Stress and Coping of Caregivers
to Individuals with Dementia

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy
in Nursing
by
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The dissertation of Karen Annette Jensen is approved.

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ABSTRACT OF THE DISSERTATION

Stress and Coping of Caregivers
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Considerable literature exists on the presence of burden among caregivers, however, it has also been discovered that individuals psychologically adapt to situations in which they are involved. The purpose of this study is, utilizing an adaptation paradigm, to examine the interrelationship of factors in the caregiver's environment and the mediating role of coping mechanisms on appraisal of caregiving. The theoretical framework to guide this study was based on Roy's Adaptation model in conjunction with Lazarus and Folkman's cognitively-based theory of stress and coping. Data were collected from 129 caregivers, either wives or daughters, caring for a demented individual in their home. Instruments utilized in the study included: Global Self-Rated Health Scale, Center for Epidemiological Studies Depression Scale (CES-D), Personal Views Survey, Lubben Social Network Scale, Memory and Behavior Checklist, Ways of Coping (Revised), and Caregiver Appraisal Tool. This study utilized a quasi-
experimental design employing structural equation modeling based on Lazarus and Folkman's cognitively-based theory of stress and coping and the Roy Adaptation model of nursing to determine appraisal of the caregiving role.

The final model demonstrated the complex inter-relationship of factors in determining appraisal of the caregiving. The Comparative Fit Index (CFI .92) and Normed Fit Index (NFI .90) suggest the revised model represented adequate fit to the data. The model demonstrated that the physical health of the caregiver, patient problem behaviors, emotion and problem-focused coping had a direct significant relationship on appraisal of the caregiving role. Indirect relationships to appraisal, through problem and emotion-focused coping included depression, hardiness, social support and spirituality. The model did provide support for the Roy Adaptation model which asserts the intermediary role of coping mechanisms on appraisal of the caregiving role. The study offered preliminary confirmation that appraisal of the caregiving role can include positive aspects for caregivers and the need to investigate possible stages of caregiving.
CHAPTER ONE

Introduction

Statistics indicate that there are now 1.8 million Americans with severe dementia, so severe that others must care for them, and another 1.5 million who are moderately to mildly demented (Congress of the United States Office of Technical Assessment (USOTA), 1990). Families provide care for over 2.4 million impaired persons at home, with over one million of these having Alzheimer’s disease or Dementia. Most of these families provide 80-90% of the care at home without pay, and 80% provide care seven days a week, spending an average of eighty hours a week in caregiving activities (Alzheimer Foundation, 1991).

The families taking care of these patients at home are defined as "the informal care system" or caregivers. This system includes families and friends who are extensively involved in caregiving without formal training or pay. These individuals provide a necessary service to their country and community, and it is estimated that it would cost approximately $54 billion to replace the current system with full-time care (Alzheimer Foundation, 1991).

There is significant interest, from a resource and financial standpoint, to help sustain these caregivers in their current roles. Caring for the caregivers is of significance to nursing with the current emphasis on cost containment. Support for
the informal caregiver must be forthcoming, to prevent premature institutionalization of a large number of Alzheimer patients. In order to maintain these patients at home, support should be offered assisting the caregivers in reaching their goal of living a life that is as normal and productive as possible, maintaining the dignity of their loved one, and keeping the family intact and functioning as long as possible. Nurses, with their knowledge of physical and mental health, are in an excellent position to identify and teach informal care providers the elements of health maintenance including coping mechanisms for dealing with the stress of continued long term caregiving.

Studies of dementia victims have indicated that caregivers experience considerable stress in the role (Barusch & Spaid, 1989; Brody, 1985; Cantor, 1983; Deimling & Bass, 1986; Gilhooly, 1984). The majority of studies on the negative aspect of caregiving deal with the burden of caregiving or "the psychological state resulting from a combination of physical work, emotional pressure, social constraints and financial demands accruing because of patient care requirements" (Dillehay & Sands, 1990, p.264). The greatest volume of recent literature on caregiving has been focused on the burden experienced by the caregiver. In addition, recent research has included an increasing use of the Lazarus and Folkman (1984) model of stress and coping to assess the caregiver's coping mechanisms as a predictor of burden or satisfaction in the caregiving role (Haley, Brown, & Bartolucci, 1987; Kinney & Stephan, 1989; Lawton, Kleban, Moss, Rovine & Glicksman, 1989; Prucho & Resch,
1989). Often missing in the previous literature is the concept of examining the caregiver's appraisal, or evaluation of the situation, in relationship to burden and satisfaction in the caregiving role.

During the course of life events, it has been discovered that individuals psychologically adapt to circumstances in which they are involved (Costa et al., 1987). Individuals accommodate by a gradual increase in satisfaction (Campbell et al., 1976), and acclimation to the particular situation (Cantril, 1966). This adaptation process, used by Roy (1984, 1988, 1991) in her nursing model, is defined as "the human system's capacity to adjust effectively to changes in the environment and, in turn, to affect the environment" (Roy, 1984, p.12). The adaptation occurs through environmental adjustments and the use of coping mechanisms, and can be measured by the caregivers' appraisal of their performance in the caregiving role.

While both the theoretical and empirical literature report the outcomes of caregiving on the caregivers, studies are sparse that investigate the impact of the factors in the environment, and the use of various psychological coping mechanisms upon the adaptation to the caregiving role.

Statement of the problem

The purpose of this study is to examine the interrelationships of factors in the caregiver's environment and the mediating role of the coping mechanisms on
adaptation to the caregiving role. An adaptation paradigm is used to formulate and to test the adequacy of a predictive model for explaining psychological adjustment to the caregiving role.

**Theoretical Framework**

The theoretical framework utilized in this study is derived from a nursing model, the Roy Adaptation model (Roy, 1991), based on systems theory (VonBertalanffy, 1968) and Helson's (1964) adaptation level theory. This study will investigate the use of the Roy Adaptation model and operationalize the subcomponents of the adaptation model, the regulator and cognator system, according to the stress and coping theory of Lazarus and Folkman (1986).

A nursing theoretical framework was chosen for this study since it has been a continuous goal of the profession to include, as an important part of the development of nursing as a science, the application and testing of the conceptual models. The Roy Adaptation model was developed and is used as the conceptual framework of many nursing curriculum and practice settings throughout the world. The pertinence of the Roy model to this study was the link connection between the systems approach, of the model, which includes the concept of the mediation effect of coping mechanisms on the adaptation of the individual. It is the goal of this study to increase the body of research on the model, particularly the area not included in previous
research, the investigation of the role of the regulator and cognator subsystem of the model.

**Roy's Adaptation model**

The adaptation model is a nursing model based on a systems theory, of personal and environmental action. The environment is defined as "all conditions, circumstances, and influences surrounding and affecting the development and behavior of persons or groups" (Roy, 1984a). The environment has internal and external components and is constantly changing. The internal and external environments are the sources of inputs or stimuli into the system. These stimuli in the environment are mediated by the cognator and regulator system to produce an output, or behavior, which is either adaptive or ineffective. Adaptive responses, according to Roy, are those that "promote the integrity of the human system: survival, growth, reproduction, and mastery" (Roy, 1984a). Ineffective responses do not contribute to the goals listed. Incorporating a systems perspective, the person and the environment then operate in a cyclic manner in which the responses act as feedback, to elicit a change in environment or cognator and regulator activity.

The Adaptation model conceptualizes the interaction between the person and environment as the adaptation level. In this perception, the adaptation level is defined as "a constantly changing point . . . which represents the person's own standard or
the range of point to which one can respond with ordinary adaptive responses" (Roy, 1984a). Each individual has a zone of adaptation, such that a stimulus falling within the zone will result in a positive or adaptive response, and any response outside the zone will lead to an ineffective response.

The Roy Adaptation model defines the person as a holistic adaptive system. Holistic pertains to the idea that the "human system functions as a whole and is more than the mere sum of its part" (Andrews & Roy, 1986). The individual is described as a bio-psycho-social-spiritual being in constant interaction with a changing environment. A person uses both innate and acquired mechanisms to adapt to the environment (Andrews & Roy, 1986). As the system (person) receives input or stimuli from the environment, along with feedback, it processes the information and responds by producing an output. This resulting output or behavior may be adaptive or ineffective. An adaptive behavior is one which promotes integrity in terms of the goals of the human system.

The person, as an adaptive system, has two major internal control processes termed the regulator and cognator subsystems (Roy, 1984a). These subsystems are deemed as innate or acquired coping mechanisms, used to respond to the changing internal and external environment. The regulator mechanism receives stimuli from the internal and external environments, both of which are basically chemical or neural, and receives all inputs into the central nervous system. A regulator activity is
apparent through the activity of the autonomic responses of the neural, chemical and endocrine management processes. The bodily responses are brought about through the chemical-neural-endocrine channel, and are used as feedback and additional stimuli to the regulator system (Roy, 1984).

The second mechanism, the cognator subsystem, identifies, stores and relates stimuli so that symbolic meanings can be attached to the behavior. The cognator subsystem involves processes of social and psychological components. The social and psychological components are processed by way of four cognitive/emotive pathways described as: 1) perceptual and information processing, including the activities of selective attention, coding, and memory; 2) learning, involving imitation, reinforcement and insight; 3) judgment, which involves the process of problem-solving and decision-making; and 4) emotion, which is manifested in defenses to seek relief and affective appraisal and attachment. These four pathways process and produce responses which indicate the person's ability to respond to both internal and external influences from social and psychological effects (Roy, 1984).

Hence, a person's intrapsychic activities have cognitive and perceptual components; one's emotions have feeling states; and one's behaviors have actions and responses. All of the above represented dimensions of intrapsychic processes are directed toward a desired outcome, adaptation. The Roy model does not operationally define the methods by which the cognator subsystem functions. However, the closest
approximation can be in the definition of coping mechanisms by Lazarus and Folkman (1986).

Coping Theory

This study will combine two theoretical frameworks and utilize the coping theory of Lazarus and Folkman (1986), to operationally define the cognator subsystem of adaptation theory. Coping, according to Lazarus and Folkman (1986), is defined as the "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Folkman, 1984, p. 842). This definition, like the adaptation model, is process-oriented rather than trait-oriented and is concerned with what the individual does or thinks (cognitive) in a specific context. Coping theory contains no assumptions of what is beneficial or harmful but simply describes the individual’s effort to manage demands.

In coping theory, the stage between the environmental stressor and response is the process of cognitive appraisal, which closely approximates the cognator subsystem of adaptation theory. Through cognitive appraisal, the person evaluates whether a particular incident is germane to one’s well-being, and if so, by which means. Personal factors that have been identified as influencing cognitive appraisal include commitments, intellectual capacity, beliefs, and the degree of control over the
situation (Lazarus & Folkman, 1984). Commitments, or what is important to the individual, influence an individual’s decisions by assessing items associated with deeper commitment, as more threatening or harmful, when faced with a decision related to the commitment. The individual’s intellectual capacity affects the appraisal process by influencing the degree to which multiple complex variables can be processed. Beliefs influence how one interprets stress and bias, and whether one believes he/she have control in the situation. Control is the generalized belief that an individual has concerning the extent to which he or she can influence the outcomes of an encounter. Thus, cognitive appraisal, or the action of the cognator subsystem serves to regulate the individual’s response to a stressor in the environment.

According to Lazarus and Folkman (1984), cognitive appraisal involves two processes: primary and secondary appraisal. Primary appraisal is the judgment that an encounter is irrelevant, benign, positive, or stressful. The process of secondary appraisal includes the judgment of what may or may not be done in a situation. It involves the process of evaluating what coping options will serve the purpose and the estimation of the results of using a specific strategy. Inherent in the process of reappraisal is the changing of appraisal based on new information in the environment.

In the case of the caregiver to an individual with dementia, cognitive appraisal has been termed "caregiving appraisal" (Lawton, 1989) and refers to both primary and secondary appraisal of the potential caregiving stressors and the efficacy of one’s
coping effort. The caregiver attempts to impose meaning on the caregiving process and one's role in it; the attached meaning may lead to positive or negative responses in relation to caregiving demands. Such a positive response is termed caregiver mastery or caregiving satisfaction (Lawton, 1989) and the opposite response encompasses the feeling of burden (Zarit, Todd & Zarit, 1986); both represent the view on one's ability and behaviors during the caregiving process (Lawton, 1989). In as much as caregiving mastery, satisfaction, or burden is a self-perception, conditioned by what happens during the course of caregiving, it encompasses an aspect of caregiving appraisal.

In coping theory certain coping mechanisms have been identified by Lazarus and Folkman (1986) which include emotion-focused coping used to regulate emotions or distress, and problem-focused coping used to manage the obstacles which cause the distress. Research has demonstrated that emotion-focused strategies are used in situations which are not amenable to change; whereas, problem-focused strategies are used more frequently in situations assessed as changeable (Folkman, Lazarus, Dunkel-Shetter, Delongis & Gruen, 1986).

In investigating coping styles, Lazarus and Folkman (1986) have defined eight styles of coping: six emotion-focused (e.g., distancing, self-control, escape-avoidance, social support, and accepting responsibility) and two problem-focused which include planful problem-solving and confrontation. A response with an emotion-focused
strategy is distancing, which involves efforts to detach oneself from the situation. Another emotion-focused response involves the use of self-control, in which the individuals attempts to regulate their own feeling. Escape/avoidance or wishful thinking to emotionally control the situation, is another example of an emotion-focused coping style. A fourth type of emotion-focused coping involves such techniques as seeking social support, which includes not only using networking, but also information seeking. The remaining emotion-focused coping mechanisms include accepting one’s own role in the problem or accepting responsibility, as well as positive reappraisal, or creating positive meaning from the situation by focusing on personal growth. The second subcategory of coping is the problem-solving approach, which includes the response of planful problem-solving or an objective effort to define the problem, generate solutions, weigh the alternatives in terms of advantages and disadvantages, and act upon the problem. The last form of problem-solving is confrontation, in which the individual engages in aggressive efforts to alter the situation.

Validation studies underlying the theoretical framework for coping responses were designed to evaluate the extent to which the individual’s primary and secondary appraisals of a situation vary under stressful conditions. One such study by Folkman and Associates (1986), using the Ways of Coping Checklist, evaluated the relationship between the cognitive appraisal, primary appraisal, of a stressful situation and the
physical health status. The results demonstrated a significant relationship between primary appraisal, coping, and physical health; with the individual having more to risk in the encounter and utilizing emotion-focused coping mechanisms having a poorer health status. In other subjects, using problem-solving coping, they exhibited mastery of the situation and a subsequently improved in their health condition. In addition, the more the individuals invested in the encounter the more likely they were to experience symptomatology. The individual who utilized planful problem-solving showed fewer physical manifestations, as compared to the individual utilizing more confrontive problem-solving experiencing more symptomatology (Folkman et al, 1986). The study pointed out the need to identify the aspects of primary appraisal within the context of the encounter.

Other studies to investigate coping theory have included the relationship of primary and secondary appraisal and the use of specific coping mechanisms. Folkman and Associates (1986a) ascertained that when the subjects viewed the situation as a threat to self-esteem, they used more confrontive coping, self control, responsibility, escape avoidance and less social support types of coping mechanisms. In the same Folkman (1986a) study, when the stress involved the "loved one's well-being", subjects used more confrontive and escape avoidance coping, less planful problem-solving and distancing as coping mechanisms. When faced with encounters that were appraised as changeable, the subjects used more acceptance of
responsibility, confrontive planful problem-solving, and reappraisal. In instances in which the outcome had to be accepted, in general, there was more use of distancing, escape avoidance, and emotion-focused strategies. A more positive outcome was associated with planful problem-solving and reappraisal, and a more unsuccessful outcome with confrontive methods. In another study, using the framework of emotion and problem-focused coping, McCrae (1982) examined and assessed stressors in the light of the potential for loss, threat, or challenge. When subjects were faced with a challenging situation they responded by rational action, perseverance, wishful thinking, intellectual denial, restraint, self-adaptation, drawing strength from adversity, and humor. When faced with loss they responded with faith and fatalism. The results pointed to the fact that coping was not a unitary process but a variety of different mechanisms dependent upon the different stressors.

Integration of Adaptation and Coping

According to adaptation theory, all input into the system is channeled through the processes of the regulator and cognator and produces responses through four modes: physiologic, self-concept, interdependence and role. The physiologic mode is associated with the individual’s response as a physical being to a stimulus in the environment, and includes six areas of need: oxygenation, nutrition, elimination, protection, activity and rest. The self-concept mode focuses on the psychological and
spiritual aspect of the individual and the need is for psychic integrity, or the need to know who one is so that one can exist with a sense of unity. The interdependence mode focuses on the interaction related to giving and receiving love, respect and value. The fourth mode is the role function, which is defined as the set of expectations about how a person occupying one position behaves toward a person occupying another position in society. The need in this mode is for social integrity or the need to know who one is in relationship to another, so that one can act.

The study of the role function mode will be the primary focus of this study. The role mode investigates the individual in terms of primary, secondary, and tertiary roles. The primary role of an individual is determined by gender and the stage of growth and development. The secondary roles include all roles necessary, in a variety of settings, to maintain the individual in his or her primary role such as the role as mother, father, and professor. Tertiary roles are temporary roles that an individual chooses to occupy for the purpose of fulfilling some minor task associated with one's current developmental stage such as girl-scout leader, choir member. Of concern to the caregivers, is the secondary role, that of being a full time caregiver to a demented individual.

Although the modes are separated to define the components, it is crucial from a holistic standpoint to remember that they are interrelated and overlap. Specifically, the modes of self-concept, role, and interdependence often overlap in scope and
function. The goal of nursing, from an adaptation viewpoint, is to promote adaptation in the four modes, thereby contributing to the person’s health, quality of life, and dignity in dying.

Factors Influencing Adaptation and Coping

In the systems theory of person and environmental interaction, Roy describes environment as having internal and external components which are constantly changing. The internal and external environments are the sources of inputs, or stimuli into the adaptive system. The inputs are termed stimuli from Helson’s (1964) adaption theory. Possible stimuli, or factors within the environment, identified in the literature in conjunction with the caregiving role have been: physical health, social support, behaviors of individuals with dementia, depression, and two not identified in the current literature, hardiness and spirituality.

Physical health is one of the environmental influences or stimuli which provide alternative explanations by others that sway the coping efforts of individuals. Lazarus & Folkman, 1986 in a study on 150 community-residing residents, concluded that there was a significant relationship between an individual’s appraisal of the situation, coping efforts and health status.

Social Support is another of the environmental factors, researched extensively in relationship to the caregiver of a demented individual. Social support is defined as
"the exchange of resources between at least two individuals, and is perceived by the
provider or recipient to be intended to enhance the well being of recipient"
(Shumacher & McKay, 1984, p.27). The assumption underlying social support is that
individuals who are supported are healthier than unsupported individuals. Social
support is then envisioned to have a buffering effect against stress (Cohen & McKay,
1984). Social support is also viewed as a stress reducer by the process of cognitive
appraisal in which there occurs an interpretation of a broader variety of coping
options through utilization of the social support system.

The behaviors of individuals with dementia such as impaired cognition,
emotional lability, disorientation, decreased ability to conceptualize, and decreased
verbal abilities (Dawson, Klein, Wiancho & Wells, 1986; Petrie, 1985), have also
been identified as environmental variables within the caregiving situation. Deimling
and Bass (1986) identified impaired cognition as having an indirect effect on the
caregiver's burden or satisfaction, with the more frequent and antisocial behaviors
being associated with increased stress. Several sources of literature suggest that some
behavioral problems invoke greater stress than others (Deimling & Bass, 1986;
Quahagen & Quahagen, 1988; Zarit, 1989). The number of problem behaviors and
the degree of distress may cause the caregiver to experience increasing burden. On
the other hand, the ability to adapt to these behaviors may influence the adaptation the
caregivers experience in their role.
Depression is another factor identified in many research studies as associated with caregiving. Depression is often identified as an outcome variable in Alzheimer caregiver studies. Caregivers have been found to have a higher depression rate than a noncaregiving control group when matched for age or gender (Haley, Brown, & Bartolucci, 1987; Neundorfer, 1991; Schultz, Visintainer, & Williamson, 1990). In a study of caregivers by Fitting, Rabine, Lucas, & Eastman (1986), women were at greater risk for depression than men, and younger women felt more lonely than older women and men in all age groups. Although depression has been viewed as an outcome of caregiving, once depression has occurred, it becomes an environmental factor or stimulus that further influences the caregiver's utilization of coping mechanisms and ultimately adaptation to caregiving.

The environmental stimuli receiving less attention in caregiver research is the role of religious or spiritual involvement and its influence on satisfaction or burden. An overall assumption is that spirituality is involved in human health and well-being. Research on religious involvement has found that individuals with strong religious faith report higher levels of life satisfaction, greater personal happiness, and fewer negative psychosocial consequences of traumatic life events than the nonreligious (Ellison, 1991). Therefore, the ability of the caregiver to invoke involvement of a higher power might be hypothesized as affecting adaptation to the caregiving role.

Hardiness is another environmental variable identified in the literature, which
may be a factor affecting adaptation to caregiving. Kobasa (1985) defined hardiness as a personality style consisting of the interrelationship of commitment, control, and challenge. Studies conducted to measure the effects of hardiness indicate that those highly stressed but healthy individuals who have a greater sense of control over their lives and those persons under stress, who feel committed to the various areas of their lives, will remain healthier than those who feel alienated (Kobasa, 1979). She also concluded that hardiness may have a direct influence on the individuals’ ability to cope with situations. At the present time research has not included the relationship of hardiness to coping with the strains of long-term caregiving.

**Summary of Theoretical Framework**

In utilizing adaptation theory in this research, the caregiver is examined as a bio-psycho-social-spiritual being. The caregiver is in contact with the constantly changing environment as he/she cares for a person with dementia. The caregiver must use innate and acquired mechanisms to adapt to the behavioral changes of the impaired care recipient. The caregiver receives all stimuli from the environment, processes the information (primary appraisal), and responds. If the response is one that promotes growth and mastery, the response is adaptive or in other terms there is adjustment to
the caregiving role (secondary appraisal). If the response is effective, it promotes growth and mastery in the role of caregiver. If the response is ineffective and does not promote growth or mastery, the result is caregiver burden. Caregiver burden has been defined as "psychological state resulting from a combination of physical work, emotional pressure, social constraints and financial demands accruing because of the patient care requirements" (Dillehay, 1990, p. 19).

The caregiver receives stimuli from the environment, and two internal control processes, defined according to Roy as the regulator and cognator mechanisms, regulate the individual's response to the changing environment. The cognator mechanisms in the Roy model are defined as perceptual and information processing, learning, problem-solving, decision-making and emotional mechanisms such as the affective appraisal of the situation. This approximates primary appraisal in coping theory, in which the individual first assesses the situation as harmful or beneficial. The definition of the Lazarus and Folkman's coping framework of emotion-focused and problem-focused coping mechanisms, or secondary appraisal, determining which mechanisms to utilize, appear to be a close theoretical match with the regulator and cognator system of Adaptation model.

In utilizing the Roy model to guide this research, the examination of the caregiver will involve investigation of the role mode. The area of research for this study is the stimuli in the environment and the function of cognator or coping systems
which aid in the adjustment to the caregiver role. Adaptation for this study is defined as the appraisal of the caregiving role.

From adaptation theory, the stimuli in the environment that affect the caregiver are the patient's problem behavioral characteristics, such as inability to perform activities of daily living, wandering, incontinence and paranoia. Other stimuli that can affect the caregiver include physical health, depression, social support, hardiness and spirituality. These environmental stimuli are external events which when mediated through the cognator responses of emotion-focused or problem-focused coping, result in a level of adaptation by the caregiver which can be interpreted as adjustment or burden in the caregiver role.

**Causal Framework**

Based on the adaptation nursing model (Roy, 1986) and a coping paradigm (Lazarus and Folkman, 1986), the theoretical framework guiding this study investigates the person-environment influences, or stimuli in the environment, as regulated by the individual's coping mechanisms on the caregiver's adaptation level (Figure 1-1). The model looks at internal and external stimuli or stressors which influence the individual response, the coping mechanisms, and the level of adaptation as measured by the cognitive appraisal of the caregiver. The stimuli are identified as physical health, depression, patient problem behavior characteristics, hardiness, social
Figure 1.1 Hypothesized relationship among physical health, depression, hardiness, social support, patient behavior, spirituality, emotion-focused coping, problem-focused coping, and appraisal of caregiving role.
support and spirituality. The relationships of the variables between stimuli, coping mechanisms, and level of adaptation are complex and interrelated. The relationships in this study are based on the review of previously conducted studies, and variables may overlap, but were directionally hypothesized based on previous research.

**Theoretical Definitions**

**Appraisal of the Caregiving Role** - All cognitive and affective appraisals and reappraisals of potential stressor in the caregiving situation and the efficacy of one’s coping efforts. Appraisal consists of three aspects: satisfaction, impact and burden.

**Satisfaction in the Caregiving Role** - Uplifts, or small events that evoke some response of pleasure, affirmation or joy, which elicit the feeling that the activities one performs as a caregiver elicits a source of personal fulfillment.

**Impact of the Caregiving Role** - The interpretation of how the caregiving role has intruded upon one’s social life, daily activities, work, and so on.

**Burden in the Caregiving Role** - Psychological state resulting from a combination of physical, emotional, social and financial demands placed on the caregiver due to the patient care requirements.

**Coping** - Constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person.
Problem-focused Coping - Purposeful strategy aimed at managing or altering the problem causing the distress, including such techniques as planful problem-solving and confrontation.

Emotion-focused Coping - Purposeful strategy aimed at regulating the emotional response to the problem causing distress, including such techniques as escape-avoidance, distancing, self-control, social support and accepting responsibility.

Physical Health - Physical well-being and absence of illness, of the caregiver, as determined by self-report of health status.

Depression - Mood of sadness that consists of feelings of helplessness and hopelessness as well as lack of appetite, energy, and rest.

