FAMILY ADAPTABILITY, FAMILY COHESION, SPIRITUALITY AND CAREGIVER STRAIN IN WOMEN AS CAREGIVERS OF ELDER KIN

by

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DEDICATION

This thesis is dedicated to my mother and father who have always given me love, support, encouragement and respect. You taught me the most valuable lesson--to believe in myself and know that I have the ability of accomplishing my goals. I love you both.

To my best friend Michael, without whose respect of my values and beliefs, support, and unconditional love, this project would not have been completed. To my beautiful children, Mason and Megan, may you also pursue the challenge and reap the rewards of higher education.

Lastly, to the elders who have enriched my life by sharing their life experiences and wisdom.

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I am indebted to the caregivers who participated in this study. This thesis would not have been possible without these women who gave not only to their elders but graciously invited me into their home and shared their caregiving experience. Their contributions exceeded the provision of data by reaffirming my belief in the universal interconnectedness of humanity.

Finally, I wish to thank my family, friends, classmates and colleagues for believing and assuming that I could accomplish my goals. I would like to especially thank Kay Baker and Laura Holt for being supportive friends and colleagues and their encouragement and belief that I could accomplish this educational achievement.

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ABSTRACT

A descriptive correlational study investigated the relationships between family adaptability, family cohesion, spirituality, and caregiver strain in women who are caregivers of elder kin.

Four questionnaires were administered to a convience sample of 40 women aged 32 to 77. The majority of the caregivers (77.5%) were daughters of the elders, with 40% working full time outside of the home. The mean number of months the caregivers had been providing caregiving activity to their elder was 87.5 or 7.3 years with a mean of 43.5 hours per week or 6.2 hours per day. The majority (45%) of the subjects rated their health at least as good as their age cohort and 60% rated their health as about the same since becoming a caregiver. The elders ranged in age from 72 to 99, the majority (87.5%) were female and 65 percent lived with the caregiver.

No statistically significant relationship was found between family adaptability, family cohesion, spirituality, and caregiver strain. However, the data identified statistically significant relationships between the model variables and demographic variables. Multiple regression analysis revealed that only 10% of the variance in caregiver strain is explained by family adaptability, family cohesion, and spirituality.

CHAPTER 1

INTRODUCTION

Caring for an impaired older relative has historically been the responsibility of the female linked kinship network. Today, care of aging kin is but one of a number of competing responsibilities confronting women and one which often creates a stressful situation. In consideration of the magnitude of this long-term care dilemma facing our society as well as the individual caregivers, it is evident that there is a need to explore those variables which may be potential mediators of caregiver strain.

This study will investigate the relationships between family adaptability, family cohesion, spirituality and caregiver strain in women who are caregivers of their elder kin. Chapter One substantiates the need for research providing an overview of the problem of women providing care for an older relative, the significance of the problem, the conceptual framework and the purpose of the study.

Overview of the Problem

Population aging is now recognized as a worldwide phenomenon that commands immediate attention if effective societal responses are to be made to changing demographic realities. In view of the numerical growth of older persons, the aging of the world's population is expected to progress at an impressive rate of over two percent a year during the next 55 years. According to the latest United Nations

projection, the global aged population (65 years old and greater) of 761 million in 2025 will be nearly three times the size of the aged population in 1980 (Myers, 1985).

The increasing world attention to the role of families and other informal efforts in providing social care for the older population was explicitly articulated in the Plan of Action adopted by 98 countries at the United Nations sponsored World Assembly on Aging held in Vienna in 1982 (Cantor & Little, 1985). Branch and Jette (1983) define the "informal support network or informal support system . . . as an elder's spouse, living children, siblings, other relatives, friends, and neighbors--those significant others with whom the elder has close contact" (p. 51). Cantor (1975) identifies four separate support elements involved in the primary or kinship network: spouse, children, siblings, and other relatives (e.g., cousins, grandchildren, etc.).

Within the past decade considerable research has emerged which validates the role of family and other informal supports in the care of frail and chronically ill elderly. Branch and Jette (1983) report that most elders who use long-term assistance rely solely on the informal support network. Additionally, without the care given by informal support networks, many more community dwelling elders would probably be forced to enter institutions (Branch & Jette, 1983; Brody, 1981; Brody, Poulshock, & Masciocchi, 1978; Cantor, 1983; Jones & Vetter, 1984; Shanas, 1979a, 1979b). In most parts of the world, family members--especially spouses, daughters, and daughters-in-law--provide the majority of care received by chronically ill elderly. Children (second

only to spouses) are a most critical element in the informal support system of older people. "All major studies of kinship structure in all parts of the world suggest that the adult child-aging parent relationship is special within the family constellation with respect to emotional bonds and interactions as well as service exchanges" (Cantor & Little, 1985, p. 754).

A survey of family support patterns in developed nations (Gibson, 1981) reveals that most older people have one or more living children, that there is generally at least one child who lives nearby, and that there is usually frequent interaction and bonding between parents and children (Cantor & Little, 1985). Robinson and Thurnher's (1979) study reports that most older parents have children within easy visiting distance.

In regard to the adult child providing the major amount of assistance, every study points to the preponderance of daughters as providers of direct day-to-day care (Brody, 1981). As caregivers, sons provide emotional support, financial aid, and linkage services in almost the same proportion as do daughters. However, they are less likely to help with instrumental, hands-on services (Horowitz, 1985).

As older people become frailer and more dependent, a shift occurs in the type of support needed and the patterns of assistance. Typically, kin respond with a substantial increase in help. "Symbolic of alterations in the nature of the help is a change in the nomenclature employed by researchers in describing the helping

relationships: caregiver and care-receiver replace the parent-child dyad" (Cantor & Little, 1985, p. 758).

A review of the studies involving the impaired elderly (ranging from persons with moderate functional limitations to the homebound and bedfast) indicates that the helping patterns are altered in the following areas (Cantor & Little, 1985, p. 758).

1. The time frame of assistance changes from intermittent and crisis-oriented to continual and long-term.
2. The degree of family involvement in the day-to-day lives of the elderly increases from relatively minimal to considerable.
3. Assistance is no longer balanced and reciprocal but flows more clearly from children to parents.
4. The nature of the tasks changes from peripheral to more central, including direct intervention in housekeeping, personal care, and total management of affairs.

Research emerging from many nations (including the United Kingdom, Japan and Germany as well as the Unites States) is documenting the considerable stress and strain involved in providing long-term care to elder kin (Cantor & Little, 1985). Brody (1985) reports that "when there is an increase in reliance on children to meet a parent's dependency needs, the family homeostasis, whether it is precarious or well-balanced, must shift accordingly. Such shifts have potential for stress, particularly because they augur increasing dependency in the future" (p. 22).

Although stress is a potential element of the caregiving role, most people willingly provide assistance to their elder kin and derive a sense of satisfaction in doing so. In addition, some adult children negotiate this challenge without undue strain and as Brody (1985) states, "experience growth during the process" (p. 21). Although cultural, religious, and childhood experiences undoubtedly influence the degree of involvement and commitment kin have toward their elders, the factors that lend support to women caregivers to alleviate, prevent or decrease strain are yet to be identified.

Research has been conducted on the burdens/strains of the caregiver (Archbold, 1980; Hausman, 1979; Horowitz, 1985; Poulshock & Deimling, 1984; Robinson, 1983; Zarit, Reever, & Bach-Peterson, 1980). Research has been conducted also on the traditional tasks of the caregiver for the elder person (Brody, 1981; Brody, Johnsen, & Fulcomer, 1984; Jones & Vetter, 1984; Townsend & Poulshock, 1986; Treas, 1977). Research has failed to specifically explore those factors which may lend support to women caregivers to alleviate or decrease the strain associated with caring for elder kin. This study is designed to explore these factors.

Significance

Caring for an impaired older relative begins when the caregiver is in middle age or early old age. Similar to child-rearing, meeting the needs of an elder can be physically and psychologically demanding. Unlike childrearing in which the offspring's physical and emotional dependence gradually decreases, caring for an elder kin requires the

caregiver to meet the sustained or increasing physical and emotional needs of the older person (Archbold, 1983). Kin resources may readily become over extended in the day-to-day care of aging relations. Increasingly, other responsibilities and constraints compete with caregiving duties toward elder family members.

Kivett (1985) investigated the patterns of relationships between older adults and their consanguinal and affinal kin with respect to amount of help received. The data revealed that consanguinal and affinal kin beyond the child, child-in-law levels are of relatively little functional importance in the helping network of older adults. However, according to the data from nationwide surveys of noninstitutionalized persons age 65 and over, the extended family of the old person is the major social support in time of illness and the tie of the elderly to the community. The extended family includes members of the old person's immediate family and siblings, nieces, nephews and other relatives by blood or marriage (Shanas, 1979a, b).

References to adult children as caregivers usually means adult daughters. Horowitz (1985) reports that every study of family relationships in old age has documented the bias toward the female-linked kinship network. In addition, the sex of the adult child is one of the most important and consistent predictors of caregiving involvement. Daughters predominate as providers of direct services (Brody, 1981; Brody, 1985; Cantor, 1983; Shanas, 1979a, 1979b; Treas, 1977) whereas sons participate more in decision-making and the provision of financial assistance (Treas, 1979).

As mothers enter middle and old age, they anticipate both understanding and support from their daughters which are unparalleled to that of other parent-child pairs (Johnson, 1978). Factors which are usually cited that explain why daughters have dominated as primary caregivers include: their traditional assumption of nurturing tasks, stronger emotional ties with their family of orientation than the sons, and the fact that they have more flexible time as homemakers than their male counterparts in occupational roles (Horowitz, 1985). However, two major demographic trends suggest the limitation of future availability of daughters to serve as primary caregivers to their older kin. First is the decrease (with the exception of the post-World War II baby boom) in the birth rate. The average family size is expected to decrease to 3.1 by 1990 which will reduce the size of available caregivers and the probability that the available offspring will be female (Horowitz, 1985). Second is the trend toward increased proportions of women in the labor market. Currently 51% of all women of age 18-65 are employed. Sixty percent of women 45 to 54 years of age (the age most likely to confront caregiver responsibilities) are in the labor force (Brody, 1981). This represents a significant difference when compared with only 11.1% in 1940 (Treas, 1977).

Today, care of aging kin is but one of a number of competing responsibilities confronting women. A greater proportion of middle-aged women are married and have children than in previous generations. A comparison of white women surviving from ages 20 to 50 in the 1980-1984 birth cohort versus those born during 1930-1934 estimates that spinsterhood had declined from 10% to 4.5% while women with childless

marriages decreased from 22.5% to 5.5%. More so than their predecessors, this younger cohort of women aged 41 to 45 in 1975 have husbands and children whose concerns must be balanced against those of aging kin (Treas, 1977).

These trends have converged to produce the phenomenon which Brody (1981) has characterized as the "woman in the middle." Such women are in the middle from a generational position, and in the middle in that the expectations of their multiple roles compete for their time and energy.

Horowitz (1985) found in a study of the differences in sons and daughters as caregivers to older parents that " . . . the experience of caregiving for an older parent remained one of considerably greater strain for an adult daughter than for an adult son even when both were providing similar levels of care" (p. 616). Several other investigators support this persistent relationship between gender and caregiver stress (Cantor, 1983; Robinson & Thurnher, 1979). Robinson and Thurnher (1979) hypothesized that the greater stress is due to the fact that women feel a greater responsibility for the emotional well-being of others.

As the mainstay of family support systems, it is daughters who have taken mothers into their homes and provided care. Devoted though sons may be, it is clear that the major responsibility for psychological sustenance and physical maintenance of the aged has fallen traditionally to female members of the family. "Current enthusiasms for alternatives to institutionalized care of the aged must

be tempered by realistic expectations of the willingness and ability of modern American women to provide continued services for aging kin" (Treas, 1977, p. 488).

In summary, the rapidly expanding population of persons over 65 years of age, a declining birth rate (which decreases potential available caregivers), and the entrance of more women (traditional caregivers of kin) into the labor market may result in what Wright, Pratt, and Schmall (1985) term as a "collision course between social roles and filial responsibility" (p. 33). In consideration of the magnitude of this long-term care dilemma facing our society as well as the individual caregivers, it is evident that there is a need to explore those variables which may be potential mediators of caregiver strain.

Recognized by nurses who interface with the caregiver/elder dyad, the effect of caregiver strain is commonly observed by the Community Health Nurse. An investigation of the relationship between such potentially mediating variables (including family adaptability, family cohesion, spirituality and caregiver strain) may increase the awareness and sensitivity of the Community Health Nurse who interfaces with the informal caregiver system. In addition, this investigation may allow for the development of assessment strategies which may facilitate the identification of those caregivers who are experiencing caregiver strain and the development of intervention modalities which may strengthen the individual caregivers' capacities to assist their elder kin.

Conceptual Framework

The conceptual framework for this study is based on family and nursing theories. This section examines the relationship between family systems theory, Rogers' conceptual model, and Fawcett's conceptual framework.

Family theory was developed to provide an explanation for the nature of recurrent family patterns. The purpose was to understand the order and disorder that occurs within the family and between the family and other institutions within society (Jones & Dimond, 1982).

The systems theories of family functioning emerged in the late 1950's. This approach focuses on the individuals, the context, and the feedback loops that connect them. The underlying concept is the world as organization. From this perspective, the family unit is perceived holistically and must be analyzed and approached as an integrated whole. Included in the systems approach are the family's connections with the extended family and its spatial and social relationship to society. According to a systems framework, the family is a type of living organism involved in a web of relationships with the environment (Minuchian, Rosman, & Baker, 1978).

In terms of a nursing conceptual model, Rogers's formulation of unitary human being reflects a viewpoint complementary to the family systems approach. According to Rogers' (1970), "the interrelatedness of ideas that gives wholeness and unity to nursing's conceptual system is built around the life process in human beings" (p. 89). This process is characterized by wholeness, openness, unidirectionality, pattern and organization, sentience and thought (Rogers, 1970). An

energy field is the fundamental unit of the living system and identifies the conceptual boundaries of the individual. It is postulated that the boundary of the human field is contiguous with the boundary of the environment. The interaction between the two fields occurs across the conceptual boundaries which together are coextensive with the universe. It is this field which gives meaning to the concept of wholeness/interconnectedness (Rogers, 1970).

Fawcett (1975) presents a conceptual framework of the family as a living open system, consistent with a complementary individual environment relationship. The family is viewed as one environmental field in which the individual is embedded. As a group of interacting individuals who make up the basic unit of society, the family may be viewed as a system of coextensive four-dimensional energy fields. The individuals are differentiated from one another by the visible configurations of the fields. From this perspective, the family is viewed as an energy field itself, an entity just as the individual is. Engaged in a complementary relationship with its environment, the family system and the environment are coextensive, and are together coextensive with the universe. The family is a living open system constantly exchanging energy with the environment. This exchange may be seen in the observable behavior of the family system. As a living system the family grows, develops, and evolves tending toward increasing order, complexity, and heterogeneity. The family is a system of relationships, a system that is new, emergent, different from the individuals who make up the relationship.

