 11 items. Furthermore, the percent of each value response is calculated. The frequency analysis for each item from the Spiritual/Philosophical subscale is represented in Table 12.

Interpretation of Frequency Analysis by Item and Response Value

In Table 12, the number of responses for each item are represented. The frequency analysis is more thoroughly explained through the use of another statistical test. The last statistical analysis that was carried out on the data was ranking of scale items by greatest percentage of "always or almost always" responses

Table 12

Item-by-Item Frequency and Per Cent Analysis By Response Value for the Spiritual/Philosophical Subscale, N=278.

Item	Response Value	Frequency	Per Cent
1	Never or Rarely	7	2.5
	Sometimes	71	25.5
	Often	64	23.0
	Always or Almost Always	133	47.8
	Missing	3	1.1
2	0[a]	6	2.2
	1[b]	93	33.5
	2[c]	85	30.6
	3[d]	93	33.5
	9[e]	1	.4
3	0	7	2.5
	1	23	8.3
	2	43	15.5
	3	204	73.4
	9	1	.4

Table 12 (Continued)

Item	Response Value	Frequency	Per Cent
4	0	12	4.3
	1	82	29.5
	2	106	38.1
	3	75	27.0
	9	3	1.1
5	0	0	00.0
	1	40	14.4
	2	85	30.6
	3	152	54.7
	9	1	.4
6	0	81	29.1
	1	61	21.9
	2	56	20.1
	3	78	28.1
	9	2	.7
7	0	23	8.3
	1	69	24.8
	2	101	36.3
	3	83	29.9
	9	2	.7

Table 12 (Continued)

Item	Response Value	Frequency	Per Cent
8	0	34	12.2
	1	76	27.3
	2	85	30.6
	3	81	29.1
	9	2	.7
9	0	9	3.2
	1	111	39.9
	2	117	42.1
	3	39	14.0
	9	2	.7
10	0	2	.7
	1	42	15.1
	2	109	39.2
	3	124	44.6
	9	1	.4

Table 12 (Continued)

Item	Response Value	Frequency	Per Cent
11	0	3	1.1
	1	77	27.7
	2	79	28.4
	3	118	42.4
	9	1	.4

[a]Never or Rarely.

[b]Sometimes

[c]Often

[d]Always or Almost Always

[e]Missing Data: (Some participants chose not to answer all questions in the self-administered questionnaire although all 278 participants answered some of the questions).

to each specific item. Table 13 contains the ranking on these items for this family caregiver sample. Ranking is utilized in this study to determine those items in the Spiritual/Philosophical subscale that received the majority of "almost or almost always" (3) responses. This technique is useful in determining, from the participants, which items received the highest rank and therefore possibly represent the most meaning to them. Additionally, this information will be useful in the future development of scales that measure only the concept of spirituality by allowing the researcher to delete those items that may more represent the concepts of religion or religiosity. Furthermore, this information will only be gathered with repeated usage of the subscale on varied ethnic and cultural groups. Ranking for all responses are reported for descriptive purposes only.

In this section, an interpretation of each question and the rank order for responses will be discussed. Items from the Spiritual/Philosophical subscale are presented according to the item that received the highest percentage in the "always or almost always" category. In this way, a better understanding of the expression of spirituality by the primary family caregivers in this study will come to be understood.

"I believe in a power greater than myself."

Most of the respondents (n=204, 73%) to this question chose "always or almost always" as their response to this question. This item reflects a personal philosophy and belief. Only 2% of the caregivers circled "never or rarely."

Table 13

Rank Order of Items in Spiritual/Philosophical Subscale With Highest Percentage of Response for Each Value, N = 278.

	Always or Almost Always			Often			Sometimes			Never or Rarely		
Specific Item	RK[1]	NO[2]	%	RK	NO.	%	RK	NO.	%	RK	NO.	%
I believe in a power greater than myself.	1	204	73	9	43	15	11	23	88	6	7	2
I know what is important in life.	2	152	55	5	85	31	10	40	14	10	0	0
I accept the mysteries of life and death.	3	133	48	7	64	23	6	71	26	6	7	2
My values and beliefs help me to meet daily challenges.	4	124	45	2	109	39	9	2	15	9	2	.7
I accept problems that I cannot change.	5	118	42	6	79	28	4	77	28	8	3	1
I can make sense out of my world.	6	93	33	5	85	31	2	93	33	7	6	2
I pray or meditate.	7	83	30	4	101	36	7	69	25	3	23	8

Table 13 (Continued)

Specific Item	Always or Almost Always			Often			Sometimes			Never or Rarely		
	RK[1]	NO[2]	%	RK	NO.	%	RK	NO.	%	RK	NO.	%
I seek to grow spiritually.	8	81	29	5	85	31	5	76	27	2	34	12
I attend church or religious meetings.	9	78	28	8	56	20	8	61	22	1	81	29
Certain traditions play an important part in my life.	10	75	27	3	106	38	3	82	29	4	12	4
I take time to reflect on my life.	11	39	14	1	117	42	1	111	40	5	9	3

[1] = Rank Order

[2] = Number

"I know what is important in life."

When a family member is diagnosed with cancer, it causes a time for reflection. Perhaps this question, in some way, is an indicator of the reflection that is going on. Cancer, which in most instances represents a crisis, clarifies priorities. Cancer affects the entire family (Oberst & Scott, 1988; Hinds, 1985; Oberst & James, 1985), and because it is not an expected disease, no time for planning is made. In a family caregiving situation, priorities must be made in relation to the role being an all consuming task (George & Gwyther, 1986). There were no "never or rarely" responses to this question. Perhaps this reflects that each caregiver has had the time to begin to understand the potential loss involved in the diagnosis of cancer.

"I accept the mysteries of life and death."

This question could tie in with the belief in a power greater than self. Human beings have long questioned the mysteries of life and death. With cancer, and the uncertainty of prognosis, life and death hang in the balance (Northouse, 1984; Lewis, 1982). One has to come to the acceptance of diagnosis and work through the prescribed treatment regimen. The entire family is affected not only by the disease, but by the effects of treatment as well (Dodd, 1987). Weisman (1979) discusses how one of the first concerns of individuals with cancer, their family and friends, is related to matters of life and death.