Patient Problem Behaviors - Behavioral characteristics exhibited by the individual with dementia resulting from memory loss such as indecision, disorientation, personality change, loss of ability to perform activities of daily living, incontinence, wandering, immobility and aggression.

Hardiness - A personality characteristic of a robust individual who is able to understand multiple negative stimuli in the environment due to possession of three underlying characteristics: commitment, control and challenge.

Commitment - An individual who tends to involve him/her self in whatever activities he/she are engaged in. A committed individual believes in the authenticity of the activities in which he/she are engaged and knows the importance and value of
the activities. Inherent in commitment is a sense of mission and purpose.

**Control** - The belief of an individual that he/she can influence the events in their experiences rather than experience them as powerless when faced with external challenges.

**Challenge** - The conception of an individual that life’s changes are the norm and to be expected and when faced with changes view them as an opportunities for growth rather than a cause for insecurity.

**Social Support** - Exchange of resources between individuals that can include expression of a positive affect, endorsement of another’s behaviors or material aid to another with the intent of enhancing the well-being of the recipient.

**Spirituality** - Unifying force that assist in attributing meaning to situations through a sense of relationship to an external dimension that transcends the self, and empowers the individual.

**Hypothesis**

The model for the study implies nine hypotheses involving four hypothesized direct relationships and five hypothesized indirect relationships. The expected relationships of the environmental variables on cognator activity and the level of adaptation are summarized in the following hypotheses:
**Hypothesized Direct Relationships:**

H1 Better physical health will result in high appraisal scores indicating the caregiving role is more satisfying, less burdensome, and with lesser impact on the caregiver’s life.  

H2 Depression will result in lower appraisal scores, indicating that the caregiving role is less satisfying, more burdensome, and with a greater impact on the caregiver’s life.

H3 Problem-focused coping will result in high appraisal scores indicating that the caregiving role is more satisfying, less burdensome with lesser impact on the caregiver’s life.

H4 Emotion-focused coping will result in lower appraisal scores, indicating the caregiving role as less satisfying, more burdensome and with a greater impact on the caregiver’s life.

**Hypothesized Indirect Relationships:**

H5 Greater depression will result in less problem-focused coping, which in turn will result in lower appraisal scores indicating the caregiving role as less satisfying, more burdensome, with a greater negative impact on the caregiver’s life.

H6 Hardiness will result in more problem-focused coping, which in turn will result in higher appraisal scores indicating the caregiving role as more satisfying, less burdensome, with a lesser negative impact on the caregiver’s life.
H7 Greater social support will result in more problem-focused coping, which in turn will result in higher appraisal scores indicating the caregiving role as more satisfying, less burdensome, with a lesser negative impact on the caregiver’s life.

H8 Patient problem behaviors will result in more emotion-focused coping, which in turn will result in lower appraisal scores indicating the caregiving role as less satisfying, more burdensome, with a greater negative impact on the caregiver’s life.

H9 Greater spirituality will result in an increase in emotion-focused coping, which in turn will result in lower appraisal scores indicating the caregiving role as less satisfying, more burdensome, with a greater negative impact on the caregiver’s life.

The third aim of this study is to test the goodness of fit between the theoretical model (Figure 1-1) for explaining adaptive behavior in the caregiving role.

Significance of the study

The significance of this research exists in its potential contribution to nursing theory development and improvement in clinical practice. Although there has been extensive recent research in the area of Alzheimer caregiving, there has been little investigation of factors which enable caregivers to adapt to their caregiving activities or promote adaptation. A systematic investigation of factors affecting satisfaction in the caregiving role may provide direction to future intervention studies which enhance
caregiver adaptation. The variable of spirituality is a factor not clearly investigated in caregiving research at this time, and would add to the total dimension of investigation of an individual human experience.

The research also has strong implications for theory development. An increasing body of knowledge on the Roy Adaptation model will serve as a useful guideline for the design and validation of the theoretical components of the model. This study provides another opportunity to increase the research-based studies testing the Roy Adaptation model.
CHAPTER TWO

Review of the Literature

This chapter consists of a review of the literature including appraisal of the caregiving role, coping, physical health, depression, patient behaviors, hardiness, social support, and spirituality. Included will be a review of the demographic variables: informal caregiver, gender, and length of caregiving experience.

Appraisal of the Caregiving Role

Because of the severity of the disease and associated symptoms and the great amount of energy involved in caregiving with an individual with dementia, the current literature on the caregiver's adjustment to caregiving includes a wealth of articles on the concept of the caregiver burden. In the 1980's, "caregiver burden" was defined by Zarit as the "extent to which the caregivers perceive their emotional or physical health, social life and financial status as suffering as a result of caring for their relative" (Zarit, Reeve & Bach-Peterson, 1980, p.651). Poulshock & Deimling (1984) defined "burden" as the mediating construct between elder impairment and the impact of caregiving on the caregiver's relationship, social activities, etc. Caregiver burden was also defined as the "psychological state resulting from a combination of physical work, emotional pressure, social constraints and financial demands accruing because of the patient care requirements." (Dillehay & Sands, 1990, p.264).
Conceptualization of caregiver burden, and the tools developed to measure such burden, including the Zarit Burden Scale (Zarit, Reeve & Bach-Peterson, 1980) reflected the measurement of emotional health, physical health, social activity and financial status components on the caregiver. The scale contains twenty-nine items written in a unidimensional fashion with negative caregiving attitudes emphasized. Items include statements such as "I feel resentful" with only two of the items stated to elicit a positive response to the caregiving situation. The Zarit Burden Scale was used in a significant number of studies investigating burden in the 1980's and 1990's (Barusch & Spaid, 1986; Davies, 1985; Harper & Lund, 1990; Novak & Guest, 1989; Wright, 1991; Young & Kahana, 1989; Zarit, Todd & Zarit, 1986). This conceptual framework of caregiver burden is based on a model in which the care recipient is viewed as a source of stress to the caregiver, demanding the caregiver's energy and time, which results in the caregivers feeling burden and experiencing the stress and strain of the situation. The focus of these studies have been on the adverse outcomes to caregivers.

In the recent literature there has been an increasing number of researchers who have expanded the theoretical conceptualization of caregiver burden. Kosberg (1990) developed an instrument to measure burden that identified the individual components of burden such as the effect of personal and social restrictions, physical and emotional problems, economic costs, and a new component: the value investment in caregiving.
The identification of the individual components, rather than a global burden score, was produced to identify the specific burden component which may be responsive to interventions. As the researchers examined the aspect of burden, the element missing in the early development was the caregivers' subjective appraisal of the meaning of the caregiving situation. Vitaliano (1991) developed a theoretic arithmetical model of caregiving burden or distress. The constructs in the model include the distress in response to the caregiving role, the exposure to stress operationalized as the care recipients function in all areas of daily living, vulnerability of the caregiver as measured by health problems, anger and anxiety, and the resources available to the caregiver including the coping mechanisms, outlook on life, and social support. The model arithmetically derives a distress score by adding the exposure to stressor and vulnerability scores by the marks on the psychological and social resources scales. The resultant score indicate the degree of burden experienced by the caregiver.

In an attempt to broaden the understanding of burden, authors have also expanded the notion to include the stress model developed by Lazarus (Lazarus & Folkman, 1984). In a model proposed by Lawton, Kleban, Moss, Rovine & Glicksman (1989), the term burden is instead referred to as "caregiver appraisal" in which the potential stressors of caregiving are viewed in relationship to the caregivers' coping efforts. The term "caregiver appraisal" changes the focus of the experience of caregiving to a more positive spotlight, in that all aspects of the
caregiving experience would not necessarily be interpreted as stressful. Thus, in the terms of broadening the concept of burden to caregiving appraisal, the definition is expanded to include uplifts, or small events which evoke some response of pleasure, affirmation, or joy in the caregiver which may play an integral part of the caregiving experience and may offset some of the negative experiences.

Another more balanced interpretation of adjustment to caregiving was also addressed by Phillips & Rempusheski (1986) in describing the need for an alteration in the model of caregiving in which the caregivers' personal imperatives, standards, and values might be realized in the caregiving situation, and the role as caregiver might form a positive experience for the caregiver. Motenko (1989) also identified the need for balancing the investigation of burden to include satisfaction in the caregiving role.

In investigating factors related to burden from previous studies, an important predictor of burden in the caregivers of persons with dementia appears to be the cognitive and behavioral difficulties experienced in dealing with the care recipient (Barusch, & Spaid, 1989; Brashares, 1994; Harper & Lund, 1990; Novak & Guest, 1989; Vitaliano, Russo, Young, Teri, & Maiuro, 1991). Kinney (1989) found that caregivers of socially responsible yet behavioral inappropriate care recipients experience the greater amount of hassles or burden when compared with a comparison group of older adults in the community.
The length of time involved in caregiving is another factor investigated as a predictor of caregiver distress in the caregiver literature. The results have been conflicting, with the relationship of the amount of burden experienced not always proportionate to the length of time engaged in caregiving activities. Novak and Guest (1989) found the relationship between length of caregiving and burden to be nonsignificant. However, newer studies have identified stages in the caregiving process (Kobayshi, Yuasa, & Noguchi, 1995). Stages in the caregiving career such as the encounter, the enduring and the exit stage (Lindgren, 1993) have been examined in recent years. Gaynor (1990) determined burden to be higher in long term caregivers, with burden lowest in the first two years, then rising to mild to moderate from the second to the fourth year and rising successively thereafter.

In the area of psychological variables affecting burden, mental health has been identified as a factor in a number of studies. Young and Kahana (1989) using the Symptoms Checklist (Derogatis, Lipman & Covi, 1973), assessed mental health symptomatology, and demonstrated that elevated burden, as measured on the Burden Inventory (Zarit, Reeves, & Bach-Peterson, 1981), was associated with increased mental distress. In another study, using self-reported mental health problems, Vitaliano, Russo, Young, Teri and Maiuro (1991) demonstrated that burden, as measured by appraised distress in response to caregiving experience, was associated with increased mental distress (Motenko, 1989). Other research demonstrated that the
psychological variables of high anger, low resources, or poor health, multiplied by a
negative outlook on life, was associated with increased burden (Vitaliano, Russo,
Young, Teri & Maiuro, 1991).

In studies in which subjective factors such as values, attitudes, or appraisal of
the caregiving process have been associated with burden, the results have varied. In a
study by Harper and Lund (1990), caregiver life satisfaction was measured by the
Life Satisfaction measure (Wood, 1969). Results demonstrated that the caregivers' lack of life satisfaction was a major contributor to burden. In another study, involving subjective factors in caregiving, the negative attitude of the caregiver toward the family was positively correlated with burden (Cantor, 1983). In a study by Motenko (1989), caregivers who experienced greater gratification from caregiving had a higher general well-being than those who experienced less gratification in the role. This study pointed out that the meaning of caregiving was more important to the caregiver's well being than the amount of care provided. In another study, the subjective perception of caregiving, rather than the objective variable of patients’ mental deterioration, accounted for 45% of the variance in the Cost of Care Index, a multidimensional measure of caregiver burden (Kosberg, Cairl, & Keller, 1990). Caregivers in one study (Reed, Stone, & Neal, 1990) reported more negative events and negative appraisals of daily life experiences than a control group. In addition, contrary to the predominance of evidence in the literature, the same study failed to
support the hypothesis that the demands of caregiving markedly disrupt the general activities of the caregivers.

Relatively new in the caregiving literature are studies which examine the mediating effects of coping mechanisms and appraisal on the caregiving situation. One study by Brashares and Catanzaro (1994) identified a positive relationship between active coping and depressive symptoms. This study also found that active coping, such as confronting or solving the problem in some way, was positively associated with depression when the situation was uncontrollable. The same study indicated that in many situations, emotion-focused problem-solving in the face of an uncontrollable disease is associated with increased depression, whereas emotion-focused problem-solving that encourages an optimistic outlook could assist the individual in feeling better.

A study with a conflicting conclusion was investigated by Kinney (1989), where it was determined that viewing, with a positive outlook, those aspects of caregiving particularly related to providing assistance in the area of activities of daily living, were related to the caregiver's sense of well-being. An unexpected finding of the same study revealed that more uplifts were related to greater depression. The author concluded that the more intensely the caregivers were involved in the caregiving experience, the more they reported uplifts and thus the positive as well as the depressive aspects of caregiving occurred simultaneously (Kinney, 1989). A
related finding in a study by Lawton (1992), included the conclusion that the more assistance given by a caregiver contributed to a greater sense of burden, but, in addition, to an increased satisfaction in the caregiving role. Burden and satisfaction have been found to co-exist and may occur independently.

Summary: Appraisal

As indicated in the above review, a number of previous studies have been conducted in the area of appraisal of the caregiving role. The majority of studies conducted in the 1980's were conducted using the Zarit Burden scale an instrument with most questions posed in the negative direction with the negative consequences of caregiving emphasized. Not included on the scale, was the meaning of the caregiving situation to the caregiver, including possible rewards of engaging in the caregiving role. The construction of the newer scales measuring the wider variety of responses to caregiving have yet to be fully tested on a large number of caregivers. The ability to assess the subjective values of caregiving have yet to be determined. Other variables such as the cognitive and behavioral problems of the individual with dementia as well as the length of time in the caregiving situation have produced contradictory evidence in relationship to appraisal of the caregiving role. Inherent in the measurement in the length of time in the caregiving situation, is the difficulty in defining when the caregiver assumed full time responsibilities in the caregiver role.

As recent literature attests, there has been an increasing need for the
researcher to expand the conceptual framework of the burden literature to include the subjective appraisal, including the meaning of caregiving and the coping efforts caregivers utilize in dealing with the stresses of the caregiving role. The instruments developed have enabled researchers to expand the model of caregiving in which some of the activities of caregiving might result in the caregiver satisfaction within the role.

The problems inherent in the burden literature include the variety of outcome measures used in caregiving studies to measure different aspects of the caregiving role. Some of the variables associated with burden in previous studies include the cognitive behavioral difficulty experienced in dealing with the dementia, length of time in the caregiving situation, and the caregiver burden of the caregiver. More recently introduced into the caregiver burden literature is the aspect of caregiver appraisal, or life satisfaction within the caregiving role, and the investigation of the role it plays in mitigating some of the strains experienced by caregivers.

**Coping**

In reviewing literature on caregivers to demented individuals, there exists a number of research studies using the Lazarus and Folkman conceptual framework. The purpose of a study by Haley Brown and Bartolucci (1987), was to identify factors which related to the quality of adaptation among 54 caregivers for demented elderly. The study identified the stressors faced by the caregiver as measured by the severity

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of the patients' cognitive impairment and behavioral problems. The coping mechanisms utilized included information seeking, problem-solving, and emotional discharge. This study did not utilize the Ways of Coping Checklist (Folkman & Lazarus, 1986), but the results demonstrated that the caregivers experienced extreme stress from the behavior problems exhibited by the individuals with dementia. A problem-solving and informational approach on the part of the caregiver led to an increase in life satisfaction.

In another study, Pucho and Resch (1989) examined the role of emotion-focused or problem-focused coping as a mediator between stress and outcome. In addition they examined the probability of emotion-focused and problem-focused coping having uniform effects on well-being regardless of the degree of stress. In investigating 315 Alzheimer caregivers, using a new coping instrument, the researchers determined that the coping mechanisms used were multidimensional, with the majority of coping strategies used by caregiving spouses being emotion-focused. The results also supported the Lazarus and Folkman theoretical framework that emotion-focused and problem-focused coping are mediators between stress and the outcomes of physical health and depression.

In another caregiving study examining coping strategies, Borden and Berlin (1990) examined the role of sexual differences in the use of different coping strategies. In a study of 61 spousal caregivers, 36 women and 25 men, utilizing the
Ways of Coping Checklist to measure coping ability, Borden and Berlin (1990) discovered that female caregivers demonstrated a higher level of distress, as measured by the Memory and Behavior Checklist, Part B (Zarit & Zarit, 1983), in the caregiving role. The researchers discerned that there were no differences in coping strategies between male and female caregivers, and the most frequently used coping mechanisms used by both groups were emotion-focused. It was hypothesized that emotion-focused coping is often used in situations in which the individual cannot change the circumstances and therefore must regulate the distressing effects around the situation to decrease distress.

In another recent study, Wallsten (1993) looked at the daily "hassles" of caregivers as a predictor of stress for caregivers. In a sample of 41 subjects, 21 caregivers of demented individuals and a control group of 20 noncaregivers, researchers examined the differences in depth of everyday experiences between the two groups. The results demonstrated that caregivers experienced a significantly greater number of inconveniences in their daily lives. The experiences were viewed differently in terms of the challenges of daily life. The caregivers experienced higher nuisances related to personal grooming, rarely having privacy, and attendance at social functions, items which were all rarely rated as a challenge to noncaregivers. In this study there was no attempt to link inconveniences with coping mechanisms; however, the study did point to differences in stressors between the normal elderly
and elder caregivers.

Pruchno and Kleban (1993) assessed coping strategies by means of open ended questions devised by the researchers. In a study of 424 adult children with parents in a nursing home, researchers used a structural equation model testing based on a stress and coping model; researchers determined that coping strategies used are multidimensional including both emotion-focused and problem-focused. The use of emotion-focused strategies, which distorted reality, were found to be adaptive when the stressful situation was unavoidable, such as caregiving to a demented parent. The use of problem-focused coping was not associated with positive mental health in these caregivers.

In an intervention study, Intrieri and Rapp (1994) tested the assumption that by teaching caregivers of cognitively impaired adults self-control skills, such as systematic problem-solving, information seeking and reappraisal, the knowledge of such skills would result in a decreased feeling of burden. Results demonstrated that with increased memory and behavior problems in the care recipient, there was a subsequent rise in the feeling of burden among the caregivers. However, after teaching self-control skills to the caregiver, there was a decreasing feeling of burden and a lessening of psychological distress among the caregivers; in addition there were fewer memory and behavior problems among care recipients. Caution must be used in this small sample of 44; however, this study points to the positive outcomes of
teaching self-control skills which may lead to the perception of less stress by the caregiver.

Summary: Coping

Coping as a theory and the identification of coping strategies have been utilized to identify the process of adjustment to many stressful situations. The process of coping involves the cognitive appraisal of the situation to identify the threat to the individual and what actions can be taken concerning the threat. Theory suggests eight different forms of coping to deal with stress: two problem-solving and six emotion-focused types.

A number of studies on the coping ability of caregivers have been conducted using the Lazarus and Folkman theoretical framework. Results from the studies have concluded that most caregivers experience stress in the caregiving role. Studies have demonstrated that both male and female caregivers use emotion-focused coping strategies in the face of an uncontrollable stress, such as caring for persons with dementia. Studies have demonstrated that the use of problem-focused coping strategies, such as self-control, reappraisal, seeking social support or distancing, in the face of an unchangeable situation might be the most effective in adjusting to the stress. To the contrary, the use of emotion-focused coping mechanisms such as confrontive coping, an aggressive form of managing a situation, might only serve to impede adjustment to the caregiving role.
Health

Previous studies on caregivers have indicated that a high percentage of the population are affected with health problems. Chenoweth and Spencer (1986) reported that 21% of caregivers became ill or injured while giving care. Archbold (1980) reported that most caregivers face some form of health problems related to the caregiver role. In a study of 42 caregivers, Baldwin (1988) discovered that the health concerns most often stated were fatigue, malaise, mood swings, depression, insomnia, gastrointestinal upset, extreme weight gain or loss, and headaches.

Burnout, a syndrome of physical and emotional exhaustion involving negative self-concept and attitude, a loss of concern and feeling for others, and a loss of one’s focus on life, was the center of a study by Ekberg (1986). Burnout was identified as occurring in three stages. The first stage was characterized by emotional and physical exhaustion, insomnia, migraine headaches, gastric ulcer, heavy perspiration, muscle tightness, and heart palpitations. Also included might be weight loss, shortness of breath, and depression. The second phase was depicted by a negative cynical dehumanizing attitude toward others and the use of drugs or alcohol for relief. The third phase involved detachment, disgust and a sour attitude. In studying 30 caregivers of the chronically ill, Ekberg (1986) discovered that the spouses exhibited the characteristics of the first two stages of burnout, but not the third.

Research on the health of caregivers has often been conducted within the

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context of quality of life. Jones and Peters (1992) studied the consequences on the quality of life of caregivers as measured by stress, anxiety, depression, and self-reported health problems. Two hundred fifty-six informal caregivers participated with the majority (71%) females (79% wives, 21% daughters). This sample reported a negative effect on their health only 26% of the time. The daughters were more affected than the spouses, and the more dependent the person with dementia behavior was, the more the health of the caregiver was affected.

In investigating the possible health-related stressors of long term care, a group of Ohio scientists (Kiecolt-Glaser, Glaser, Shuttlework, Dyer, Ogracocki & Spiecher, 1987) studied the effects of chronic stress on the immune system of family caregivers of Alzheimer victims. Thirty-four Alzheimer caregivers were matched with a comparison group and measured on comparison variables of depression, social contact, behaviors of the patient, and function of the immune system. They measured immune function by assaying T-cells, helper cells and Epstein-Barr titer. In this study, family caregivers of Alzheimer victims were more distressed than the comparison group. Caregivers were also found to have decreased immunity as demonstrated by lower T-lymphocytes, lower helper suppression cell ratio, and an increase in antibody titer to the Epstein-Barr virus. The percentage of natural killer cells and T-lymphocytes did not differ. These differences were not a function of nutrition, alcohol or coffee intake, or amount of sleep. Greater amounts of behavioral
impairment in the Alzheimer patient was also associated with an increase in distress and loneliness in the caregiver. The overall conclusion of the scientists was that the caregivers appeared more distressed and had poorer immune functions than well-matched peers.

In another study in which a physiological measurement of stress was used, Uchino et al (1992) studied the changes in cardiovascular response in terms of blood pressure as a function of the chronic stress of caregiving. The mediating factor to cardiovascular response was proposed as social support. In a study of 36 caregivers and a matched control group, caregivers with enlarged social support systems experienced a decrease in heart rate reactivity, whereas caregivers with small social support experienced a statistically significant increase in systolic blood pressure.

In another well constructed research study, Hooker and Associates (1992) examined the traits of neuroticism and dispositional optimism as they affected the mental and physical health outcomes of caregivers. In a study of 51 caregivers, 26 female and 25 male, there was no direct relationship between the degree of optimism of the caregiver and physical health. Optimism was related to the caregiver’s mental health through the process the caregiver’s perception of stress in the caregiving situation. Neundorfer (1991) conducted a study with 60 caregiver (63% wives and 27% husbands) which looked at the health outcomes in spouse caregivers of persons with dementia, utilizing the Lazarus and Folkman coping framework. This
researcher discovered that the caregiver's appraisal of the stress in caregiving was a significant predictor of depression and anxiety, but neither the severity of the patient's problems nor appraisal of the coping options was a significant predictor of any of the health outcomes. The coping pattern most associated with depression and anxiety was wishful thinking and emotion-focused coping.

Summary: Health

Most studies of caregivers which looked at health outcomes as outcome variables indicate that there are problems with health, ranging from fatigue and headache to depression of the immune system and increased cardiovascular response. Most studies included a measure of health as an indicator of quality of life. In examining health as an antecedent variable, it would appear from the research that the physical health would directly affect the positive adjustment to the caregiver role. It might be hypothesized that the process of natural selection in that caregivers in poorer health would not be able to engage in caregiving activities.

The critique of the analysis of health in relations to caregivers has been that the majority of studies have included a self-report of the caregivers health with no corresponding substantiating data. The studies by Kiecolt-Glaser (Kiecolt-Glaser, Flaser, Shuttlework, Dyer, Ogracocki & Speicher, 1987) are the exception to this criticism, and those studies do support the relationship between the stress of caregiving and poorer physical health. Long term studies of the relationship between
physical health with standard parameters such as weight, blood pressure, cholesterol measured would serve to improve this body of knowledge.

**Depression**

In previous studies, caregivers of individuals with various forms of dementia have been observed to experience depression. In research targeted on caregiver well-being, the single measure used most often to assess mental status among caregivers is depression. In most studies, the increase in strain and the experience of burden are associated with elevated levels of depression. In reviewing studies on depression in dementia caregivers, the rates of depression range from 14% to 81% of the samples (Dura, Haywood-Naibe & Kiecolt-Glaser, 1990).

Depression may be defined as a mood of sadness that consists of feelings of helplessness and hopelessness, as well as lack of appetite, energy and rest (Robinson, 1989). In using the American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders Third Edition (DSM III) 1987, a major depressive episode consists of a depressed mood or loss of interest or associated symptoms for at least two weeks. The depressed mood must be present most of the day, nearly every day and must reflect a change from prior functioning. In addition to the mood disturbance, at least four other symptoms must be present, including weight and appetite change, sleep disturbance, psychomotor agitation or retardation, low energy.
or fatigue, feelings of worthlessness or excessive guilt, poor concentration or indecisiveness, or recurrent thoughts of death (Becker, 1981). A depressive neurosis is the depressed mood for most of the day for two years and with an additional two or more of the above listed symptoms. Adjustment disorders are defined as a maladaptive reaction to an identifiable stressor that occurred within three months prior to the onset of the disorder. A maladaptive reaction can occur by impairment in social or occupational functioning, and remits when the stressor ceases or a new level of adaptation is reached. Another diagnosis related to depression is an adjustment disorder with a despondent mood in which the individual exhibits melancholy mood, tearfulness and hopelessness predominating during a six month period. Most caregivers to demented individuals do not fit into any of the above named categories. The category of depression most pertinent to caregivers would probably be the category of depression not related to mental disorder. One variety of this classification is uncomplicated bereavement, in which the individual exhibits sleep and appetite disturbances in addition to a depressed mood, fatigue or low energy level. This is the best possible diagnosis according to DSM III, since most caregivers have had no previous depressive episodes and they are living with the functional loss of their loved one on a gradual basis; this depression is relieved once the realization of the loss occurs.