The unified whole of the family system engages in mutual, simultaneous interaction with the unified whole of the environment. The family system is patterned and organized, evolving unidirectionally and irreversibly through time and space, and is sentient and thinking. The family system may be described and explained by the principles of helicy, synchrony, and resonancy, and that these principles predict the evolution of the family system (Fawcett, 1975).

There is congruence between the approaches of Rogers, Fawcett and family systems theory as both see boundaries as more perceptual than real, everything is connected to everything else. Pattern and organization characterize the system. A change in one portion of the system affects changes in the whole which may create reverberations within the system in a wavelike pattern.

Bowen's (1971) theory of family therapy which describes the emotional functioning of a family is congruent with the broader views of Rogers and Fawcett. Bowen (1976) maintains that all organisms are capable of adapting to short amounts of acute anxiety. Protracted anxiety presents a more difficult problem. The organism develops tensions manifested as symptoms or dysfunction or sickness when the anxiety intensifies and/or remains chronic. An important fact is that anxiety is infectious within a family. Bowen views the family as a combination of emotional (the force that motivates the system) and relationship (the ways it is expressed) systems. Subsumed under relationship are communication, interaction, and other relationship modalities (Bowen, 1971).

Considered essential to Bowen's theoretical approach to family therapy are the concepts of circular causality and overadequate-inadequate reciprocity. A fundamental implication of viewing the family as a system, then, is that family relationships are reciprocal, patterned and repetitive. Circular causality is the concept through which Bowen outlines the view that family relationships have circular rather than linear motion. The concept of overadequate-inadequate reciprocity is closely related to the notion of circular causality. Bowen describes this concept as dysfunctioning and overfunctioning existing together. "On one level, such functioning is smooth-working; if the system is flexible, the reciprocating mechanism of one member overfunctions to compensate for the dysfunction of another and allows the system to continue without stress. However, in a more chronic and fixed state of overfunctioning and dysfunctioning, the flexibility is lost and stress occurs on the system" (Jones, 1980, p. 44).

Bowen cites the example of a dominating (overfunctioning) mother and passive father. The overfunctioning of one member is to compensate for the poor functioning of the other. Overfunctioning may be valid in a temporary situation such as the convalescence of surgery but in chronic states there is evidence that dysfunction appears later to compensate for overfunctioning in the other. Allowed to advance beyond a certain point, anxiety drives the mechanism to panic, which increases both overfunctioning and dysfunctioning. Such increased pressure can lead to a paralyzed collapse of the disabled one. Symptoms develop when dysfunction approaches nonfunctioning. Families frequently do not seek help until flexibility of the system is lost and

severe impairment of one member occurs. Even at this point recovery can begin with minimal decrease of the overfunctioning, or a slight decrease in the dysfunction (Jones, 1980).

Two of Bowen's eight inter-locking concepts--"Differentiation of Self" and "Nuclear Family Emotional Process" will be discussed as they provide further support and clarification to this study. Differentiation of Self is the concept most basic to Bowen's theory. Differentiation of Self as explained by Bowen has three connotations: the inter-psychic element describing a degree of emotional stuck-togetherness in families; second, the intra-psychic element describing an individual according to the degree of fusion experienced between emotional and intellectual functioning; and third, the inter-psychic element describing an individual according to a level of maturity of self. In addressing the first connotation Bowen observes that theoretically, fusion is present to some degree in all families except those in which family members have attained complete emotional maturity. In such families individual members are contained emotional units who do not become involved in emotional fusions with others.

The second connotation has to do with the degree of fusion or differentiation between emotional and intellectual functioning within a person. Bowen suggests that low levels of differentiation are considered a negative characteristic in that the emotional and intellectual levels are so fused that the individual's life is dominated by an automatic emotional system. The intellect exists as an appendage of the feeling system which renders such individuals as

inflexible and emotionally dependent on others. At the other end of the continuum are those individuals who possess a high level of differentiation between emotional and intellectual levels. Such an individual can retain relative autonomy for each of the two levels in periods of stress, and consequently is more flexible in the presence of emotionality.

The third connotation of the differentiation of self has to do with the levels of solid self and pseudo-self in a person. The basic, solid self is that part of the personality which is relatively fixed and unchangeable. This portion is composed of clearly defined beliefs, opinions, conviction, and life principles. The pseudo-self is negotiable in the relationship system. Created by emotional pressure, it can be modified by external circumstances.

The concept of nuclear family process describes the patterns of emotional functioning within a family in a single generation. Certain basic patterns between parents and children are replicas of past generations and will be repeated in the generation to follow.

The family and nursing theories which were presented in the conceptual framework provide the conceptual underpinnings for this study. Family systems theory, Rogers, Fawcett and Bowen share the perspective of an interconnectedness of the parts as it relates to the family system, the environment and the universe. A fundamental principle is that a change in one part of the system will have an effect on the system as a whole. Lastly, a feature which is unanimously shared is that the life process, family system and family relationships are characterized by patterns.

Conceptual Model

This study is conceptualized within a framework (Figure 1) derived from family systems theory and was formulated from the results of an inductive study done by this author. The dependent variable is caregiver strain which is referenced by the construct of caring/caregiving. The framework contains three independent variables which are referenced by the constructs: adaptation, cohesion, and spirituality.

Adaptation is a difficult construct to define. Numerous definitions have been proposed in the literature from Nursing, Biology, Physiology and Psychology perspectives. Moreover, many disciplines use adaptation and adjustment interchangeably.

Adaptation comes from Latin--adaptare, meaning to fit (Dorland, 1965). In this study adaptation is defined as "a positive response to changes in the individual's internal or external environment that maintains integrity" (Rambo, 1984, p. 3). Internal environment may include the processes of metabolism which takes place in every cell of the body from conception until death. External environment may include a range from such simple physical changes as those in illumination, temperature, and humidity, to the most subtle and complex changes of all, those in human relations (Hofling et al., 1967).

Rambo (1984) further clarifies the construct as follows: "Adaptation is always a positive response that maintains one's biopsychosocial integrity or functioning and promotes well-being" (p. 7). Adaptation may be viewed as a series of techniques or

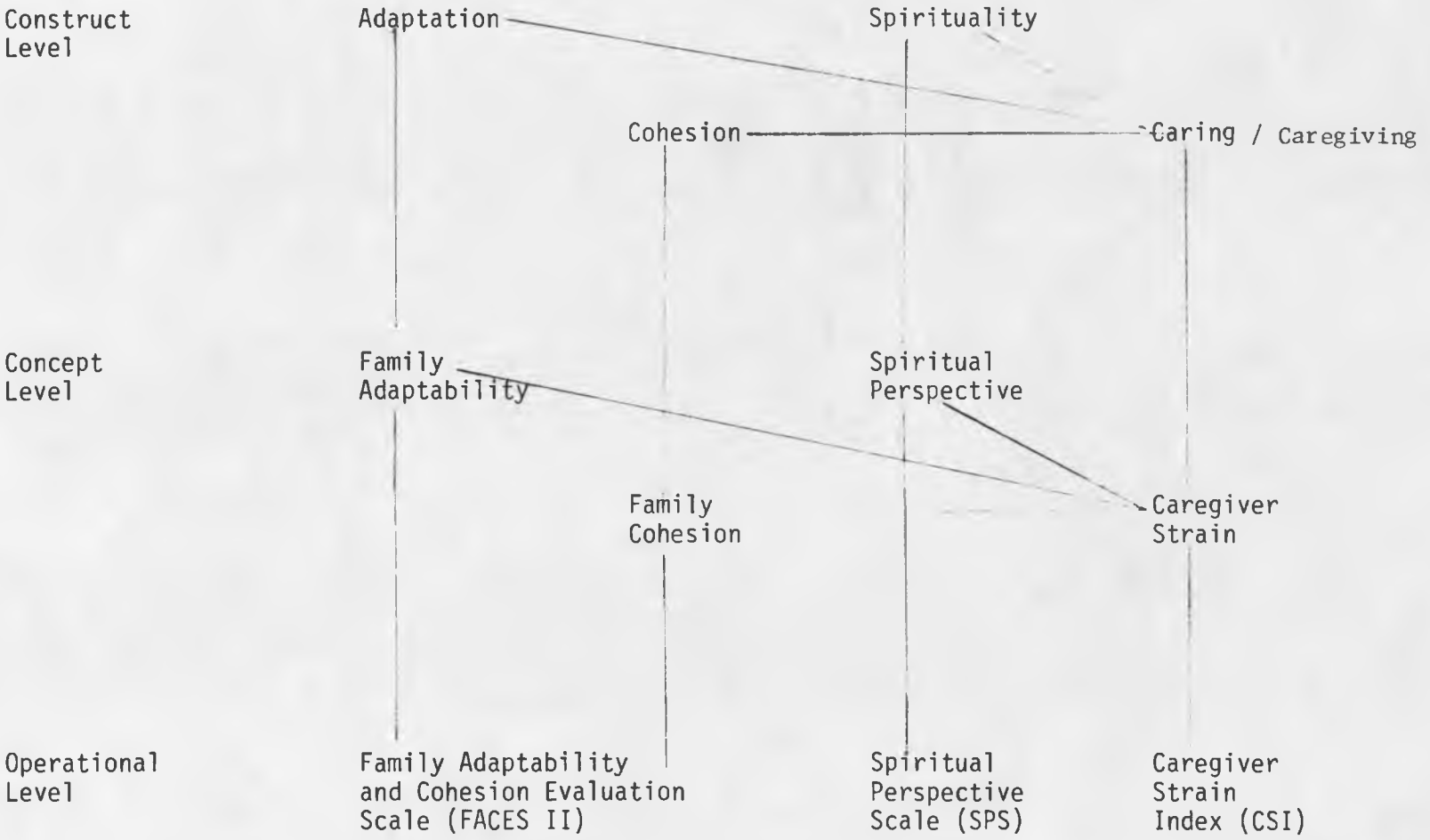

Figure 1. Conceptual Model

processes by which the individual copes with or adjusts to changes in order to maintain a satisfactory equilibrium within the environment (Rambo, 1984). Adaptation must be viewed as a dynamic, not static process (Helson, 1964).

The concept family adaptation is defined as the ability of the family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress (Olson, Bell, & Portner, 1979). Family adaptation and its relationship to caregiver strain emerged from a qualitative, inductive study of eight (McEwen, 1985) using grounded theory methodology as conceptualized by Glaser and Strauss (1967). The purpose of the study was to explore the impact of parent-caring on the middle-aged daughter. Constant comparative analysis of data produced clusters of qualities and activities which described adaptation. Examples of data bits included: "All of us have managed, I don't know why we can and some can't"; "It's nothing you're not perfectly willing to make a few adjustments for"; "You have to do some compromising"; "I'm ready for whatever happens"; "They [the elders] just have to say they are in need of something and if I'm not available, another family member is right there."

As this property was further scrutinized, it became evident that adaptation functioned as a resource which contributed to caregiver acceptance and adjustment to the role. Thus, the independent variable of family adaptation for this current study is believed to facilitate adjustment to the changes experienced by women who are caregivers of their elder kin.

The link between family adaptability and caregiver strain is illustrated in a grounded theory study of 39 caregivers who were theoretically sampled using newspaper advertising to explore their perceptions of providing home care for frail elders and to generate a theoretical model (Phillips & Rempusheski, 1986). Findings demonstrated that among those caregivers who answered the "abusive" relationship advertisement, there was more divergence between their proscriptions and their perceived reality of caregiving. Reconciliation of proscriptions with the perceived reality of caregiving is defined as the degree to which the caregiver's observations and perceptions of the situation diverge from the caregiver's beliefs about propriety. Additionally, their proscriptions appeared more rigid and less negotiable than those of other caregivers. These caregivers (as opposed to those who responded to the "good" relationship ad) perceived that reality seemed farther away from their proscriptive ideal and, consequently, their role beliefs reflected a more punitive, controlling attitude than that of the caregivers who responded to the "good" relationship advertisement.

Cohesion which is defined as the bonds of unity running through family life appears as an organizing dimension in the thinking of family scholars trained in a variety of disciplines, including family sociology, psychiatry, social psychology, and anthropology (Russell, 1980). Thus the significance of the cohesion dimension is underscored by the wide range of social science disciplines which have utilized the dimension or concepts related to it.

A large variety of concepts have been used to describe aspects of cohesion and a diversity of operational measures may be found in the literature. Rooted in family sociology, integration, first identified by Angell (1936), referred to the ". . . many bonds of coherence and unity running through family life, of which common interests, affection, and a sense of economic interdependence are perhaps the most prominent" (1965, p. 15).

For the purpose of this study, the concept of family cohesion is defined as: the emotional bonding family members have with one another (Olson, Russell, & Sprenkle, 1983). Family cohesion and its relationship to caregiver strain emerged from a qualitative, inductive study (McEwen, 1985) using grounded theory methodology as conceptualized by Glaser and Strauss (1967). The purpose of the study was to explore the impact of parent-caring on the middle-aged daughter. Constant comparative analysis of data produced clusters of qualities and activities which described cohesion. Examples of data bits included: "We've always been close, now we're closer"; "I'd worry about her if she wasn't with us"; "It's something you're glad to do because they're such loving people . . . it comes natural--it's a love gift"; " . . . bred into you, my parents cared for their parents"; "loving and giving"; " . . . it helps for all of us to draw closer together"; "It's nice having an older person in the house as a reinforcement of ideas and values that you're trying to teach your children."

Further review of this property reinforced that cohesion functioned as a resource which contributed to caregiver acceptance and

integration of the role. Thus, the independent variable of cohesion for this study is believed to facilitate integration of the caregiver role.

Spirituality has a variety of meanings depending upon the context in which it is used. Moberg (1971) identifies the spiritual as one's inner resources. "It is the basic value or ultimate concern that guides one's conduct" (Moberg, 1979).

Frankl (1965) notes, "Man lives in three dimensions: the somatic, the mental, and the spiritual. The spiritual dimension cannot be ignored, for it is what makes us human" (px.). The spirituality of man is a thing-in-itself, it cannot be explained by something not spiritual. Spirituality is irreducible.

Luckmann (1967) defined spiritual values as "supernatural, transcendent qualities which are characteristic of a central power or related powers in the universe, such as God, life, love, good or truth" (p. 57). Spiritual values are ordered to create a meaningful view of the universe, and individuals identify with the values they select as being most significant for them (Hall, 1986).