"My values and beliefs help me to meet daily challenges."

Caregiving is a daily challenge causing stress (Montgomery, 1985; Oberst & James, 1985; Poulshock & Deimling, 1984; Thompson & Doll, 1982). It is difficult to meet these daily challenges without values and beliefs to serve as a resource for coping. Values and beliefs may not change the situation, but they may change the way the caregiver perceives and/or reacts to daily stress (Benson & Klipper, 1976). A belief system serves as a source of spiritual strength, comfort, guidance, and taps into the communal support and values common to persons sharing that belief (Faelten & Diamond, 1988).

"I accept problems that I cannot change."

With the diagnosis of cancer must come acceptance. It takes a concerted effort on the part of the individual with cancer and the family to work through the treatment evolving around the cancer experience. "Cancer patients must contend with impermanence and uncertainty more than is true for most illnesses" (Weisman, 1979; p. 13). Cancer does not negate problems that already exist in an individuals life, it may aggravate them. One way of accepting problems that cannot be changed is through prayer and/or meditation. Perhaps acceptance is achieved by carrying out the tangible tasks of the caregiving role.

"I can make sense out of my world."

Ninety eight percent of caregivers reported that they were mostly able to make sense out of their world. This may be difficult related to the fact that many people question why they or a loved one are diagnosed with cancer. The immediate question is

"why me?" Persons who have been conscious of their health as a life-long process are especially questioning of what it is that they did that caused them to get cancer. It takes incredible insight to be able to make sense out of the diagnosis and go on with life as normally as possible.

"I pray or meditate."

The majority of caregivers (66%) carry out this activity "often" or "always or almost always." Only 23 family caregivers (8%) "never or rarely" engage in this task. Prayer changes the way you think about things. According to Faelten and Diamond (1988):

> Prayer elicits relaxation and breaks up the chain of worrisome thought, the anxiety cycle. . . When rooted in religious belief, prayer also helps to put problems in perspective, further reducing overall anxiety (p. 312).

Faelten and Diamond's statement is consistent with Hammer and Marting's (1988) belief that spiritual/philosophical beliefs may serve to "define the meaning of potentially stressful events and to prescribe strategies for responding effectively" (p. 3).

"I seek to grow spiritually."

As discussed in Chapter III of this document, spirituality is often intertwined with words such as religion and religiosity. Not much is known about spirituality as a concept or domain in and of itself. Often the word spiritual is associated with cultures and traditions from Eastern societies that are not well understood in the Western hemisphere. This is especially true of persons over the age of forty who did not experience the Flower Children years.

Since the mean age of this sample of family caregivers of individuals with cancer is 55 years of age, perhaps this fact can account for the 60% response in the highest value categories. Thirty four individuals (12%) reported they "never or rarely" sought to grow spiritually.

Many times, growth occurs without conscious thought. In accordance with Rogers' abstract system, all change involves growth and the caregiving role represents a repatterning of human beings' lives resulting in growth. Growth and change are inevitable and irreversible (M. E. Rogers, personal communication, July 7, 1989). Perhaps this question requires deep, inner reflection that the caregiver is not yet able to accomplish.

"I attend church or religious meetings."

Discussion of this item has been presented earlier in this chapter. This question ranked number one in the "never or rarely" category (n=81, 29%). This data is consistent with the information reported under descriptive variables in relation to attending a religious service during the past month. In that question, 81 caregivers reported attending a religious service once every week in the past month. The sample size for "always or almost always" in this question was 78 or 28 per cent. "Often" was reported by 56 caregivers (20%).

"Certain traditions play an important part in my life."

Traditions are important to family caregivers. Only 39% reported that tradition was "sometimes" or "never or rarely" important in their life. Sixty five per cent (n=181) responded that

traditions were "often" or "always or almost always" an important part of their life. With all the change and fluctuation that cancer creates in the lives of families, it may be important to hold on to traditions that have been stable in the past.

"I take time to reflect on my life."

Eighty two percent of family caregivers (n=228) responded that they "sometimes" or "often" took the time to reflect on their lives. Only nine (3%) reported that they "never or rarely" engaged in this reflection. One would think that the diagnosis of cancer in a family member or significant other would cause one to reflect on her/his life. This ties in with the definition of environment utilized in this research. The environment is the role of caregiver for an individual with cancer.

An explanation for this item falling at number eleven (last) in the ranking might be the fact that caregivers verbally expressed to research interviews during telephone conversations that they had not thought about many of the areas about which they were being questioned. Participation in the study, in some instances, actually caused the caregiver to reflect on certain situations that they might not have had time to do before. Logistically, the great majority of these caregivers do not have the time to reflect on their lives.

Summary of Rank Order Interpretation

In summary, spirituality is a dimension in the lives of family caregivers for individuals with cancer. The great percentage

of high responses reflects this belief. Spirituality, perhaps as an entity that is not consciously thought about, does seem to serve as a resource for this sample of family caregivers. Interpretation by this researcher is based on personal philosophy and belief. Others may interpret the answers to these questions differently, based on their own personal philosophy and beliefs. If each human being is unique and individual, and manifests her/his pattern in a unique manner, this conclusion is logical. However, it can not be disputed that family caregivers of individuals with cancer are able to self-report their expressions of spirituality. Chapter VI is devoted to further summary and conclusions.

As previously discussed, many caregivers do not have the time or do not wish to attend a place of worship. This should not exclude them from the spiritual dimension. Spirituality can be expressed through religion, but it is much more than that. Persons that do not attend church or religious meetings should not be judged on their spiritual dimension through this question only. The church or religious meeting attendance question tests more the concept of religion or religiosity than it does spirituality.

It is interesting to note that five of the items are above the mean of 2.0. Therefore, the five most common expressions of spirituality by family caregivers of individuals with cancer are:

1. **I believe in a power greater than myself.**
2. **I know what is important in life.**
3. **My values and beliefs help me to meet daily challenges.**
4. **I accept the mysteries of life and death.**

5. I accept problems that I cannot change.

The mean of the top five responses was 2.32 with a standard deviation of .80. These five specific items also reflect congruently with the definition of spiritual/philosophical proposed by Hammer and Marting (1988). Within the definition developed by these two researchers are the words values, personal philosophy, beliefs and familial tradition.