One problem in research on caregivers is in making the differential diagnosis

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of depression in a chronically heavily stressed person, especially the elderly. The difficulty arises in differentiating the extent to which the stress reaction is a consequence of stressor demands as compared to the natural manifestations of aging. The problem in using DSM III classifications in making a differential diagnosis is that virtually every psychosocial factor alleged to be conducive to a depression not related to a mental disorder occurs within the context of caring for demented individual: guilt, loss of control, financial expenses, constriction on social action and concerns regarding genetic implications.

There are different theories for the high incidence of depression in the caregiver. One such theory, learned helplessness, asserts that depressive symptoms are associated with a cognitive attributional style of behavior. With this theory, the causes of negative outcomes are perceived to be the results of internal (versus external), stable (versus unstable), and global (versus specific causes) characteristics. There have been mixed results on this theory in investigating caregivers to demented individuals. In a study by Pagel and Associates (1985), the tendency for the caregiver to make internal attributions for the patients' impairments was associated with an increase in depression in the caregiver. In another study on learned helplessness, Cohen and Eisdorfer (1988), found there was no relationship between internal attribution and depression level among caregivers.

Another theory concerning depression among caregivers is the premise that the
interpsychic strains of caregiving can cause the self-concept to be damaged. The two mechanisms that may cause this loss of self-concept to occur are role captivity and loss of self. With role captivity, the individual unwillingly and involuntarily is the recipient of the caregiving role. In a sense the caregivers are captives when they know that it is their desire to do something other than the caregiving tasks in which they feel compelled to be engaged. The sense of helplessness with this situation can lead to depression. The second mechanism, loss of self, occurs when the identity and life of the caregivers are closely bound to the patient. Since the caregivers self-identity is closely aligned to the ill individual’s identity, any loss in the patient’s ability impinges on the caregivers sense of worth (Pearlin, Mullan, Semple & Skaff, 1990).

Depression among caregivers has also been linked theoretically to the caregiver’s relationship orientation, or the individual’s characteristic approach toward interaction with others. An individual with a communal orientation, is one who has a high concern over other’s needs and feels more responsible for meeting those needs. An individual with low communal orientation is one who has little concern over other’s needs and feels less responsible in meeting other’s needs. In a study by Williams and Schultz (1990), results indicated that caregivers with low communal orientation experience more depression than caregivers with a support system. The same study investigated the previous relationship between the caregiver and patient,
and discovered an early distant relationship with the patient was associated with a higher depression level in the caregiver. There was an identified gender difference in this study, with men from low communal orientation and a distant relationship with the patient exhibiting high depression scores; whereas, women who had low communal orientation and a close relationship with the patient exhibiting high depression scores.

Other perceptual variables that have been investigated in terms of depression among caregivers to demented individuals include boundary ambiguity and role mastery. Boundary ambiguity is a situation in which the demented patient is considered on the outside of the family system, and is the measure to which the caregiver is preoccupied and unsure of the relationship with the patient. Role mastery is the sense that the caregiver has over how he/she manages the stressful situation of caregiving for the demented patient. Boss, Caron, Horbal & Mortimer (1990), have found a statistically significant correlation between boundary ambiguity, mastery, and depression, independent of the functional status of the patient. Results indicate that if the caregivers perceive the dementia victim as psychologically absent, the less masterful and the more depressed they are in their caregiving role.

The "wear and tear" model of caregiving (Haley & Pardo, 1989) looks at the results of caregiving and the resulting outcomes, such as depression, over time. It is hypothesized that the caregiver's physical and psychological stamina decreases over
time. In a two-year longitudinal study of stressors and depression, with data taken at four points of time, Schultz and Williamson (1991) determined that depression in caregivers to demented individuals varied over time and by gender. These researchers demonstrated evidence of a high level of depression among caregivers consistent with patient decline. Gender differences were also discovered, with women reporting high and stable rates of depression throughout the study and male caregivers experiencing an increase in depression over time. These results are consistent with other research studies (Eagles, 1987; Gallagher, 1989; Moritz, 1989; Schultz, 1986). Male caregivers have exhibited an increase in depression over time, in studies by Moritz (1989) and Eagles (1987). The relationship between depression and the number of patient problem behaviors has also been well documented (Dura, Haywood-Niler & Kiecolt-Glaser, 1990a; Schultz and Williamson, 1991).

The majority of studies on depression in caregivers used standardized research instruments with reported reliability and validity scores. A commonly used instrument is the Beck Depression Inventory (Dohen & Eisdorfer, 1988; Dura et al, 1990a; Dura, Stukenberg & Kiecolt-Glaser, 1990b; Haley, Brown, & Bartolucci, 1987; Kiecolt-Glaser, 1987; Morrisey, Becker, & Rupert, 1990). The Center of Epidemiologic Studies Depression Index has been used in most of the studies on depression in caregivers (Bergman, 1993; Folkman et al, 1986; Lawton et al, 1989; Pearlin, Mulkin, Semple & Skaff, 1990; Pruchno, 1989a, 89b, 90a, 90b; Reed, 86a,
In studies of caregiver burden or strain, Morycz (1985) and Bashares (1994) identified that greater caregiver burden was associated with increased depression. In most studies, increased strain has been identified with an increase in depression. It has been documented that spousal caregivers to demented individuals who have a higher level of negative affect, are more likely to use psychotropic drugs, and have more symptoms of psychological distress than the general population counterparts matched for age and gender (Morycz, 1985).

The more symptoms and problem behaviors in the impaired person the greater the burden felt by the caregiver, and this is associated with an increased level of depression (Lawton, 1992). The appraisal of caregiver’s inability to manage behavioral problems was linked to depression in a study by Haley and Associates (1987). In another study, Pruchno and Resch (1989) identified certain types of patient behaviors, such as wandering, that were linked to depression.

In investigating the coping style of caregivers as it related to the mental health of the caregiver, Pruchno and Resch (1989) investigated 315 caregivers. The results indicated that coping strategies used by caregivers were multidimensional, with the majority being emotion-focused. Wishfulness as an emotion-focused strategy led to an increase in depression in this study and in another study by Williamson and Schultz.
On the other hand acceptance led to a decrease in depression in both studies (Pruchno & Resch, 1989; Williamson & Schultz, 1993). Coping strategies which involved problem-solving and attempts to find solutions led to an decrease in depression. Pruchno and Resch (1989) also discovered that the depressed individual, in general, used less effective coping mechanisms than a caregiver who was not depressed.

Research findings on the relationship between depression and physical health are sparse and nonconclusive. In linking physical health to depression, Pruchno and Associates (1990) studied 315 caregivers’ mental and physical health and found that depression predicted poor physical health status and burden. Robins and Associates (1989) found a negative relationship between total health and depression for wives of men with irreversible memory impairment. George and Gwyther (1986) found that although caregivers used more mental health services than the general population, there was no evidence of difference between the caregivers’ physical health and medical services use than that of those of the general population.

In a study of social support in relationship to depression, Bergman and Associates (1994) determined that with a decline in social support there was a significant increase in depression among caregivers, and the caregivers' unmet expectation of social support was another predictor of depression. In a two-year longitudinal study of depression among caregivers, Schultz and Williamson (1991)
found that when social support decreased, there was a corresponding increase in depression. In a study of the chronic stressor of caregiving, Morrisey, Becker and Rupert (1990) investigated the perceived negative impact on the dimension of life changes in crucial areas of life such as activity level and work. They found that the perceived negative impact on work was a stronger predictor of depression than the spouse’s disability level. In the analysis, a restricted home-making activity level significantly correlated with depression; however, the same result was not found among the subjects engaged in an occupation outside the home.

Summary: Depression

In summary, there is ample evidence of the existence of depression among caregivers of demented individuals. Theories of depression include the hypothesis of learned helplessness, damaged self-concept, the previous state of interaction with the patient, role ambiguity/role mastery and the "wear and tear" hypothesis. The most common instruments used in Alzheimer research to measure depression include the Beck Depression Inventory (Beck, 1972) and the Center of Epidemiological Studies Depression Index (Radloff, 1977).

The difficulty in the areas of depression in caregivers relates to the problems the creation of the definition for depression in this group of chronically stressed, usually elderly adults. The DSM III has offered little clarification in this regard. The instruments, used to measure depression, have remained consistent in the research to
date. Another critique of the study of depression has been difficulty in differentiating
the interrelationship between depression and social support, burden, patient behavior
characteristics and the use of various coping styles.

In most previous studies depression has been examined as a dependent variable
and occurs as a result of the caregiving role. These studies have demonstrated that
depression in caregivers lead to an increase in burden and dissatisfaction with the
caregiving role and a lack of adjustment with caregiving. However the nature of the
caregiving situation might give rise to the cyclical situation in which the depressed
caregivers in general demonstrate less effective coping mechanisms than the caregiver
who was not depressed. The ability to think through a problem and use problem-
focused coping is diminished. A decrease in use of social support might result in an
increase in depression.

Patient Behavior Characteristics

The individual with dementia exhibits certain behavioral characteristics which
the caregiver might find particularly stressful. The impaired individual exhibits such
conduct as memory loss, indecision, disorientation, personality change, loss of ability
to perform activities of daily living such as feeding and dressing, incontinence,
wandering, immobility, and aggression. Often exhibited are "sundowning", the
period of confusion or disorientation at the end of the day, and insomnia in which
there is a loss of the day-night sleeping rhythm. Other significantly distressing behaviors may include "shadowing" or following the caregiver, and other demanding repetitive behaviors such as continual questioning, delusions, hallucinations, and paranoia. Any of these behaviors can become a source of stress to the caregiver.

Research has demonstrated that certain behavioral problems such as wandering, incontinence, and aggression are extremely distressing to the caregivers (Green, 1982; Rabins, 1982; Sanford, 1975). In a study of 256 caregivers, Jones (1984) identified that incontinence caused a great deal of distress to the caregivers. In another study on 73 caregivers, using multiple regression techniques, the caregivers identified patient memory and behavior issues as the most important caregiving problems faced (Brashares, 1994). Kinney (1989) identified that caregivers to patients who were socially responsible yet behaviorally inappropriate experience more stress in the caregiving role than other caregivers.

Identified patient behavioral characteristics were identified as a source of stress in the burden literature. Eagles (1987) determined that caregivers' scores on a stress scale were correlated with the care recipients' level of impairment and behavioral disturbance. In a study on 409 caregivers, Harper (1990) discovered a major contributor to burden was the patients' score on the functional dementia scale, indicating the patients' cognitive performance. Another research study indicated that patient behavioral and cognitive difficulties, as measured on the memory and behavior
checklist, emerged as the most important predictor of burden (Barusch & Spaid, 1989). Davies (1985) identified that caregiver burden was not related to the tasks performed during caregiving but was related to the troublesome behaviors exhibited by the patient.

There have been a few studies in which patient behavioral characteristics were not linked to a sense of burden. In a study on nursing home placement, Zarit (1986) found that relocation was more convincingly related to the subjective feeling of burden than the objective measures of the severity of the Alzheimer patient's behaviors. In another study, the subjective perceptions of the caregiver rather than the subject patient characteristics such as patient behaviors accounted for most of the feelings of burden, (Novak & Guest, 1989).

Summary: Patient Behavior Characteristics

The majority of studies in the caregiving literature identify patients' behaviors as distressing to the caregiver. The accompanying feeling of distress elicited by these behaviors can elicit a high level of stress among caregivers. Many of the current studies on patient behavior characteristics have been with large sample populations.

In critiquing many of the previous studies it is unclear whether the patterns of patient behavioral characteristics were measured in a longitudinal pattern. For example, studies to determine whether at certain stages of caregiving certain behavior characteristics are distressing to the caregiver. The clarification of stages of
caregiving and the division of sample population into stages might add clarity to the relationship of patient behavior to distress or satisfaction in the caregiving role.

It would appear that since many of these patient behavior characteristics are outside the control of the caregiver, the emotion-focused coping mechanisms according to previous research are most effective in dealing with situations. Therefore the disruptive patient behavior characteristics might lead to an increase in emotion-focused coping mechanisms.

**Hardiness**

A hardy individual is one "able to withstand fatigue, deprivation, etc.; robust, vigorous" (New Work Dictionary, 1987). A conceptual definition according to Kobasa (1979) of a hardy individual is a highly stressed but healthy individual with a multifaceted personality style termed "hardiness." Hardiness is separated into three different characteristics: commitment, control and challenge.

The commitment portion of hardiness defines persons high in responsibility who tend to involve themselves in whatever they are doing, rather than performing in an alienated, perfunctory manner (Kobasa & Maddi, 1982). Commitment is the ability to believe in the truth, and know the importance and value of who one is and the activities in which one is engaged. There is the tendency for the committed individual to become involved in the variety of life situations including work, family,
interpersonal relations, and social institutions. Inherent in commitment is the overall sense of a mission (Kobasa, 1980). The measure of commitment is constructed by a twelve-item Alienation Scale (Maddi, Kobasa & Hoover, 1979). The opposite of alienation is commitment and the scale measures functioning in work, social institutions and interpersonal relationships, and family. Lack of commitment is related to self-estrangement, normlessness, cultural separation, and social isolation (Seeman, 1983).

The second component of hardiness is control, which includes the notion that individuals high in control believe and act as if they can influence the events of their experiences rather than be powerless in the face of outside forces (Kobasa & Maddi, 1982). Persons with control seek explanations for events not in relationship to other's actions or fate but with emphasis on their own responsibility. In other words, individuals who demonstrate control are capable of acting effectively on their own behalf. (Kobasa, 1980). Hardy people are seen as individuals who reject the notion that luck, fate, change, or an unfriendly power determine one's fate, and they optimistically believe that they can shape their destiny.

The third component of a hardy personality is the concept of challenge. Persons high in challenge regard life's changes to be the norm, rather than the exception, and anticipate these changes as stimuli to growth rather than as threats to security (Kobasa & Maddi, 1982). Much of the disruption associated with the
occurrence of a stressful life can be anticipated as an opportunity and incentive for personal growth. Characteristic of the challenge is the openness and cognitive flexibility to tolerate ambiguity. Challenge is measured by the fifteen item Security Scale of the California Life Goals Evaluation Schedule (Kobasa & Maddi, 1982).

It has been hypothesized that hardy individuals handle stress better because they exhibit control or the capability of independently selecting among various courses a plan of action. Hardy individuals might also have cognitive control, or the ability to interpret, appraise, and incorporate various sorts of stressful events into an ongoing life plan, thus defusing their deleterious effects. The robust individual might also have a greater repertoire of coping skills suitable for responses to stress, along with an underlying motivation to succeed across all situations.

The concept of commitment acts to enable the hardy individual to remain healthier because a stressful encounter is tempered by a sense of purpose that prevents one from giving up. A committed individual experiences an involvement with others that serves as a resource against stress (Antonovsky, 1974). An individual who is devoted also turn to social support system for assistance in meeting demands. In addition to dedication to others, this type of person also has a strong sense of commitment to self and the ability to set goals and comprehend one’s capability. A committed individual has a sense of internal balance and structure necessary in making an accurate assessment of the stressful circumstances.
The challenge portion of hardiness assists individuals in remaining healthy by allowing a cognitive flexibility, which permits them to integrate and effectively appraise a fresh situation. The basic endurance allows them to explore and pursue the quest for answers to the problem and eliminates some of the strain of the stressor. Hardiness might also function by altering the appraisal of the potential stressful life events more favorably than individuals who are less robust.

Research began on the concept of hardiness in 1979 with four initial studies (Kobasa, 1979); (Kobasa, Maddi, & Kahn, 1982); (Kobasa, Maddi & Puccett, 1982a); (Kobasa, & Puccett, 1983) which involved investigation of hardiness in male managers from a midwestern utility company. Hardiness in all four of the studies investigated the function of hardiness in buffering against illness. Both prospective (Kobasa, 1979) and retrospective studies (Kobasa et al, 1982) confirmed the role of hardiness as a buffer between stressful life events and illness. In another study, Kobasa (1982a) investigated the role of hardiness and its interaction with exercise as a buffering effect on illness. Investigators found that hardiness and exercise interacted with stressful life events to decrease illness, but that both hardiness and exercise were distinct variables that preserved physical health in the face of a stressful life event. In the fourth study (Kobasa et al, 1983), hardiness and its relation to social support as a buffering effect upon illness was investigated. A positive mediating relationship between hardiness and social support was indicated; executives under stress who had

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high hardiness and social resources were healthier than other executives.

Another popular population for hardiness studies were college undergraduate students. In studying both male and female students, Bank and Gannon (1988) investigated the influence of hardiness on the relationship between stressors and psychosomatic symptoms. Other studies demonstrate the moderating effect of hardiness upon stress. The results indicated that students high in hardiness characteristics experienced less frequent stressors and perceived more events as minor and less stressful. In another study among students, investigating the role of hardiness as it related to preventive health behavior, Nagy and Nix (1989) found that hardiness and preventive health behaviors were related. Another study of undergraduates investigated the proposed mechanisms whereby hardiness moderated stress. High and low hardy individuals were given threatening tasks which were manipulated in order to influence the individual’s appraisal of the task in a manner consistent with hardiness theory (Wiebe, 1991). Results demonstrated that students scoring high in hardiness exhibited higher frustration tolerance, appraised the task as less threatening, and responded with more positive and less negative effect than those scoring low in hardiness. Female and male students did exhibit variations in the physiologic response to stress, with less hardy men exhibiting elevations in heart rate and hardy men lower elevation of heart rate, but with no influence detected on the heart rate of women.
Most studies on undergraduate students confirmed the buffering effect of hardiness. One study on students investigated the role of exercise, self-perceived fitness, and hardiness in providing a stress moderation effect upon illness, but demonstrated no support for the stress buffering effect of either fitness or hardiness. The authors felt that hardiness may affect health indirectly by altering the subjective interpretation of stressful life events. It would appear in studies among the college population that there is some positive data confirming the stress-buffering effect of hardiness on physical illness.

In the older adult population, Magnani (1990) conducted a study on hardiness, self-perceived health, and activity among independently functioning elderly adults. Results indicate that hardiness was an antecedent variable for successful aging, and hardiness was related to the elder’s self-perceived health. Another study on the elderly examined the role of hardiness, self-care practice, and perceived health care status (Nichols, 1993). Results of this study demonstrated that elderly adults with a higher level of hardiness involved themselves in more positive self-care practices and perceived their health status as significantly higher than the general elderly population. In a study by Lee (1991) on the effect of hardiness in the elderly the relationship between hardiness, current life events, and perceived health was investigated in male ranchers. Results indicated that the hardy ranchers had better mental and social health, but not physical health, in relationship to current life events.
In a study of women with rheumatoid arthritis, Lambert et al (1990) investigated the relationships among hardiness, social support, severity of illness, and psychological well-being. Results demonstrated that satisfaction with social support, hardiness, and length of morning stiffness were the best predictors of psychological well-being. In another study of ailing individuals (Blaney, Goodkin, Morgan, Feaster, Millon, Szipochick, & Eisendorf, 1991), 57 males infected with early HIV infections were studied to determine the relationship of stress-moderating effects of hardiness to psychological distress. In this population, no tempering of psychological distress was established, either as commitment or overall measurement of hardiness.

One critique of hardiness is that it appears to be a response style rather than a set of personality variables that change stressful events. For example, it is hypothesized that a hardy individual would focus on positive events of his/her life and therefore not report as much distress as the non-hardy. The mechanism in the pessimistic individual might include an affinity for depression, hostility, and anxiety, which affect the manner in which he/she appraises the experience (Allrod & Smith, 1989).

**Summary: Hardiness**

A critique of the hardiness concept is its lack of unitary construction in devising the components of hardiness: commitment, challenge, and control. The construct and three components appear poorly conceived, particularly in the manner in
which the components relate. The components also influence health outcomes differently, with only commitment and control relating to health outcomes in a systematic order (Hull, Van Trevren & Vimelli, 1989). In reviewing the literature the component of hardiness that has been identified as the most important construct is the sense of control, since control can be linked to the ability to combat stress (Cohen & Edwards, 1989).

The concept of hardiness has been studied in relationship to its buffering effect on physical health. The first studies were completed on male middle managers, and many studies on college students have indicated the positive buffering effect on health outcomes of a hardy personality. Few studies have investigated hardiness among the well elderly in stressful situations. The conceptual basis of hardiness has yet to be demonstrated; also undetermined is whether hardiness is a latent variable manifested in three ways: control, challenge and commitment. It has been hypothesized that hardy individuals may use different coping mechanisms to moderate the stressful situation and this may influence their view of the situation. Thus an individual high in hardiness who is committed to the challenge of caregiving might use an increased number of problem-focused coping mechanisms in dealing with the caregiving situation.
Social Support

Research on environmental factors which influence coping has often focused on the role of social support. Social support is envisioned as having a buffering effect against stress (Cohen & McKay, 1984). Using the Lazarus and Folkman (1984) stress and coping perspective, social support is viewed as a stress reducer through the process of cognitive appraisal. Social support serves to mediate stress by offering a broader interpretation of the available coping options.

Interest in the concept of social support developed in the mid-1970's when early authors described the deleterious effect of social isolation and low social integration on health outcomes. Social support has been defined as "something that maintains or sustains the organism by promoting adaptive behavior or neuroendocrine responses in the face of stress or other health hazards" (Cassel & Cobb, 1976, p. 116). Kahn (1979), another early pioneer in the area, described social support as "the interpersonal transactions that include one or more of the following: the expression of a positive affect of one person toward another, the affirmation of endorsement of another person's behaviors, perceptions, or expressed views, and the giving of symbolic or material aid to another" (p. 86). A more recent definition of social support includes the "exchange of resources between at least two individuals and is perceived by the provider or recipient to be intended to enhance the well-being of the recipient" (Shumaker & Brownell, 1984, p. 18).
The terms "social support" and "social network" are often used interchangeably and can lead to confusion. Social network refers to the "structural inter-relationships of family, friends, neighbors, coworkers, and others who provide support" (Tilden & Weinert, 1987, p. 613). The characteristics of the social network include size, density, frequency of contact, durability/length of relationships, and homogeneity. Social support on the other hand incorporates the psychosocial and tangible aid provided by the network and received by the recipient (Tilden & Weinert, 1987). The three characteristics of social support are: (1) emotional assistance, such as trusting, caring, liking or loving, appraisal; (2) information support, such as advice and information; (3) instrumental aid, such as provision of tangible goods, service or financial assistance.

The functions of social support have been identified in terms of different dimensions: support as relational provisions, as informational access, as structural components and as interaction. Support as a relational provision (Weiss, 1974) is social backing in terms of attachment, social integration, reassurance of worth and stability of a reliable alliance. Support which functions as a provision of information access includes the dimension that one is cared for and loved, that the individual is esteemed by others. Social support is viewed from the structural components as to size, density, homogeneity; social attributes such as age, sex, socioeconomic status and religious beliefs. The functions of social support in terms of interaction include
the aspects of content, or the meaning the individual gives to the relationship, directiveness, the sharing or reciprocity in the relationship, and intensity, or the willingness to invest time in the relationship.

The function of social support is also believed to be stress-decreasing. Using the stress and coping framework, stress is hypothesized to decrease through the process of cognitive appraisal, or primary appraisal, which broadens the individual's interpretation of the event and promotes a clearer understanding of the event. Thus, by having a source of social support, the individual can reflect on the meaning of the event on members of the social support network. In the second process of coping, secondary appraisal, or appraisal of coping options, social support functions to increase the number of coping options, enabling others to model emotional and behavioral coping strategies. Social support also serves to increase the individual's access to professional service agencies and encourages the individual to seek out assistance.

This stress-buffering model of social support operates on the premise that social support "buffers" the individual from the potential pathological influence of stressful events by two modes. The first is that stress is decreased when there are individuals within the environment who may assist with the problems. Second, the stress-buffering effect from social support only occurs when there is a match between the needs elicited by the stressful event and the ability of the support systems to meet
the needs of the individual (Cohen, 1988).

The stress-buffering model of social support includes four types of models (Cohen, 1988); information-based, identity and self-esteem, social influence, and tangible resource models. In the first information-based model the stress may elicit the support network to provide information about the nature of the potential stressful event or about ways of coping with the event. The information serves to decrease the potential threat/harm in the context of the existing coping mechanisms. This perception of support might actually be there even if no support is being provided. The resulting information might lead to health-enhancing behaviors and a regime of health maintenance. The identity and self-esteem model is based on the premise of others’ willingness to help and/or enhance the ability to cope, based on the increasing feeling of self-control and self-esteem. This increased feeling of control might serve to suppress the neuroendocrine response, enhance the immune function, or promote health-enhancing behaviors.

In the third framework, the social influence model, social support serves to buffer stress by the mechanism in which social control and perspectives serve to influence the individual’s coping. Using this theory, the social network pressures the individual to adopt particular modes of coping, and gives positive reinforcement to enhanced positive efforts to deal with a stressful event. The last model, the tangible resources model, adheres to the belief that the stress-buffering effect of social support
comes from the aid and tangible economic resources, which help to add a reappraisal and assistance to look at the event as less harmful than it would have been without resources.

Individual differences influence the development of social support systems and include many factors. One such factor, which influences the development of social support, is the perception of the exchange of assistance or reciprocity for the favor. If the individuals feel that they might not be able to return the courtesy they may be reluctant to ask in the first place, and such perception might affect the exchange. The individual variables affecting the exchange of social support include affiliative needs, privacy needs, stability of self-concept, autonomy and locus of control (Shumaker & Brownell, 1984). Other variables that influence the use of social support have been identified as the nature of the crisis situation, timing of the event, characteristics of the support network, nature of support offered, perceived adequacy of support, adaptive responses to stress, and environmental resources (Diamond & Jones, 1983). The problems affecting the chronically ill population often include the decreased ability to develop networks based on physical mobility limitation, and the stigmatization of the disease or disorder which makes help-seeking difficult. A lack of free time to develop a support network, as well as depression, also influences the ability to seek out appropriate support.