Theological inferences about the human spirit are meaningful. The spirit provides an individual with capacity for God-consciousness, however "God" may be defined. The Judeo-Christian belief purports the spirit to be that component which allows a person to experience meaningful relatedness to Deity (Stallwood & Stoll, 1975, p. 1087).

This study employs Reed's definition of spirituality which is "that which relates people to a transcendent or non-physical realm, or

which relates people to something greater than themselves without disregarding the value of the individual" (1986a, p. 37).

For the purpose of this study, the concept spiritual perspective is defined: "in terms of personal views and behaviors that express a sense of relatedness to a transcendent dimension or to something greater than the self" (Reed 1986b, p. 4). There is a dearth of research on religion and health; and, there is a paucity of literature dealing specifically with the relation of spirituality and caregiver strain.

Spirituality and its relationship to caregiver strain emerged from a qualitative, inductive study (McEwen, 1985) using grounded theory methodology as conceptualized by Glaser and Strauss (1967). The purpose of the study was to explore the impact of parent-caring on the middle-aged daughter. Constant comparative analysis of data produced clusters of qualities and activities which described spirituality. Examples of data bits included belief in a supreme being, faith, guidance, inner direction, prayer, formal religious affiliation, church activities, and reading from the Bible. Spirituality may or may not incorporate religious rituals and behaviors nor necessarily involve participation in a religious organization. Reed (1986b) supports these examples as indicators of spirituality.

As this property was further scrutinized, it became evident that spirituality in addition to other data bits, also served to describe supports, motivators, and resources which contributed to caregiver acceptance and maintenance of the role. Thus, the independent variable of spirituality for this current study is believed

to serve as an integrative and adaptive function for women who are caregivers of their elder kin.

Caring/Caregiving and care appear to have multiple characterizations and conceptualizations. Although numerous definitions have been proposed in the literature, there are few that define the generic concept of care (Leininger, 1980).

During the past 17 years Leininger has been investigating the definitions, nature, and scope of care and caring, using an ethnoscience approach. The study of the cultural usages, meanings, and functions of caring in various cultures appears closely related to the social structure and cultural beliefs of people. To date, approximately 30 cultures have been studied by direct interviews, structured questionnaires, library data, and direct observations focused upon beliefs and practices related to caring. From these data, a taxonomy of caring constructs, theories, and hypotheses are being developed.

This study applies Leininger's (1980) proposed generic definition of caring/caregiving as those assistive, supportive, or facilitative acts toward or for another individual or group with evident or anticipated needs to ameliorate or improve a human condition or lifeway" (p. 9). Leininger (1980) maintains that caring processes, patterns, and expressions might well become extinct if we do not recognize caring and value it in our existence. "Caring helps to bridge human relatedness, concern, and compassionate help to others.

Human care appears to have existed through time and is universal to human existence and helping processes . . ." (p. 8).

Assuming that the projections of longevity are correct, more and more adult children will be involved in assistive, supportive or facilitative acts toward their elder kin who express evident or anticipated needs in an effort to ameliorate or improve their life. However, despite the best of intentions, caring for a frail, dependent elder frequently involves considerable strain as well as family disruption. The current generation of caregiving children is experiencing what Pearlin (1980) has identified as an unscheduled lifestrain (i.e., events that are not regular consequences of life-cycle transitions).

Pearlin and Schooler (1978) define strains as those enduring problems that have the potential for arousing threat, a meaning that establishes strain and stressor as interchangeable concepts. For the purpose of this study, caregiver strain is defined as the physical, emotional, social, and financial burdens that can be experienced by individuals caring for an elder.

The operational level of the conceptual framework identifies the instruments which will be used to measure the variables under investigation. The instruments will be discussed in Chapter 3.

Purpose of the Study

The purpose of this study is to investigate the relationships between family adaptability, family cohesion, spirituality and

caregiver strain in women who are caregivers of their elder kin. The following questions are to be investigated:

1. What is the relationship between family adaptability and caregiver strain?
2. What is the relationship between family cohesion and caregiver strain?
3. What is the relationship between spirituality and caregiver strain?
4. How much variance in caregiver strain is explained by the combined effect of family adaptability, family cohesion and spiritual perspective?

Summary

Caregiver strain may be affected by an individual's perceived family adaptability, family cohesion and spirituality. This study was designed to investigate the relationships between family adaptability, family cohesion, spirituality, and caregiver strain in women who are caregivers of their elder kin.

This chapter provided an overview of the problem related to women providing care for an elder relative, the significance of the problem, and the purpose of the study. The identified constructs and their definitions, concepts and their definitions and the relationships constitute the Conceptual Framework for this study.

CHAPTER 2

REVIEW OF THE LITERATURE

The review of the literature is comprehensive and therefore is not confined to one field of specialization. Disciplines that have been examined for research which bear a relationship to this study include: family literature, sociology, psychology, theology and nursing. Criteria for inclusion of references in the review was that the study provide background of significant material which is theoretically or conceptually related to the current study. The literature is organized and examined in four sections: family adaptability, family cohesion, spirituality, and caregiver strain.

Family Adaptability

Family adaptability appears as an important concept in the family literature. It appears in the family crisis literature as well as in the family problem solving and family process literature. However, this investigator found a scarcity of literature which specifically addresses the relationship between family adaptability and caregiver strain.

For the purpose of this study family adaptability is defined as: the ability of the family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress (Olson, Bell, & Portner, 1979). This definition is highly compatible with the definition of family systems

as noted by Wertheim (1975). This author purports openness of systemic boundaries as a necessary condition for the successful adaptation of the family system. "An ideal, adaptive family system can be conceptualized as one characterized by an optimal, socio-culturally appropriate balance between stability-promoting, "self-corrective" processes, or morphostasis, and change-promoting, "self-directive" processes, or morphogenesis" (p. 286). Such an ideal family would be expected to endure as a system while experiencing successive transformations in response to changes in the internal and external environment.

Lennard and Bernstein (1969) support this conceptualization by adding that continuous adjustments and new adaptations are required and must be accomplished by a social structure to accommodate the diversity of influences that impinge upon it. These authors identify, ". . . one criterion for the adaptive capacity of a social system might be its ability to deal with extrasystem stresses through internal interactional and sequential modifications without being disrupted" (p. 17).

Phillips and Rempusheski (1986a) incorporated the concept of family adaptability into the development and empirical testing of a measurement instrument (N = 260) designed to identify caregivers who were at potentially high risk for providing poor caregiving. The Beliefs about Caregiving Scale (BACS). One subscale of the Family Adaptability and Cohesion Evaluation Scales (FACES) (Olson et al., 1979) was used to measure rigidity of family adaptation. These researchers report a modest relationship between three subscales of the

BACS and the rigidity (Monitoring 1 r = -.40; Monitoring 2 r = -.28; Assessing r = .29) which was the expected direction. The findings suggest that caregivers who are rigid (lack adaptability) are prone to punitive views of caregiving and tend to not view caregiving as a nurturing activity.

Johnson and Catalano (1983) isolated two categories of adaptive strategies used by caregivers (N = 115) in order to alleviate the strains of care. The first is an enmeshing technique wherein the caregiver focuses almost exclusively on the care dyad while the second and opposite technique involves the caregiver resorting to distancing to reduce the intensity of the strain.

Assisting frail homebound elders not only involves worry and strain but often requires changes and adjustments in lifestyle on the part of the primary caregiver. Cantor (1983) asked respondents about areas of activity and the degree to which their lives had been affected by their caring role. The extent of impact on the life of the caregiver appeared to be clearly related to the closeness of kinship bond and the availability of the caregiver for continual involvement. "Findings suggest that caregivers forced to adjust their lives to encompass the increased demands of a dependent older person were most likely to give up those things which had some elasticity and were more marginal to personal or family equilibrium and survival" (p. 600).

A three generation (N = 403) survey conducted by Brody et al. (1984) revealed that adjustment of family schedules and help with costs of professional health care were seen as appropriate caregiver requests

for adult children. However, adjustment of work schedules and sharing of households were not considered as appropriate requests.

In younger families, those comprised of parents and adolescents, Olson et al. (1979) recognize adaptability as a significant dimension of family behavior. The researchers have developed a model with family adaptability as a core concept in which they propose that there needs to be a balance on the adaptability dimension between too much change (which leads to chaotic systems) and too little change (which leads to rigid systems).

To test the major hypothesis that balanced family types are more functional than extreme types, a variety of studies using the FACES and FACES II have been done focusing on the range of emotional problems and symptoms in couples and families. In a review compiled by Olson, Portner, and Lavee (1985), the original FACES instrument was used in a study of 210 parent/adolescent triads. The alpha reliability for adaptability was .75. FACES II was developed (1981) in which 464 adults responded to 90 items of the original instrument. On the basis of factor analysis and reliability (alpha) analysis, the initial scale was reduced to 50 items. For the reduced scale, the Cronbach alpha reliability for adaptability was .80. An additional study of 2,412 respondents justified further reduction to 30 items (Cronbach alpha for adaptability was .78). Additional empirical studies (Portner, 1981; Bell, 1982; Garbarino, Sebes, & Schellenbach, 1984) provide further support of the hypothesis that balanced family types are more functional than extreme types (Olson et al., 1985).

Olson and Sprenkle (1980) compiled an extensive literature review related to adaptability. The first study to explicitly test hypotheses related to the power concept in the adaptability dimension was conducted by Sprenkle and Olson (1978). The marital interactions of 25 couples receiving marriage counseling with a matched group not in counseling were studied while participating in an interaction game. It was predicted that couples in counseling would either have no leadership or authoritarian leadership, whereas nonclinic couples would have more equalized leadership with power shifting between the husband and wife. The hypothesis was strongly supported but not until the stress level increased. Tallman and Miller (1974) demonstrated the importance of examining role expectations as they relate to leadership patterns. Bahr and Rollins (1971) found that couples with more democratic leadership patterns pre-crisis, were more likely to change leadership in the game simulation crisis. Tallman (1970) suggests that more competent families may have greater leadership adaptability and therefore measuring leadership changes may be a promising technique. Miller and Westman (1966) used changes in leadership patterns as a measure of adaptability. A recent empirical update of role relationships was done by Nye (1976). Family rules, both implicit and explicit, have been investigated by Jackson (1965). In spite of the diversity of operational and conceptual definitions, the relationship between adaptability and family functioning was generally supported.

Initial investigations of family adaptability lends support to Olson's hypothesis. Hill, in 1949, utilized this concept in the study of war separation and reunion (1971). This researcher found that

highly adaptable families had the best adjustment to both events. Angell, in 1936 identified family flexibility as an integral dimension of understanding family success in adjusting to prolonged unemployment (1965).

Family Cohesion

Family cohesion appears as an equally important concept in the family literature to family adaptability. Angell (1965) noted that "External changes are accommodated to most easily where there is a maximum of integration and at the same time a maximum of flexibility." The significance of the cohesion dimension is attested to by the variety of terms from many different disciplines that refer to cohesion. For the purpose of this study, family cohesion is defined as: the emotional bonding family members have with one another (Olson et al., 1983).

Brody et al. (1984) conducted a three generation (N = 403) survey which focused on the opinions and preferences of women with regard to helping elderly parents. The findings reveal the overwhelming preference of all generations for children as the primary source of affective support. The multilayered character of the women's opinions and preferences underscores individual and family diversity and illustrates the continuing emotional interdependence of family members.

Goldstein, Regnery, and Mellin (1981) interviewed 25 caregivers and when asked why they decided to maintain the elder at home, the response of most of the caretakers was generally a combination of an

affective bond to the patient and an aversion to what is usually the only perceived alternative--nursing home placement. A characteristic response was, "If you love her, you can't put her in a nursing home." Moral principle of reciprocity also appeared to be important: "He was good to me, and now I have to care for him." Despite the hardships of doing so, caretakers seem to be strongly and genuinely motivated by the desire to keep the elder at home (p. 25).

Phillips and Rempusheski (1985) incorporated enmeshment which is a conceptual companion of the concept of family cohesion into the development and empirical testing of a measurement instrument designed to identify potentially high risk caregivers: The Beliefs about Caregiving Scale (BACS). One subscale of the FACES (Olson et al., 1979) was used to measure enmeshment. The researchers report that among the caregivers in this study, the total amount of enmeshment was extremely low. In fact, these caregivers tended to be disengaged from their elder rather than enmeshed. The hypothesis which predicted a bivariate correlation between the Enmeshment subscale of the FACES and the BACS at r = .60 or better was rejected. The researchers postulate that enmeshment may occur between young children and their parents but not between adult caregivers and their elders.

The thesis that caregiving exerts substantial strains on filial bonds is supported by clinical literature. Cantor (1983) focused on elderly and their caregivers and report that although 70% or more of the caregivers reported feeling "very close" to their care-receivers, an inverse correlation existed between the closeness (or degree) of kin

relations and ability to get along well. Correlates of strain was also examined; findings reveal that the closer the bond, the greater the amount of strain. Spouses were the group at highest risk, followed by child, other relative, and friends and neighbors. Thus, the concept of centrality, both kinship and functional, clearly relates to the dimension of strain and stress in the caregiving situation. An additional variable, the attitude toward family and the role of family as measured by a familism scale (Leichter, 1967) revealed that commitment to family as a positive value is positively associated with strain. "The importance of familism as a predictor of strain suggests that a sense of family and a belief in family cohesion is an underlying dimension in the caregiving situation" (p. 602). Individuals who share such values are more likely to become deeply involved in caring for an older person and are apparently more likely to experience pervasive strain.

Olson et al. (1979) support the salience of the concept by recognizing cohesion as an underlying dimension for the multitude of concepts in the family field. In their inductive work, at least 40 concepts emerged which relate to this dimension. A number of social science fields have used this concept even though their conceptual and operational definitions are quite varied. The multi-disciplinary use of the concept also lends support to its relevance and generality.

Family cohesion may be viewed on a continuum in which at the extreme high is enmeshment and at the extreme low is disengagement. Enmeshment is defined as an overidentification with the family that results in extreme bonding and limited individual autonomy.

Disengagement is characterized by low bonding and high autonomy from the family. Olson et al. (1979) hypothesize that when the levels of cohesion are balanced, there will be a more functional balance of the issues identified and the family will deal more effectively with situational stress and developmental change.

To test this hypothesis, a number of studies have been conducted using the FACES and FACES II instruments. The original FACES instrument was used in a study of 210 parent/adolescent triads. The alpha reliability of cohesion in this study was .83 (Olson et al., 1985). FACES II was developed (1981) in which 464 adults responded to 90 items of the original instrument. On the basis of factor analysis and reliability (alpha) analysis, the initial scale was reduced to 50 items. For the reduced scale, the Cronbach alpha reliability for cohesion was .91. An additional study of 2,412 respondents justified further reduction to 30 items (Crohnbach alpha for cohesion was .87) (Olson, 1985).