The family caregivers sampled in this research are able to express spirituality and therefore, have a high personal resource in this domain which may serve to assist them in living with and through the cancer caregiving experience. The way in which each family caregiver in this study utilizes this resource is unique and individual to each of them. Since caregivers were not questioned as to how they are able to persist, or cope, with their caregiving role, it is not evident from this analysis how each person incorporates her/his spirituality into the daily life experience or how spirituality is utilized by each caregiver as a resource. A qualitative study may serve to answer some of these questions. Further studies need to be conducted to determine how spirituality may serve as a resource for family caregivers of individuals with cancer.

One can examine the top five answers and <u>speculate</u> as to how these spiritual/philosophical reflections <u>may</u> serve family caregiver's of individuals with cancer as a resource. At first glance, the top five questions reflect beliefs, acceptance and knowing what is important in life. These are internal, abstract feelings that

may lead one to a sense of hope and define the meaning of human existence. Burkhardt (1989) states that the manifestation of hope is related to a person's sense of spirituality, which is related to her/his sense of health and awareness of environment. Hope may be a resource associated with spirituality for family caregiver's of individual's with cancer.

Beliefs may further lead one to a sense of purpose in life and facilitate the ability to make choices in how one will live out their life. Each human being is capable of making choice, and beliefs and values may serve as a guide in the decision-making process. Freedom of choice may serve as a resource for family caregiver's.

Spirituality may further serve caregiver's as a source of strength and courage in meeting the challenges of the caregiving role. One's sense of humanity may be enriched when the spiritual dimension is an important and tangible part of a human being's life. The ability to be concerned, and to care for another, may be outcomes of a strong spiritual life component. Perhaps when someone else is suffering (the individual with cancer), one (the family caregiver) can acknowledge her/his own suffering and hurt, and in doing so, care for the hurt of others (Schmitt, 1981). Perhaps this ability to care may serve as a resource.

Perhaps it is within the caregiving experience that an individual comes face to face with her/his own mortality. At this point, acceptance of life becomes paramount so that the experience

of living, in the future, may be fulfilling and satisfying. Meaning to one's existence may also be strengthened by spiritual beliefs. Acceptance and understanding may lead to growth for individual's who possess a strong sense of their spirituality and who feel their life has meaning. Surely this understanding is a resource during difficult times and situations.

Communication and support from and with other person's who are able to express their spirituality may be an important resource. Wright, Pratt and Schmall (1985) report that spiritual support was significantly ($p<.001$) correlated with an internal coping strategy called reframing.

> Reframing is the caregiver's ability to redefine a demanding situation in a more acceptable way in order to make the situation more manageable. Spiritual support may allow meaning to be found in the tremendous losses that accompany Alzheimer's disease (p. 24).

It is this researcher's belief that spirituality is a trait. This is in keeping with the philosophy of the whole being greater than and not equal to the sum of the parts. If spirituality is a dimension of all human beings, including the bio-psycho-social, then it is not realistic to look only at the spiritual or to assume some human beings are aspiritual. Spirituality is not a state in that it is not learned. Each human being is capable of choice, and each has the ability to choose how it is that she/he will incorporate and/or cultivate the dimension of spirituality in their own existence, making it entirely personal and unique.

Spirituality may serve family caregivers as a resource by accentuating their personal beliefs and philosophies related to

life and death. Spirituality may also assist caregivers in having a more optimistic attitude related to cancer and cancer treatment.

Many suppositions can be speculated as to how spirituality may serve as a resource. According to Hammer and Marting (1988), if individuals score high on the Spiritual/Philosophical subscale, this score may help health care professionals to accentuate this portion of individuals' lives during stressful and difficult times. Spirituality may serve as a positive aspect of a difficult life experience.

Another interesting conclusion that this researcher came to upon examining the top five questions in this sample was that none of the questions reflect religion or religiosity. Therefore, one may conclude that spirituality can be extrapolated from the concrete. Spirituality does warrant further research so that an increased understanding and awareness of the concept may be learned. In Chapter VI, other conclusions and suppositions are presented.

Summary

In this chapter, the results of the study were provided and characteristics of the family caregiver sample presented. The spiritual dimension of human beings can be tapped with the use of a questionnaire. Personal philosophy, tradition and beliefs and values appear to be important to the majority of family caregivers in this study. This finding is consistent with the definition of spiritual/philosophical proposed by Hammer and Marting (1988) in

development of the Coping Resources Inventory. In the last chapter, Chapter VI, a brief discussion of the findings will be provided. The primary conclusions arrived at by this researcher will also be discussed. This will be followed by discussion on the implications of the findings for nursing research, the direction for future research into the concept of spirituality, education and primary practice.

CHAPTER VI

Summary and Conclusions

Overview

A descriptive study was conducted to identify and describe the self-reported expressions of spirituality among family caregivers of individuals with cancer. Data for this study had been collected as part of a grant from the National Center for Nursing Research, "Family Homecare for Cancer - A Community Based Model," conducted by B. A. Given, Ph.D., R.N., F.A.A.N.

Martha Rogers' Science of Unitary Human Beings was utilized to guide the investigation. The concept of spirituality, as defined by Hammer and Marting (1988), was also used.

The 278 participants were family caregivers of individuals with cancer who completed a screening, intake interview and self-administered questionnaire. Descriptive variables to characterize this research sample were presented in Chapter V.

In this chapter, a summary of the research question and the primary conclusions arrived at from analysis of data are presented. These sections will be followed by discussion of the implications of the research findings for nursing practice, education and research. The limitations of the study, with information related to possible research avenues to follow in the future, are also discussed.

Summary of Research Question

The research question addressed in this study was: "What are the self-reported expressions of spirituality among family caregivers of individuals with cancer?" In this study sample, 278 family caregivers of individuals with cancer, were able to self-report their expressions of spirituality. This expression of spirituality is evidenced, in part, by the statistical analysis of the Spiritual/Philosophical subscale described in detail in Chapter V and the five top ranked items which were:

I believe in a power greater than myself.