Results of research studies on caregivers of individuals with dementia have
often investigated the role of social support on the outcome variables. The main sources of social connection for caregivers are family and friends (Barusch & Spaid, 1989). A social support network of caregivers for demented spouses has been broadly defined to include home health assistance and confidants (Novack & Guest, 1989); however, a nucleus of household members is usually responsible for the long-term care needs of this population (Birkel, 1989; Novak & Guest, 1989). In a large number of cases there is one member of the family designed as primary caregiver. In a study that investigated the relationship of other family members to the primary caregiver, when the primary caregiver was a sibling, Brody and Associates (1989) discovered that the primary caregiver reported more strain from caregiving and demonstrated increased complaints and fewer interactions with other siblings than the other family member. In this study the primary caregiver also used guilt to elicit support of other family members.

The experience of caregiver burden was discovered by Zarit (1980) to be lessened when the caregiver made increased visits to the demented individual. There has been contradicting evidence concerning the stability of support systems over the period of caregiving. Clipp and George (1990), in a year long longitudinal study, found that support patterns remained stable over time. Miller (1987), on the other hand, found that such supportive relationship was drastically altered when faced with a cognitive impaired spouse.
In comparing caregivers of individuals with dementia to other groups of caregivers, Birkle and Jones (1989) looked at the comparison of caregiving networks of elderly individuals who were lucid and those who were demented. They discovered that families of elders with dementia relied more on social support within their own family systems than caregivers of lucid individuals. Results included the fact that caregivers of elderly demented were sustained in networks significantly different in terms of size, structure and composition than those of lucid individuals. One of the hypothesized factors affecting this outcome is the difficulty in locating assistance from individuals trained in the care of the cognitively impaired. In another study by Montgomery, Kosalaski, and Borgatta (1991) researchers looked at the differences between caregiving in noncognitively versus cognitively impaired elders. Their results demonstrated that more time was spent in services to the cognitively impaired elderly with an associated higher level of duty/obligation to this group than in noncognitively impaired elderly. There was higher hospital usage among the noncognitively impaired, but home health usage was about equal for both groups.

In other studies, researchers have investigated the types of social support needed by caregivers. Norbeck, Chaftez and Weiss (1991) looked at the types of support needed from three groups of severely mentally ill; adult schizophrenics, elder Alzheimer and children with developmental disorders. Their results demonstrated that the elderly Alzheimer caregivers were in need of emotional support, including social
involvement, feedback support including affirmation, listening and talking, and instrumental support in terms of respite, care help, backup and general household assistance. All three groups identified the single highest need was for information concerning the illness.

In a study investigating the stress-buffering effect of social support, Bailey, Norbeck, and Barnes (1988) discovered that the perceived stress of caregiving was related to psychological stress. The variable of the individual with dementia's mental condition, level of functioning, and the caregivers' length of time in caregiving related to the caregivers' stress level. The caregiver's satisfaction with social support was negatively related to psychological distress. In this study, there was evidence to support the role of social support mediating perceived caregiver stress and psychological distress. Clipp and George (1990) investigated the intervening variables that affect social support, such as caregiver characteristics, economic resources, physical and mental health. They found that the caregivers who had adequate financial resources, strong support, and better mental health had increased number of social support needs met. On the other hand the individuals with the greatest caregiving needs were those least likely to receive tangible support.

Kiecolt-Glaser and Associates (1988) discovered that caregiver and control groups had similar contacts in terms of frequency, helpfulness, and closeness of relationships; however, caregivers whose relatives had more behavioral problems
related to Alzheimer disease were more distressed and had more distressing relationships with others than the control group. Miller (1990) discovered the occurrence of self-withdrawal of caregivers from social activities and or/decreased invitations followed the assumptions of caregiving for a cognitively impaired spouse. Sanford (1975) found that 42% of caregivers identified social restriction as a major problem.

The role of social support in the caregiving situation often interacts with other factors, such as overall life satisfaction and physical health. For example, in using the Lazarus and Folkman theoretical framework of stress and coping in attempting to identify factors which related to adaptation among dementia caregivers, researchers discovered that social support led to 26% of the variance in life satisfaction and 28% of variance in the health of caregivers (Haley, Brown & Bartolucci, 1987).

In most studies, the concept of social support was measured by a scale developed specifically for the study and was not elder specific. An instrument was developed by Lubben (1988) specifically to measure social support and social network of the elder population. The instrument was developed to measure the individuals from whom the caregiver can rely for support. The scale measures friends, peers and looks at the quality of social support and reciprocity of helping behavior. The instrument was also tested on a culturally diverse population.
Summary: Social Support

The influence of social support on the caregiving experience has been of interest to researchers for years. However, the numerous studies do not put together a clear picture of the role of social support on the caregiving situation. The picture has concluded that the family of an individual with dementia has different sources of social support than do the ill elderly with one family member usually assuming the caregiving role. The buffering role of social support has not been proven. There have been numerous studies, and the comparisons of results are extremely difficult. The concept of social support was frequently measured qualitatively or with instruments developed specifically for the study which make comparisons difficult. There were few longitudinal studies to test causal relationships among the variables affecting caregiving.

The role of social support might be to broaden the caregivers ability to utilize problem-focused coping techniques. The availability of more individuals in the environment to contribute suggestions and provide information and support might boost the caregivers ability to engage in more effective coping mechanisms. Social support might also affect the emotion-focused coping strategies used by the caregiver; for example a member of the support network might encourage the caregiver to positively reappraise or use control in the situation, both are included as emotion-focused coping types of coping, according to Lazarus and Folkman (1984).
The critique of the literature on social support in relationship to caregivers has included the measurement issues in which there is a lack of consensus on instruments used across studies to measure social support. One reason for the multiple measures is the lack of clarity in defining the concept of social support, which makes it difficult to define, interpret and compare studies. Another area of concern in social support is the multi-dimension nature of social support; for instance the multiple factors which influence social support, such as the nature of the disease process, patient behavioral characteristics, economic status, proximity of family and depression. Often overlooked in caregiving studies is the point that social support can be stress-producing rather than stress-relieving.

Spirituality

Spirituality has been identified as one of the facets of human health and wellness affecting physical and emotional health. Spirituality was defined by the 1971 White House Conference on Aging as "man's (sic) inner resources, especially his ultimate concern, the basic value around which all other values are focused, the central philosophy of life . . . which guides a person's conduct, the supernatural and non-material dimensions of human nature," (Mosberg, 1971, p. 10). This concept includes the personal questions regarding the meaning of life, illness, and death. A definition of spirituality is as a "unifying force or vital principle of the
person that integrates all manifestations of the individual" (Burkhardt, 1989, p.71). Another expanded definition for spirituality is the "propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that empowers and does not devalue the individual" (Reed, 1992). This spiritual relationship can be experienced as connectiveness to oneself (interpersonally), in relationships to others and the environment (intrapersonally) and in relationship to God or a power greater than oneself (transpersonally). Spirituality then displays itself in interconnectiveness and enables the individual to step beyond the mundane to bestow the ordinary with extraordinary meaning.

The concept of spirituality also may include related concepts of religiosity "perception of one's belief and behaviors that express a sense of relatedness to a spiritual dimension or something greater than the self" (Reed, 1986, p.27). Religiosity has been as narrowly defined as attendance at formalized religious services. A wider perspective includes five dimensions of religiosity: the ideologic dimension (belief), ritualistic dimension (religious services), experiential (feeling), intellectual (information known) and consequential (religion affects health) (Glock, 1962). Spirituality, which includes the ability to produce self-transcendence, could be envisioned to assist with stress reduction. Self-transcendence is the expansion of one's conceptual boundaries inwardly through introspective activities, outwardly, through concern about others' welfare, and temporally by integrating the perceptions
to one's past, present, and future to enhance the future.

The components of spirituality have been identified as hope, generativity, inner meaning, mystical experiences, and religious behavior (Reed, 1992). The qualities a spiritual person possesses include compassion, wisdom, receptivity, creativity, openness, connectiveness, intuition and spirituality. Clinebell (1966) identified spiritual needs as the demand for meaning and purpose in life, the desire to give and receive love and the wish for hope and creativity.

It has been suggested that religion may enhance well-being in four ways. The first is through social integration and support. This enhancement of well-being might be provided through the opportunity for exchange of individuals with similar values and thinking and through the increase in the size of social networking from which the individual derives support. Religion might also provide rules and norms for behavior set within rituals which are imparted with significant meaning. The second means by which religion may enhance well-being is through the establishment of a personal relationship with the Divine Other. This relationship may produce solace and guidance, boost self-esteem and self-efficacy. Third, religion provides a value system which includes forgiveness of sins, which serves to mitigate guilt and decrease self-blame for situation which are irreconcilable. Fourth, religion gives a pattern of organization and personal lifestyle. All of these qualities enable an individual to develop coherence to values when faced with high level stress; thus religion is
hypothesized to have a buffering effect upon stress.

Research studies have investigated the role of religion in health and well-being of elders. In a study of 380 well elders 94% of respondents felt that religion was important to their life, they also increased religious behaviors such as prayer when symptoms of illness appeared (Mull, Cox & Sullivan, 1987). Studies have also demonstrated that women are significantly more religious than males (Blazer & Palmore, 1976), and uphold increased religious beliefs when faced with a terminal illness (Reed, 1986). In another study of 450 adults on the effect of religious involvement on the subjective feeling of well-being, it was determined that individuals with strong religious faith reported a higher level of life satisfaction, greater personal happiness, and fewer negative psychosocial consequences of traumatic life events. The study demonstrated that Protestants, Jehovah Witnesses, and Mormons have a greater life satisfaction than the other religious groups. The study did not support the stress-buffering effect of religion on traumatic life events. This study was conducted in the area of the strongly religious Bible Belt of the south.

A study conducted by Bearson and Koening (1990), on the use of prayer in health and illness, indicated that 75% of the subjects believed that health was a blessing from God. The same group did not believe that illness was a punishment of sin, or a means to determine the individual’s strength. The same study indicated that 53% of the subjects prayed when faced with medical symptoms, with prayer used
selectively for some symptoms over others. In another study, 100 white elders in South Carolina, were investigated on the use of religion and other emotions regulating coping strategies (Koening & George, 1988). Researchers determined that the most commonly used coping mechanism in dealing with the worst event in their life was trusting in God, prayer, and finding help and strength in God.

In investigating the role of religion among healthy and terminally ill adults, Reed (1986) discovered that the terminally ill experienced a significant increase in religiousness over the healthy group. In another study investigating 300 subjects comparing terminally ill hospitalized adults, nonterminal hospitalized adults, and healthy adults, Reed (1987), determined that as compared to nonterminal and healthy adults the terminally ill exhibited the greatest degree of spirituality. This spiritual perspective was positively related to well-being among terminally ill hospitalized adults. A significant, change in perspective, in a larger number of the terminally ill group was the movement toward spirituality as compared to the nonterminally ill, or well adults.

Summary: Spirituality

Spirituality has been defined and identified as an important component in quality of life in a number of studies, in both well and ill individuals. Many of the studies were conducted in the Bible Belt of the South. However, in a number of other studies the significance of a spiritual perspective in relationship to increased life
satisfaction has been confirmed, along with the relationship of increasing spiritual
dimension to life when faced with a life threatening illness. There have, to this date,
been no studies dealing with the effects of the spiritual dimension affecting the lives
of caregivers of persons with dementia when faced with the everyday strain of
caregiving.

When faced with the stress of a caregiving situation the ability to call upon a
higher power to alleviate stress might be significant. The use of a spiritual dimension
might serve to regain the caregiver’s sense of control of the situation or lead to a
positive reappraisal of the situation; the caregivers involvement in an organized parish
or church might offer additional social support at a time of need. These mechanisms
are a portion of emotion-focused problem-solving according to Lazarus and Folkman

Demographic Data Characteristics

Informal Caregivers

The definition of informal caregivers has varied throughout the research
literature. Caregivers of demented individuals have been defined as loosely as "an
individual required to provide some level of care to a memory impaired adult"
(George & Gwyer, 1986, p. 255). In another study the investigator defined caregiver
as an individual "principally responsible for providing or coordinating the resources required by the person with dementia, such as housekeeping, financial help, and shopping" (Zarit, Reever & Bach-Peterson, 1980, p.652). A more comprehensive definition is "the member of the patient's informal support system (family/friend) who carries the primary responsibility for providing a range of care to the patient at home without financial reimbursement and for a specified length of time" (Wilson, 1989, p.96). Malonebach & Zarit (1991) have suggested that the definition of caregiving be based on the functional status of the client, number and duration of caregiving tasks, and delineation of minimum involvement with the client.

In a research study, Bower (1987) identified five conceptual categories of parental caregiving. The first category, anticipatory caregiving, is based on a type of care delivery which involves anticipating the possible needs of a parent. A second category, preventive caregiving, involves activities carried out for the purposes of preventing illness, injury, complications, physical and mental deterioration. In the third category, supervisory caregiving, the caregiver is actively and directly involved in monitoring and assistance. Instrumental caregiving, the fourth category, involves actually doing for the individual with hands-on assistance. In protective caregiving, the final category, the caregiver functions to protect the care recipient from danger, either physical or psychosocial. As opposed to the care of a physically ill elder, the caregiver of the individual with dementia is involved in all stages of caregiving from
the onset of the disease. In the care of the physically ill elder, management is usually more involved and deals with physical attention at the termination of the illness. The category of protective caregiving is the most integral portion of the role of the caregiver from the outset of signs and symptoms of the disease.

Defining the amount of responsibility for providing care is a critical issue, in order to understand factors which contribute to the adjustment to the caregiving process. In one study, Stone (1982) divided caregiving responsibilities into four categories. In the first category, the primary caregiver was the person mainly responsible for taking care of the disabled individual with no other assistance. A second category, primary caregiver with informal help, was the person who had the main responsibility but was one of several unpaid individuals supervising the elder. The primary caregiver with formal and informal help was the third category, and included the human being who had main responsibility for care with unpaid and paid assistance. In the fourth category, secondary caregiver, the identified caregiver does not have primary responsibility for supervision but assisted on an as-needed basis. Thus it can be seen that the responsibility an individual caregiver assumes varies across a wide spectrum.

Literature on caregiving generally has had a limited examination of the individual dynamics between the individual being cared for and the caregiver, and the resulting satisfaction or burden in the caregiving role. Cantor (1983) describes
caregiving involving a two person dyad, the person receiving assistance, the care receiver and the individual providing care, the caregiver. In recent research, Motenko (1989) identified the positive relation of marital closeness to gratification in the caregiving role. The research demonstrated the relationship between the ability to abstract a positive meaning to the caregiving experience with satisfaction in the caregiving role.

A factor related to defining the caregiver concerns the living arrangements between caregiver and care receiver. Some caregiving research clearly deals with live-in caregivers while other studies include both resident caregivers and those whose care recipient is institutionalized (George & Gwyer, 1986; Gilhooly, 1986). Since the dynamics of the relationship varies dependent on the living arrangement, the definition of responsibility and living arrangement appears essential. The length of time the caregiver has been involved in the caregiving process also appears to be significant in the amount of stress experience by the caregiver. Stress scores have been found to be lowest in the first two years of caregiving; they then rise to a mild to moderate range at two to four years and remain at that level throughout the caregiving experience (Gaynor, 1990).

As in the case of most caregivers to elderly adults, the caregivers to demented individuals tend to be women and spouses of the elderly. In the noninstitutionalized elderly 38% of the care is provided by spouses, with 68% by wives and 32% by
husbands (Barusch, 1989). In relationship to the nonspouse "when the needs of the elder parent grows, the sex of the adult child is one of the most important and consistent predictors of caregiving involvement" (Horowitz, 1985, p. 613). Research has indicated that the female siblings are the primary caregivers to frail parents and that sons tend to be caregivers only in the absence of a female child or a wife who assumes responsibility (Horowitz, 1985). On a whole women tend to be involved in more caregiving than men (Barusch, 1989); (Kosberg, 1990); (Young & Kahana, 1989).

Summary: Informal Caregivers

In defining the informal caregiver, definitions have encompassed a number of components including the level of involvement of the caregiver, tasks performed, criteria for nonmonetary reward, amount of additional assistance obtained, sex, living arrangement and proximity. In a limited number of studies, the researcher investigated the emotional dependence and appraisal of the situation by the caregiver and care recipient. Based on these findings it would appear that the definition of a primary caregiver, without receiving monetary award, living with an individual with dementia and having the majority of the care for the individual, would provide a definition for the primary caregiver in this research.
Gender

Predominant in the literature is the fact that most informal caregivers to individuals with dementia are largely female. In a long term national survey identifying the demographic profile of caregivers (Stone, 1987) 72% of caregivers are female, either wives, daughters, or daughters-in-law. In a study to identify under which conditions sons take responsibility for caregiving, it was only when they were most geographically available, that sons accepted the responsibility for caregiving (Horowitz, 1985). This study investigated gender differences involved in the type of caregiving. Results demonstrated males exhibiting more financial assistance with the females more hands on care. Overall sons exhibited less stress than daughters in the caregiver role (Horowitz, 1985).

In other research the majority of studies have found women to exhibit increased stress in the caregiving role. In a study of 32 wife and 31 husband caregivers it was found that wives exhibited more stress initially to caregiving but there was no difference after a two year period (Zarit & Todd, 1986). In a study of 131 caregivers of which 79% were women (Barusch & Spaid, 1989), the ladies experienced a higher degree of burden on the burden scale by Zarit (1986). In another study in which the sample included 64% women, the females were again found to exhibit more burden and stress in the role (Kosberg, 1990).

In investigating the effect on the preponderance of females in the caregiving
role and from the data indicating that female caregivers perceive a different level of stress in the caregiving situation, it appears that selection of sample subjects based on sex would be appropriate in this study.

**Overall Summary**

In reviewing the literature it is apparent that the majority of studies conducted on adjustment to caregiving deal with the concept of burden. The concept of satisfaction to the caregiving role is a relatively new dimension in the caregiving literature. The role of coping mechanisms, in dealing with a stressful situation, has been researched in a number of different populations. The value of emotion-focused coping techniques in the face of an unchangeable situation has been well documented.

Literature, in abundance, has supported the role of depression as an outcome of caregiving. Other well researched factors have included the effect of social support and patient behavioral characteristics on adaptation to the caregiver role. Hardiness and spirituality are two factors which have yet to be investigated in relationship to the caregiver.

A rich body of knowledge is available for theory building. The major variable in adaptation to the caregiving role appear to be identified. However, researchers have yet to examine these variables in attempt to clarify 1) the completeness of the causal network, 2) the direction of causality among the complex relations, and 3) the
influence of hardiness and spirituality in the caregiver population.

The present research tested the hypothesis that satisfaction and burden in the caregiving role is mediated by coping mechanisms, both problem-focused and emotion-focused. It is postulated that the caregiver's pre-existing physical health and depression will have a direct effect on adjustment to the caregiving role. Patient behavior characteristics (e.g., socially disruptive) will affect the use of emotion-focused coping. The caregivers hardiness and social support will positively influence problem-focused coping and spirituality will positively affect the use of emotion-focused coping.
CHAPTER THREE

Research Aim, Questions, and Operational Definitions

The purpose of this chapter is to describe the research aim and identify the specific research questions which this study addresses. In addition variables are theoretically and operationally defined. In conclusion specific hypothesis are outlined.

Research Aim and Questions

The general aim of this research was to test a theoretical model of adaptation to the caregiving role among caregivers to individuals with dementia. In this model, the caregiver's physical health, depression, hardiness, social support, perception of patient behaviors and spirituality, as mediated by the cognator subsystem in the form of the caregiver's coping mechanisms, were hypothesized as having an effect on the caregiver's appraisal of the caregiving role.

Research Questions:
The research questions addressed in this study included:

1) What types of coping mechanisms according to Lazarus and Folkman are utilized frequently by caregivers?

2) What types of behaviors on the part of the individual with dementia elicited greater distress in the caregiver?
3) What types of behaviors on the part of the individual with dementia elicited little distress in the caregiver?

4) What factors are appraised as burdensome by caregivers, and to what degree?

5) What factors are appraised as offering satisfaction or indicate mastery in the role by caregivers?

The research questions related to the conceptual framework that address the hypothesized relationships in the model. These include:

1) What is the effect of physical health on appraisal of the caregiving role?

2) What effect does depression have on problem-focused coping mechanisms used by the caregiver?

3) What impact does depression have on problem-focused coping mechanisms employed?

4) How does hardiness influence utilization of problem-focused coping mechanisms?

5) What influence does social support have upon the use of problem-focused coping mechanisms?

6) How does the patient's behavior affect the use of emotion-focused coping mechanisms?

7) Does spirituality influence the use of emotion-focused coping mechanisms?

8) How do problem-focused and emotion-focused coping influence caregiver appraisal of the caregiver role?
9) What is the relationship between physical health, depression, patient problem behavior, hardiness, social support, spirituality and use of emotion and problem-focused coping mechanisms in mediating appraisal of the caregiving role.

**Theoretical and Operational Definitions**

**Dependent Variable**

Appraisal of the caregiver role is the dependent variable in this study, and is viewed in relationship to the potential stressors, stimuli in the caregiving environment, and viewed in relationship to the caregiver’s coping efforts. The caregiver’s appraisal is defined as the cognitive and affective assessment and reassessment of the potential stressor and the mastery of one’s coping attempts. Caregiving appraisal consists of three aspects: caregiving burden, including subjective distress linked to caregiving; caregiving satisfaction, a subjective feeling that what one does or feels as a caregiver gives a source of personal fulfillment; and caregiving impact, the demand of caregiving which is a subjective appraisal of the caregiving situation and whether the demands of caregiving are stressful. The concept of appraisal in terms of the Roy Adaptation model to the caregiving role, is influenced by the caregiver’s interpretation of the impact of the caregiving situation on one’s life, incorporating burden, satisfaction and impact of the caregiving role.
Independent Variables

Physical Health. Physical health is the subjective feeling state, signs, or symptoms, as evidence of illness which affects the performance capacity of the individual. The physical health status of the caregiver in this study will be determined by the self-report. The instrument used to measure physical health was the Global Self Rated Health Scale (LaRue et al., 1979). This instrument has been used widely in gerontological studies and has been found to correlate highly with physical examination (LaRue, et al., 1979).

Depression. Depression is a mood of sadness that consists of feelings of helplessness and hopelessness, as well as lack of appetite, energy and rest (Robinson, 1989). Depression was measured, in this study, by the Center of Epidemiological Studies Depression Index (CES-D) (Radloff, 1977).

Hardiness. Hardiness is a personality style consisting of a complex interrelationship of commitment, control, and challenge. Commitment is the ability to dedicate oneself to the task, project or relationship. This is not an inherently blind commitment, but also has an element of realism in evaluating the level of responsibility needed in this situation. Control is the power to offer direction to a situation. In the case of hardiness, control is the ability to obtain as much power as one needs for comfort or to remain committed to a situation. Challenge is the special effort or dedication that a task demands. Challenge also assists individuals to accept
errors as errors rather than as personal faults. The interrelationship of commitment and control in viewing relationships enables the individual to view situations as problems or challenges rather than crisis. The use of commitment and control also allows one to know when to give in or to ignore the situation. Therefore, although there are three distinct aspects to hardiness, they interact to create a unified concept. In this research hardiness was measured by the Personal Views Survey (Kobasa & Maddi, 1984).

Social Support/Social Network. Social network incorporates all the individual's social contacts and are "described along structural and interactional dimensions including size, source of ties, member homogeneity, frequency of contacts, and opportunity for reciprocal exchange of support" (Ell, 1984, p.135). Social network consists of various components including networks of family and friends, confidants, assistance to others, and living arrangements. Social support is assistance and support of resources between two or more individuals intended to enhance the well-being of the individual such as involvement in financial and instrumental activities (e.g. shopping, recreation, and emotional support). In this research social network was measured by the Lubben Social Network Scale (Lubben, 1988) and addresses size of active network, size of intimate network, confidant relationships and frequency of contact. Social support was measured by the Formal and Informal Social Support Scale (Hassinger, 1985) and addresses support in terms...
of shopping, recreation and emotional support.

**Patient Problem Behavior.** Patient behavior is behavioral characteristics demonstrated by the person with dementia such as memory loss, indecision, disorientation, personality change, loss of ability to perform activities of daily living, incontinence, wandering, immobility or aggression. Problematic behavior was measured by Part A of the Memory and Behavior Checklist (Zarit et al., 1982). These questions are completed by the caregiver concerning the care receiver. The tool measures the frequency of a variety of problematic behaviors, including ability to conduct activities of daily living. Part B of the Memory and Behavior Checklist measures the caregiver's evaluation of how stressful the behavior identified in part A is to the caregiver. The distress is rated in degrees from not distressful to extremely distressing.

**Spirituality.** Spirituality is the perception of one's belief and behaviors that express a sense of relatedness to a supernatural dimension or something greater than the self (Reed, 1989). Spirituality has a broader meaning than religiosity, which may or may not include religious rituals and behaviors, and does not necessarily involve participation in organized religion. Spirituality has been suggested as a means by which to enhance well-being. Spirituality was measured for this study by two questions devised for this study, one on how important religion is to the subject's life and the other on how important religion is to one's health. Responses are recorded...
Coping Mechanisms. Coping mechanisms are constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person (Folkman, 1984). Lazarus and Associates (1986) defined eight styles of coping under two separate categories: emotion-focused and problem-focused. The types of styles included under emotion-focused coping include distancing, self-control, escape/avoidance, seeking social support, accepting responsibility, and positive reappraisal of the situation. Problem-focused coping mechanisms include planful problem-solving and confrontation. To measure the use of coping mechanisms based on the Lazarus and Folkman definition, the Ways of Coping (WOC) Scale, a 66 item subjective self-report was utilized (Folkman & Lazarus, 1986). The tool contains eight subscales: two measure problem-focused coping and six emotion-focused coping. Analysis was conducted utilizing the two types of coping emotion-focused and problem-focused coping.