Additional empirical studies using FACES and FACES II have been compiled by Olson et al. (1985). Portner (1981) compared 55 families in family therapy (parent and adolescent) with a matched control group of 117 non-problem families. As hypothesized, more nonclinic families demonstrated a balance in the cohesion dimension than the clinic families (58% and 42% respectively). Bell (1982) also utilized FACES to study 33 families with runaways and compared them with the same 117 non-problem families used in the Portner (1981) study. As hypothesized, significantly more non-problem families as described by

the mother and adolescents were found in the balanced area compared to runaway families. Garbarino et al. (1984) compared 27 high risk families with 35 low risk families focusing on the type of family systems using FACES. Again, their findings were congruent with the previous studies. These investigations provide further support of the hypothesis that when the levels of cohesion are balanced there will be a more functional balance of the issues identified and the family will deal more effectively with situational stress and developmental change.

An extensive literature review related to the cohesion dimensions in couples and families conducted by Olson and Sprenkle (1980) reveals congruence of findings across studies using different conceptual and operational definitions (Kohn, 1969; Minuchin et al., 1967; Reiss, 1971a, 1971b; Sandberg et al., 1969; Straus, 1968; Strodtbeck, 1958). These findings continue to support the potency of this dimension.

Additional work related to family cohesion includes: Stierlin (1974) "binding mode"; Bowen (1965) "undifferentiated family ego mass"; and Wynne et al. (1958) "pseudo-mutuality." Glueck and Glueck (1950) conducted an exploratory study to examine the cohesiveness of family groups and found that those families who were described as having "good" quality relationships among family members demonstrated a strong "we feeling." This was evidenced by cooperativeness, group interests, pride in the home, affection for each other--"all for one and one for all."

Hill (1971), in a study of war separation and reunion, investigated integration, a variable which is conceptually related to

cohesion. This author incorporated and tested findings from previous studies which resulted in five items that relate to family integration. This concept involved the unifying bonds of economic and emotional independence: strong emotional ties among family members, pride in family traditions, and high participation as a family in joint activities.

Controversial findings related to family cohesion are addressed in the literature. The family literature (Olson et al., 1979) report that extreme bonding with the family is associated with limited individual autonomy. Cantor (1983) examined correlates of caregiver strain and findings revealed that the closer the bond, the greater the strain.

Family adaptability and family cohesion are important concepts in the family literature. However, this investigator found that most of the research which involves these two variables has been conducted with younger families who have adolescent children. There is an absence of literature which specifically addresses the relationship of family adaptability and family cohesion in caregivers of elder kin.

Spiritual Perspective

For the purpose of this study, the concept spiritual perspective is defined: "in terms of personal views and behaviors that express a sense of relatedness to a transcendent dimension or to something greater than the self" (Reed, 1986b, p. 4). There is a dearth of research on religion and health; and, there is a paucity of

literature dealing specifically with the relation of spirituality and caregiver strain.

Spirituality has been studied from a variety of perspectives. The association between spirituality or one's particular religious/ ethical belief system and health and illness has become a topic of interest within the health care community. With concern in nursing for the holistic bio-psycho-social-spiritual nature of human beings, the spiritual dimension is receiving notable attention. Advocates of the concept of holistic care have focused particularly on the spiritual needs and care of an individual (Byrne, 1985; Dickinson, 1975; Ellis, 1980; Fish & Shelly, 1983; Piepgras, 1968; Stallwood & Stoll, 1975; Stoll, 1979; Vaillot, 1970; Wright et al., 1985). These researchers believe that the person's perceived relationship to a higher being (God, deity) and the way that person believes the higher being affects their life must be explored (Stoll, 1979) and that spiritual factors may profoundly affect a person's response to health, illness, crisis, or death (Ellis, 1980).

Wright et al. (1985) assessed coping strategies used by family caregivers of dementia patients and caregivers' sense of burden. Two hundred and forty caregivers participated in this study. The Caregiver Burden scale was used to assess subjective feelings about caregiving. The Family Coping Strategies (F-COPES) instrument was used to measure five external coping strategies. The five external strategies reflect the degree to which families actively utilize the external social support systems that may be available to them, including "spiritual support," "extended families," "friends," "neighbors," and "community

resources." Caregiver burden scores were significantly ($p \leq .01$, correlated with two external coping strategies (extended family, $r = -.16$; and spiritual support, $r = -.25$). Spiritual support was also significantly ($p \leq .001$) correlated with reframing, and internal coping strategy ($r = .41$) which refers to the caregiver's ability to redefine a demanding situation in a more acceptable way in order to make the situation more manageable. Data indicate that those families who use "spiritual support" as a coping strategy, pursue advice from clergy, attend church services, participate in church activities, and express faith in God. Additionally, although spiritual support was associated with lower burden scores, some respondents admitted that the role of caregiver severely tested their religious faith. These authors conclude that spiritual support is a valuable resource for families facing the stressful experience of caregiving for a dependent relative. "The spiritual dimension of health care is an integral part in the total well-being of both the . . . patient and the caregiver" (Wright et al., 1985, p. 36).

Reed (1986a) compared terminally ill adults with healthy adults for differences in religiousness and sense of well-being. Religiousness was defined as "the perception of one's beliefs and behaviors that express a sense of relatedness to spiritual dimensions or to something greater than self" (p. 36). One hundred and fourteen participants completed two questionnaires: The Religious Perspective Scale and the Index of Well-Being. A Pearson product moment correlation was used to address the relationship between the scores. A

significant positive relationship between these two variables was found in the healthy group ($r = .43$, $p \leq .001$). In a later study Reed notes that spirituality is a broader concept than religion or religiosity. Although the term "religiousness" was used in operationalizing the abstract concept of spirituality (1986b), "spirituality is more accurate" (p. 4).

Research generally reveals that indices of mental well-being such as happiness, feelings of usefulness, and personal adjustment increase with religious activity and interests (Kivett, 1979; Shaver, Lenauer, & Sadd, 1980). Kivett (1979) employed a general regression model to determine the relative importance of 10 independent variables to the dependent measure of religious motivation. Findings suggest that intrinsically motivated individuals internalize their religious creed in a manner that will assist them in the transcendence of personal interests and needs. "This religious stance appears to be important in the processes necessary for successful adaptation in middle and later life" (Kivett, 1979, p. 113).

There is convincing evidence that several dimensions of religion are inextricably bound to measures of adjustment in middle and later life (Blazer & Palmore, 1976; Edwards & Klemmack, 1973; Spreitzer & Snyder, 1974). O'Brien (1982) examined faith as associated with adjustment to long-term hemodialysis. The results demonstrated that 93 (73.8%) of the study group participants ($N = 126$) held the opinion that religious or ethical beliefs were to some degree associated with acceptance of their disease and the treatment regimen of maintenance hemodialysis. These findings are supported by Baldree, Murphy and

Powers (1982), who also studied hemodialysis patients, discovering that "prayer and trust in God" were frequently used coping methods. Miller (1983) identified "enhancing one's spiritual life" as the second-most-commonly used coping strategy (p. 27).

Thus, spiritual perspective may be a significant resource for caregivers of elder kin. This dimension may profoundly affect integration and adaptation of experiences which may act as potential mediators of caregiver strain.

Caregiver Strain

Review of longitudinal data from psychosociological studies of normative transitions of the adult life-span reveals that the caregiving functions many adults were performing for their elders were perceived as stressful in that they were having a major impact both on the caregivers' present lives and their plans for the future. Descriptive studies report high levels of strain in the family and perhaps an erosion of family supports either because of the high level of stress generated or because of the competing commitments of family members (Brody, 1981; Cantor, 1980; Johnson & Catalano, 1983). These later reports are more consistent with demographic trends which indicate that realistic impediments to long-term family supports exist in terms of the numbers and availability of relatives (Brody, 1981; Treas, 1977, 1981).

How is one's life affected by being a long-term caregiver? Studies report that the caregiver role affects virtually all aspects of the caregiver's life to some degree, but the impact varies with the

individual. Goldstein et al. (1981) report in their findings from interviews of 25 caregivers of chronically ill elders that the caregiver role usually entails both rewards and conflicts. The expectations and demands of different roles collide with each other, producing conflict and strain. Some caregivers reported that caregiving adversely affected their physical and mental health. Some tasks were physically taxing, sleep disruption and financial problems were also reported. In spite of the candid talk about the burdens and stresses of caregiving, nearly all caregivers expressed their determination to maintain their elder at home to avoid or defer institutionalization.

Robinson and Thurnher (1979) report from a longitudinal study of adult children caring for an aged parent consistent findings with other studies. Stress also resulted when the caregiving relationship was experienced as confining. Confinement was linked to infringements on the lifestyle or hoped for lifestyle of the adult child more clearly than to the physical or mental status of the elder parent.

In a followup study, Robinson (1983) empirically validated a series of questions for use as a screening instrument for detecting caregiver strain. Ten stressors were identified in the previous study (1979) which served as the basis for the instrument. A literature review contributed three new stressors. The stressors were: inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behavior, the parent seeming to be a different person, work

adjustments, feelings of being completely overwhelmed, sleep disturbed, physical strain, and financial strain.

Eighty five individuals who provided varying degrees of care to recently hospitalized hip surgery and heart patients (over age 65) participated in the study. Internal consistency (Cronbach's alpha) for the 13-item CSI on 81 cases was .86. Evidence of construct validity was obtained in three areas: ex-patient characteristics; subjective perceptions of the care-taking relationship by caregivers; and emotional health of caregivers. The elders demonstrated intact intellectual functioning and good to excellent health and therefore the demands for care were not high. The author notes, ". . . when it is, we would expect it to be reflected in strain on caregivers" (p. 346). There were positive correlations between the caregivers CSI score and the elders age, rehospitalization within 2 months, and mental status. CSI scores were correlated negatively with ex-patient's abilities to perform activities of daily living and satisfaction with progress during convalescence. Caregivers' self-reports of experiencing situations that conflicted with giving help to ex-patients also were associated significantly with CSI scores, one-tailed $t(0,00)$[sic] = 6.46, $p < .001$. Emotional strain on caregivers is evident in the negative correlation between CSI scores and morale and positive correlations with the anxiety, depression, and hostility factors on the Profile of Mood States (POMS) instrument. The author indicates that the CSI is an instrument which may be a useful tool for research and screening purposes.

Johnson and Catalano (1983) studied family supports of 115 individuals 65 years and older after discharge from the hospital and again an average of 8 months later. A comparison of those patients who were dependent during the 8-month period to those who had achieved independent functioning, revealed that caregiver strain was higher (48% versus 11%). Findings from Cantor's (1983) study of strain among caregivers reveals that among children, the normal strains of caring for an ill older person seemed to be compounded by intergenerational differences. Only 20% of the children felt that they shared similar perspectives on life with their parents. In terms of strain experienced in the areas of emotional, physical and financial stress, financial strain ranked lowest in importance and emotional strain ranked first. Further analysis of those factors which conceptually appeared to be associated with strain in caregivers revealed that the type of caregiver and the relationship to the care-receiver was by far the most important. "The closer the bond, the greater the amount of strain. Thus, the concept of centrality, both kinship and functional, clearly relates to the dimension of strain and stress in the caregiving situation" (p. 601).

Although most research has focused on the primary caregiver, Brody (1985) addresses the effects on the family. The family is affected by interference with life-style, privacy, socialization, vacations, future plans, income, and by the diversion of the caregiver's time and energy away from other family members and the potential negative effects on her health. Emotional support from other family members mitigates the caregivers' strains (Horowitz, 1985;

Sussman, 1977; Zarit et al., 1980). However, when changes in the family homeostasis stimulate interpersonal conflicts, relationships are affected negatively between husbands and wives, among adult siblings, and across the generations (Brody, 1985).

Zarit et al. (1980) and Poulshock and Deimling (1984) have contributed to the literature from investigations of caregiver burden. Burden has been broadly defined and differentially measured which provides an overlap into the measurement of caregiver strain. Poulshock and Deimling (1984) define burdens as emotional costs qua feelings of embarrassment and overload to specific changes in caregivers' day-to-day lives such as disruption of daily routine. Other areas include financial difficulties, role strain, and physical health deterioration. Instruments designed to specifically measure caregiver burden are illustrated in both Zarit and associates (1980) and the more recent Caregiver Strain Index (Robinson, 1983). Both of these instruments include (1) an explicit focus on caregiving (e.g., questions ask how caregiving influences respondents' lives), (2) items tapping multiple dimensions in which burden could be experienced (e.g., physical health, emotional symptoms, social activities), and (3) yield total scores indicating overall levels of burden (George & Gwyther, 1986).

Zarit et al. (1980) investigated factors related to the amount of burden experienced by the principle caregivers of older persons with senile dementia. The measurement of the degree of burden was made with a 29-item self-report inventory, administered to the primary caregiver

during an assessment interview. Burden was found to decrease with visits from relatives to the dementia patient. Severity of behavioral problems was not associated with higher levels of burden.

Poulshock and Deimling (1984) provided further evidence that there was a moderate-to-strong empirical link between elder impairment characteristics and the corresponding perception of burden. The elders' ADL impairments and burdens are more highly correlated with restrictions in caregivers' activities. These investigators advise that it is important to differentiate the varying dimensions of impairment, burden, and impact. Further, it is important to take into account the depression level of the caregiver as it affects measures of both burden and impact (p. 235). In summary, these authors suggest the concept of burden should be used to refer to the subjective perceptions of caregivers related to the degree of problems experienced in relation to elders' specific impairments. "Further, these impairments should be differentiated in terms of the mental and physical capacities of the elder. Second, burden, as subjectively interpreted by caregivers, should be treated as an intervening measure between impairment and other more objective indicators of caregiving effects. . . . caregivers do report feelings of burden and they are linked both to the impairment that gives rise to them and to changes in objective conditions within the family" (p. 238).

Summary

The literature review indicates that family adaptability, family cohesion, and spirituality need further investigation in

relation to caregiver strain. Findings indicate that caregivers engage in adaptive strategies which include changes and adjustments in their lifestyle in order to alleviate the strains of caregiving. Findings also suggest that the greater the cohesion, the greater the caregiver strain. Spirituality has been associated with lower caregiver burden scores and has been inextricably bound to measures of adjustment in middle and later life. No research has been done relating these three factors and caregiver strain in women who are caregivers of their elder kin.