I know what is important in life.

My values and beliefs help me to meet daily challenges.

I accept the mysteries of life and death.

I accept problems that I cannot change.

The subscale alpha was .86 with an item mean of 2.02 and a standard deviation of .56 based on response values of zero to three. The mean scale score was 22.12 with a standard deviation of 6.26 based on a possible scale score range of 0-33. The analysis led this researcher to several conclusions which follow.

Primary Conclusions

Several primary conclusions were reached after analysis of the data. The major conclusions are presented with discussion as to the value of the information.

Conclusion #1: Family caregivers of individuals with cancer are able to self-report expressions of spirituality.

Through this research it has been learned that family caregivers do possess the dimension of spirituality and are able to report this expression through use of a research instrument. This conclusion is substantiated by the data analysis presented in Chapter V.

Conclusion #2: An essence, or portion, of spirituality can be captured through the use of a scale.

The Spiritual/Philosophical subscale (Hammer & Marting, 1988) is one research instrument that can be administered to family caregivers of individuals with cancer to assess their level of spirituality. This research subscale is short, concise and easy for participants to answer. Concerns in relation to several of the items have been discussed in Chapter V.

Conclusion #3: Spirituality is an important dimension in the lives of family caregivers of individuals with cancer.

In the statistical analysis of the data, it became apparent that the questions answered by the family caregivers of individuals with cancer, held special meaning for them. Given the fact that responses are on a 4-point Likert scale ranging from "never or rarely" to "always or almost always", family caregivers were able to choose those answers they felt most described their personal beliefs and philosophies. As a result, individual family caregivers were able to express their personal preferences and individual variances were noted. The actual range of scale scores for this sample of family caregivers was 5 to 33. If spirituality was

not a dimension of their existence, the mean for the scale would have been much lower. This information lends support for the wholistic approach to all human beings. This includes being aware of the bio-psycho-social-spiritual dimensions of every individual.

Data from this study also support the belief that spirituality is present during many life transitions and not only during the terminal phase of life. Family caregivers in this study were in good health and not in immediate threat of personal death.

It is this researcher's assumption that given the incredible experience of being a family caregiver for an individual with cancer, caregivers are able to persevere, in part, related to the spiritual dimension and the resource spirituality may offer family caregivers. Whether the spiritual dimension exists only as a coping resource needs to be further studied. However, the spiritual dimension does seem to give strength, comfort and hope to family caregivers as they live out their caregiving role.

Another assumption this researcher makes in relation to family caregivers of individuals with cancer is: when faced with extreme stress and burden (as the caregiving role has been described in the literature), caregivers are able to manage the stress and burden through the use of spirituality, perhaps unconsciously, as one form of resource. The great majority of family caregivers in this sample did not have a health care background, by virtue of education or profession, and yet were able to deal with the difficult circumstances involved in their caregiver role, and do so effectively.

Conclusion #4: Spirituality is a dimension of family caregivers of individuals with cancer that should be assessed.

It has been concluded by the analysis of the data from this study, and by the fact that family caregivers of individuals with cancer were able to answer questions in a self-administered booklet, that spirituality does exist as a dimension of human beings. In an assessment of caregivers of individuals with cancer, the spiritual dimension should not be neglected. It is important to keep in mind that the spiritual dimension may serve as a resource for coping, strength and hope and should be accentuated when possible by the health care professional.

It may also be important for nurses in advanced practice to consider the five items which were consistently responded to in a strong manner (answer of "always or almost always"). Because variance does occur in the subscale scores, it is imperative to approach all human beings an unique and individual. Mutual, open relationships should provide a safe environment in which individuals feel free to express their personal beliefs.

In the next section of this paper, the relationship of the conceptual framework, presented in Chapter II, will be related to nursing practice. The implications for the Clinical Nurse Specialist, practicing in primary care settings, will also be presented.

Relationship of Framework to Nursing Practice

Human beings must be viewed in their totality. This includes the bio-psycho-social-spiritual dimensions as well as their

interaction with the environment. It is not satisfactory for the nurse to assess only one dimension of human existence.

Rogers (1970) states "the science of nursing is a body of abstract knowledge arrived at by scientific research and logical analysis" (p. 121). Nursing is also an art. When combined with abstract knowledge, the outcome is service to human beings. Nursing practice is creative, imaginative, insightful, knowledgeable, compassionate and wholistic.

The functions of nursing are collaborative with the human being. In therapeutic relationships there should exist a mutual respect, trust and willingness to share, listen and communicate. Only when human beings feel a commitment by the nurse can an exchange of energy flow smoothly between the two.

Promotion, by the nurse, should be to assist the human being (family caregiver) to strengthen symphonic interaction between themself and the environment. Patterning and direction can be assisted by the nurse. In the family caregiver situation, skills such as imagery, relaxation techniques and open communication can be taught, and ways to maintain one's integrity and decrease burden and stress can be discussed.

The nurse should be able to perceive the human being and envision her/his developmental transition. The nurse can assist the family caregiver to achieve or maintain positive health, especially in the spiritual and emotional dimensions. This can be accomplished by accepting the family caregiver for who she/he is, and listening and sharing positive communication when called upon.

Rogers (1970) expounds on the interaction between the nurse and human beings.

> Positive health measures will be directed toward determining individual differences and assisting people to develop patterns of living coordinate with environmental changes rather than in conflict with them. This is not to propose that man is simply to accept environmental changes as they occur. Rather, man and environment change together and man plays his role in directing change, both consciously and unconsciously. But, whatever goals may be set, the mutuality of the process is a significant factor in their achievement (p. 123).

Rogers (1970) believes that "nursing exists to serve people" (p. 122). The nurse, in synchrony with the family caregiver, develops a unique and individual environment for positive outcome and growth to take place. This can be accomplished by assessing and viewing human beings as existing within the dimensions of bio-psycho-social-spiritual domains. Human beings are in control of their own personal destiny, and it is the responsibility of the nurse to participate in this process to the extent that the family caregiver wishes.