Potentially Intervening Variables

Relationship of caregiver to carereceiver. The caregiving process consists of the dynamics of two individuals: the person receiving assistance, the care receiver; and the individual providing the care, the caregiver. In the literature, the definition
of informal caregiver has been as loosely stated as "an individual required to provide some level of care to a memory-impaired adult" (George & Gwyer, 1986, p.254). In this study, the need to tighten this definition for research purposes was examined. In investigating the caregiving population in the noninstitutionalized elderly, the largest proportion of the care is provided by spouses with 68% of the care delivered by wives, and 32% by husbands. In relationship to nonspouses "when the needs of the elder parent grows, the sex of the adult child is one of the most important and consistent predictors of caregiver involvement" (Horowitz, 1985, p. 613). Research has also indicated that the female siblings are the primary caregivers to frail parents, and that sons tend to be caregivers only in the absence of a female child or a wife who assumes responsibility (Horowitz, 1985). On a whole women tend to be involved in more caregiving than men, and women tend to perceive more burden in their caregiving roles (Barush, 1989). For this study, since there was a difference in perception of burden between male and female caregivers, and the largest proportion of caregivers were female, sample subjects were limited to female caregivers, either wives or daughters.

**Primary responsibility/living arrangement of caregiver.** Defining the amount of responsibility for providing care is a critical issue in understanding the factors which contribute to the adjustment to the caregiving process. The primary responsibility of a caregiver for a care receiver in a nursing home is a different
category of responsibility than for a caregiver with the care receiver at home. One factor that would enter into the difference is the amount of hours the caregiver spends with the care recipient. Since the dynamic of the caregiving experience varies, dependent upon the definition of responsibility and living arrangement, a clear definition of both is necessary. For this study the sample subjects were limited to caregivers who maintained primary responsibility for caring for the care receiver and also who lived in the same household. Data were collected on the number of hours per day the caregiver spent with the care receiver.

Length of caregiving. The length of time the caregiver has been involved in the caregiving process also appears to be significant to the amount of stress experienced by the caregiver. Stress scores have been found to be lowest in the first two years of caregiving; then they rise to a mild to moderate range at two to four years and remain at that level throughout the caregiving experience (Gaynor, 1990). This study included caregivers of all durations but data on length of caregiving was assessed in terms of months and years since commencement of caregiving activities. Recent research has defined the Alzheimer caregiver as engaged in a fatalistic career process with identifiable levels including the encounter stage, enduring stage and exit stage (Lindgren, 1993). Another group identified two stages in the caregiver career as beginning and awakening (Kobayashi, Yusasa & Noguchi, 1995). Thus the newer studies suggest stages in the caregiving process which are related to length of time
engaged in caregiving activities.

Educational level. The educational level might affect the ability to choose between thinking through solutions to caregiving problems and the use of problem-focused versus emotion-focused coping. The educational levels of both caregivers and carereceiver were assessed in years in both high school and college.

Statement of the Hypothesis

The major hypothesis tested was that the proposed theoretical model would fit the data when tested, using structural equation modeling (SEM). Structural equation modeling is a statistical methodology that takes a hypothesis-testing approach to multivariate analysis of a structural theory. One advantage of SEM is that it takes a confirmatory rather than exploratory approach to data analysis. The second advantage is that whereas traditional multivariate procedures are incapable of either assessing or correcting for measurement error, SEM provides definite estimates of error parameter. In this model, the physical health, depression, hardiness, social support, patient problem behaviors and spirituality as mediated by the caregiver’s coping mechanisms were hypothesized as having an effect on the adaptation to the caregiving role.

Specific hypotheses aimed at the research question include the following:
**Hypothesized Direct Relationships:**

H1  Better physical health will result in high appraisal scores, indicating that the caregiving role is more satisfying, less burdensome, and with lesser impact on the caregiver’s life.

H2  Depression will result in lower appraisal scores, indicating that the caregiving role is less satisfying, more burdensome, and with a greater impact on the caregiver’s life.

H3  Problem-focused coping will result in high appraisal scores, indicating that the caregiving role is more satisfying, less burdensome with lesser impact on the caregiver’s life.

H4  Emotion-focused coping will result in lower appraisal scores, indicating that the caregiving role as less satisfying, more burdensome and with a greater impact on the caregiver’s life.

**Hypothesized Indirect Relationships:**

H5  Greater depression will result in less problem-focused coping, which in turn will result in lower appraisal scores indicating the caregiving role as less satisfying, more burdensome, with a greater negative impact on the caregiver’s life.

H6  Hardiness will result in more problem-focused coping, which in turn will result in higher appraisal scores indicating the caregiving role as more satisfying, less burdensome, with a lesser negative impact on the caregiver’s life.
H7 Greater social support will result in more problem-focused coping, which in turn will result in higher appraisal scores indicating the caregiving role as more satisfying, less burdensome, with a lesser negative impact on the caregiver's life.

H8 Patient problem behaviors will result in more emotion-focused coping, which in turn will result in lower appraisal scores indicating the caregiving role as less satisfying, more burdensome, with a greater negative impact on the caregiver's life.

H9 Greater spirituality will result in an increase in emotion-focused coping, which in turn will result in lower appraisal scores indicating the caregiving role as less satisfying, more burdensome, with a greater negative impact on the caregiver's life.

According to the review of the literature, the above directional hypotheses for appraisal of the caregiving role are proposed. Testing of the model will be based on the relationship of the proposed interaction of the hypotheses.
CHAPTER FOUR

Methods

The purpose of this chapter is to describe the methods utilized to collect and analyze data for this study. The rationale for design including setting, sample, procedures and instruments are described. Statistical and theoretical assumptions, in addition to as management of data and analytic techniques are reported.

Design and Rationale

This study used a quasi-experimental design and employs causal modeling, based on Lazarus and Folkman's (1966) cognitively-based theory of stress and coping and the Roy Adaptation model of nursing in a population of caregivers of persons with dementia. Although there is a body of knowledge showing relationships between physical health, depression, patient behavior characteristics and social support, and the relationship between these psychosocial variables as related to burden in the caregiving role, currently there is no model which analyzes the combination of variables. In addition, the roles of hardiness and spirituality as well as the mediating function of coping mechanisms utilized to increase adjustment to the caregiving role have not been fully explored. Furthermore, while there is some certainty that these factors play a role in adaptation to the caregiving role, there is substantial uncertainty
about the nature of the causal pathways involved.

The study used a group of female caregivers, either wives or daughters who cared for an individual with a dementing disease such as Alzheimer's at home. These caregivers were the primary caretakers for this individual. By focusing on an exclusively female sample, it was hypothesized that the potentially confounding influences of different stress levels and coping mechanisms on female versus male caregivers could be eliminated (Borden & Berlin, 1990). Of particular interest in this study was the identification of significant relationships between the indirect method in which coping mechanisms mediated between the multiple external and internal variables and the level of appraisal of the caregiving role. Latent factor structural modeling was utilized on the data to accomplish this task.

Settings

Subjects were recruited through the Los Angeles Alzheimer’s Association "Helpline" and the UCLA Geriatric Behavioral Neurology clinic. Individuals who called the "Helpline" with questions, or who were patients at the clinic and met sample study criteria, were selected as potential applicants. The largest proportion (99%), of subjects were recruited from the Alzheimer’s Association "Helpline" following the protocol described under data collection procedures. Contact was initiated by a letter of explanation and request to participate in a structured interview
in their home, taking approximately one to two hours. Interviews were conducted at the subject’s convenience and at a location mutually agreed upon by the interviewer and sample subject. For example, a restaurant or other location was chosen, if the caregiver felt uncomfortable meeting the researcher in their home. Ninety-five percent of the sample subjects agreed to be interviewed in their home.

Sample

The target population identified for this study were English speaking female caregivers, either wives or daughters, who were the primary caregivers to a patient with Alzheimer disease or related dementing disorder such as multi-infarct dementia. The caregiver had to be living in the same household as the care recipient, thus eliminating subjects who had placed the care recipient in a skilled nursing facility. Nonprobability convenience sampling was used to solicit a total of 129 subjects, 99% who were recruited through the Alzheimer’s Helpline and 1% from the UCLA Geriatric Behavioral Neurology clinic.

A projected sample of 130 was suggested by Dr. Lynn Brecht (personal communication, 1993) using the rule-of-thumb of 5-20 subjects per estimated model parameter (Tabachnick & Fidell, 1989). Because analysis often produces unstable results with the minimum subjects per parameter, an attempt was made to obtain the largest sample possible, taking into account the practical constraints of time involved
Sample selection criteria included caregivers who were: 1) female; 2) the wives or daughters of an Alzheimer or related disorder care recipients; 3) the primary caregivers to the person with Alzheimer's disease or related disorder; 4) living in the same household as the care recipients; and 5) English speaking. Sample selection in previous research on these variables have included both male and female caregivers, with gender differences noted in the area of depression and burden in the role. Thus a single gender of subjects was chosen for the present study. The largest percentage of caregivers are female and therefore this population was target for this study.

Data Collection Procedures

A request was made to the Alzheimer's Association of Los Angeles to utilize their "Helpline" to gather sample subjects. The application process included a submission of the biosketch of the researcher, human subjects approval, and a copy of the entire research proposal. The medical and Scientific Advisory Board approved the proposal and rated it as acceptable, which was defined as scientifically sound, ethical, and feasible. Sample subjects were then recruited by a monthly visit by the researcher to the Alzheimer's Association Los Angeles office to examine "Helpline" intake forms from the previous month. The only potential subjects contacted were callers to the "Helpline" who stated on the intake form that they were willing to take
part in research and who met the sample subject criteria. Out of 461 potential subjects 129 participated, with a 30% post card rate for participation. Only potential subjects' name, address, telephone number and relationship to the individual with dementia were compiled and a copy of the list left with the Program Director at the Association. The list of potential subjects was kept confidential by the researcher with anonymity assured by the identification of the subject by an assigned research subject number.

A subsequent letter requesting the individual’s participation in the study was sent to prospective subjects (Appendix A). The letter included a short introduction of the researcher, purpose of the study, sample selection criteria, length of time involved in data collection and the fact the subject would be paid $10 upon completion of the interview. Enclosed in the letter was a stamped post card, indicating interest in participation in the study and the best time to contact the subject by telephone. There was also the researcher’s telephone number both day and evening, in the event the subject had additional questions.

Upon receipt of the post card indicating interest, the researcher or a trained research assistant contacted the subject by telephone. An appointment date and time were set for the interview. The interview was held either in the subjects’ home or at a mutually agreed upon location. Either the researcher or one carefully trained research assistant collected data. The researcher collected data on the first ten
subjects and after that all the remaining data were collected by a research assistant. The research assistant was precisely trained by the researcher and directly supervised in the initial data collection. Instruction included the method of questioning in order not to lead the subjects toward the answer.

Questions on the questionnaire (Appendix C) were asked verbally by the researcher, who also recorded the response in writing on the questionnaire. This was to insure that all questions were answered. Selections for response using the Likert scale were printed on white cards with large print to assure the subject to remember the possible responses. Completion of the questionnaire took approximately one to two hours, depending upon the individual subject.

Instruments

Physical Health

The Health of the caregiver was measured by the Global Self-Rated Health scale. This consists of one question on a five-point Likert-type scale on how the individuals rate their own health (Appendix C, Item 7). The response ranged from excellent, very good, good, fair and poor. A score of one was assigned to excellent health and scores decreased with poor health allocated a five. Thus, the poorer an individual’s self-rated health the higher the score. This instrument has been used widely in gerontological studies and has been found to correlate highly with
physician-related health (La Rue, et al., 1979). The scale has been used with both men and women. In this study an alpha coefficient (0.47) for physical health determined by two items, one the Global Self-Rated Health scale and a single item on the Caregiver Appraisal Tool (Lawton, 1988) related to health (Appendix B, Item 7 and Section B Item 7).

**Depression**

The level of depression in the caregiver was measured by the Center for Epidemiologic Studies Depression scale (CES-D) (Radloff, 1977). The CES-D is one of the two most frequently used instruments in caregiver studies, the other being the Beck Depression Inventory (Beck, 1967). The Beck Depression Inventory is more biologically based and therefore the CES-D was chosen since it is particularly appropriate for the measurement of depression in older adults, and because it contains a minimum of two items that focus on somatic problems, the majority being affective, unlike some other depression scales (Gallagher, Thompson & Levy, 1980). The CES-D is a 20-item self-report scale designed to identify individuals at risk for depression (Appendix C, Section D).

The instrument measure asks respondents to indicate levels of symptoms in the past six months on a five-point scale (zero to four), with "never" assigned a zero and "always" assigned a four, the higher score indicating increased depression. CES-D scores are calculated by adding scores for each item in the scale. Scores range from
0 to 60, with higher scores reflecting more depressive symptoms. Individuals scoring 16 or more are generally believed "at risk" for clinical depression. Internal consistency, tested in several samples, has been 0.85 or greater (Radloff, 1977). The instrument has been used in both male and female populations. In this study the alpha coefficient on the CES-D twenty items was 0.91.

Hardiness

The personality style of hardiness was measured by the Personal Views Survey (Kobasa, 1984) a fifty-item survey with three subscales to measure the variables; commitment, challenge and control (Appendix C, Section E). The items are measured on a four-point Likert scale with "not true" responses scored one, and "completely true" responses a four. The scale contains a possible two hundred points. The three sub-scales do not stand alone and are not intended to be used as separate entities; hardiness is an interactive compound rather than an isolated element. The reliability index coefficient alpha on the commitment scale 0.92; control 0.90; challenge 0.89 and overall hardiness 0.92 with test re-test 0.93 (personal correspondence Hardiness Research Institute, Skip Dane). A high score indicated a high level of hardiness. In this study the alpha coefficient was conducted on overall hardiness as 0.88. All scoring of this scale was performed by the Hardiness Research Institute, since information regarding subscales was not divulged. The Hardiness Research Institute indicates, although the initial reliability and validity was conducted
Social Support

Social support was measured by the Lubben Social Network Scale (LSNS) (Lubben, 1988) a tool developed for use in gerontological studies which examines size of intimate network; family relationships, friend relationships and interdependent mutual support relationships (Appendix C, Section H). The scale consists of ten items the total LSNS score is obtained by adding the scores from each of the ten individual items. The total LSNS scores can range from zero to fifty. Low scores indicate a willingness or ability on the part of the caregiver to accept assistance in caregiving activities. Reliability analysis was developed on the ten-item scale in three different large samples (N > 1000) of elderly individuals (Cronback alpha .70). Alpha coefficient for this study based on ten items was 0.72. The measure of social support was also measured by the Formal and Informal Social Supports (Hassinger, 1985) (Appendix C, Section F). The instrument measures three types of assistance: in-home paid help, in-home unpaid help, and social support network including frequency of contact. The scale contains twelve items; eight in six-point Likert-format, from "not-at-all", to "extremely", and a separate measurement of social network in a variable Likert scale. The original scale had test-retest reliability. Alpha coefficient on the Formal and Informal Social Supports in this study was 0.04. In investigating the scale the variable Likert format for items nine and ten could have
been the cause of this low test-retest reliability. In this study, due to the low reliability of the Hassinger instrument, only the Lubben scale was utilized to measure social support. Original testing of the Lubben Social Network Scale was conducted on a population of elderly in California, with approximately two females to every male (Lubben, 1988).

**Patient Behavioral Characteristics**

The measure of frequency of problematic behaviors in the individual with dementia was measured on the Memory and Behavior Checklist (Zarit, Reever, Bach-Peterson, 1980) (Appendix C, Section C). The checklist was developed and tested using both male and female caregivers. The caregiver reports on the frequency of troublesome behaviors such as inability to perform of activities of daily living, and such other frequent behaviors as wandering, asking repetitive questions, forgetting, or night waking. The frequencies were recorded on a Likert scale zero-to-five, with zero having "never occurred" and five "would occur if not supervised". The second portion of the scale measures distress, or how much the behavior bothers the caregiver when this occurs on a five point scale from zero to four, with zero signifying "no distress", and four indicating the behavior as "extremely distressing". Scores for frequency tolerance cross product were obtained by summing scores for individual items. Split-half r = 0.62 to 0.66. In this study the alpha coefficient was reestablished at 0.90.
Spirituality

Spirituality was measured by two items developed for this study (Appendix C, Items 13 & 14). The two questions requesting information on how important religion is to the individuals' life and health are on a five-point Likert scale ranging from "not important" to "extremely important". The lower the score the more the individual attributes religion to his/her life, and the higher score indicating a minimal degree of self-attributed spirituality in the individual's life. The score was obtained by summing the scores on the individual items. The alpha coefficient for this study was 0.84.

Coping Mechanisms

The caregiver's coping mechanisms were measured on the Ways of Coping (Revised) (Lazarus, 1985) (Appendix C, Section A). This scale measures a broad range of behavioral and cognitive strategies individuals use to manage internal or external demands of specific stressful situations. The Ways of Coping Scale was developed and tested on both male and female college students. The scale consists of a four point Likert scale from zero, technique not used, to three technique used quite a bit. The larger number indicates frequency in use of coping mechanism. This scale consists of a 60 item tool with eight scales, one problem-focused, and seven emotion-focused. Validity and reliability were established utilizing factor analysis with eight scales established with alpha coefficients: problem-focused 0.85, wishful thinking 0.84, distancing 0.71, emphasizing the positive 0.65, self-blame 0.75, tension...
reduction 0.65 and self-isolation 0.65.

In the initial analysis of 90 subjects involved in this study, validity and reliability of the coping scales with the eight subscales provided alpha coefficients extremely low. Reanalysis of the data included a decision to redivide the coping scales. The new scales were reestablished as follows:

Problem I - confrontive coping mechanisms (Appendix C, Section A, Items; 5,6,7,45,48)

Problem II - planful problem solving (Appendix C, Section A, Items; 1,25,34,38,47,51,56)

with overall alpha for the two combined scales at 0.76. Emotion focused coping was divided as follows:

Emotion I - positive reappraisal (Appendix C, Section A, Items; 14,18,22,29,35,37)

seeking social support (Appendix C, Section A, Items; 9,17,21,30,41,44)

Emotion II - use of self-control (Appendix C, Section A, Items; 1,13,23,34,36,42,53)

accepting responsibility (Appendix C, Section A, Items; 8,24,28,52,64)

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Emotion III - distancing (Appendix C, Section A, Items; 4,10,11,12,26,40,43,46,49)
escape avoidance (Appendix C, Section A, Items; 3,15,19,20,31,32,33,39,54,56,58,59)
the combine alpha for the emotion focused coping was 0.79.

The Ways of Coping Scale has been criticized in recent literature (Carver, Scheier & Weintraub, 1989). One critique is that the responses to the items compose several factors rather than just emotion-focused and problem-focused coping. For example, some of the emotion-focused responses involve denial, positive reinterpretation of the results, or the use of social support -- responses which all have different implications in investigating outcomes. Other problems identified with the Ways of Coping Scale (Carver, Scheier & Weintraub, 1989) include divergence between subscales. An example is that problem-focused coping contains two subscales: planful problem-solving, and confrontive coping, both of which indicate different techniques in dealing with stress. Another example, "seeking assistance" is included in the emotion-focused scale of seeking social support rather than under problem-focused coping. The second difficulty is a lack of clear focus in some of the items, for instance "took a big chance and did something risky" can be interpreted as broad and as reckless as drug usage or as narrow as not concentrating on driving while thinking of something stressful. The third critique of the Ways of Coping...
Scales, results from the fact that the instrument was constructed empirically rather than theoretically and was constructed from typical coping responses identified as in frequent usage instead of from an established theoretical framework.

Another critique on the self-report Ways of Coping Scales (Greenberg, Kennedy-Moore & Newman, 1991) include questioning the applicability of the scale to different types of stressful events. For example, some Ways of Coping items may not be applicable to certain types of stressful situations. An example of this would be the item "realize I brought the problem on myself" when caring for a individual in which there no control over the disease or situation. Another issue inherent in the tool is the lack of definition of the period of time in which the coping efforts occur. For example, the type and amount of strategies that are performed may differ depending on defining the coping period. Another criticism of the Ways of Coping Scale is the measurement of extent response, since each item is scored on the extent to which the subject used the item, such as used "somewhat," "used quite a bit," and "used a great deal." For example, one item in the instrument is "looks for the silver lining, so to speak, look at the brighter side of things". The response could mean the frequency the respondent used this strategy; or could also mean the duration of time having this thought, the effort that the person utilizes in thinking in this method, or the usefulness in using this method to alleviate the distress of the problem. Despite all the identified problems with the instrument, the Ways of Coping Scale remains in
frequent usage in the coping literature.

**Appraisal in the Caregiving Role**

The measurement of the dimensions of attitudes of the caregiver in the caregiving role was measured by the Caregiver Appraisal Tool (Lawton et al., 1989), which assesses three factors which reflect caregivers' appraisal of the caregiving situation, including burden, satisfaction and caregiving impact (Appendix C, Section B). The 28-item instrument is assessed by a five-point Likert scale eliciting how people sometimes feel when taking care of another person, and responses range from never, with a score of one, to nearly always with a score of five. Items were written in both positive "that helping him has made you feel closer to him," to negative "isolated and alone as a result of caring for him." Items included in three subscales; burden (Appendix C, Section B, Items 2,7,11,16,18,19) the higher the numerical score the higher the degree of burden; impact (Appendix C, Section B, Items 1,4,6,9,12,20) the higher the numerical score the greater the impact the caregiving experience on the caregiver; and satisfaction (Appendix C, Section B, Items 3,5,8,10,13) the higher the numerical score the higher the degree of satisfaction with the caregiving role. Reliability and validity of this instrument were developed in a group of caregivers using respite services and coefficient alpha were: burden 0.85; caregiving satisfaction 0.67; impact 0.70 (Lawton et al., 1989). In the current study, the alpha for burden was 0.86, satisfaction 0.78 and impact 0.72.
Protection of Human Subjects

All subjects were notified of the purpose, benefits, risks, and procedures of the study, both in written form and orally by the investigator or the research assistant. Subjects were informed that their participation was entirely voluntarily and that they could refuse to participate or end their participation at any time without jeopardy. Subjects were informed that only those individuals directly involved in the research would have access to the information and that the answers would be analyzed by groups rather than individually, and no specific subject or answer to a specific question would be revealed. Subjects signed two consent forms (Appendix B) before beginning the data collection; one copy was left with the subject. Data were seen only by the researcher and the research assistant.

Data Management

The initial data were entered by the researcher and an assistant into a personal computer data management program tailored to this study by the researcher, using Data Manager (Chen & Woodward, 1991). The researcher, after setting up the data entry screens, entered the data from the first 20 subjects to assure that the program was correctly written. After the first 20 subjects, a research assistant entered the remaining data. All data were entered directly from the subject’s questionnaire to insure a minimum of error.
Data were checked by the researcher prior to giving it to the research assistant for data entry. Once data were entered, the researcher again reviewed all the entries to assure validity of data entry. Few data points were missing because of home visit technique and recording of data by researcher. When single items were missing, the computer program was programmed to compute averages of non-missing items, and the average was inserted.

**Data Analysis**

Structural equation modeling (SEM), a statistical technique that utilizes a hypothesis-testing approach to a multivariate analysis of a structural theory, was used in this research. An important feature of structural equation modeling technique includes the ability to study the causal relationships between variables in a study as represented by a series of regression equations. Structural equation modeling also allows the relationships between variables to be described pictorially, as shown in the model shown in Figure 5-1 (Chapter 5). The hypothesized model is then tested statistically with a concurrent analysis of the entire model to determine if the model is compatible with the data. Using this technique, if the goodness-of-fit between the data and the model is sufficient, there is argument for acceptability of the relationship among the variables of the model. If the goodness-of-fit between the data and the model is insufficient, the proposed model is rejected. The goal is exploration, as well
as confirmation of causal relationship presumed on theoretical and substantive grounds, thus the term "causal modeling" (Bentler, 1980).

Advantages of using the structural equation model include the fact that SEM takes a confirmatory rather than an exploratory approach to the data analysis. A second advantage is that SEM can be used for inferential purposes, by initially designating the relationship and direction of variables. The third advantage, over traditional multivariate analytical data analysis, is the ability of SEM to correct for measurement error by providing precise estimates of these parameters.

An additional advantage of SEM is that it can include both unobserved (latent) and observed variables. Latent variables are defined as those representing a theoretical construct that cannot be observed directly, and are inferred to exist in the specific observed assessments or factors. Since latent variables cannot be observed directly, their measurements are obtained in an indirect fashion. The latent variables are then operationally defined in respect to behaviors which are believed to be linked to the concept. Thus, the scores on various scales are observed variables and with SEM they serve as indicators of the construct they represent. An example from this study of a latent variable would be the concept of hardiness, which includes the observed factors of commitment, control, and challenge.

The usual statistical procedure for analyzing relationships between sets of observed variables and latent variables is factor analysis. This technique enables the
researcher to investigate covariance among the variables in order to gather data on the underlying factors. In the event that theory has demonstrated that there are underlying relationships among factors, confirmatory factor analysis can be utilized. The evaluation of the model would be based on statistical analysis to determine the goodness-of-fit—between the data and the model. A perfect fit between model and data is unlikely, therefore the discrepancy between the observed model is termed the residual.

In this study, the EQS/PC and EQS/EM (Bentler, 1989) programs were utilized to analyze the model shown in Figure 5-1. In utilizing EQS, fit of the data to the model is determined based on fit indices and probability value. Bentler and Bonnet's (1980) Normed Fit Index (NFI) is the criterion of choice in evaluation of fit between model and data. Values for the NFI range from zero to 1.00 and a value greater than .90 indicates an acceptable fit to the data (Bentler, 1992b). The NFI has been shown to underestimate fit in small samples and therefore Bentler (1990a) proposed the Comparative Fit Index (CFI) to take into account the sample size. Values of the CFI range from zero to 1.00 and again a desirable value is a fit greater than .90 (Bentler, 1990a).