CHAPTER 3

METHODOLOGY

Introduction

This study utilized a descriptive correlational design to investigate the relationship between family adaptability, family cohesion, spirituality, and caregiver strain in women who are caregivers for their elder kin. This chapter presents the setting, sample, protection of human subjects, instruments, and methodology including data analysis, assumption, and limitations of the study.

Questions to be answered include the following:

1. What is the relationship between family adaptability and caregiver strain?
2. What is the relationship between family cohesion and caregiver strain?
3. What is the relationship between spirituality and caregiver strain?
4. How much variance in caregiver strain is explained by the combined effect of family adaptability, family cohesion and spiritual perspective?

Setting and Sample

The setting for this study is a county in Southern Arizona of approximately 624,300 people. A convenience sample of 40 women were asked to voluntarily participate in the study. Subjects were

identified through their association with several churches and as caregivers of geriatric patients from an outpatient clinic. Subjects were also contacted through individuals known to the researcher. Criteria for inclusion in the study were as follows:

1. Subjects are female.
2. Subjects are English-speaking.
3. Subjects are able to read and write English.
4. Subjects provide some type of caregiving activity for an elder kin of 65 years or older.

Protection of Human Subjects

The proposal was reviewed and approved by the Human Subjects Committee at the University of Arizona College of Nursing (Appendix A). Each participant was given a written disclaimer form, assuring them of confidentiality in the collection of data and anonymity in the reporting of findings (Appendix B). By responding to the questionnaire, subjects gave consent to participate in the study.

Instruments

Three questionnaires were utilized to collect data:

1. FACES II (Family Adaptability and Cohesion Evaluation Scale) (Olson et al., 1982).
2. Spiritual Perspective Scale (Reed, 1986b).
3. Caregiver Strain Index (Robinson, 1983).

Demographic data that was collected is noted in Appendix C.

Family Adaptability and Cohesion Evaluation Scale

The Family Adaptability and Cohesion Evaluation Scale was originally developed in 1978 in the dissertation work of Portner (1981) and Bell (1982). The 111 item self-report scale was constructed to specifically measure the two dimensions of family behavior: cohesion and adaptability. Family cohesion measures the degree to which family members are separated from or connected to their family. Family cohesion is defined as: the emotional bonding that family members have toward one another (Olson et al., 1982, p. 5). Family adaptability refers to the extent to which the family system is flexible and able to change. Family adaptability is defined as: the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress (Olson et al., 1982, p. 5).

FACES II (Appendix D) was developed (Olson et al., 1982) in order to overcome some of the limitations with the original instrument. More specifically, to develop a shorter instrument, reduce the number of double negatives and provide a 5-point response scale. Lastly, the task was to develop a scale with two empirically reliable, valid and independent dimensions.

On the basis of factor analysis and reliability computation, the initial scale was reduced to 30 items. The final 30-item scale contains 16 cohesion items and 14 adaptability items. There are two items for the following eight concepts related to the cohesion dimension: emotional bonding, family boundaries, coalitions, time, space, friends, decision-making, and interest and recreation. There

are two or three items for the six concepts related to the adaptability dimensions: assertiveness, leadership, discipline, negotiation, roles and rules.

Construct validity for FACES II was estimated through factor analysis. Internal consistency was measured by Cronbach's alpha from a sample of 2,412 respondents divided into two equal sub-groups. For the total sample: cohesion was .87; adaptability was .78; and the total scale was .90.

Responses to each of the 30 items on the FACES II were selected using a 5-point Likert-type scale that is anchored with descriptive words (Almost never = 1; Once in a while = 2; Sometimes = 3; Frequently = 4; Almost Always = 5). The format for scoring adaptability and cohesion was done by summing the scores of the items in each of the subscales and reversing the scores on the negatively worded items. The final range of an individual score on adaptability is between 15-70; cohesion is between 16-80.

The FACES II instrument underwent further revision when used in a descriptive study with caregivers (n = 99) for community-dwelling elders (Phillips & Rempusheski, 1986). This resulted in an instrument which is specific to the caregiver-elder population in the dimensions of family adaptability and cohesion. Internal consistency was measured by Cronbach's alpha: Cohesion .90 and Adaptation .74. Bivariate correlation coefficient between dimensions was computed at .74.

The Spiritual Perspective Scale

The Spiritual Perspective Scale (SPS) (Reed, 1986b) (Appendix E) measures the saliency of spiritual beliefs and behaviors in the participant's life. Specifically, the SPS measures participants perspectives of the extent to which they maintain certain spiritual beliefs and engage in spiritually-related interactions with others and with "God." The 10-item instrument (modified from the Religious Perspective Scale, Reed, 1983) was developed from sets of scales by King and Hunt (1975) and from a review of the literature in three areas: religiousness and spirituality, particularly of Western culture; adult development; and spirituality in health and illness experiences. The SPS operationalizes beliefs and interactional behaviors associated with personal forms of spirituality yet does not exclude organized expressions of spirituality.

Responses to each of the 10 items on the SPS were selected using a 6-point Likert-type scale that is anchored with descriptive words (Not at all = 1; Less than once a year = 2; About once a year = 3; About once a month = 4; About once a week = 5; About once a day = 6). The number selected indicates either a level of agreement with an item or the frequency of occurrence of the item in the respondent's life. The SPS is scored by averaging across all responses. Potential range of scores is 10-60, with 60 indicating greater spiritual perspective. The instrument may be administered in a questionnaire or an interview format.

The SPS has been tested on over 400 adults of all ages, including healthy, hospitalized, and seriously ill groups. Reliability, estimated by Cronbach's alpha, is rated consistently above .90 with very little redundancy among the items. Average inter-item correlations range from .54 to .60 across the adult groups. All item-scale correlations are above .60. The SPS has demonstrated criterion-related validity (Reed, 1983) and discriminant validity (Reed, 1986a).

Caregiver Strain Index

The Caregiver Strain Index (CSI) (Robinson, 1983) (Appendix F) identifies strain within informal care providers. The 13 item dichotomous scale has been tested on 81 informal caregivers of elders (age 65 and over). Ten of the 13 stressors were derived inductively from a series of open-ended interviews with adult children caring for elderly parents (Robinson & Thurnher, 1979). The initial questionnaire of 10 stressors consisted of: inconvenience, confinement, family adjustments, changes in personal plans, competing demands on time, emotional adjustments, upsetting behavior, the parent seeming to be a different person, work adjustments, and feelings of being completely overwhelmed. Following this, the relevant literature was reviewed and three new potential stressors were added: sleep is disturbed, physical strain, and financial strain. This resulted in a questionnaire format for later validation as a caregiver strain index (Robinson, 1983).

The CSI is computed by summing the 0 (no) and 1 (yes) responses for the 13 items. Potential range of scores is 0-13, with 13 indicating greater caregiver strain. The study (Robinson, 1983) which constructed the CSI with a study sample of 81, was not designed to identify high or low strain among the caregivers. The distribution of respondent scores ranged from 0-12, with a mean of 3.519 and a median of 3.0 with a distribution greatly skewed to the right. The internal consistency as measured by Cronbach's alpha was found to be 0.86. The alphas for the scale were not improved with the deletion of any single item. Construct validity of the CSI was examined in three areas: ex-patient characteristics; caregivers' subjective perceptions of the caretaking relationship; and the physical and emotional health of the caregiver. Items within these areas were selected from the ex-patient and caregiver interviews for their face validity reflecting strain.

Data Collection Procedure

Forty subjects who met criteria previously outlined were contacted directly for participation in this study. Subjects completed the questionnaires either at home or at a location convenient to them. The demographic data instrument was completed first, the remaining questionnaires were randomly administered. Completion of the questionnaires required approximately 20 minutes of the participants' time. The investigator was present during data collection to provide clarification of items on the instruments. The subject's right to refuse participation in the study was inherent in the questionnaire design.

Data Analysis Plan

After data collection, the demographic data were analyzed. Frequencies, means, and percentages were computed to describe the sample population in relation to demographic variables. Alpha reliabilities were computed for the FACES II and its two subscales (family adaptability and family cohesion) and the Spiritual Perspective Scale. The Spearman-Brown prophecy formula was used to compute the reliability of the Caregiver Strain Index.

To answer research questions one to three, the Pearson Product Moment Correlation Coefficient was calculated to express the direction and magnitude of the relationships among the demographic variables, family adaptability, family cohesion, spirituality and caregiver strain. The significance level was preset at the 0.05 probability level.

To answer research question number four, multiple regression was used to describe which of the following variables significantly affect caregiver strain in women who are caregivers of their elder kin:

1. Family Adaptability
2. Family Cohesion
3. Spirituality
4. Demographic variables

The level of significance for variables entered in the equation was established at $p \leq .05$.

Assumption

1. The subjects who participated in this study answered the questionnaires honestly and to the best of their ability.

Limitations

1. The sample was not randomly selected.
2. The Caregiver Strain Index was previously used only with caregivers (only 11% were daughters or daughters-in-law) of elderly persons during the convalescence period following a major episode of illness or surgery.

Summary

This study utilized a descriptive correlational design to investigate the relationships between family adaptability, family cohesion, spirituality, and caregiver strain in women who are caregivers of elder kin. The setting and sample, instrument descriptions and scoring method and the data collection procedure were discussed. The analysis plan includes frequencies, means, and percentages to describe the sample. The Pearson Product Moment Correlation Coefficient was computed to analyze the data and describe relationships among the study variables. Alpha reliabilities were calculated for the FACES II and the SPS. Reliability for the Caregiver Strain Index was ascertained with the Spearman-Brown prophecy formula. Multiple regression analysis was performed to determine the impact of the study variables on caregiver strain. Assumptions and limitations were addressed at the conclusion of the chapter.

CHAPTER 4

PRESENTATION OF DATA

Introduction

This study was designed to examine the relationships among family adaptability, family cohesion, spirituality and caregiver strain in women who are caregivers of their elder kin. The following questions were investigated:

1. What is the relationship between family adaptability and caregiver strain?
2. What is the relationship between family cohesion and caregiver strain?
3. What is the relationship between spirituality and caregiver strain?
4. How much variance in caregiver strain is explained by the combined effect of family adaptability, family cohesion and spiritual perspective?

This chapter presents characteristics of the sample and statistical analysis of the data. Results of the reliability testing of the FACES II (Olson et al., 1982) and its two subscales (family adaptability and family cohesion), the Spiritual Perspective Scale (SPS) (Reed, 1986), and the Caregiver Strain Index (CSI) (Robinson, 1983) will be presented and discussed. Data from the FACES II and the two subscales, the SPS and the CSI will then be presented and

discussed. The relationships between the study variables will be discussed. Finally, the results of the multiple regression analysis will be presented. The significance level was preset at the 0.05 level for this study.

Characteristics of the Sample

A convenience sample of forty women caregivers of elder kin participated in the study. Subjects included individuals associated with several churches, an outpatient clinic and women known to family and friends of the researcher.

As presented in Table 1, ages of the subjects ranged from 32 to 77, with a mean age of 53 (S.D. = 10.53) and a median age of 54.5. This is consistent with the literature which reports that caring for an impaired older relative begins when the caregiver is in middle age or early old age (Archbold, 1983). Phillips and Rempusheski (1986) report a caregiver age median for four study groups as 54, 46, 57 and 59. Archbold (1983) reports on a study sample (N = 30), a mean age of the care-providers as 56.8 years.

Table 2 presents the data on the religious affiliation of the caregiver. Twenty six subjects (65%) were Protestant, eight (20%) were Catholic, five (12.5%) were Jewish and one identified herself as "other" (2.5%). This sample had less Catholic and more Jewish participants as compared to Reed's 1986b) investigation.

The caregiver's relationship to the elder is described in Table 3. Thirty-one (77.5%) of the caregivers were daughters of the elder, four (10%) were daughters-in-law, three (7.5%) were granddaughters and

Table 1. Characteristics of Subjects by Age (N = 40)

Age in Years	Number of Subjects	Frequency (percent)
30 - 40	6	15.0
41 - 50	7	17.5
51 - 60	17	42.5
61 - 70	9	22.5
71 - 80	1	2.5
Total	40	100.0%

Table 2. Characteristics of Subjects by Religion (N = 40)

Religion	Number of Subjects	Frequency (percent)
Protestant	26	65.0
Catholic	8	20.0
Jewish	5	12.5
Other	1	2.5
Total	40	100.0%

Table 3. Characteristics of Subjects by Relationship to Elder (N = 40)

Relationship	Number of Subjects	Frequency (percent)
Daughter	31	77.5
Daughter-in-law	4	10.0
Granddaughter	3	7.5
Other (Niece-in-law)	2	5.0
Total	40	100.0%

two (5.0%) were nieces-in-law. Again, these findings corroborate other investigations (Brody, 1981; Brody, 1985; Cantor, 1983; Phillips, 1986; Shanas, 1979a, 1979b; Treas, 1977) which report that daughters predominate as providers of direct services to their elders. In contrast to Kivett's (1985) study, 12.5% of the primary caregivers in this investigation were beyond the child, child-in-law levels, which Kivett reports are of relatively little functional importance in the helping network of older adults.

Table 4 presents the data on the educational levels of the subjects. The level of education was recorded as the highest grade of school completed. Two subjects (5.0%) completed some high school, five (12.5%) graduated from high school, four (10%) graduated from a Vocational/Technical School, nine (22.5%) completed some college, seven (17.5%) graduated from college, three (7.5%) completed some graduate school, eight (20%) completed a master's degree, and two (5.0%) have a doctorate. In the total sample, 29 (72.5%) have some college education. This sample represents relatively well educated women.

The data which identifies the occupation of the caregiver is presented in Table 5. Twenty two (55%) of the sample identified their occupation as professional, six (15%) as homemakers, four (10%) as business owner/manager, four (10%) as clerical/sales, two (5%) as Artisan, one (2.5%) as skilled/technical, and one (2.5%) as student. Twenty six (65%) of the sample are employed. Sixteen (40%) of the caregivers are employed full time, ten (25%) work part time, nine

Table 4. Characteristics of Subjects by Education (N = 40)

Level of Education	Number of Students	Frequency (percent)
Some High School	2	5.0
High School Graduate	5	12.5
Vocational/Technical School Graduate	4	10.0
Some College	9	22.5
College Graduate	7	17.5
Some Graduate School	3	7.5
Master's Degree	8	20.0
Doctorate	2	5.0
Total	40	100.0%

Table 5. Characteristics of Subjects by Occupation and Employment (N = 40)

Occupation	Number of Subjects	Frequency (percent)
Professional	22	55.0
Homemaker	6	15.0
Business Owner/Manager	4	10.0
Clerical/Sales	4	10.0
Artisan	2	5.0
Skilled/Technical	1	2.5
Student	1	2.5
Total	40	100.0%

Employment	Number of Subjects	Frequency (percent)
Full time	16	40.0
Part time	10	25.0
Retired	9	22.5
Unemployed	4	10.0
Other (student)	1	2.5
Total	40	100.0%

(22.5%) are retired, four (10%) are unemployed and one (2.5%) responded as other (student).