The family caregiver's essence of spirituality will assist her/him to repattern their life and assimilate their new role into dynamic interactions. It is out of this context that the nurse may assist, especially when the family caregiver is a client. Perhaps it may also be the purpose of the nurse to allow a client to ventilate, discuss and even explore her/his spiritual dimension.

In using Rogers' abstract system, one conceptualizes human beings as having the capacity to search for meaning in life and

environmental situations that they encounter. It may be that family caregiver's are able to persist in carrying out tasks because of their inner source of strength and conviction. This area needs to be explored further.

The nurse is also a human being possessing bio-psycho-social-spiritual dimensions and interacting with her/his environment. In the framework proposed in Figure 3, the nurse enters the human being's (family caregiver) environment at a point when a need is perceived or by the individual's choice. The important aspect is that the nurse must recognize the human being as a whole and must also consider her/his environment. The larger spiral represents the transition of becoming a family caregiver for an individual with cancer. The widening reflects incorporation of the passing of time, in an irreversible direction.

After the family caregiver has repatterned the change into her/his life, they return to the consistent, continuous pattern represented by the spirals returning to baseline and displaying the uniqueness in shape and size that is characteristic for that unique caregiver. It is at the point of transition when the nurse may be needed by the family caregiver in assisting her/him to adapt to the newly acquired role or with whatever the caregiver feels is important for her/him at the time.

Finally, the nurse must be able to do a spiritual assessment of all client's. An assessment may be a challenge related to the difficulty of measuring or directly observing this phenomenon. However, if the nurse recognizes the existence of the spiritual

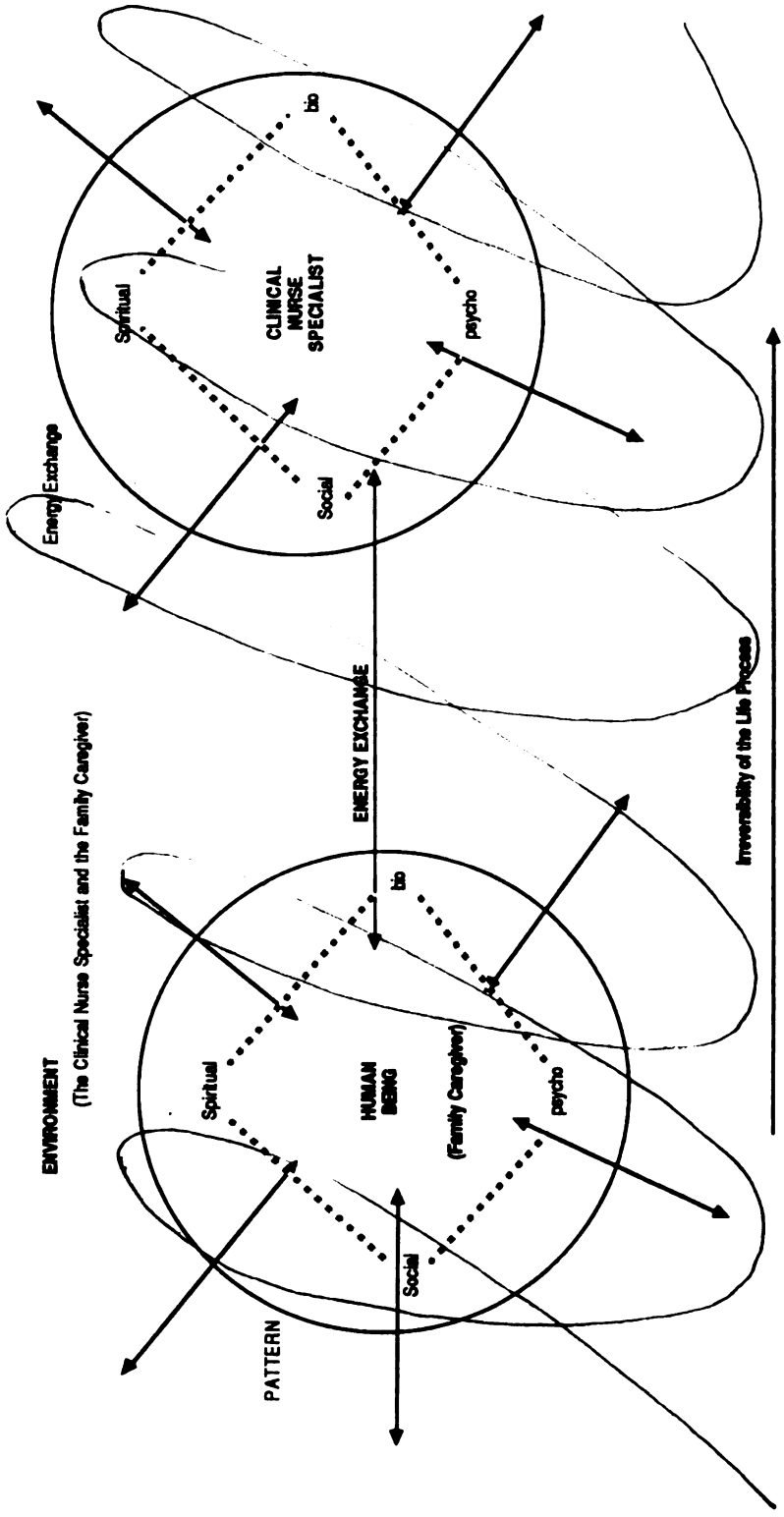

Figure 3. Conceptualization of The Family Caregiver of an Individual with Cancer and the Clinical Nurse Specialist.

dimension, and recognizes that environment plays a major role in the life process, she/he is on the path to a wholistic approach to practice. Assessment of the level of spirituality, and how it may serve the client as a resource, is imperative in advanced practice.

Based on Hammer and Martings' (1988) definition of spiritual/philosophical, spirituality may guide the actions of family caregivers through stable and consistent beliefs and values which may lead to utilization of strategies to decrease stressful events. If the nurse comes to recognize these individual strategies as beneficial to the caregiver's physical/mental/emotional health, the nurse can then assist the caregiver to strengthen these beliefs and values through a variety of interventions which would be guided by the caregiver. Examples of some strategies the nurse may introduce are life review, reminiscence, music therapy, listening, therapeutic communication and touch, imagery, relaxation techniques and humor to name a few. These strategies are most generally utilized at an advanced practice level.