Another feature of utilizing EQS is the addition of two other tests of significance: the LaGrange Multiplier test and the Wald test. The purpose of the LaGrange Multiplier test is to determine whether, in a subsequent EQS run, the
specifications of certain parameters as free rather than fixed would lead to a better representation of the data (Byrne, 1994). The Wald test (Wald, 1943) determines if parameters, identified as free in the model, could be set to zero without considerable loss of fit in the model. In using either the LaGrange or Wald test, caution should be exercised in basing the deletion or addition of parameters based on theoretical basis rather than have the model be data-driven.

The Statistical Procedures for the Social Sciences (SPSS-PC) was utilized to analyze data to describe the sample subjects. The choice of structural equation modeling using EQS is consistent with the theoretical model testing. The Roy Adaptation model is based on a systems theory approach with the structure and functional relationships defined. The model assumes that there is a linear relationship between variables. Thus, with the systems theory approach, it can be suggested that a linear relationship between variables can be assumed. Research on the validation of theoretical models is an appropriate method for theory validation.

**Statistical Assumptions**

Since multiple regression is the technique used as the basis for structural equation modeling the fundamental assumptions regarding multiple regression serve as a basis for structural equation modeling. The first requirement for multiple regression analysis is that the model needs to be specified correctly in terms of functional form; for example, the linear relationships between variables. In addition, the variables
must be correctly identified, based on underlying theory and previous research, with no variables excluded or included when they are irrelevant. It is also assumed that there is no extreme multicollinearity, or two variables measuring the same thing. Two other assumptions concerning regression are first, that the variables are normally distributed, and second that there has been care taken to assure accuracy in measurement. The error term is assumed to have a mean of zero, a constant variance for all values, and no autocorrelation. The independent variable is assumed to be uncorrelated with the error term (Lewis-Beck, 1980). In this study these assumptions were tested and verified for multivariate analysis, using EQS.

Theoretical Assumptions

The theoretical assumptions of this study included the belief that the subjects were capable of identifying their feelings and were able to express them in terms of the questions posed by the researcher. The second assumption is that natural events are assumed to occur with a sense of orderliness and that the study is an attempt to engage in an understanding of cause and effect among relationships. The third assumption based on the Roy Adaptation model is that coping mechanisms serve as a mediator between the environment and the appraisal of the specific role as caregiver.
CHAPTER FIVE

Results

This chapter consists of the results of the study, including the sample characteristics, identification of coping mechanisms and frequency of use by caregivers, patient behaviors eliciting distress in the caregiver, and data regarding the caregiver's appraisal of the caregiving situation. The results of the analysis of the hypothesized model are discussed.

Sample Characteristics

Of a total of 461 potential subjects contacted for this study, a total of 128 subjects participated, with a 70% of the potential subjects not returning the response postcard. Most subjects were obtained through the Los Angeles Alzheimer's Association "Helpline". There were 73 wives (57%) and 55 daughters (43%) in the study. All caregivers were the primary caregivers and lived in the same household with the person with dementia. The years of caregiving experience ranged from less than a year to thirteen years with a mean of three years (Table 5-1), and the hours spent with the patient ranged from 6-24 hours per day with a mode of 19-24 hours (Table 5-2).

The age of the caregivers ranged from 30-86 years (Table 5-3), with a mode of 66-75 years. Ninety-one subjects were Caucasian (71%), 21 African-American
(21%), 9 Hispanic (7%) and 1 Asian (.8%). The caregivers and their spouses were on the whole a well educated group with 93% of the caregivers having completed high school. The groups of high school graduates who attended college (87), included 25% with an associate degree, and 31% a bachelors degree or higher. The care receivers were also well educated, with 74% completing high school. Of the high school graduates who attended college (61) 20% obtained an associate degree, and 65% a bachelors degree or higher. The caregivers were also a healthy group with 20% stating that their health was excellent, 19% very good, 34% good, 21% fair and only 6% poor (Table 5-4).

Table 5-1
Frequencies and percentages of caregivers length of caregiving in years (N = 128)

<table>
<thead>
<tr>
<th>Years of caregiving</th>
<th>Frequency</th>
<th>Percent of caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less 1 year</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>1 year</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>2 years</td>
<td>22</td>
<td>18</td>
</tr>
<tr>
<td>3 years</td>
<td>21</td>
<td>16</td>
</tr>
<tr>
<td>4 years</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>5 years</td>
<td>12</td>
<td>9</td>
</tr>
<tr>
<td>6-13 years</td>
<td>17</td>
<td>13</td>
</tr>
</tbody>
</table>
Table 5-2
Frequencies and percent of caregivers hours per day spent with patient (N=126)

<table>
<thead>
<tr>
<th>Hours per day</th>
<th>Frequency</th>
<th>Percent of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-6 hours</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td>7-12 hours</td>
<td>10</td>
<td>8</td>
</tr>
<tr>
<td>13-18 hours</td>
<td>27</td>
<td>21</td>
</tr>
<tr>
<td>19-24 hours</td>
<td>82</td>
<td>64</td>
</tr>
</tbody>
</table>

Table 5-3
Frequency and percent of age of caregiver (N=128)

<table>
<thead>
<tr>
<th>Age</th>
<th>Frequency</th>
<th>Percent of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>30-45 years</td>
<td>18</td>
<td>14</td>
</tr>
<tr>
<td>46-55 years</td>
<td>23</td>
<td>18</td>
</tr>
<tr>
<td>56-65 years</td>
<td>33</td>
<td>26</td>
</tr>
<tr>
<td>66-75 years</td>
<td>38</td>
<td>30</td>
</tr>
<tr>
<td>76-86 years</td>
<td>16</td>
<td>12</td>
</tr>
</tbody>
</table>
Table 5-4

Frequency and percent of health perception of caregiver (N=128)

<table>
<thead>
<tr>
<th>Perception of Health</th>
<th>Frequency</th>
<th>% of Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Excellent</td>
<td>25</td>
<td>20</td>
</tr>
<tr>
<td>Very Good</td>
<td>24</td>
<td>19</td>
</tr>
<tr>
<td>Good</td>
<td>44</td>
<td>34</td>
</tr>
<tr>
<td>Fair</td>
<td>27</td>
<td>21</td>
</tr>
<tr>
<td>Poor</td>
<td>8</td>
<td>6</td>
</tr>
</tbody>
</table>

Identification of coping mechanisms utilized by caregivers

Data were analyzed to determine the usefulness of different forms of coping mechanisms. The types of coping mechanisms according to classification included problem solving coping; including confrontation and planful problem solving. The emotion-focused categories included: reappraisal, seeking social support, use of self control, accepting responsibility, distancing and escape-avoidance.

Confrontive Problem Solving

In identifying the most commonly used types of problem-focused coping mechanisms, confrontation and planful problem-solving the following results emerged.
In identifying the types of problem-solving coping mechanisms used by the caregivers, the most frequently confrontive strategy (Table 5-5) used by 71% of the caregivers, "quite a bit" or a "great deal" was to double their efforts when faced with adversity. Another frequently utilized confrontive coping mechanism was to stand one's ground, which was utilized "quite a bit" to a "great deal" by 52% of caregivers. The methods of bargaining or attempting to get the individual to change his position were used infrequently. The most commonly used planful problem-solving technique (Table 5-6) was to analyze the situation, with 66% of the caregivers using this technique "quite a bit" to a "great degree", and 59% using development of a plan of action to a larger extent than other mechanisms. Techniques not frequently used by caregivers, included drawing on past experience, and role-playing the situation, with 59% of participants stating either that they did not use this method or it held limited usage.

Self-Control Techniques

In identifying the most commonly used types of emotion-focused coping mechanisms; self-control, positive reappraisal, accepting responsibility, seeking social support and distancing, the following results emerged. When using self-control to regulate emotion-focused coping, the largest proportion of caregivers (67%) used concentration on the next step in dealing with the situation. A mechanism least likely to be used was keeping feelings to themselves (Table 5-7).
Table 5-5
Percent of caregivers utilizing confrontive problem solving techniques (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bargain or Compromise</td>
<td>20</td>
<td>36</td>
<td>26</td>
<td>17</td>
</tr>
<tr>
<td>Doing something (even though might not work)</td>
<td>25</td>
<td>35</td>
<td>27</td>
<td>13</td>
</tr>
<tr>
<td>Get person to change</td>
<td>33</td>
<td>34</td>
<td>23</td>
<td>10</td>
</tr>
<tr>
<td>Stand one's ground</td>
<td>17</td>
<td>31</td>
<td>29</td>
<td>23</td>
</tr>
<tr>
<td>Double one's effort</td>
<td>7</td>
<td>22</td>
<td>39</td>
<td>32</td>
</tr>
</tbody>
</table>

Table 5-6
Percent of caregivers utilizing planful problem solving techniques (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not Apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analyze the situation</td>
<td>8</td>
<td>23</td>
<td>38</td>
<td>29</td>
</tr>
<tr>
<td>Develop plan of action</td>
<td>13</td>
<td>31</td>
<td>35</td>
<td>21</td>
</tr>
<tr>
<td>Change something/positive</td>
<td>12</td>
<td>33</td>
<td>42</td>
<td>13</td>
</tr>
<tr>
<td>Draw on past experience</td>
<td>59</td>
<td>18</td>
<td>8</td>
<td>15</td>
</tr>
<tr>
<td>Develop several solutions</td>
<td>11</td>
<td>41</td>
<td>37</td>
<td>12</td>
</tr>
<tr>
<td>Role play</td>
<td>27</td>
<td>32</td>
<td>26</td>
<td>14</td>
</tr>
</tbody>
</table>
Table 5-7
Percent of caregivers utilizing self-control coping techniques (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not Apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Concentrate on next step</td>
<td>10</td>
<td>23</td>
<td>38</td>
<td>29</td>
</tr>
<tr>
<td>Keep feelings to self</td>
<td>32</td>
<td>33</td>
<td>18</td>
<td>15</td>
</tr>
<tr>
<td>Wait and see</td>
<td>28</td>
<td>35</td>
<td>25</td>
<td>12</td>
</tr>
<tr>
<td>Maintain pride &amp; keep stiff upper lip</td>
<td>4</td>
<td>28</td>
<td>38</td>
<td>20</td>
</tr>
<tr>
<td>Keep other knowing severity</td>
<td>41</td>
<td>37</td>
<td>14</td>
<td>8</td>
</tr>
<tr>
<td>Keep feelings from interfere</td>
<td>8</td>
<td>37</td>
<td>37</td>
<td>18</td>
</tr>
</tbody>
</table>

Positive Reappraisal

In using the positive reappraisal form of emotion-focused coping, the most common technique utilized to a greater degree by 68% of the caregivers was to "look for the silver lining" (Table 5-8). Another popular technique, for 51% of the caregivers, was to look at caregiving as a positive growth-producing experience. Prayer categorized as positive reappraisal was used a "great deal" by 48% of the caregivers, and another 20% utilized the technique "quite a bit". Another common form of reframing the situation, occurring in 64% of the caregivers "quite a bit" to a "great deal".
"deal", was to see the situation from the other person's point of view. A positive appraisal technique not identified frequently was to think of how a person one admires would handle the situation, with 58% of caregivers not using this technique at all.

Table 5-8
Percentage of caregivers utilizing positive reappraisal coping techniques (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Look for silver lining</td>
<td>4</td>
<td>27</td>
<td>45</td>
<td>24</td>
</tr>
<tr>
<td>Tell self things that make one feel better</td>
<td>17</td>
<td>36</td>
<td>31</td>
<td>16</td>
</tr>
<tr>
<td>Changing/growing for good</td>
<td>17</td>
<td>31</td>
<td>30</td>
<td>21</td>
</tr>
<tr>
<td>Come out experience better</td>
<td>23</td>
<td>20</td>
<td>34</td>
<td>23</td>
</tr>
<tr>
<td>Find new faith</td>
<td>26</td>
<td>30</td>
<td>31</td>
<td>13</td>
</tr>
<tr>
<td>Rediscover/important</td>
<td>16</td>
<td>25</td>
<td>40</td>
<td>19</td>
</tr>
<tr>
<td>Change something in self</td>
<td>22</td>
<td>38</td>
<td>30</td>
<td>10</td>
</tr>
<tr>
<td>Pray</td>
<td>14</td>
<td>18</td>
<td>20</td>
<td>48</td>
</tr>
<tr>
<td>Think how person you admire would handle situation</td>
<td>58</td>
<td>24</td>
<td>13</td>
<td>5</td>
</tr>
<tr>
<td>See others point of view</td>
<td>8</td>
<td>28</td>
<td>43</td>
<td>21</td>
</tr>
<tr>
<td>Think of worse it could be</td>
<td>13</td>
<td>23</td>
<td>37</td>
<td>27</td>
</tr>
</tbody>
</table>

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Accepting responsibility

Another emotion-focused coping mechanism is accepting responsibility for the situation. The most common mechanisms utilized by the caregiver, in 50% of the caregivers, was to accept the situation, since nothing could be done about it (Table 5-9). The majority (73%) of the caregivers did not think that they brought the problems on themselves nor did they think that they had to apologize for the situation they were in.

Table 5-9

Percent of caregivers utilizing accepting responsibility (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criticize/lecture self</td>
<td>27</td>
<td>33</td>
<td>22</td>
<td>18</td>
</tr>
<tr>
<td>Apologize/ or makeup</td>
<td>23</td>
<td>36</td>
<td>29</td>
<td>11</td>
</tr>
<tr>
<td>Realize brought on problem myself</td>
<td>73</td>
<td>14</td>
<td>10</td>
<td>3</td>
</tr>
<tr>
<td>Accept/nothing to do</td>
<td>18</td>
<td>31</td>
<td>27</td>
<td>24</td>
</tr>
<tr>
<td>Do something different next time</td>
<td>27</td>
<td>37</td>
<td>30</td>
<td>6</td>
</tr>
<tr>
<td>Prepare for worst</td>
<td>27</td>
<td>34</td>
<td>20</td>
<td>19</td>
</tr>
</tbody>
</table>
Social support

In using the emotion focused coping mechanism of seeking social support, the majority of caregivers (70%) had found someone to talk with "quite a bit" to a "great deal" concerning the situation (Table 5-10). In this group, the mechanism of social support not identified as applying to them as caregivers was to seek professional help, with 53% of this population identifying that this mechanism was not used, and other 18% using professional help only "somewhat".

Table 5-10

Percent of caregivers utilizing seeking social support coping mechanisms (N = 128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Try not burn bridges</td>
<td>10</td>
<td>32</td>
<td>40</td>
<td>17</td>
</tr>
<tr>
<td>Accept sympathy and understanding</td>
<td>12</td>
<td>41</td>
<td>34</td>
<td>13</td>
</tr>
<tr>
<td>Get professional help</td>
<td>53</td>
<td>19</td>
<td>17</td>
<td>11</td>
</tr>
<tr>
<td>Talk to someone who can do something concrete</td>
<td>18</td>
<td>31</td>
<td>34</td>
<td>17</td>
</tr>
<tr>
<td>Ask friend respect advice</td>
<td>17</td>
<td>31</td>
<td>39</td>
<td>13</td>
</tr>
<tr>
<td>Talk someone/how feeling</td>
<td>6</td>
<td>34</td>
<td>42</td>
<td>18</td>
</tr>
</tbody>
</table>
Distancing

In examining "distancing" as an emotion-focused coping mechanism, most caregivers did not use this mechanism a "great deal" in dealing with the situations faced. The majority of caregivers did not use the techniques of hoping for a miracle, going on as if nothing happened, refusing to think about it or making light of the situation (Table 5-11). When faced with a situation which demanded the time and attention of the caregiver the majority of caregivers did not use the method of removing themselves from the environment by detachment from the situation.

Table 5-11

Percent of caregivers utilizing distance coping mechanisms. (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not Apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time will make difference</td>
<td>32</td>
<td>28</td>
<td>28</td>
<td>12</td>
</tr>
<tr>
<td>Hope for a miracle</td>
<td>38</td>
<td>22</td>
<td>14</td>
<td>26</td>
</tr>
<tr>
<td>Go along fate/bad luck</td>
<td>60</td>
<td>25</td>
<td>11</td>
<td>3</td>
</tr>
<tr>
<td>Go on nothing happened</td>
<td>56</td>
<td>24</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>Accept next best/what want</td>
<td>10</td>
<td>39</td>
<td>38</td>
<td>13</td>
</tr>
<tr>
<td>Don’t let it get to me/refuse</td>
<td>45</td>
<td>37</td>
<td>16</td>
<td>2</td>
</tr>
<tr>
<td>Make light of situation</td>
<td>47</td>
<td>28</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Take out on others</td>
<td>68</td>
<td>25</td>
<td>6</td>
<td>1</td>
</tr>
</tbody>
</table>
Escape-Avoidance

The caregivers in this study did not turn to escape-avoidance coping mechanisms in dealing with the situation of caregiving. The only escape-avoidance mechanism used by a great deal of caregivers "quite a bit" to a "great deal" was to wish they could change what happened (66%) (Table 5-12). The second most used mechanisms, but to a lesser degree, is caregivers turning to creative activities or work as stress reduction. Caregivers as a whole did not use sleep, risky behavior, daydreaming, or eating, drinking, smoking or use of drugs or medications, to alleviate stress.

Behaviors in individual with dementia and degree of stress elicited

The research question in this study also addressed the type of patient behaviors as reported by the caregiver eliciting distress. The patient behaviors that precipitated the greatest distress in the caregivers were wandering and getting lost which caused moderate to extreme distress in 49% of caregivers. Waking up at night elicited anguish in 44% of caregivers, and restless activity disturbance caused distress in 47% of caregivers. The inability to stay alone elicited discomfort in 43% of caregivers, hallucinations and illusions elicited moderate to extreme distress in 35% of caregivers, behaviors dangerous to self and others was distressing to 30% of caregivers, but incontinence elicited distress in 21% of caregivers (Table 5-13).

Another area of research in this study was the analysis of behaviors which
elicited little distress in the caregiver. Items such as forgetting the day was exhibited by 122 out of the 128 individuals with dementia and elicited little to no distress in 70% of the caregivers. Other items that caregivers adapted to included the

Table 5-12

Percent of caregivers utilizing escape-avoidance coping mechanisms (N=128)

<table>
<thead>
<tr>
<th>Technique</th>
<th>Not Apply</th>
<th>Somewhat</th>
<th>Quite a bit</th>
<th>Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Work/ substitute activity</td>
<td>13</td>
<td>30</td>
<td>36</td>
<td>21</td>
</tr>
<tr>
<td>Sleep more than usual</td>
<td>80</td>
<td>10</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Creative Activity</td>
<td>21</td>
<td>32</td>
<td>31</td>
<td>16</td>
</tr>
<tr>
<td>Forget whole thing</td>
<td>69</td>
<td>18</td>
<td>8</td>
<td>5</td>
</tr>
<tr>
<td>Get away vacation/rest</td>
<td>38</td>
<td>40</td>
<td>16</td>
<td>5</td>
</tr>
<tr>
<td>Eat, smoke, drink,drugs</td>
<td>62</td>
<td>21</td>
<td>8</td>
<td>9</td>
</tr>
<tr>
<td>Risky Behavior</td>
<td>64</td>
<td>32</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Avoid being with people</td>
<td>73</td>
<td>18</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Wish change happened</td>
<td>8</td>
<td>25</td>
<td>34</td>
<td>33</td>
</tr>
<tr>
<td>Daydream about a better time</td>
<td>42</td>
<td>26</td>
<td>22</td>
<td>10</td>
</tr>
<tr>
<td>Wish situation over with</td>
<td>33</td>
<td>32</td>
<td>12</td>
<td>23</td>
</tr>
<tr>
<td>Fantasies concerning how</td>
<td>46</td>
<td>30</td>
<td>15</td>
<td>9</td>
</tr>
<tr>
<td>situation will turn out</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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care recipients starting and not finishing projects, inability to dress either partially or
totally themselves, and inability to feed and perform simple tasks (Table 5-14).

Table 5-13

**Absence or presence of recipient behaviors and degree of distress elicited by**

**behaviors as reported by caregivers in percent (N = 128)**

<table>
<thead>
<tr>
<th>Behaviors</th>
<th>Absent</th>
<th>Present</th>
<th>None</th>
<th>Little</th>
<th>Mod.</th>
<th>V. Much</th>
<th>Extreme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wandering</td>
<td>56</td>
<td>72</td>
<td>46</td>
<td>5</td>
<td>5</td>
<td>15</td>
<td>30</td>
</tr>
<tr>
<td>Losing or misplacing</td>
<td>19</td>
<td>109</td>
<td>23</td>
<td>24</td>
<td>20</td>
<td>16</td>
<td>17</td>
</tr>
<tr>
<td>Night Waking</td>
<td>49</td>
<td>79</td>
<td>45</td>
<td>11</td>
<td>8</td>
<td>16</td>
<td>19</td>
</tr>
<tr>
<td>Restlessness</td>
<td>40</td>
<td>88</td>
<td>42</td>
<td>11</td>
<td>23</td>
<td>12</td>
<td>12</td>
</tr>
<tr>
<td>Dangerous</td>
<td>79</td>
<td>49</td>
<td>64</td>
<td>3</td>
<td>2</td>
<td>15</td>
<td>16</td>
</tr>
<tr>
<td>Hallucinations/ Illusions</td>
<td>51</td>
<td>77</td>
<td>52</td>
<td>13</td>
<td>12</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>Incontinence</td>
<td>74</td>
<td>54</td>
<td>71</td>
<td>4</td>
<td>7</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Inability to stay alone</td>
<td>31</td>
<td>91</td>
<td>50</td>
<td>7</td>
<td>15</td>
<td>14</td>
<td>14</td>
</tr>
<tr>
<td>Repeating same question</td>
<td>19</td>
<td>108</td>
<td>24</td>
<td>17</td>
<td>27</td>
<td>15</td>
<td>16</td>
</tr>
</tbody>
</table>
### Table 5-14

**Absence or presence of recipient behaviors and degrees of stress elicited by behaviors as reported by caregivers in percent (N=128)**

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Number</th>
<th>% Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Absent</td>
<td>Present</td>
</tr>
<tr>
<td>Forgetting day</td>
<td>6</td>
<td>122</td>
</tr>
<tr>
<td>Start &amp; not finish project</td>
<td>44</td>
<td>84</td>
</tr>
<tr>
<td>Dress/ inability</td>
<td>62</td>
<td>66</td>
</tr>
<tr>
<td>Feed/ inability</td>
<td>96</td>
<td>32</td>
</tr>
<tr>
<td>Inability to do a simple task</td>
<td>34</td>
<td>94</td>
</tr>
</tbody>
</table>

**Caregivers appraisal of caregiving situation in terms of burden and satisfaction**

The data also was examined to identify the caregivers appraisal of the caregiving situation addressing the aspects of burden and satisfaction with the caregiving role. The factor associated with burden in these caregivers was fatigue as a result of providing care which was exhibited "frequently" to "nearly always" in 54% of the caregivers (Table 5-15). In addition, 73% of caregivers reported it was "frequently" to "nearly always" impossible to plan ahead, and 72% reported that the

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care receiver's needs prompted how their day was to be spent.

Table 5-15

Caregiver's appraisal of burden in the caregiving role in percent (N=128)

<table>
<thead>
<tr>
<th>Appraisal: Burden</th>
<th>% Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>Always</td>
<td></td>
</tr>
<tr>
<td>Not enough time for self</td>
<td>33</td>
</tr>
<tr>
<td>Health suffered</td>
<td>30</td>
</tr>
<tr>
<td>Isolated</td>
<td>16</td>
</tr>
<tr>
<td>Unable provide/much longer</td>
<td>31</td>
</tr>
<tr>
<td>Lost control of life</td>
<td>33</td>
</tr>
<tr>
<td>Tired/result caregiving</td>
<td>10</td>
</tr>
<tr>
<td>Hard to plan ahead</td>
<td>9</td>
</tr>
<tr>
<td>His needs determine my day</td>
<td>6</td>
</tr>
</tbody>
</table>

Caregivers appraisal of satisfaction and mastery

This group of caregivers experienced a great deal of satisfaction and mastery in their role in addition to the burden of caregiving. Over 71% felt quite or nearly often pleased when the care recipient was pleased over some little thing. The caregiver's
reward and the show of appreciation by the care recipient added to the pleasure of 58% of the caregivers. Most caregivers were not in the caregiving experience to give their ego's a boost, but 86% felt reassured as long as they were providing the proper care. The caregivers demonstrated a high percentage of positive appraisal of their level of mastery of the caregiving role (Table 5-16).

Table 5-16
Caregiver's appraisal of satisfaction and mastery in the caregiving role in percent
(N=128)

<table>
<thead>
<tr>
<th>Appraisal: Satisfaction</th>
<th>% Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>Enjoyed being with him</td>
<td>3</td>
</tr>
<tr>
<td>He shows appreciation</td>
<td>10</td>
</tr>
<tr>
<td>His pleasure over something gives you pleasure</td>
<td>3</td>
</tr>
<tr>
<td>Taking responsibility increases your self-esteem</td>
<td>27</td>
</tr>
<tr>
<td>Reassured proper care while you are caring for him</td>
<td>2</td>
</tr>
<tr>
<td>You should be doing more</td>
<td>28</td>
</tr>
<tr>
<td>You should be doing better</td>
<td>31</td>
</tr>
</tbody>
</table>

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Figure 5-1  Factor loading and error variances in depression, hardiness, social support, patient behavior, spirituality, problem-focused coping, emotion-focused coping and caregiver appraisals.

Physical Health

Problem-Focused Coping

Depression

Hardiness

Social Support

Patient Behavior

Spirituality

Emotion-Focused Coping

Appraisal

Burden < .45
Satis. < .90
Impact < .59

Positive Path

Negative Path

Nonsignificant Path

* P ≤ .05

Physical Health

Problem-Focused Coping

Depression

Hardiness

Social Support

Patient Behavior

Spirituality

Emotion-Focused Coping

Appraisal

Burden < .45
Satis. < .90
Impact < .59

Positive Path

Negative Path

Nonsignificant Path

* P ≤ .05

Physical Health

Problem-Focused Coping

Depression

Hardiness

Social Support

Patient Behavior

Spirituality

Emotion-Focused Coping

Appraisal

Burden < .45
Satis. < .90
Impact < .59

Positive Path

Negative Path

Nonsignificant Path

* P ≤ .05

Physical Health

Problem-Focused Coping

Depression

Hardiness

Social Support

Patient Behavior

Spirituality

Emotion-Focused Coping

Appraisal

Burden < .45
Satis. < .90
Impact < .59

Positive Path

Negative Path

Nonsignificant Path

* P ≤ .05
Figure 5-2

Structural equation model of hypothesized relationships.