A study conducted by Archbold (1983) revealed that 67% of the women who managed the provision of care for their elder were employed as compared to only 20% of those who actually provided caregiving. In addition, this study demonstrated that care-managers were from a higher socioeconomic background than care-providers as measured by income, education, and occupation.

The caregivers were asked to state how many months they had had responsibility for providing services to the elder. The results of this question are presented in Table 6. The number of months ranged from eight to 300, with a mean of 87.50 or 7.29 years. Phillips and Rempusheski (1986) report from their four studies a mean (months) of 62, 83, 74, and 68 respectively.

An investigation conducted by Archbold (1983) reported that 67% of caregivers were responsible for providing services to their elder parents for five years and greater. In contrast, 80% of the adult children who managed the care of their elder parent had been responsible for this service less than five years. In order to ascertain the number of hours per week the caregiver provided care they were asked, "There are 168 hours in a week; what is the average number of hours per week that you provide caregiving activities for your elder?" The responses ranged from one to 168 hours with a mean of 43.50 hours per week or 6.21 hours per day. It should be noted

Table 6. Characteristics of Subjects by Time Spent as Caregiver (N = 40)

Total Months as Caregiver	Number of Subjects	Frequency (percent)
1 - 40	9	22.5
41 - 80	17	42.5
81 - 120	5	12.5
121 - 160	2	5.0
160 - 200	3	7.5
200 and Above	4	10.0
Total	40	100.0%

Hours/Week as Caregiver	Number of Subjects	Frequency (percent)
1 - 20	21	52.5
21 - 40	7	17.5
41 - 80	3	7.5
80 - 120	4	10.0
120 - 160	5	12.5
Total	40	100.0%

however, that 52.5% of the sample provided 20 hours or less per week of caregiving activities for their elder.

Subjects were asked to rate their health in comparison to other women of their age. Table 7 presents the numbers and percentages of caregivers in each category. The majority (45%) of the subjects rated their health at least as good as others their own age. When asked to rate their health since becoming a caregiver, the majority (60%) of the subjects rated their health as about the same. Nine subjects (22.5%) rated their health as somewhat worse while five (12.5%) rated much better.

Table 8 presents the data which describes the elder. The elders ranged in age from 72 to 99, with a mean age of 84 (S.D. = 6.66). Thirty five elders (87.5%) were female and five elders (12.5%) were male. This data is similar to findings reported from a study by Phillips and Rempusheski (1986), the median age of the elder was 83, 67% were female and 33% were male. Archbold (1983) reports from the study data the mean age of the elder parent was 82 years and 84% of the elder sample were women.

The data which describes where the elder lives is reported in Table 9. Twenty six (65%) of the elders lived with the caregivers, nine (22.5%) lived alone and five (12.5%) lived with someone else which included residency in a boarding home. Phillips and Rempusheski (1986) report from their four study groups on residence of the elder: with caregiver 71%, 28%, 63%, 80%; alone or other 29%, 72%, 37%, 20%. On the other hand, from a study profile of a population of

Table 7. Characteristics of Subjects by Health (N = 40)

Health Compared to Age Cohort	Number of Subjects	Frequency (percent)
Much Better	10	25.0
Somewhat Better	7	17.5
About the Same	18	45.0
Somewhat Worse	5	12.5
Much Worse	0	0.0
Total	40	100.0%

Health Since Becoming a Caregiver	Number of Subjects	Frequency (percent)
Much Better	5	12.5
Somewhat Better	1	2.5
About the Same	24	60.0
Somewhat Worse	9	22.5
Much Worse	1	2.5
Total	40	100.0%

Table 8. Characteristics of Elders by Age and Sex (N = 40)

Age	Number of Subjects	Frequency (percent)
70 - 80	15	37.5
81 - 90	17	42.5
91 - 100	8	20.0
Total	40	100.0%

Sex	Number of Subjects	Frequency (percent)
Female	35	87.5
Male	5	12.5
Total	40	100.0%

Table 9. Residence of Elder (N = 40)

Variable	Number of Subjects	Frequency (percent)
With Caregiver	26	65.0
Alone	9	22.5
With Someone Else	5	12.5
Total	40	100.0%

middle-generation women (N = 172), Brody (1981) reports that 20% of the women have a parent living with them.

Reliability of the Family Adaptability and Cohesion Evaluation Scale

Reliability was estimated for the Family Adaptability and Cohesion Evaluation Scale (FACES II) by means of computation of Cronbach's alpha based on the study data. Reliabilities were initially computed for the entire scale and then for each of the two subscales (Family Adaptability and Family Cohesion).

Thirty six of the 40 subjects answered all of the questions on the FACES II instrument. Their data were used in computing the Cronbach's alpha coefficient of reliability for the total scale which was .89. The alpha coefficient of reliability for the Family Adaptability subscale (N = 38) was .81. The Family Cohesion subscale (N = 36) had an alpha reliability coefficient of .85. Caregivers whose elder was cognitively impaired reported difficulty in responding to the "we" items on the questionnaire (i.e., "We each have input regarding major family decisions"). In addition, several subjects reported difficulty in scoring the negatively worded items (numbers 3, 9, 12, 15, 19, 24, 25, 28 and 29). The result was missing data on four of the FACES II instruments.

The computed alpha coefficients of reliability in this study are consistent with the reliabilities obtained for the original FACES II instrument. Olson et al. (1982) report the total scale alpha reliability coefficient was .90; the Family Adaptability subscale

was .78 and the Family Cohesion subscale alpha coefficient of .87. Phillips and Rempusheski (1986) report from their sample of caregivers (N = 99) for community-dwelling elders, a Cronbach alpha coefficient of .74 for Family Adaptation and .90 for Family Cohesion.

The alpha reliability coefficient for the complete instrument meets the .80 criterion level for a mature scale (Carmines & Zeller, 1979). The item-total statistics demonstrate that the deletion of one item (number 12) may improve the alpha for this total scale and that five items (numbers 9, 10, 15, 16, and 21) should be monitored for stability.

The inter-item correlations for the Family Adaptability subscale in this study range from -.19 to .69. The item-total statistics for this subscale suggest that the alpha may be improved by the deletion of two items (numbers 16 and 24) and that items 10 and 28 should be monitored for stability. The Family Cohesion subscale inter-item correlations range from -.16 to .65. The item-total statistics suggest the deletion of two items (numbers 15 and 21) and that items 13 and 25 should be monitored for stability. These results indicate that the FACES II (and subscales) may be unstable with this population and requires instrument revision for stability.

In addition, a bivariate correlation coefficient was computed for the dimensions of Family Adaptability and Family Cohesion. The bivariate correlation coefficient of 0.76 reveals a high relation between the two subscales. This compares favorably with Phillips and Rempusheski's finding of 0.74.

Reliability of the Spiritual Perspective Scale

Reliability was estimated for the Spiritual Perspective Scale (SPS) by computation of Cronbach's alpha coefficient. All forty of the caregivers answered every item on the SPS. The alpha reliability coefficient was computed as .94. This is consistent with Reed's (1986a) findings of .90 or greater. Inter-item correlations in this study range from .35 to .83 compared to that obtained by Reed of .54 to .60. These findings lend further support that very little redundancy was demonstrated among the items in the SPS. All item-scale correlations are above .60 with the exception of item five (Seeking forgiveness is an important part of my spirituality) which is .52.

Reliability for the Caregiver Strain Index

The Caregiver Strain Index (CSI) (Robinson, 1983) was developed to measure strain within informal care providers during the period of time in which they provided caregiving activities for elders age 65+, who were recently hospitalized for hip surgery or cardiac care. In this current investigation, rather than providing care for a defined period of convalescence, the caregivers were providing care to their elders for an indefinite period of time.

The Spearman-Brown prophecy formula was used to compute the reliability for this dichotomous scale. All forty of the caregivers answered every item on the CSI. The coefficient alpha for part one (items 1-7) of the scale was .63, part two (items 8-13) was .56. The alpha for the combined parts (unequal-length Spearman-Brown) was .80 which is less than .86 reported by Robinson. This finding may be

demonstrating a decrease in the sensitivity of the CSI to conditions other than those in the original study (e.g., episodic versus chronic care). Inter-item correlations in this study range from -.29 to .50 with a mean of .20. The item-total statistics suggest that all the items performed well and that the alpha for the scale would not improve with the deletion of any single item.

Findings Related to the Family Adaptability Subscale

A 14-item family adaptability subscale of the FACES II was used to measure the dimension of family adaptability (Appendix D). Subscale items which measure family adaptability are the even numbered items with the exception of number 30. The response options were "almost never," "once in a while," "sometimes," "frequently," "almost always," with assigned point values of 1, 2, 3, 4, and 5 respectively. For items 12, 24, and 28 the assigned point values were reversed. The potential range of an individual score was 14-70, with 70 indicating greater family adaptability. The study results revealed a range from 24 to 57. The mean score was 39 (S.D. = 8.4). Table 10 presents the range, mean, and standard deviation for the Family Adaptability subscale.

Findings Related to the Family Cohesion Subscale

A 16-item family cohesion subscale of the FACES II was used to measure the dimension of family cohesion (Appendix D). Subscale items which measure family cohesion are the odd numbered items and number 30. The response options were "almost never," "once in a while,"

Table 10. Ranges, Means, and Standard Deviations for Family Adaptability and Family Cohesion Subscales, Spiritual Perspective Scale, and Caregiver Strain Index

Instrument	Range	Mean	Standard Deviation
Family Adaptability Subscale (N = 38)	21 - 57	39.8	9.6
Family Cohesion Subscale (N = 37)	33 - 65	52.0	6.5
Spiritual Perspective Scale (N = 40)	18 - 60	49.0	10.9
Caregiver Strain Index (N = 40)	0 - 13	7.3	2.9

"sometimes," "frequently," "almost always," with assigned point values of 1, 2, 3, 4, and 5 respectively. For items 3, 9, 15, 19, 25 and 29 the assigned point values were reversed. The potential range of an individual score was 16-80, with 80 indicating greater family cohesion. The study results revealed a range from 33 to 65. The mean score was 52.0 (S.D. = 6.5). Table 10 presents the range, mean, and standard deviation for the Family Cohesion subscale.

Olson (1982) reports study findings based upon the parents (N = 2,082) and adolescents (N = 416) that participated in the National Survey. Only cases with complete data for 30 items were used. The findings for both the female and male parents and adolescents were so similar, they were combined. The mean score for family cohesion for the parents was 64.9 (S.D. = 8.4) and for the adolescents, the mean score was 56.3, S.D. = 9.2).

Findings Related to the Spiritual Perspective Scale

The 10-item Spiritual Perspective Scale operationalized beliefs and interactional behaviors associated with personal forms of spirituality yet does not exclude organized expressions of spirituality (Appendix E). The response options were "not at all," "less than once a year," "about once a year," "about once a month," "about once a week," "about once a day" with assigned point values of 1, 2, 3, 4, 5, and 6 respectively. The potential range of scores were 10-60, with 60 indicating greater spiritual perspective. This investigation revealed a total instrument score range from 18-60. The mean score was 49.0 (S.D. = 10.9). An investigation by Reed (1986a) revealed a mean score

for the terminally ill group (N = 57) as 41.3 and that for the healthy group (N = 57) was 34.4. (Mean scores were calculated by averaging across items). Table 10 presents the range, mean, and standard deviation for the Spiritual Perspective Scale.

Findings Related to the Caregiver Strain Index

The Caregiver Strain Index, a 13-item dichotomous scale identifies strain within informal care providers (Appendix F). The scale is computed by summing the "no" and "yes" responses which are assigned point values of 0 and 1 respectively. The potential range of scores was 0-13, with 13 indicating greater caregiver strain. This investigation revealed a range from 0 to 13. The mean score was 7.3 (S.D. = 3.0). Table 10 presents the range, mean, and standard deviation for the Caregiver Strain Index.

The distribution of respondent scores produced in Robinson's (1983) investigation demonstrate a range in scores from 0-12, with a mean of 3.5 and a median of three with a distribution greatly skewed to the right. An increase in the CSI score in this current investigation (mean = 7.3) may be explained by the chronicity of the caregiving as opposed to the episodic care provided by Robinson's subjects.

Analysis of Relationships

The Pearson Product Moment Correlation Coefficient was calculated to explore the relationships between family adaptability, family cohesion, spirituality and caregiver strain. The level of statistical significance was set at $p \leq 0.05$. The following section

will discuss the findings as they relate to each of the four relationships that were investigated in this study. In addition, other significant correlations will also be discussed.

1. What is the relationship between Family Adaptability and Caregiver Strain?

The result of the Pearson Product Moment Correlation Coefficient is presented in Table 11. This demonstrates that there was not a statistically significant correlation at the probability level of 0.05 between the variables of family adaptability and caregiver strain ($r = -.17$, $p = .31$).

2. What is the relationship between Family Cohesion and Caregiver Strain ($N = 37$).

The data, as presented in Table 11, did not reveal a statistically significant relationship between family cohesion and caregiver strain ($r = .05$, $p = .78$).

3. What is the relationship between Spirituality and Caregiver Strain?

As reported in Table 11, there was no statistically significant correlation between the variables Spirituality and Caregiver Strain ($r = .14$, $p = .39$).

4. How much variance in caregiver strain is explained by the combined effect of family adaptability, family cohesion and spiritual perspective?

Multiple regression analysis was performed to ascertain the effect of family adaptability, family cohesion and spirituality on caregiver

Table 11. Pearson's Product Moment Correlation Coefficient between Model Variables

Dependent Variable	Independent Variables
	Family Adaptability (N = 38)
	-.17
Caregiver Strain	Family Cohesion (N = 37)
	.05
	Spiritual Perspective (N = 40)
	.14

strain. The forced step-wise method was utilized (N = 37). R squared was calculated to be 0.10 with an F of 1.20 (with a probability of 0.33). Thus, the amount of variance (R^2 in caregiver strain explained by family adaptability, family cohesion and spirituality was only ten percent. Variables listed according to beta weight are shown in Table 12. It appears, then, that other factors should be considered in explaining the variance in caregiver strain.