Advanced Practice

The Clinical Nurse Specialist (CNS) practices at an advanced level incorporating clinical judgement, decision making, theory and research into the nursing process. The client should be therapeutically approached through a wholistic framework which includes the bio-psycho-social-spiritual dimensions of each human being and the

unique interaction with her/his environment. The CNS should utilize assessment and evaluative techniques and research tools to synthesize and interpret expressions of spirituality.

As a **clinician** and **assessor**, the CNS formulates a nursing diagnosis and management plan, with input from the client. Included in the nursing diagnoses should be existing or evident client strengths. Spirituality as an asset and resource should be documented and reinforced with open communication, therapeutic listening, silence and a non-judgmental attitude.

If the client is not concretely aware of her/his spirituality or chooses not to express her/his spirituality to the CNS, respect and time should be afforded the client. Through ongoing relationships and the development of rapport, spirituality may become a portion of the CNS/client interaction. It is not necessarily within the role of the CNS to explore the dimension of spirituality by repeated direct questioning. Advanced clinical judgement skills and sophisticated communication techniques should be utilized when exploring the dimension of spirituality.

Additionally, the CNS should function as **consultant** for sharing expert skills and knowledge in the arena of caregiving. Support groups, focus groups, workshops and seminars can be planned for families in relation to spirituality and how spirituality may serve as a resource for hope and coping. The roles of **educator** and **counselor** are also demonstrated in these informational, teaching modalities.

The CNS should also function as client **advocate** by empowering the family caregiver in seeking out assistance for the individual with cancer and themselves when needed and necessary. The CNS does not do for but with the client.

Personal philosophy and beliefs should be integrated into the CNS practice role. Through **role modeling**, the CNS should be able to articulate to peers their own needs, abilities and expression of spirituality by first exploring the existence of the dimension in their own life.

In the **researcher** role, the CNS should investigate the concept of spirituality through literature and research instruments. Short spiritual assessment tools are available and should be explored. Findings should be shared and published to add to the current body of knowledge.

The focus of the CNS is on the family and their environment. Therefore, the CNS is perhaps ideally prepared, at a graduate level, to practice wholistically, which includes knowledge of the spiritual dimension and how clients utilize that dimension as a source of hope, strength and coping resource.

The CNS role of clinician, assessor, counselor, consultant, educator, advocate, role model and researcher has been briefly described. The relationship of the framework for this study and nursing practice has been presented. Implications for advanced practice have also been addressed. In the following section, the concept of spirituality and how it relates to nursing education will be discussed.

Nursing Education

It is difficult to put into practice that which has not been learned, especially at an educational level. When the dimensions of human beings are presented in the majority of basic nursing education programs, the dimensions consist of the bio, psycho, social and spiritual. Much time is spent on the biological aspect of human beings. After all, is that not the primary focus of the majority of health care?

The next phase of basic education goes on to discuss the impact of biological health on the psychological. However, not much time is spent on how the two domains relate. In community or public health, the social dimension is addressed, but mainly in relation to the biological. The spiritual dimension, if addressed at the basic level of education at all, is gone over briefly and not expounded on. Most assessment tools do not take into account the spiritual dimension. Religion may be attended to, but as discussed in this manuscript, that is only one small aspect of the spiritual.

Many graduate level nursing education programs are more generous in presentation of the spiritual dimension of human beings. The true essence of spirituality, however, is not explored in detail.

Perhaps the reason for this lack of educational preparation lies in the lack of research into the concept of spirituality. Perhaps it is related to the confusion of definition and what to do with the spiritual information once it is gathered. Perhaps the

fault lies in the fact that the spiritual is intangible and difficult to describe. So what can be done about this lack of educational preparation?

Spirituality needs to be addressed as a part of basic nursing education. The concept needs to be explored, and the importance of the spiritual dimension of human beings should not be negated. It is not enough to talk about the topic of spirituality; it must be incorporated into the clinical component.

Some ways in which this may be accomplished are now presented. The varied definitions proposed by researchers for the dimension of spirituality should be discussed. At the same time, it should be taught that the expression of spirituality is unique for each individual that is come in contact with. Discussing the topic and varied research that has been conducted into the concept of spirituality should be part of the basic nursing curriculum at an early stage of the learning process.

Acceptance and non-judgmental communication techniques should be paramount as aspects of spirituality may be expressed in varied, unique behaviors which may not be immediately understood by the health care professional. Understanding that it is not the nurse's role to lead one to a spiritual dimension is extremely important. Allowing a person the freedom and safety of discussing her/his personal, innermost thoughts and beliefs is the approach that should be taken in developing wholistic communication techniques. It is not necessary to have the same beliefs related to the spiritual dimension to develop an open and trusting relationship in which the

individual feels comfortable in expressing their sense of spirituality.

Seminars into the spiritual dimension should be a mandatory requirement for every nursing student, and other health care professions, in both basic and advanced education. Every student should be required to administer a spiritual assessment and incorporate the information into the clinical write-up. If this were accomplished, faculty and student alike would realize spirituality is a dimension of human existence that can be dealt with comfortably and can give a wealth of knowledge into the person's very being.

Perhaps the educational learning experience into the realm of spirituality would help to alleviate misunderstanding of some human behavior with which the health care professional is not familiar. There exist many manifestations of the expression of spirituality. Ethnic groups that one has not grown up with, or is not familiar with, may have their own personal behavioral manifestations that actually come from the spiritual realm. It is imperative to elicit the meaning of specific behaviors from each individual. Too often that which is not understood is labeled inappropriate.

Finally, to share this personal dimension of spirituality with another human being is a positive journey that can only lead the professional to more insight and understanding into the lives

of the human beings she/he will be working with in her/his profession. It is possible for educated professionals to learn from, and share with their clients.