$X^2(185) = 376.13$
NNFI ** = 0.77
NFI *** = 0.83
CFI **** = 0.87

** Bentler Bonnet Non-Normed Fit Index
*** Bentler Bonnet Normed Fit Index
**** Comparative Fit Index

Physical Health

Depression

Hardiness

Social Support

Patient Problem Behavior

Spirituality

Problem-Focused Coping

Emotion-Focused Coping

Appraisal

* $P \leq 0.05$

Positive Path

Negative Path

Nonsignificant Path
Theoretical Model Testing

The research question for this study included the interrelationships of factors in the caregiver's environment and the mediating role of coping mechanisms on appraisal to the caregiving role. The model depicted in Figure 5-2 was tested, utilizing structural equation modeling using the EQS program (Bentler, 1993). This technique enables a set of hypothesized regression equations to be estimated simultaneously, generating an estimated covariance matrix.

Data were collected on a total of 128 subjects. A total of 5-20 subjects per path are needed. In the hypothesized model, a total of nine paths were identified. Data on seventeen subjects per path, the high end of the acceptable range were collected.

In EQS, all variables fall into two categories; either measured (observed) or unmeasured (unobserved or latent variables). In Figure 5-1, the measurement model, a circle is used to represent all unobserved or latent variables and a rectangle to represent all measured variables. Path coefficients for regression of one factor onto another is indicated by a line with an arrow indicating direction. Residual errors in prediction of an unobserved factor is indicated by a symbol pointing to the variable within the enclosed residual error. Covariances are indicated by a dark line with circles interrupting the line (Figure 5-4). All coefficients reported in this study are standardized coefficients. The correlation coefficients for the theoretical model

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testing can be found in Appendix D and the correlation matrix in Appendix E.

**Measurement Model**

In investigating the model for factor loadings and measurement error variances, the data in Table 5-17 and Figure 5-1 demonstrates the measurement model parameters. The factor loadings for depression, hardiness, spirituality, social support, problem-focused coping, are uniformly high, indicating that these factors are well-identified. Within emotion-focused coping, the emotion one variable, factor loading is only 0.63 also within the appraisal construct the satisfaction factor loading only 0.44. Factor analysis with varimax rotation confirmed that emotion one, which includes positive reappraisal and seeking social support loaded onto emotion-focused coping, in addition, satisfaction loaded on appraisal.

The error variances associated with the measurement model were varied throughout the constructs. None of the error variances were significant, indicating a lack of a significant amount of measurement error. This upholds the underlying assumption of the structural equation modeling technique that there is an assurance of accuracy in measurement of the constructs.
Table 5-17

Factor loadings and error variance in constructs identified in the hypothesized Model

<table>
<thead>
<tr>
<th>Construct Name</th>
<th>Factor Loading</th>
<th>Error Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression 1</td>
<td>0.88</td>
<td>0.46</td>
</tr>
<tr>
<td>Depression 2</td>
<td>0.73*</td>
<td>0.68</td>
</tr>
<tr>
<td>Depression 3</td>
<td>0.75*</td>
<td>0.66</td>
</tr>
<tr>
<td>Hardiness</td>
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</tr>
<tr>
<td>Commitment</td>
<td>0.82*</td>
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<tr>
<td>Challenge</td>
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</tr>
<tr>
<td>Control</td>
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<tr>
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</tr>
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<tr>
<td>Patient Behavior 2</td>
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Table 5-17 Continued

<table>
<thead>
<tr>
<th>Construct name</th>
<th>Factor Loading</th>
<th>Error Variance</th>
</tr>
</thead>
<tbody>
<tr>
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<td></td>
</tr>
<tr>
<td>i20</td>
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</tr>
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<td>i21</td>
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<td>0.60</td>
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<tr>
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<td></td>
<td></td>
</tr>
<tr>
<td>Problem 1</td>
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<td>0.62</td>
</tr>
<tr>
<td>Problem 2</td>
<td>0.74*</td>
<td>0.68</td>
</tr>
<tr>
<td>Problem 3</td>
<td>0.73*</td>
<td>0.69</td>
</tr>
<tr>
<td>Emotion-Focused Coping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion 1</td>
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<td>0.78</td>
</tr>
<tr>
<td>Emotion 2</td>
<td>0.89*</td>
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</tr>
<tr>
<td>Emotion 3</td>
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<tr>
<td>Appraisal</td>
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</tr>
<tr>
<td>Burden</td>
<td>-0.89*</td>
<td>0.45</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>0.44</td>
<td>0.90</td>
</tr>
<tr>
<td>Impact</td>
<td>-0.83*</td>
<td>0.59</td>
</tr>
</tbody>
</table>

*Parameter significant, p<0.05 (parameter estimate exceeds standard error by ratio of ≥ 1.96)
Direct Hypothesis testing

The secondary research questions regarding the direct and indirect relationships of environmental variables; physical health, depression hardiness, social support, patient problem behaviors and spirituality, on cognator activity; problem and emotion-focused coping, on adaption; appraisal are outlined in Figure 5-2. The numbers on the directional paths indicate the path coefficient and are defined by Wright (1934) as the fraction of the standard deviation of the dependent variable (with the appropriate sign) for which the designated variable is directly responsible, in the sense that the fraction which would be found if this factor varies to the same extent as in the observed data while all others (including residual factors) are kept constant. Initial analysis of the data did not support the hypothesis that better physical health would have a direct positive effect on caregiver appraisal to the caregiving role. The relationship was tested and found to be nonsignificant (0.03). The second hypothesis, that depression would result in the appraisal of the caregiving role as less satisfying, more burdensome, and with a greater impact on the caregiving role was supported (-0.64). In examining the direct effects of emotion-focused and problem-focused coping, it was confirmed that problem-focused coping resulted in appraisal of the caregiving role as more satisfying, less burdensome with a lesser impact on the caregiver’s life (0.24). Emotion-focused coping was discovered to result in appraisal of the caregiving role as less satisfying, more burdensome and with a greater impact.
on the caregiver's role (-0.24).

**Indirect Hypothesis testing**

In investigating the indirect hypotheses, the data did not support the hypothesis that depression had an negative effect on problem-focused coping. Instead depression was found to have a significant direct positive effect (0.30) on problem-focused coping, which in turn resulted in appraisal of the caregiving role as more satisfying, less burdensome with a greater impact on the caregiver's role. Hardiness was also found to have a significant positive effect on problem-focused coping (0.26) which in turn resulted in appraisal of the caregiving role as more satisfying, less burdensome with a lesser negative impact on the caregiver's role. Greater social support was not found to have a result in more problem-focused coping and instead the results were insignificant (0.07). Patient problem behavior did result in an increased use of emotion focused coping (0.61) which in turn resulted in appraisal of the caregiving role as less satisfying, more burdensome with a greater negative impact on the caregiver’s role (-0.24). Finally, greater spirituality was found to have an insignificant relationship to emotion focused coping (-0.12).

The hypothesized model drawn from the literature did not fit the data well (Figure 5-2) ($\chi^2 = 376.13, df=185, p<0.001$); the Normed Fit Index (NFI) was 0.83 and the Comparative Fit Index (CFI) 0.87. Poor fit however, was due to missing paths. The Wald and LaGrange multiplier test were utilized for adding parameters.
Development of Revised Model

The model was then tested using a subtractive approach (Chou, Bentler, & Sattora, 1991) starting with a saturated model in which all paths and all correlations among the independent variables were included whether or not hypothesized. All nonsignificant paths and correlations were then removed, applying the Wald test. The $\chi^2/df$ ratio and CFI were again used as criteria for goodness-of-fit. The factor loadings and error variances of the new model are presented in Table 5-18 and Figure 5-3. The factor loadings and error variances on the revised model remain uniformly stable and high as in the original model.

Based on this revised model, the goodness-of-fit indices for the respecified model were: $\chi^2 (191)=307.33, p<0.001 \chi^2/df= <2.0, NFI=0.90, CFI=0.92,$ indicating a desirable fit of greater than 0.90 in the NFI (Bentler 1990a). The resulting model (Figure 5-4) demonstrated the correlations between physical health and depression, physical health and hardiness, depression and patient behaviors, depression and hardiness, emotion and problem-focused coping mechanisms. The new paths added included relationships between social support and emotion-focused coping, spirituality and problems-solving, patient problem behaviors and both problem-focused coping and appraisal of the caregiving role. In addition paths between depression and physical health and hardiness, hardiness and depression, depression and patient behavior problems emerged.
Figure 5-1  Factor loading and error variances in depression, hardiness, social support, patient behavior, spirituality, problem-focused coping, emotion-focused coping and caregiver appraisals.

Physical Health

Depression

Problem-Focused Coping

Hardiness

Social Support

Emotion-Focused Coping

Patient Problem Behavior

Spirituality

Appraisal

Physical Health

Burden < .45

Satis. < .90

Impact < .59

Positive Path

Negative Path

Nonsignificant Path
Figure 5-4 Revised equation model.

Physical Health

Depression

Hardiness

Social Support

Patient Problem Behavior

Spirituality

Problem-Focused Coping

Emotion-Focused Coping

Appraisal

\[ X^2(191) = 307.33 \]

\[ \text{NNFI}^{**} = 0.81 \]

\[ \text{NFI}^{***} = 0.90 \]

\[ \text{CFI}^{****} = 0.92 \]

---

\[ * \quad P \leq 0.05 \]

- Positive Path
- Negative Path
- Nonsignificant Path

---

** Bentler Bonnet Non-Normed Fit Index
*** Bentler Bonnet Normed Fit Index
**** Comparative Fit Index
<table>
<thead>
<tr>
<th>Construct Name</th>
<th>Factor Loading</th>
<th>Error Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression 1</td>
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</tr>
<tr>
<td>Depression 2</td>
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<td>0.63</td>
</tr>
<tr>
<td>Depression 3</td>
<td>0.76*</td>
<td>0.65</td>
</tr>
<tr>
<td>Hardiness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Commitment</td>
<td>0.82*</td>
<td>0.58</td>
</tr>
<tr>
<td>Challenge</td>
<td>0.79*</td>
<td>0.61</td>
</tr>
<tr>
<td>Control</td>
<td>0.94</td>
<td>0.34</td>
</tr>
<tr>
<td>Social Support</td>
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<td></td>
</tr>
<tr>
<td>Social Support</td>
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<td>0.90</td>
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<td>0.71</td>
</tr>
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<td>Behavior 2</td>
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</tr>
<tr>
<td>Construct Name</td>
<td>Factor Loading</td>
<td>Error Variance</td>
</tr>
<tr>
<td>------------------------------</td>
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</tr>
<tr>
<td><strong>Spirituality</strong></td>
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</tr>
<tr>
<td>i 21</td>
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<td>0.53</td>
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<td></td>
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<tr>
<td>Problem 1</td>
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<td>0.69</td>
</tr>
<tr>
<td>Problem 2</td>
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<td>0.62</td>
</tr>
<tr>
<td>Problem 3</td>
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<td><strong>Emotion-focused Coping</strong></td>
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<td>Emotion 1</td>
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<td>Emotion 3</td>
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<td>0.30</td>
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<td>Burden</td>
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<tr>
<td>Satisfaction</td>
<td>0.46</td>
<td>0.88</td>
</tr>
<tr>
<td>Impact</td>
<td>- 0.85*</td>
<td>0.52</td>
</tr>
</tbody>
</table>

*Parameter significant, p < 0.05 (parameter estimate exceeds standard error by ratio of ≥ 1.96)
In the revised model Figure 5-4, three paths were nonsignificant: the path from hardiness to problem-focused coping (0.12), which had been significant in the first model, from social support to problem-focused coping (0.11), and spirituality to emotion-focused coping (-0.13). A strong positive path developed between patient problem behaviors and emotion-focused coping (0.55) and patient behavioral problems and problem-focused coping (0.58). There emerged a new and clear path between depression and patient problem behaviors (0.69). The most convincing path was the direct negative path between patient problem behavior and appraisal (-0.77).

Changes in the revised model included the relationship between physical health and appraisal, which in the original model was nonsignificant, changed to negative direction (-0.17). Hardiness, which has a positive significant path in the hypothesized model was nonsignificant in the revision and instead, hardiness had a significant negative (-0.22) path to emotion-focused coping. Social support also developed a positive path to emotion-focused coping (0.19), and patient problem behaviors had significant positive paths to both emotion-focused (0.55) and problem-focused (0.58) coping and a negative relationship directly to appraisal (-0.77). In the revised model spirituality also developed a negative path to problem-focused coping (-0.43). In addition, there was a significant relationship between emotion-focused and problem focused coping (0.58).

In conclusion the revised model was constructed based on a mathematical and
not theoretical model of relationships. The data and paths were constructed to offer
the best goodness of fit among the variables. With these restrictions in mind care
must be taken in interpretation of the revised model and additional investigation of
possible links to the theoretical basis must be investigated.
CHAPTER SIX

Discussion

The results of this research are discussed in five sections. The first section incorporates the results of the research questions as compared to previous studies. The second section addresses the research questions as they relate to the proposed and revised version of the structural equation model. A comparison to results of previous studies are addressed offering possible interpretations of results. The third portion deals with the structural equation model as it relates to the Adaptation model of nursing theory. The strengths and limitations are discussed in the fourth section and the extent to which the results can be generalized. The final section includes implications for nursing theory, practice, and education, as well as implications for further research and conclusions.

Discussion of research questions leading to satisfaction in caregiving role.

The results of this research found that both emotion-focused and problem-focused coping were used with this population of caregivers of individuals with dementia. Previous literature focused on the coping strategies of caregivers as being multidimensional, including both emotion-focused and problem-focused strategies (McCrae, 1982; Prucho & Resch, 1989). This finding supports reports of previous
literature in which coping strategies of caregivers of people were multidimensional (Prucho & Resch, 1989).

In the conceptualization of problem-focused coping (Folkman, Lazarus, Dunkel Shetter, Delongis & Gruen, 1986), the researchers proposed that problem-focused coping was more often utilized in situations amenable to change, and emotion-focused coping in situations which needed to be endured. In previous caregiver literature, Brashares and Catanzano (1994) linked behavioral problems in the care recipient with the caregivers' use of problem-focused coping techniques, such as information-seeking and problem-solving. The same study indicated that in many cases emotion-focused coping, in the face of an uncontrollable disease, is associated with increased depression, whereas emotion-focused problem-solving that encourages an optimistic outlook could assist the individual in decreasing the potential for depression. However, dementia caregivers who used emotion-focused coping in the present study, were found to have lower appraisal indicating increased burden, lower satisfaction and increased impact in the caregiving role. One explanation may be that when faced with certain types of behavioral problems of the dementia victim, the situation might be one in which active interventions, such as a plan of action, might enable the stressful encounter to be relieved. The caregivers in the current study utilized planful problem-solving a "great deal" or "quite a bit", by analyzing the situation 66% of the time, or developed a plan of action 59% of the time. To a large extent these
caregivers demonstrated the utilization of at least two planful problem-focused coping techniques, in dealing with the stress of caregiving.

Previous studies had indicated that when individuals were faced with a threat to their self esteem, or their loved one’s well-being was endangered, they utilized confrontive coping (Folkman, 1986a). Caregivers in the present study used to a "great deal" or "quite a bit", confrontation techniques, such as standing their ground, 52% of the time, and doubling their effort, 71% of the time. Thus, this population of caregivers demonstrated the use of confrontive coping techniques, evident in previous studies.

Since the caregiving situation for an individual with dementia is not frequently an event which is amenable to change, the most constantly utilized types of coping strategies, as documented in previous literature, were the emotion-focused type strategies (Borden & Berlin, 1983; Prucho & Resch, 1989; Zarit & Zarit, 1983). Data from this study confirms the previous literature, in that the subjects demonstrated the extensive use of emotion-focused strategies in the form of the following techniques: look for the silver lining (60%), feeling that they are growing in a positive way (51%), prayer (48%), reframing the situation (64%), accepting the situation (50%), and seeking social support in the form of talking with another individual (70%).

The emotion-focused strategies of escape that were utilized to a lesser degree
(range of 1-9%) by this cohort of caregivers, except for the techniques of "wishing that the situation was going to change" (66%), and "turning to creative activities or work" (61%). This group of caregivers did not utilize escape coping mechanisms such as sleep, engaging in risky behavior such as abuse of food, alcohol or drugs, or smoking to relieve stress. It can be hypothesized that the reluctance of this group of caregivers in utilizing these mechanisms could be the incompatibility of engaging in the escape-coping mechanisms while still monitoring and caring for the care recipient. The subjects in this study had chosen to care for their relatives at home, and it can be speculated that any potential subjects engaging in the use of escape-avoidance techniques, may lead to possibly placing their loved ones in a skilled nursing facility. The use of escape-avoidance techniques could be hypothesized to be incompatibility with the functions of full-time caregivers and therefore this types of coping might have been eliminated in the current study by sample subject criteria.

The behaviors in individuals with dementia that elicited the highest degree of distress to the caregiver, according to the literature, include wandering, aggression, and incontinence (Green 1982; Rabins, 1982; & Sanford, 1975); with incontinence being frequently identified as the most distressful of the behaviors (Jones, 1984). In the current study, behaviors identified as stressful by the caregiver included wandering, night waking, restless activity, inability to stay alone, hallucinations, and behavior dangerous to themselves and others. Incontinence was only rated as
moderately to extremely distressing in 16% of the caregivers.

In examining the data, it is helpful to analyze the frequency in which the behaviors occurred in relationship to the amount of distress to the caregiver. The behavior of wandering was present in 56% (n=72) of this population, and 45% of the sample experienced "very much" to "extreme distress". Behaviors dangerous to the individuals themselves or others were observed by 38% (n=49) of the caregivers, of which 31% stating it was either "very" or "extremely" distressing. Night waking was identified as occurring in 62% (n=79) of the individuals with dementia, and 35% of the caregivers experienced "very" or "extremely" distress with the behavior.

Hallucinations and illusions were experienced by 60% (n=77) of the demented individuals and 23% of the caregivers found the hallucinations "very" to "extremely" distressing. In this population, incontinence was experienced by 42% (n=54) of the patients, and 18% found it a "very" to "extremely" distressing behavior. The engagement in restless activity by the care recipient was present daily in 68% (n=88) of the population and elicited a higher degree of stress in only 24% of the caregivers. The ability to stay alone was identified as a behavior by 71% (n=91) of the caregivers, but elicited a great deal of distress in 28% of the cases. Thus, in investigating the data for the relationship of the frequencies of the behaviors to the percentage of high level stress, this group of caregivers found stressful behaviors to be: wandering, behaviors dangerous to self and others, night waking, hallucinations,
incontinence, restless activity, and inability to stay alone. This is consistent with the literature (Lawton, 1992; Prucho & Resch, 1989) on wandering, aggression and incontinence as distressing behaviors. The unusual findings are the high distress levels found in individuals with restless activity, and inability to stay alone. This possibly could reflect the sample population with 53% (n=68) of the sample having engaged in caregiving activities for less than two years, and thus possibly faced with the early stages of the disease in which restless activity and inability to leave to the loved one alone might pose the most immediately distressing problems in the early stages of the caregiving experience.

The behaviors in the care recipients that elicited the smallest degrees of stress in the caregivers were dressing and feeding behaviors. The inability to dress themselves was present in 52% (n=66) of the care recipients but elicited "very much" to "extreme" stress in only 10% of the caregivers. The inability to feed themselves was present in only 25% (n=32) of the individual with dementia but elicited the higher level of stress in only 1% of caregivers. These data however support the findings of Kinney (1989), that the positive aspects associated with an increase in caregivers feelings of well-being were associated with the caregiver assisting the care recipient in the activities of daily living. This result is contrary to the work of Wallstein (1993), in which increasing distress was linked to tasks of personal grooming. The result from the present study could indicate that by the time the
individual with dementia had reached the level of dependence needing these types of assistance, the caregiver had managed to find successful interventions to manage these behaviors without it creating a stressful situation.

In examining the burden component of caregiver appraisal, data revealed that 74% (n=95) of the caregivers found it "frequently" or "nearly always" difficult to plan ahead, and 71% (n=91) stated that the needs of the care recipient determined how their day was to be spent. However, in examining whether these same caregivers felt that they did not have enough time for themselves, only 21% felt they were "frequently" or "nearly always" confined in this manner, and only 36% felt isolated. These results support the study of Reed, Stone and Neale (1990) in that caregivers felt that the caregiving process did not markedly restrict their activities. A great degree of fatigue in the caregiving experience was experienced "frequently" or "nearly always" by 54% (n=69) of the caregivers. This supports the study of Baldwin (1988) that one of the health concerns most often stated by caregivers was fatigue.

In this group of subjects, even with the restrictions imposed upon them by their caregiving roles, there was a great deal of satisfaction and mastery in their caregiving role. There has been little confirmatory research on the positive aspects of caregiving, other than the study by Lawton and Associates (1989). The current data indicate that there are positive aspects of caregiving, with 86% (N=110) of the
caregivers "frequently" or "nearly always" feeling reassured that they are delivering the proper care to their loved one. The intrinsic reward in caregiving came from pleasure over any form of happiness they could give to their relative. Most wives and daughters had a high level of mastery in the role, with only 7% of caregivers feeling they "nearly always" should be doing more for the individual with dementia, and only 9% of caregivers felt that they should "nearly always" be doing better. These results indicate that there are some positive aspects to the caregiving situations.

Research question related to proposed structural equation model

Physical Health

The first direct relationship tested in the structural equation model was the hypothesis that physical health would have a direct positive effect on the caregiving role. This hypothesis was found to be nonsignificant in the original model. The measurement of health in this research was based on the Global Self-Rated Health Scale (LaRue et al, 1979) a one item self-assessment. The Alpha coefficient for the Global Self-Rated Health scale in this study was reached by comparing the one item Global Health Rating Scale to one item on the Caregiver Appraisal Tool (Lawton et al., 1989) which indicates the amount the caregiver’s health has suffered due to the care he/she must deliver, with the resulting Alpha of 0.48. An Alpha Coefficient of 0.60-0.70 is required to indicate adequate reliability. Although this scale has been

160
used widely in gerontological studies, and has been found to correlate highly with the physician-related health, the reliability in this population is inadequate. In this study, no significant results might be related to the choice of this single instrument with limited demonstrated reliability in this population.

In research on the health of caregivers, the majority of research studies have investigated health in terms of outcome criteria, or as an indicator of quality of life. In this study, physical health was used as an antecedent variable and it was proposed that a physically healthy individual would appraise the caregiving situation in a more positive manner, and therefore would report less burden and more satisfaction in the role. In this group of caregivers 73% (n=93) stated that their health ranged from good to excellent, and 27% (35) rated their health as fair to poor. These data are consistent with the findings of Chenoweth and Spencer (1986), who reported that 21% of caregivers became ill while delivering care. Although this current study does not address the cause and effect of caregiving and illness, the Chenoweth and Spencer (1986) study showed 21% became ill; the Chenoweth study did not investigate how many were in poor health before caregiving and how many became ill during the caregiving experience. In investigating results of the original model in this study, perhaps with a larger sample, the use of a different and more reliable instrument and reanalysis of data on caregivers who only rate their health as good to excellent would produce a direct positive relationship to appraisal of the caregiving role.
The examination of the revised structural model indicates a negative and significant relationship between good physical health and appraisal. It is difficult to interpret the negative rather than positive relationship between physical health and appraisal other than to examine the unreliability of the instrument and the fact the path was generated based on a mathematical rather than theoretical basis. Another interesting path, added in the revised model, includes the positive significant relationship between good physical health and higher depression scores. This path contradicts the work of Pruchno and Associates (1990) who in a study of 315 caregiver found that high depression predicted poor physical health status. The results also conflicted with the work of Robins and Associates (1989) which found a negative relationship between total health and depression for wives of men with irreversible memory impairment, while those wives with good total health were found to have low depression scores.

The revised structural equation model includes the negative and significant path between hardiness and physical health with subjects having high scores on hardiness tending to be in poorer health. It is difficult to interpret this negative path based on the original hardiness research, since the initial research on hardiness investigated the function of hardiness as a stress buffer between stressful life events and illness (Kobasa, 1979; Kobasa et al, 1982; Kobasa et al, 1982a; Kobasa et al, 1983). Hardiness studies on the older adult population by Magnani (1990) also
confirmed the fact that hardiness was related to the elder's self-perceived health status. A study with contradictory findings, and one that supports the revised model, is one by Lee (1991) which indicated that among a male population, hardy individuals had improved mental but not physical health.

Depression

Depression produced the largest significant negative direct path to appraisal in the original model, in that caregivers who were more depressed, had low appraisal scores meaning low satisfaction, higher burden and greater negative impact on the caregiver's role. This confirms the studies of Morycz (1985) and Bashares (1994), which identified that greater caregiver burden, a component of caregiver appraisal, was associated with increased depression. Depression in most studies has been studied as the dependent variable. However in investigating depression, a condition common to most caregivers, the effect of depression on the appraisal of the caregiving situation can be examined in terms of its influence on other variables and a cyclical process rather than the outcome variable. In this case the influence of depression was investigated in terms of appraisal of the caregiving situation and use of problem-focused coping.

Depression, as predicted, resulted in a significant negative path to problem-solving coping. Persons who scored high on depression tend to use fewer problem-solving coping strategies. This confirms the studies of Prucho and Resch (1989), that
the depressed individual used less effective problem-focused coping mechanisms than the non-depressed caregiver. The depression, in the caregiver, is hypothesized to lead to less effective problem-solving ability and more confrontive mechanisms when faced with the stress of caregiving.