Other Findings

The Pearson Product Moment Correlation Coefficient was calculated to explore the relationships among variables in the model and selected demographic variables. Table 13 demonstrates that the statistically significant ($p \leq 0.05$) relationships between the model and demographic variables were between spirituality and caregiver age ($r = .30$, $p = .06$) which indicates that the older the caregiver, the greater the spiritual perspective; caregiver strain and health of the caregiver ($r = .44$, $p = .004$) meaning the worse the caregiver health, the greater the strain; age of caregiver and hours of caregiving provided per week ($r = .49$, $p = .001$) indicating that the older the caregiver, the more hours per week were provided for caregiving. The relationship between health of the caregiver compared to their own age cohort and caregiver strain ($r = .35$, $p = .028$) suggests that the poorer the caregiver health is when compared to their age cohorts the greater the caregiver strain. Health of the caregiver compared to their age cohort and health since becoming a caregiver ($r = .51$,

Table 12. Predictor of Caregiver Strain by Family Adaptability, Family Cohesion and Spirituality: Multiple Regression Analysis (N = 36)

Variable	Beta
Family Adaptability	-.31076
Family Cohesion	.19895
Spirituality	.24520

R^2 = .1007; F = 1.20

Table 13. Pearson's Product Moment Correlation Coefficients for Variables in the Model and Demographic Variables

	Spiri-tuality	Care-giver Strain	Family Cohe-sion	Care-giver Age	Hours per Week (cg*)	Health Since Becoming Caregiver
Family Adaptability			.76 (36) p = .000			
Caregiver Age	.30 (40) p = .03				.49 (40) p = .001	
Hours per Week of Caregiving				.48 (40) p = .001		
Employment Status				.50 (40) p = .001		
Health Since Becoming Caregiver		.44 (40) p = .002				
Health Com-pared to Age Cohort		.35 (40) p = .028				.51 (40) p = .001

*caregiving

p = .001) indicates that the greater the health compared to the age cohort, the greater the health since becoming a caregiver.

Summary

Forty women caregivers aged 32 to 77 participated in this study designed to investigate the relationships among family adaptability, family cohesion, spirituality and caregiver strain. The majority of the caregivers (77.5%) were daughters of the elders, had some (72.5%) college education, were professionals (55%) working full time (40%) outside of the home. The mean number of months the caregivers had been providing caregiving activity to their elder was 87.5 or 7.3 years with a mean of 43.5 hours per week or 6.2 hours per day. The majority (45%) of the subjects rated their health at least as good as their age cohort and 60 percent rated their health as about the same since becoming a caregiver. The elders ranged in age from 72 to 99, the majority (87.5%) were female and 65 percent lived with the caregiver.

The Alpha reliability coefficients computed for the Family Adaptability and Family Cohesion Subscales and the Spiritual Perspective Scale compared favorably with the original instruments. The Alpha coefficient for the Caregiver Strain Index computed by the Spearman-Brown prophecy formula was .80 which was lower than that reported from the original investigation (.86).

No statistically significant relationship was found between family adaptability, family cohesion, spirituality and caregiver strain. The data identified statistically significant relationships between the model variables and demographic variables.

Multiple regression analysis (N = 37) using a forced step-wise method revealed that the amount of variance in caregiver strain explained by family adaptability, family cohesion and spirituality was only ten percent (Multiple R = 0.32, R^2 = .1007, F = 1.20 with a probability of 0.33).

CHAPTER 5

CONCLUSIONS, RECOMMENDATIONS AND IMPLICATIONS

Forty women who were caregivers for an elder kin participated in this investigation to determine the relationships among family adaptability, family cohesion, spirituality and caregiver strain. This chapter will present the conclusions of the investigation based on the findings and discussion in Chapter 4. In addition, recommendations for further research and implications for nursing will be discussed.

Conclusions

As the conceptual framework represented in Chapter 1, caregiver strain was believed to be affected by an individual's perceived family adaptability, family cohesion and spirituality. These concepts were tested in their operational forms. No statistically significant relationship was found between the questionnaire scores of family adaptability, family cohesion, spirituality, and caregiver strain.

The findings of no statistically significant relationships were unexpected. The non-significant findings may be explained by either a problem related to the conceptual framework or with the instruments used to operationalize the concepts. Both of these possibilities will be addressed.

Wrong Framework / Right Findings

The conceptual framework used to guide this study was inductively generated by the investigator. An error may have been made

in the qualitative study process. Polit and Hungler (1983) caution that induction as the sole method is a fallible approach for arriving at knowledge and understanding because the conclusions are typically based on selective and subjective observation. Inductively derived explanations and predictions must be validated through systematic, controlled and empirical methods before they are accepted.

Although the literature does not directly respond to the relationships between the model variables, each concept is addressed individually in relationship to strain and appears to function as a mediator of strain. However, Havighurst (1948) presented the last developmental task of middle age as adjusting to aged parents. This task is defined as meeting the needs of aging kin in such as way as to make life as satisfactory as possible for both parent and middle-age generations. Blenkner (1965) shared a supporting conceptual approach by noting the need for the adult child to have the capacity to be depended on by the aging parent. Parent care was characterized as a developmental stage of life called "filial maturity"--a transitional stage preceding old age.

Both Havighurst's and Blenkner's models are reputed in the literature based on the fact that developmental stages are associated with age-linked periods of time whereas parent caring can occur during any period in life. In this investigation the majority (67.5%) of the caregivers were 51+ years of age indicating that they were in the developmental-stage of caregiving. Furthermore, these women, for the most part, demonstrated an acceptance of the caregiver role, almost as an expected, anticipated life event. All of the caregivers shared

that, because of their belief system, institutionalization of their elder had never been considered as an option. Indeed, 35 of the 40 elders in this investigation lived with the caregiver.

Unidentified intervening variables may have interacted with the model variables. "Snowballing" became the primary recruitment technique using individuals known to the caregivers. The approach may have tapped into an existing informal but supportive caregiver network which was not considered in the investigation.

Right Framework / Erroneous Findings

An alternative for the unexpected nonsignificant findings of the study is based on the theory being correct but findings being erroneous. The most obvious explanation for results which are consistent with a correct theory is that unmeasured or inadequately measured antecedent variables have influenced the model variables.

The previous lifetime relationship between the adult caregiver and elder may be a significant intervening variable. The majority of these caregivers appear to represent that subsection of the population who, based on a life-time of experience with their elder, has achieved mutual affection, interdependence, and reciprocal giving reflective of deep intergenerational bonds. This may be demonstrated by the fact that so many of these women appear to have transcended what is measured as strain in the caregiver role.

A potential contributing factor to right framework, erroneous findings may be a lack of variability in the population. An overrepresentation or underrepresentation of some segment of the

population in terms of a characteristic relevant to the research questions may have occurred.

Another "wrong finding" explanation may be related to the application of the conceptual framework to this population. The fact that these women were a relatively well educated, professional, full-time working group reflects a middle to upper-middle class status. Such a population would be expected to have access to more external resources and, thereby, report less conflict with the caregiver/elder relationship (Archbold, 1983). In spite of the socioeconomic status of these women, the caregiver strain is greater than that reported in Robinson's study (1983).

Additional findings which may support right framework, wrong findings are those statistically significant relationships demonstrated between the model and demographic variables. These variables (Table 13) may represent inadequately measured antecedent variables. For example, the literature reports that the provision of care to an elder often adversely affects the physical, emotional, psychological, and mental health of the caregiver (Archbold, 1983; George & Gwyther, 1986; Goldstein et al., 1981; Poulshock & Deimling, 1984; Robinson, 1983; Treas, 1977; Zarit et al., 1980). Findings in this current investigation related to the caregiver's health status may represent a population with a positive health value orientation. This may suggest that this population may be composed of individuals who participate in wellness behavior and initiate more preventive actions to maintain

well being. This interpretation may also support the wrong theory argument as well.

Poulshock and Deimling (1984) provide evidence that there is a moderate-to-strong empirical link between elder impairment characteristics and the corresponding perception of burden. The elders' impairments (cognitive and functional) were not measured in this investigation. Additional data provided by the caregivers in this study demonstrate that only 13 of the elders (32.5%) had severe functional or cognitive deficits. Eleven of these elders were either in a boarding home or the caregiver responsibilities were equally shared with other persons. Two of the caregivers provided total care for elder kin who had severe functional and or cognitive deficits. These women clearly reported the greatest level of strain.

A major source of error may be related to the measurement tools. The FACES II instrument may not have been appropriate for this population. The FACES II was developed to measure two empirically reliable, valid, and independent dimensions--family adaptability and cohesion. As noted in Chapters 3 and 4, the bivariate correlation coefficient for these two subscales suggest that two independent dimensions did not exist in the sample of this study. The original sample for the development of FACES II consisted of adolescents and their parents; these items may not represent adaptation and cohesion in families with elder members.

The absence of a correlation between family adaptability and caregiver strain and between family cohesion and caregiver strain suggests that these two concepts may have not been measured adequately

by the FACES II. One would expect as adaptability to the role increased, strain would decrease. Another expectation was as cohesion (bonding) increased, caregiver strain would decrease. However, the literature (Cantor, 1983; Leichter, 1967) does demonstrate that the closer the consanguinal relationship and cohesion, the greater the strain. Since the majority (77.5%) of the caregivers in this investigation were daughters, it is surprising that a correlation between family adaptability and caregiver strain and between family cohesion and caregiver strain was not noted.

Furthermore, the caregivers themselves expressed confusion and inappropriateness of this tool as it related to both dimensions. Clearly, for a caregiver with a cognitively impaired elder, this tool is difficult to use. The fact that these caregivers could not relate to the "we" items of the tool and repeatedly expressed difficulty in interpreting items suggests that FACES II did not measure these critical dimensions sufficiently. A critical analysis of the concepts related to each dimension is required.

Although the Spiritual Perspective Scale (SPS) was an easy instrument to complete and performed well with this population, it did not demonstrate a significant relationship with caregiver strain. A greater relationship was demonstrated between these two variables, but the finding represented only a trend, not a statistically significant difference. This finding was surprising in light of the study findings presented in the literature which demonstrate a negative relationship between spirituality and strain/stress. Even of greater surprise was

that this relationship was not demonstrated in this population when a significant percentage reported strong religious/spiritual ties. There was, however, a statistically significant relationship between spirituality and age of the caregiver--a relationship reported in the literature (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1985; Kivett, 1979; Reed, 1986a).

A higher caregiver strain score was demonstrated in this investigation in the Caregiver Strain Index than in Robinson's (1983) study. The caregivers expressed an identification with the items on the scale. The health demographic variables both demonstrated a statistically significant relationship with caregiver strain. Again, this relationship is clearly identified in the literature (Archbold, 1983; George & Gwyther, 1986; Goldstein et al., 1981; Poulshock & Deimling, 1984; Robinson, 1983; Treas, 1977; and Zaritt et al., 1980). This instrument appears to adequately measure the concept of caregiver strain, however, instrument revisions are suggested which would increase the sensitivity and reliability. Perhaps the dichotomous scale should be expanded to a 5 or 6 point Likert-type scale which would provide additional clarity of the items.

Because the constructs of adaptability, cohesion, spirituality and caring/caregiving evolve over time, a cross-sectional approach to the investigation may be another source of erroneous results and conclusions. This brief, one-time measurement captures only what is occurring at that moment and does not adequately portray the development of these phenomena. This is further confirmed by the

common caregiver statement, "If you would have asked me this earlier (last week, last month, etc.), the answer would have been different."

The women in this investigation like the women in the previous inductive study, express an intergenerational bonding which reflects a reciprocal, patterned relationship with their elder and that faith is an internal resource in their life. It is surprising that the study findings do not reflect a relationship between spirituality and caregiver strain.

Recommendations for Further Study

Further research is needed with the population of women who provide caregiving to elder kin. In consideration of the demographics of elders, the long-term care dilemma in the provision of resources and the ever expanding role of women in our society, it is evident that there is a need to further investigate those variables which may be potential mediators of caregiver strain. Based on the results of this study, recommendations for further research include:

1. Replication of the study utilizing a larger, more diverse sample.
2. Perform multivariate analysis techniques such as factor analysis of scores obtained on instruments that will examine more precisely the concept of caregiver strain.
3. Further investigation of the Family Adaptability and Cohesion Scale to yield greater specificity and sensitivity of these two dimensions in the caregiver population.

4. Instrument revision of the Caregiver Strain Index to increase the internal consistency.
5. Investigate the process of caregiving in families in longitudinal studies focusing on issues such as changes over time and development of adaptation strategies.
6. Return to a qualitative research design to further explore and refine qualities and activities which may function as mediators to caregiver strain. The fact that these women refer to an internal belief system which reflects a strong sense of family responsibility towards other family members and to spirituality which are not reflected in test scores suggests that perhaps intervening variables have not been identified.

Implications for Community Health Nursing

The Community Health Nurse (CHN) provides a unique and valuable contribution to the health of the entire community which is composed of individuals, families, and aggregates. A holistic, family-centered approach is critical when the client includes an informal caregiver. A thorough assessment of the family structure is required to understand the family dynamics associated with the caregiver role. The CHN is in a unique position to assess the family in their own environment, to analyze the interactions and communication patterns, to assess the function and dysfunction of the component parts.

Shifting demographics in our population and earlier discharge from acute care institutions has increased the need for informal care of elders. The CHN must be prepared to include caregiver(s) as well as

the elders in the family assessment. The CHN must be aware of the strain evoked by the caregiver relationship. Adult children and other younger relatives characteristically suffer from a multiplicity of roles. Job performance, parenting and marriages may be adversely affected by the emotional strain and pressure involved in providing care to an elder. Active involvement by the CHN and an interdisciplinary approach for reducing these strains is required if life satisfaction is to be maintained by both the caregiver and the elder. The CHN must intervene on behalf of the elder and the caregiver to maintain the integrity of the family unit while monitoring the provision of optimal client care.

The CHN is able to teach self care practices, identify changes in health status and assist the informal caregiver in obtaining community services which can serve to strengthen the family unit. The CHN needs to formulate clinical strategies to strengthen the support network of informal caregivers.

Networking with community resources, respite provisions and in-home services are essential. The pastoral community must be recognized as a potential source of support to the caregiver. The spiritual dimension of health care is an integral component in the total well-being of both the elder and the caregiver and should be included in assessment and plan of care. A thorough community assessment must be conducted; neighbors, friends, churches, unions, and neighborhood groups may provide important secondary assistance.

Too often informal caregivers seeking assistance for their elder kin are involved in time-consuming bureaucratic duplication of

effort. The CHN should advocate on behalf of the caregiver and elder to facilitate acquisition of available resources. The CHN must analyze the barriers to this population by social policies (eligibility requirements and reimbursements) and become politically active to support legislation relating to this group.

Supporting the informal caregiver network may reduce premature institutionalization of the elder which has enormous socioeconomic and family integrity implications. However, the CHN must be able to recognize and facilitate action when the informal network is "crashing" and support the caregiver. Therapeutic intervention may consist of exploring alternative options for the care of elder kin.