The next portion of this chapter will contain a discussion into the future research that needs to be conducted into the concept of spirituality. Some of the limitations identified for this study will be expanded and suggestions for how they can be researched in the future will be presented.

Implications for Future Research

The limitations for this research study were outlined in Chapter I. It is now important to reiterate some of these limitations and discuss how they may be alleviated and researched in the future.

Related to the lack of literature and research into the concept of spirituality in family caregivers of individuals with cancer, only the dimension of spirituality was addressed in this study. It was this researcher's belief that a foundation study (descriptive analysis) needed to be conducted before more sophisticated research could be attempted.

Because this was a non-random, convenience sample of family caregivers of individuals with cancer 18 years of age and older, findings may not be generalized to the greater population of caregivers. Correlational studies between various family caregiver studies need to be conducted to determine whether or not it is the

experience of caregiving itself or the existence of other independent variables that contribute to caregivers' ability to report expressions of spirituality.

The sample in this study is skewed towards those family caregivers of individuals with cancer who have a high level of education, income above poverty level and are 96 per cent Caucasian. This may or may not affect the conclusions of this study in the following ways.

1. **Those family caregivers who have an advanced level of education and a yearly income above poverty level may have additional access to available resources.**

Many self-help books are available to the general public that discuss ways to cope, describe the caregiving situation and how to live through the experience, and contain alternative/additive methods of life-style that may be comforting to the individual reading the books. It is often a comforting feeling to realize that you are not the only one in the world to be living through the experience of cancer caregiving.

Books cost money, and one has to have the transportation to get to a bookstore, or know how to access the public library system to obtain these useful references. Those persons with lower levels of education may not be able to read, may not have access to transportation, may not have extra funds to spend on reading material and may not know that libraries have services to offer without the expenditure of money.

The sample for this study may also be able to pursue the most advanced medical care available for the individual with cancer. Often this involves traveling out of the area in which the caregiver lives. Traveling of course involves a financial and time commitment. In addition, the majority of family caregivers in this study may have jobs that allow them the luxury of time off without penalty. Lower income persons may not be as fortunate.

There currently exist in many communities, support groups for families of individuals with cancer. Since many of these support groups are not well publicized, the family caregiver must know how to access the current system to find out if indeed there are groups in their area that offer support and help.

2. There may be a difference in the family caregiver experience related to ethnicity or culture.

Ethnic and culturally diverse groups were solicited for voluntary participation in this research study but chose not to participate. Ethnic groups were not purposefully excluded. Caregiving may or may not be different for various ethnic and cultural groups and minorities. The caregiving situation may or may not be different from the conclusions reached by analyzing the data from this mostly Caucasian group of family caregivers of individuals with cancer. In the future, minority groups should be specifically sought out so valid research can be conducted. In turn, these ethnic/minority studies then need to be comparatively analyzed against largely Caucasian samples to see if there do exist any significant

differences. Spirituality specifically may express itself differently in ethnic/minority groups.

Data for this study were collected at only one point in time. Data on spirituality need to be collected over time to determine whether there exist certain situations, circumstances or variables that lead to a decrease or increase in the ability to report expressions of spirituality. Additionally, data need to be collected before a person assumes the role of caregiver and before a person becomes ill. Does the expression of spirituality change in any way when persons are not involved in an illness trajectory? In the larger funded longitudinal study currently in progress, data on spirituality will again be collected from these family caregivers at the twelve month contact. A comparative, correlational analysis on the accumulated spiritual data should be conducted to begin to understand how the dimension of spirituality does or does not change over time.

Is the family caregiving experience for an individual with cancer the same as or similar to family caregivers of individuals with other afflictions? Does the age of the person being cared for have an effect on the caregiving situation? Does caring for a child have a more profound affect on the family caregiver? Does the type or stage of chronic illness have an effect on spirituality?

There should be a comparative analysis conducted on how the expressions of spirituality differ for the family caregiver and the individual with cancer. What is the quality of the relationship?

Are spiritual needs able to be met by the caregiver, by the individual with cancer, by religious contacts or family and friends? How can health care professionals contribute to improved and strengthened relationships related to the spiritual dimension?

Does spirituality vary with levels of positive well-being, dispositional optimism, humor, depression, anger, loneliness, hardiness? Do the number of severity of symptoms experienced by the individual with cancer have an effect on the family caregiver's expression of spirituality? Numerous questions can be postulated and explored. There is a wealth of information needed to be gathered into the spiritual dimension.

It has been concluded in this study that spirituality can be expressed by family caregivers of individuals with cancer. However, what variables may contribute to expressions of spirituality? This question has not been explained by this study.

Do race, gender, employment, personality, length of caregiving role, level of depression, income, education level, relationship to individual with cancer, physical/mental/emotional health have an effect on spirituality? Are any of these variables or concepts related to spirituality? In the future, these and other variables need to be analyzed to determine how they may or may not effect, or be related to, the expression of spirituality.

Spirituality has been expressed by family caregivers of individuals with cancer who participated in this research. It may or may not be possible to generalize the dimension of spirituality to the general population. In the future, more research needs to be

conducted into the question of how religion and spirituality are different or the same. Do cultural heritage, or creed affect how a person answers questions related to spirituality? Do subjects even know and understand what spirituality is?

In the future, spirituality should receive more attention in research. Spirituality is a dimension that exists in the lives of human beings. Researchers and health care professionals need to pay attention to what is important in the lives of average human beings and follow a path that may serve to unfold answers to many of the mysterious questions that exist.

Does spirituality change over the life cycle? Do the trajectory or illness have a negative or positive or any affect on the dimension of spirituality? There are too many unanswered questions to not explore this concept further.

Perhaps it would be wise to administer a social desirability scale along with the Spiritual/Philosophical subscale to determine if individuals answer questions related to actual belief or because answering in a certain way would be the thing to do. Additionally, it may be important to determine how the Spiritual/Philosophical subscale relates to scores on various religiosity or religion scales and if there is any correlation.

Some researchers would suggest that as death nears, spirituality beings to surface. It is this researcher's belief that spirituality is present at all times in human beings' lives, even outside of the caregiving situation. Perhaps areas to explore into

the realm of spirituality include utilizing research tools in the "normal" population.