The more completely understood are the factors which contribute to or mediate caregiver strain, the more effective the CHN may be with this population. Clearly, further consideration involving caregivers and elders is indicated.

APPENDIX A

HUMAN SUBJECTS APPROVAL

THE UNIVERSITY OF ARIZONA
TUCSON, ARIZONA 85721

COLLEGE OF NURSING

MEMORANDUM

TO: Marylyn Morris McEwen, RN, BSN
Graduate Student
College of Nursing

FROM: Ada Sue Hinshaw, PhD, RN ASH
Director of Research

Beverly McCord, PhD, RN
Associate Dean, Graduate Programs

DATE: December 22, 1986

RE: Human Subjects Review: Family Adaptability, Family Cohesion, Spirituality and Cargiver Strain in Women as Caregivers of Elder Kin

Your project has been reviewed and approved as exempt from University review by the College of Nursing Ethical Review Subcommittee of the Research Committee and the Director of Research. A consent form with subject signature is not required for projects exempt from full University review. Please use only a disclaimer format for subjects to read before giving their oral consent to the research. The Human Subjects Project Approval Form is filed in the office of the Director of Research if you need access to it.

We wish you a valuable and stimulating experience with your research.

ASH/fp

APPENDIX B

DISCLAIMER

JULY, 1986

I AM A GRADUATE STUDENT IN NURSING AT THE UNIVERSITY OF ARIZONA AND WOULD LIKE YOUR PARTICIPATION FOR A PROPOSED RESEARCH STUDY ENTITLED, "FAMILY ADAPTABILITY, FAMILY COHESION, SPIRITUALITY AND CAREGIVER STRAIN IN WOMEN AS CAREGIVERS OF ELDER KIN." THE PURPOSE OF THIS STUDY IS TO INVESTIGATE CERTAIN FACTORS WHICH RELATE TO STRAIN EXPERIENCED BY CAREGIVERS.

THE STUDY WILL BE CONDUCTED BY ASKING YOU TO VOLUNTARILY GIVE YOUR OPINION ON THE QUESTIONNAIRE STATEMENTS. BY RESPONDING TO THE 4 QUESTIONNAIRES WHICH WILL REQUIRE APPROXIMATELY 20 MINUTES, YOU WILL BE GIVING YOUR CONSENT TO PARTICIPATE IN THE STUDY. YOUR NAME WILL NOT BE ON THE QUESTIONNAIRE AND YOU MAY CHOOSE NOT TO ANSWER SOME OR ALL OF THE QUESTIONS. IF YOU WISH, YOU MAY WITHDRAW FROM THE STUDY AT ANY TIME.

I WILL BE AVAILABLE TO ANSWER ANY QUESTIONS YOU MAY HAVE. THERE ARE NO RISKS, DISCOMFORT, NOR REMUNERATION TO PARTICIPATING IN THE STUDY. THE INFORMATION USED WILL NOT IDENTIFY INDIVIDUALS WHO COMPLETE QUESTIONNAIRES. THANK YOU VERY MUCH FOR PARTICIPATING IN THE STUDY.

MARYLYN MORRIS MCEWEN
1235 E. EASY ST.
TUCSON, ARIZONA 85719

APPENDIX C

DEMOGRAPHIC DATA

ID # _____ (1-2)
RO # _____ (24)

DEMOGRAPHIC DATA

Directions: The following questions seek general information about you and your elder. Please answer each question by writing your answer on the line after the question or marking an "X" next to the answer which best describes you or your elder. Any time the word "other" is selected, please write in your answer.

1. Age of Caregiver _____ (3-4)

2. Age of Elder _____ (5-7)

3. Elder's Gender ____ M ____ F (8)
(1) (2)

4. How long have you had responsibility for providing services to the elder _____ (9-11)
in months

5. Does the elder live: (12)

_____ with you
(1)

_____ with someone else
(2)

_____ alone
(3)

6. There are 168 hours in a week, what is the average number of hours per week that you provide caregiving activities for your elder _____(13-15)

7. What is your relationship with the elder? (16)

_____ daughter (1)

_____ daughter-in-law (2)

_____ niece (3)

_____ other (7) please specify _____

_____ granddaughter (4)

_____ sister (5)

_____ significant other (female) (6)

(Please continue on next page)

ID # _____ (1 - 2)
RO # _____ (24)

8. Your religious affiliation? (17)

_____ (1) Protestant
_____ (2) Catholic
_____ (3) Jewish
_____ (4) None
_____ (5) Other please specify _____

9. What is your occupation? _____ (18)

_____ (1) Clerical/Sales
_____ (2) Student
_____ (3) Professional
_____ (4) Homemaker
_____ (5) Business Owner/Manager
_____ (6) Artisan
_____ (7) Skilled/Technical
_____ (8) Unskilled

10. Are you currently: (19)

_____ (1) working full time
_____ (2) working part time
_____ (3) retired
_____ (4) unemployed
_____ (5) disabled
_____ (6) other (please specify) _____

(Please continue on next page)

ID # _____ (1-2)
RO # _____ (24)

11. Highest level of education completed: (20-21)

_____ (1) Completed Grade School
_____ (2) Some High School
_____ (3) High School Graduate
_____ (4) Vocational / Technical School Graduate
_____ (5) Some College
_____ (06) College Graduate
_____ (07) Some Graduate School
_____ (08) Master's Degree
_____ (09) Doctorate
_____ (10) None

12. In comparison to others your age, would you say your health is: (22)

Much Better	Somewhat Better	About the Same	Somewhat Worse	Much Worse
(1)	(2)	(3)	(4)	(5)

13. Since becoming a caregiver, would you say your health is: (23)

Much Better	Somewhat Better	About the Same	Somewhat Worse	Much Worse
(1)	(2)	(3)	(4)	(5)

Thank you very much for answering the questions.

APPENDIX D

FAMILY ADAPTABILITY AND COHESION EVALUATION SCALE II (FACES II)

FACES II

ID=_____ (1-2)
RO#_____ (24)

Directions: The following are all statements that describe a close relationship. Please give your opinions about your relationship with the elder you care for as it is now and as you would like your relationship to be. There are no right or wrong answers. Remember to respond twice to the 30 items, using the following scale.

Items	Describe your Relationship Now						Ideally, How Would You Like Your Relationship to Be					
	Almost Never	Once in a While	Sometimes	Frequently	Almost Always		Almost Never	Once in a While	Sometimes	Frequently	Almost Always	
1. We are supportive of each other during difficult times.	( )	( )	( )	( )	( )	(3)	( )	( )	( )	( )	( )	(34)
2. In our relationship, it is easy for both of us to express our opinion.	( )	( )	( )	( )	( )	(4)	( )	( )	( )	( )	( )	(35)
3. It is easier to discuss problems with people outside the relationship than with my elder.	( )	( )	( )	( )	( )	(5)	( )	( )	( )	( )	( )	(36)
4. We each have input regarding major family decisions.	( )	( )	( )	( )	( )	(6)	( )	( )	( )	( )	( )	(37)
5. We spend time together when we are home.	( )	( )	( )	( )	( )	(7)	( )	( )	( )	( )	( )	(38)
6. We are flexible in how we handle differences.	( )	( )	( )	( )	( )	(8)	( )	( )	( )	( )	( )	(39)
7. We do things together.	( )	( )	( )	( )	( )	(9)	( )	( )	( )	( )	( )	(40)
8. We discuss problems and feel good about the solutions.	( )	( )	( )	( )	( )	(10)	( )	( )	( )	( )	( )	(41)
9. In our relationship, we each go our own way.	( )	( )	( )	( )	( )	(11)	( )	( )	( )	( )	( )	(42)
10. We shift household responsibilities between us.	( )	( )	( )	( )	( )	(12)	( )	( )	( )	( )	( )	(43)
11. We know each other's close friends.	( )	( )	( )	( )	( )	(13)	( )	( )	( )	( )	( )	(44)
12. It is hard to know what the rules are in our relationship.	( )	( )	( )	( )	( )	(14)	( )	( )	( )	( )	( )	(45)
13. We consult each other on personal decisions.	( )	( )	( )	( )	( )	(15)	( )	( )	( )	( )	( )	(46)
14. We freely say what we want.	( )	( )	( )	( )	( )	(16)	( )	( )	( )	( )	( )	(47)

FACES II

ID#_____ _____ (1-2)
RO#_____ (24)

		Describe your Relationship Now						Ideally, How Would You Like Your Relationship to Be					
		Almost Never	Once in a While	Sometimes	Frequently	Almost Always		Almost Never	Once in a While	Sometimes	Frequently	Almost Always	
15.	We have difficulty thinking of things to do together.	( )	( )	( )	( )	( )	(17)	( )	( )	( )	( )	( )	(48)
16.	We have a good balance of leadership in our relationship.	( )	( )	( )	( )	( )	(18)	( )	( )	( )	( )	( )	(49)
17.	We feel very close to each other.	( )	( )	( )	( )	( )	(19)	( )	( )	( )	( )	( )	(50)
18.	We operate on the principle of fairness in our relationship.	( )	( )	( )	( )	( )	(20)	( )	( )	( )	( )	( )	(51)
19.	I feel closer to people outside the relationship than to my elder.	( )	( )	( )	( )	( )	(21)	( )	( )	( )	( )	( )	(52)
20.	We try new ways of dealing with problems.	( )	( )	( )	( )	( )	(22)	( )	( )	( )	( )	( )	(53)
21.	I go along with what my elder decides to do.	( )	( )	( )	( )	( )	(23)	( )	( )	( )	( )	( )	(54)
22.	In our relationship, we share responsibilities.	( )	( )	( )	( )	( )	(24)	( )	( )	( )	( )	( )	(55)
23.	We like to spend our free time with each other.	( )	( )	( )	( )	( )	(25)	( )	( )	( )	( )	( )	(56)
24.	It is difficult to get a rule change in our relationship.	( )	( )	( )	( )	( )	(26)	( )	( )	( )	( )	( )	(57)
25.	We avoid each other at home.	( )	( )	( )	( )	( )	(27)	( )	( )	( )	( )	( )	(58)
26.	When problems arise, we compromise.	( )	( )	( )	( )	( )	(28)	( )	( )	( )	( )	( )	(59)
27.	We approve of each other's friends.	( )	( )	( )	( )	( )	(29)	( )	( )	( )	( )	( )	(60)
28.	We are afraid to say what is on our minds.	( )	( )	( )	( )	( )	(30)	( )	( )	( )	( )	( )	(61)
29.	We tend to do more things separately.	( )	( )	( )	( )	( )	(31)	( )	( )	( )	( )	( )	(62)
30.	We share interests and hobbies with each other.	( )	( )	( )	( )	( )	(32)	( )	( )	( )	( )	( )	(63)

Thank you very much for answering the questions.

APPENDIX E

SPIRITUAL PERSPECTIVE SCALE

ID # _____ (1 - 2)
RO # _____ (24)

SPIRITUAL PERSPECTIVE SCALE *

Introduction: Spirituality has different meanings for people. In general, it is defined as that which relates people to a transcendent or non-physical realm, or which relates people to something greater than themselves without disregarding the value of the individual. I am interested in your views on the questions below. There are no right or wrong answers, or course.

Directions: In answering the following questions about your spiritual views, think about what spirituality means to you personally. Answer each question by marking an 'X' in the space above that group of words which best describes you.

1. In talking with your family or friends, how often do you mention spiritual matters or spiritual activities?

/_____/_____/_____/_____/_____/_____/ (26)

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

2. How often do you share with others the problems and joys of living according to spiritual beliefs?

/_____/_____/_____/_____/_____/_____/ (27)

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

3. How often do you read spiritually-related material?

/_____/_____/_____/_____/_____/_____/ (28)

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

4. How often do you pray privately in places other than a church?

/_____/_____/_____/_____/_____/_____/ (29)

Not at all	Less than once a year	About once a year	About once a month	About once a week	About once a day

(Please continue on next page)

Spiritual Perspective Scale (continued)

ID # _____ (1 - 2)
RO # _____ (24)

Directions: Please indicate the degree to which you agree or disagree with the following statements by marking an 'X' in the space above the words which best describe you.

5. Seeking forgiveness is an important part of my spirituality.

/_____/_____/_____/_____/_____/_____/ (30)

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

6. I seek spiritual guidance in making decisions in my everyday life.

/_____/_____/_____/_____/_____/_____/ (31)

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

7. Private prayer is one of the most important and satisfying aspects of my spiritual experience.

/_____/_____/_____/_____/_____/_____/ (32)

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

8. I frequently feel very close to God in prayer, during public worship, or at important moments in my daily life.

/_____/_____/_____/_____/_____/_____/ (33)

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

(Please continue on next page)

ID # _____ (1 - 2)
RO # _____ (24)

Spiritual Perspective Scale (continued)

9. My spiritual beliefs have had an influence upon my life.

/_____/ _____/ _____/ _____/ _____/ _____/ (34)

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

10. My spirituality is especially important to me because it answers many questions about the meaning of life.

/ _____/ _____/ _____/ _____/ _____/ _____/ (35)

Strongly Disagree	Disagree	Disagree more than agree	Agree more than disagree	Agree	Strongly Agree

Thank you very much for answering the questions.

APPENDIX F

CAREGIVER STRAIN INDEX

ID # _____(1-2)
RO # _____(24)

CAREGIVER STRAIN QUESTIONNAIRE

Directions: The following are a list of things that people have found to be difficult in providing caregiving activities for an elder. Answer each question by marking an 'X' in the column which applies to you.

		Yes	No	
1.	Sleep is disturbed (e.g., because _____is in and out of bed or wanders around at night)	___	___	(37)
2.	It is inconvenient (e.g., because helping takes so much time or it's a long drive over to help)	___	___	(38)
3.	It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required)	___	___	(39)
4.	It is confining (e.g., helping restricts free time or cannot go visiting)	___	___	(40)
5.	There have been family adjustments (e.g., because helping has disrupted routine, there has been no privacy)	___	___	(41)
6.	There have been changes in personal plans (e.g., had to turn down a job, could not go on vacation)	___	___	(42)
7.	There have been other demands on my time (e.g., from other family members)	___	___	(43)
8.	There have been emotional adjustments (e.g., because of severe arguments)	___	___	(44)
9.	Some behavior is upsetting (e.g., because of incontinence; _____ has trouble remembering things; or _____ accuses people of taking things)	___	___	(45)
10.	It is upsetting to find ____ has changed so much from his/her former self (e.g., he/she is a different person than he/she used to be)	___	___	(46)
11.	There have been work adjustments (e.g., because of having to take time off)	___	___	(47)
12.	It is a financial strain	___	___	(48)
13.	Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)	___	___	(49)

Thank you very much for anwering the questions.

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