Martha Rogers expresses frustration related to lack of current language that allows total expression and understanding of her abstract system (1989). Currently, if one does not believe in the wholism and uniqueness of human beings, it is difficult to grasp the building blocks, concepts and principles that are paramount to understanding Rogers' Science of Unitary Human Beings. More research needs to be conducted utilizing Rogers abstract system as a guide for creativity and discovery. This research should then lead to enhancement of Rogers' abstraction and eventual development of sound, scientific nursing theory.

This researcher would propose adding the language of spirituality to the current Rogers framework. This is a risk of misunderstanding that is worthwhile. If readers of Rogers do not understand the conceptualization in the abstract system's current form, they will not understand it with the added dimension of spirituality.

Finally, the most obvious implication for future research into the concept of spirituality lies in the realm of qualitative research. Since spirituality is a difficult concept to define and measure, perhaps the most obvious place to begin the research process is with human beings and asking them to explain for the researcher what spirituality means to them. As discussed in Chapter V, questions for qualitative interviews may be built on the areas of beliefs and acceptance as outlined in the five top ranked

questions for this sample of family caregivers. It is only through the acquisition of knowledge through those that live the experience that one can become better able to research a concept.

Qualitative research has been defined by Roberts and Burke (1989) as: "Research that is aimed at the discovery of meaning rather than cause and effect" (p. 367). The best place to start into the much needed research on spirituality is the qualitative method. From this research, instruments can be developed that measure the multidimensional qualities of spirituality.

Summary

Within this chapter, a brief discussion of the results was presented. In addition, implications for nursing practice, education and research were discussed along with a proposed research trajectory for the future into the concept of spirituality.

Perhaps when we understand ourselves better and begin to explore human beings in their wholeness, health care professionals will better be able to understand how family caregivers persist in their task. To negate the domain of spirituality, or explain it away through other concepts, is to close the window of better understanding and the exploration of human beings as unique.

APPENDICES

APPENDIX A

OFFICE OF VICE PRESIDENT FOR RESEARCH
AND DEAN OF THE GRADUATE SCHOOL

EAST LANSING • MICHIGAN • 48824-1046

December 8, 1987

Dr. Barbara Given
College of Nursing

Dear Dr. Given:

Subject: Proposal Entitled, "Family Homecare for Cancer Patients"

UCRIHS' review of the above referenced project has now been completed. I am pleased to advise that the rights and welfare of the human subjects appear to be adequately protected and the Committee, therefore, approved this project at its meeting on December 7, 1987.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval prior to December 7, 1988.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

Henry E. Bredeck, Ph.D.
Chairman, UCRIHS

HEB/jms

APPENDIX B

MICHIGAN STATE UNIVERSITY

Cancer Family Care Study

CONSENT FORM

The study in which we are asking you to participate is designed to learn more about the ways in which caring for a family member with cancer affects the person providing the care.

Over the next year, family caregivers will be interviewed by a member of the Family Care Study research staff. The interview will take approximately one hour to complete. Caregivers will be asked to complete written questionnaires and to answer questions asked by the interviewer.

If you are willing to participate, please read and sign the following statement:

1. I have freely consented to take part in a study of family caregivers and patients with Cancer conducted by the College of Nursing and the Department of Family Practice, College of Human Medicine, at Michigan State University.

2. The study has been described and explained to me and I understand what my participation will involve.

3. I understand that participating in this study is voluntary.

4. I understand that I can withdraw from participating at any time.

5. I understand that the results of the study will be treated in strict confidence and, should they be published, my name will remain anonymous. I understand that within these restrictions, results can, upon request, be made available to me.

6. I understand that no immediate benefits will result from taking part in this study, but am aware that my responses may add to the understanding of health care professionals of the experience of being responsible for a family member with Cancer.

7. I understand that a member of the Family Care Study research staff will need to review my medical history. I consent to

allow access to my medical files and understand that this information will remain confidential.

I,_____, state that I understand what is required of me as a participant and agree to take part in this study.

Signed_____ Date_____

APPENDIX C

UNIVERSITY COMMITTEE ON RESEARCH INVOLVING
HUMAN SUBJECTS (UCRIHS)
206 BERKEY HALL
(517) 353-9738

EAST LANSING • MICHIGAN • 48824-1111

August 14, 1989 **IRB# 89-379**

Linda J. Keilman
2427 E. Mt. Hope
Lansing, MI 48910

Dear Ms. Keilman:

Re: "SPIRITUALITY AS EXPRESSED BY FAMILY CAREGIVERS OF INDIVIDUALS WITH CANCER: A DESCRIPTIVE STUDY **IRB# 89-379**"

The above project is exempt from full UCRIHS review. I have reviewed the proposed research protocol and find that the rights and welfare of human subjects appear to be protected. You have approval to conduct the research.

You are reminded that UCRIHS approval is valid for one calendar year. If you plan to continue this project beyond one year, please make provisions for obtaining appropriate UCRIHS approval one month prior to August 14, 1990.

Any changes in procedures involving human subjects must be reviewed by the UCRIHS prior to initiation of the change. UCRIHS must also be notified promptly of any problems (unexpected side effects, complaints, etc.) involving human subjects during the course of the work.

Thank you for bringing this project to our attention. If we can be of any future help, please do not hesitate to let us know.

Sincerely,

John K. Hudzik, Ph.D.
Chair, UCRIHS

JKH/sar

cc: S. King

APPENDIX D

CONSULTING PSYCHOLOGISTS PRESS, INC.

577 College Avenue (P.O. Box 60070), Palo Alto, CA 94306 (415) 857-1444

Dr. Sharon King, RN
College of Nursing
Michigan State University
East Lansing, Mich. 48824

In response to your request of 7/29/88 (Date) permission is hereby granted you to utilize the items on the spirituality subscale of the Coping Resources Inventory in your research on caregivers of disabled elderly. We would appreciate it if you would share your results with us as moredata on this new test would be most welcome.

subject to the following restrictions:

(a) Any material used must contain the following credit lines:

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By Peggy Turn Permissions Department Date 8/19/88

Agreed to by _____

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