In the revised model, three new paths emerged from depression to patient problem behaviors, physical health, and hardiness. The path between depression and patient problem behavior characteristics appeared as a significant strong positive track indicating that patient problem behaviors can generate depression in the caregiver or that a depressed caregiver reports patient behavior problems as more distressing. These results confirm the research of many scientists that link depression to the number of patient problems (Dura et al, 1990; Haley, 1987; Pruchio & Resch, 1989; Schultz & Williams, 1991). Although the current study did not measure the change in depression, dependent upon the length of the caregiving experience, it could also be suggested that the caregiver becomes depressed and continues to experience depression when faced with the gradual mental decline and loss of companionship with the carereceiver as demonstrated by the change in patient behaviors in different stages of the disease. In terms of future research it would be of assistance to investigate the level off and possible "adjustment" in depression of caregivers just as the may adjust in terms of "burden" to the caregiving situation.

The path between depression and hardiness in the revised model, was a
significant negative relationship indicating that persons who scored high on depression tended to be the less hardy individuals. There has been no known research, to date, on the relationship between hardiness and depression. However, inherent in the characteristics of hardiness: control, commitment and challenge, these qualities appear to be antithetical to depression and thus offer some explanation for the data. It can be hypothesized that even when a caregiver experienced a sense of mission and service to the care recipient, the uncontrollable world of the caregiver, in which daily activity is to a large extent by the care recipient, might interact to produce a degree of depression, even in the most committed caregiver. In addition, the individual who viewed caregiving as a challenge could be tested with the uncontrollable nature of the caregiving situation, and experience depression.

**Hardiness**

The path between hardiness and problem-solving coping, in the original model, was significant and in a positive direction meaning that hardiness will result in more problem-focused coping. The hypothesized direction of the path was based on the belief that hardy individuals would better handle stress because they exhibit control, or the ability to independently select among various courses a plan of action. Hardy individuals might also possess the ability to use cognitive control and the ability to interpret, appraise, and incorporate various forms of stressful life events into an ongoing life plan, and by this activity incorporate varied types of problem-focused
coping skills. This process was confirmed, in this population, by the relationship between hardiness and problem-focused coping.

A new path between hardiness and emotion-focused coping was supported in the revised model. The resultant path between hardiness and problem-focused coping became nonsignificant and the negative path between hardiness and emotion-focused coping became significant, meaning that hardiness has no effect on problem-focused coping but results in less emotion-focused coping. These results are contrary to the original model. Explanation of this path is difficult in terms of theoretical framework. Some clarity is obtained by investigating the paths in the theoretical definitions of emotion-focused coping and the subscales included in measuring emotion-focused coping. The subscales include: self-control, positive reappraisal, accepting responsibility, seeking social support, distancing, and escape avoidance (Lazarus, 1985). The qualities of hardiness which include control, commitment, and challenge seem to be congruent with emotion-focused of positive reappraisal, self-control, accepting responsibility and seeking social support (Kobasa, 1984); and thus a positive path might be proposed between hardiness and emotion-focused coping. However, the other aspects of emotion-focused coping, including distancing and escape avoidance, are mechanisms that a hardy individual, who feels a sense of control, challenge and commitment to caregiving, would be unlikely to utilize. In investigating the number of items in the subscales of emotion-focused scales of
Folkman and Lazarus (1986), the largest subscales are escape-avoidance and distancing. Thus, in investigating the revised model, questions arise regarding the constructs of emotion-focused and problem-focused coping.

Social Support

The hypothesized positive path between social support and problem-focused coping in the original model was not significant in this study. A study by Haley and Associates (1987) which investigated the effect of social support upon life satisfaction, utilizing the Folkman conceptual framework, found that social support led to 26% of the variance in life satisfaction, but the relationships between social support and coping mechanisms were not identified. In the current study, social support utilized by caregiver was investigated in terms of the coping mechanisms, both problem-focused or emotion-focused.

The instrument utilized in the current study was the Lubben Social Network Scale ((Lubben, 1988), which was developed specifically for use in gerontological studies and which identifies size of the network, including family friends and independent support. The reliability of this scale was re-established for this study with an Alpha coefficient of 0.73. The Formal and Informal Social Support Scale of Hassinger (Hassinger, 1985) had an Alpha coefficient of 0.03 and this instrument was not utilized in the final data analysis. By eliminating the Hassinger scale, the measurement of in-home paid help, and in-home unpaid help was deleted. It is
doubtful that the elimination of these two areas would have influenced the insignificance of the social support path in this study.

In the revised model, the path between social support and problem-focused coping remained nonsignificant, but a new positive path between social support and emotion-focused coping developed significance. Caution must be utilized in interpretation of the results; however, in examining the subscales of emotion-focused coping, seeking social support and positive reappraisal might be hypothesized as a rationale for the new direction. The positive path between social support and emotion-focused coping supports the research of Norbeck and Associates (1991) which established the same positive correlations. It may be hypothesized that the availability of the social support might serve to enhance the emotion-focused forms of coping, such as self-control and positive reappraisal, when the caregiving situation is not subject to change, and therefore must be dealt with by regulations of the caregiver's emotions.

Patient Problem Behaviors

The path between the care recipient's behavioral problems and emotion-focused coping showed one of the highest significance in a positive direction (0.61) in the original model. This preliminary evidence serves to support the hypothesis that many of these care recipient behaviors, being outside the control of the caregiver, would be subject to emotion-focused coping. In investigating the types of emotion-
focused coping utilized by this sample, the use of self-control, positive reappraisal, accepting responsibility and seeking social support were frequently used techniques. This sample used less distancing and escape avoidance, also classified as emotion-focused coping. The subjects, having been selected mainly from the Los Angeles area Helpline, in which caregivers sought information concerning caregiving issues, this method of subject selection might have resulted in a subset of the population of caregivers which used less distancing and escape avoidance techniques and more social support seeking.

In the revised structural equation model, the path between patient behavior and caregivers' use of emotion-focused coping remained significant and an additional positive path between patient problem behaviors and the caregivers use of problem-focused coping was identified. With the conceptualization of problem-focused coping to include planful problem-solving in addition to confrontive mechanisms, caregivers who remain caregiving in the home might frequently utilize planful problem-solving techniques such as analysis of the situation to develop a plan of care. This supports the previous research that caregivers utilize both emotion-focused and problem-focused coping techniques. caregiver.

Another path identified in the revised model was a large significant negative path between care recipient problem behaviors and the caregivers' appraisal of the caregiving situation. The path however, does support the studies of Davies (1985),
and Harper (1990), both of which identified the care recipient's behavior as the major contributor to burden. The results of the present study do contradict the work of Novak and Guest (1989), and Zarit (1986), whose studies identified that the subjective perception of the caregiver, rather than the objective care recipient behaviors, accounted for the caregivers' feeling of burden.

**Spirituality**

The predicted positive path from spirituality to emotion-focused coping did not reach significance in either the proposed or revised form of the structural equation models. The scale formed from the two questions, developed for this study, measuring spirituality had a coefficient Alpha established at 0.84 indicating adequate reliability. Spirituality is not a frequently measured variable, and therefore there are limited studies which offer assistance in the interpretation. A possible explanation for the lack of significance could be through the examination of the types on emotion-focused coping mechanisms. One type of emotion-focused coping under the subscale of positive reappraisal includes the use of prayer, finding new faith, and rediscovering what was important. Instead of spirituality being a separate construct, it might be considered as an emotion-focused coping mechanism utilized by a large number of the caregivers. The research question posed as "how important is religion to your life" might be too narrowly interpreted, and the question of finding new faith and use of prayer might be more appropriate in assessing spirituality.
Problem and Emotion-Focused Coping

In the hypothesized model, problem-focused coping was proposed as a direct positive path to appraisal, and the original and revised structural equation model indicated a positive significant route. This indicates that problem-focused coping will result in appraisal of the caregiving role as more satisfying, less burdensome with lesser impact on the caregiver’s life. This result supports the findings of Haley and Associates (1987), and Purcho and Resch (1989), which indicated that problem-solving techniques in caregiving led to an increase in life satisfaction among caregivers.

Emotion-focused coping emerged as a significant path to appraisal, although in the negative direction. This indicate that emotion-focused coping will result in appraisal of the caregiving role as less satisfying, more burdensome and with a greater impact on the caregiver’s life. This result supports the initial work of Folkman et al. (1986) in which subjects who viewed a stressful situation as changeable, accepted more responsibility and used confrontive coping, planful problem solving and reappraisal, all of which are elements of problem-focused coping. The same study identified individuals who viewed a stressful situation as having to be accepted used distancing and escape-avoidance, elements of emotion-focused coping techniques. Results in the current study support the research which indicates that coping is multidimensional (McCrae, 1984) (Folkman, 1984), including

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both emotion-focused and problem-focused when faced with different stressors.

The same significant negative and positive paths to emotion- and problem-focused coping remain in the revised structural equation model. In the revised model, the factors of emotion- and problem-focused coping are also postulated as correlated, as indicated by the curved line in the model (Figure 5-4). In investigating the Ways of Coping Scale (Folkman & Lazarus, 1986), the Alpha coefficient on problem-focused coping was (0.76) and emotion-focused coping (0.79), indicating sufficient reliability within this population. In analyzing the problem-focused and emotion-focused coping subscales, it is very difficult to determine items which comprise the problem-focused or emotion-focused constructs from a conceptual interpretation of the items. There is considerable overlap and controversy over the designation of the categories of emotion- and problem-focused coping. For example, seeking social support is considered a subscale of emotion-focused coping but many of the items in the scale pertain to seeking information, viewed as a stage in planful-problem solving. Thus some of the results in this study could be related to the lack of conceptual clarity in the measures.

Structural Equation Model as it Applies to the Adaptation Model of Nursing

The Roy Adaptation model of nursing and Lazarus and Folkman’s conceptual framework of coping were utilized to design this study. The Adaptation model was
utilized to select variables and organize the paths. Based on the Adaptation framework, environmental stimuli were identified such as depression, hardiness, social support, patient problem behaviors and spirituality. Such stimuli were acted upon internally and processed by cognator activity measured by problem- and emotion-focused coping, with the resultant outcome on the individual's Adaptation level as measured by appraisal of the caregiving situation in terms of burden, satisfaction and impact. Directions and paths were chosen based on the assumption that the model is a systems theory, or one in which the internal control of cognator activity receives input from the environment and internally processes the information, with the resulting output evaluated in terms of effective or ineffective behaviors. The use of the model also included the definition of the individual as a bio-psycho-social-spiritual being. In operationalizing this concept, the environmental stimuli in this study included elements of the physiologic mode; physical health, the psychological mode; depression, and the social mode; social support and spirituality.

Application of the Adaptation model is evident in the development of the paths of the structural equation model. The structural equation model organized the relationship of the variables based on the Adaptation model. For example stimuli in the environment included such variables as: physical health, depression, hardiness, social support, patient behavior problems and spirituality. Cognator activity, in the Adaptation model was operationalized to emotion- and problem-focused coping. The
resulting influence on the adaptation to the caregiving role was assessed as appraisal with the components of burden, impact and satisfaction. The operational definition of cognator activity has not been previously included in research on the Roy Adaptation theory. Previous studies utilizing the Adaptation model have only hypothesized cognator activity as an internal mechanism affecting the level of adaptation. By operationally defining cognator activity, as emotion- and problem-focused coping according to the stress and coping theory of Lazarus and Folkman, a new dimension was added to scientific inquiry on the model. The Adaptation model was used to define human activity using a systems approach which includes the premise of a cyclic response to stimuli in the environment. In using the systems approach, responses act as feedback into the system. This was demonstrated in the cyclical relationship between depression and appraisal.

In examining both the original and revised model, to determine if the cognator activity, as defined as emotion- and problem-focused coping, mediated between stimuli in the environment and level of adaptation, it appears that in both cases stimuli are mediated by the coping mechanisms. The significant paths between the environmental stimuli of depression, hardiness, patient behaviors and the coping mechanisms suggest that coping mechanisms mediate between these environmental stimuli and appraisal or adaptation. The nonsignificance of social support might be due to the fact that a social support component is included into the conceptualization.
of problem-focused coping by Lazarus and Folkman (1985). This conceptualization then changes social support from an environmental stimuli to a coping mechanism. A similar explanation for the insignificance of spirituality in relationship to emotion-focused coping could be projected, since the subscales of emotion-focused coping include some components of spirituality. The significant pathways between problem- and emotion-focused coping and appraisal in both the original and revised model also indicate that there could be a possible relationship between the coping and the appraisal of the caregiving role. In the revised model, more complex interrelationships among stimuli are indicated. In the revised model, the interrelationships among environmental stimuli, such as physical health and depression to hardiness and depression to hardiness and patient problem behaviors, and not just the relationship of environmental stimuli to coping mechanisms are demonstrated. These results indicate that the process of adaptation, as measured by appraisal, is possibly more complex than the relationship of stimuli being processed by coping mechanisms and the outcome of adaptive or ineffective behavior.

**Strengths and Limitations of the study**

The existence of a relationship between the variables of depression, hardiness, patient behaviors, and emotion- and problem-focused coping was clarified and supported. Results of the selected statistical analysis provided additional support for
the relationships. These results, which are congruent with other investigations, supported the theoretical explanations and provide added credibility to the hypothesized model. The results of the hypothesis testing lends some support to the Roy Adaptation model of nursing, but further testing is essential.

A strength of this study is the large sample for testing the original model. The sample size was calculated prior to data collection on 130 subjects. Data were collected on a total of 128 subjects. A total of 5-20 subjects per path were needed and in the hypothesized model a total of nine paths were identified. Data were collected on seventeen subjects per path, the high end of the acceptable range. In the revised model there were seventeen paths identified for a total of seven subjects per path; thus the number is still within the acceptable range.

Related to Validity

Validity is defined as the best available approximation to the truth or falsity of propositions concerning cause (Cook & Campbell, 1979). The concept of validity is divided and defined into four interrelated types; statistical conclusion, internal, external, and construct validity. According to Cook and Campbell (1979), statistical conclusion validity deals with the rationale for why researchers draw false conclusions about the covariation and the reasons for the threat to making valid inferences. Internal validity refers to the approximate validity with which we infer that a relationship between two variables is causal, or the absence of a relationship.
indicating the absence of cause (Cook & Campbell, 1979). External validity refers to
the extent to which we can assume that the presumed causal relationship can be
generalized across populations and settings. Construct validity refers to the extent to
which we can make generalizations about the operationalization of theoretical concepts
constructed to measure the variable. Issues in the present study based on the four
types of validity are discussed in the following sections.

Statistical Conclusion Validity

Statistical conclusion validity is concerned with threats to a valid inference
resulting from random error and the ill advised selection of statistical procedures
(Cook & Campbell, 1979). In this study, statistical conclusion validity may pose a
threat in the form of failure to reject the null hypothesis, due to inadequate sample
size or failure to control and isolate sources of variation. One threat to statistical
conclusion validity is low statistical power. As addressed previously, the sample size
does not produce a hazard in the hypothesized model; however, in the revised model
the number of subjects per path still meets the projected size per path, but was at the
low end of the scale.

The second threat to statistical conclusion validity results from violated
assumptions of statistical tests. The statistical assumptions for structural equation
modeling include first, that the model needs to be devised correctly and that there are
linear relationships between variables. These variables must be correctly identified
based on underlying and previous research. In the current study, six of the nine paths yielded significant paths, which were supported by previous research; it appears that the results support the underlying relationships between variables. Another statistical assumption is that there should exist no extreme multicollinearity, or two variables measuring the same concept. As mentioned previously, by surveying the model it might be hypothesized that the lack of significance in spirituality and social support could be attributed to the fact that social support also might in actuality be a component of emotion- and problem-focused coping, and spirituality might be a portion of emotion-focused coping.

Another threat to statistical conclusion validity is the problem of "fishing" or searching for relationships between variables (Cook & Campbell, 1979). The likelihood of wrongly rejecting a true null hypothesis, or Type I error, increases with "fishing" for desired results. With the revised structural equation model, the relationships between variables were generated based on a statistical program using the statistical output engineered to create a model with the best goodness-of-fit. The problem inherent in this method is the probability of drawing one or more erroneous conclusions based on the number of tests performed. Therefore care needs to be taken in interpretation of the revised structural equation model.

Statistical conclusion validity can also be threatened by the reliability of the measures utilized. The use of instruments having low reliability may inflate the error
of the estimate and lead to a Type II error, or wrongly accepting a false null hypothesis. In order to protect against this threat, a thorough examination of the reliability and validity of the tools was conducted. The result of the examination was the elimination of the use of the Formal and Informal Social Supports (Hassinger, 1985). The Lubben Social Network Scale (Lubben, 1988) demonstrated adequate reliability and was utilized exclusively to measure social support. Although there were questions regarding social support on the Ways of Coping Scale (Lazarus, 1985) there was no attempt to combine the items with the Lubben Social Network Scale. The Global Self-Rated Health Scale (LaRue, et al., 1979), a self-report measure of health status, was included in this study.

Another threat to the statistical conclusion validity can result from random irrelevancies in the experimental setting which can lead to error variances and a Type II error. The questionnaire was administered in the home setting; a potential disruption to the collection of data was the potential disruption of the care recipient. In all cases an appointment had been made at a time convenient with the subject and at a time in which limited disruptions were anticipated. In certain cases, the data collection was accomplished at a restaurant or location outside the home to limit disruptions and enable the participant to answer the questions without interruption. Therefore, in this study, an attempt was made to decrease the interruptions in the environmental setting.
Internal Validity

Internal validity is concerned with correctly concluding that an independent variable is, in fact, responsible for the variation in the dependent variable. One threat to internal validity is the effect of history, or that events other than the collection of data may affect the results. In the case of this study, a threat to internal validity was the Northridge earthquake, which occurred in the middle of data collection. Since the study deals with the variable of stress and coping, the resultant disruption to everyday activities in the Los Angeles area imposed by the quake could pose a spurious stress on caregivers. To counteract this threat during the three-month-period following the earthquake, data collection was curtailed to minimize the effects of the stress of the quake.

Another threat to internal validity, in this study, could result from the subject’s understanding of the different scales and the ability of the subjects to accurately use and discriminate among four-and-six point intervals in the instruments utilized. Changes in the calibration of instruments utilized can affect scores on the various variables. This questionnaire utilized Likert-like scales which ranged from four-point to six-point intervals. This variation in numerical choices among scales has the potential to make the discrimination judgments complex when moving from one scale to another. In order to counteract the subjects ability to accurately understand and use the Likert scale and discriminate among the four-and six-point intervals, a large
typewritten choice of responses with corresponding numerical response was placed in
front of the subject and explained and changed with each corresponding set of
appropriate responses.

An additional threat to internal validity in this study was that inter-rater
reliability was not obtained between the researcher and the research assistant. The
procedure for developing inter-rater reliability involves two individuals simultaneously
and independently recording relevant data on the same subject, and the subsequent
computation of a correlation coefficient. Inter-rater reliability data on the ten subjects
collected by the researcher and the remaining 119 performed by a research assistant
were not obtained. This weakness was an oversight on the part of the researcher who
overlooked the necessity. However, research assistant training was provided by the
researcher. The method of data collection of asking the standard questions for the
instrument with the appropriate responses on a sheet in front of the sample subject
had been clearly explained to the data collector by the researcher. In addition, during
the first few subjects the researcher observed the data collection to obtain consistency
in the process.

Subject selection is a threat to internal validity in any study in which
randomization is not used. By the use of a convenience sample, recruited primarily
through the Alzheimer’s Association Helpline, the sample could be considerably
different from the general population. An individual who calls for assistance in
caregiving problems, and who is actively caregiving on a daily basis, might be a
different type of caregiver from the general population. In addition, since the subjects
were willing to complete a battery of tests requiring approximately one to two hours
of their time, they were assuredly a self-selected group.

**Construct Validity**

The construct validity is concerned with the degree to which an instrument
measures the concept under investigation. In this study, care was taken in defining
the variables in accordance with the conceptual framework (Roy Adaptation model).
This posed problems since the Adaptation model had not clearly operationalized the
cognator subsystem. Use of the Lazarus and Folkman (1986) theoretical framework
of stress and coping appeared to be the closest approximation to the cognator system.
This operationalization of coping was performed to gain support for the role of
cognator activities in influencing adaptation to caregiving. The lack of a previous
clear definition posed a clear threat to construct validity.

Attention to construct validity was accomplished by the careful selection of
instruments for reliability and validity. An addition consideration was attempted, to
include the selection of instruments, based on the theoretical framework and theory.
Despite the attention to detail, the overlap of these constructs posed a problem to the
construct validity of this study, due to the overlapping constructs of spirituality, which
upon investigation were incorporated in emotion-focused coping; and social support,
which were included in the problem-focused scale.

Another method of obtaining construct validity is the procedure known as the multitrait-multimethod matrix method (Campbell & Fiske, 1959). Using this procedure the concepts of convergence and discrimination are utilized. Convergence is the use of different measures to identify a construct with the outcome yielding similar results. Discrimination is the ability to differentiate the concept being measured from other similar constructs. In order to accomplish the multitrait-multimethod approach a long and tedious questionnaire often has to be developed. Given that the questionnaire involved 278 questions, and took between one and two hours to administer; the duplication of scales would have involved an inordinate long and taxing data collection procedure, and therefore data collection was curtailed to one instrument per construct and the multitrait-multimethod matrix model was not utilized to establish construct validity.

External Validity

External validity is concerned with the generalizability of the research findings across populations of subjects and settings (Cook & Campbell, 1979). Generalizability of these findings are limited by the deficiency in random sample selection. Since most subjects were chosen from the Los Angeles Alzheimer Association Helpline, their original contact was with questions regarding disease or care of the individual with dementia. Thus, the results of this study can only be
generalized to the same type of population as the original sample, one who is interested in calling the Alzheimer Helpline and is willing to participate in a research project. In addition, generalizability would include a special type of sample subject - the one who agrees to have a lengthy interview. It is conceivable that subjects who agreed to this procedure might have caregiving concerns that made them interested in participation in the study and make them a unique subset of all caregivers.

Summary and Recommendation for Nursing Research

In summary, despite the limitation, the results of this investigation have provided reasonable information in clarification of the adaptation to the caregiver role. The study adds to the body of knowledge on the caregivers to demented individuals by supporting the aspect of satisfaction as well as burden that caregivers experience in the role. The effects on caregivers' coping mechanisms in dealing with the stress of caregiving has been investigated. The interaction of the environmental variables such as hardiness, depression and patient behaviors have also been supported. The patterns of interactions among the variables, and the interactions among the environmental stimuli, coping mechanisms, and appraisal of the caregiving situation, have been assessed.

The results of this study indicate that many caregivers appraise the caregiving situation in a positive light and deal with the stresses of caregiving in a manner that
supports the individual with dementia while remaining physically healthy. The negative relationship between depression and appraisal of the caregiving situation as well as the ability of the caregiver to use the more effective means of problem-solving coping is a potential intervention for the practitioners involved with these caregivers.

The implications for further research include the use of the results of this study to investigate interventions with the attention to the mental health of the caregiver. Another intervention study which develops the components of commitment, control and challenge among caregivers might give us increased knowledge of the role of hardiness in the caregiving environment. In addition, studies on a variety of dementing illness, in a variety of settings, might assist in the understanding of appraisal of the caregiving role. A study with improved and varied instruments and among different cultures would also add to the body of knowledge on appraisal of the caregiving situation.

In addition further research on this study should include the division of the population into two subsamples; wives and daughters. The investigation of the similarities and differences between the two groups of caregivers would add to the body of knowledge on the stress and coping mechanisms of different categories of caregivers.

The research in the area of adaptation to caregiving should be aimed at clarifying the Adaptation model of nursing theory and specifically the cognator.
system. The theoretical framework of emotion-focused and problem-focused coping according to Lazarus and Folkman using the Ways of Coping Scale (Lazarus, 1985) was problematic in the areas of overlap on the scales. There was considerable confounding of the constructs of emotion- and problem-focused coping. The relationship of spirituality and social support as coping mechanism also need to be investigated and refined.

Based on the subscales identified to measure emotion-focused and problem-focused coping identified in this research, a study could be replicated based with a prediction of paths identified in the revised model. A new study should be replicated in a sample of caregivers with caregivers identified into two classification; those who appraise their role as less burdensome, with more satisfaction and less impact on their daily life, as compared to those whose appraisal of the caregiving role is more burdensome, with less satisfaction and more impact upon their daily life. Qualitative research on adaptation to the caregiving role would add to the understanding of this phenomena. A phenomenological study might be proposed to discover the essence of stages of caregiving and to discover the positive aspects of caregiving. The present study suggests that there is a positive aspect to the caregiving role, and the qualitative study would add to the knowledge of adaptation to a stressful role.

Moreover, the identified linkages in the revised model are influences of importance in the coping process and necessitate further research. Such influence
include the relationship of coping mechanisms on appraisal to the caregiving role, and
the influence of hardiness, depression and patient behaviors on the use of coping
mechanisms.

Implication for Nursing Theory

The importance of patterns in structuring nursing knowledge, depicting
interactions of nursing’s concerns and bringing nursing’s authenticity into view has
long been desired (Dickoff, James, & Weidenback, 1968; Donaldson & Crowley,
1978). The source of theoretical knowledge in nursing evolves from the study of
human phenomena. By the addition of an accepted and researched definition for the
cognator and regulator system, in terms of the Lazarus and Folkman coping theory,
nursing theory was enhanced. Since nursing derives its theoretical basis from the
study of the human phenomena, the patterns of human adaptation to stressful life
situations adds to nursing’s theoretical base.

Through the use of the Roy Adaptation model as a design for this study,
testing of the relationships of the propositions within the model has been
operationalized. The testing of a nursing theory to describe, explain, and predict the
relationship of variables was accomplished. The theoretical conclusions of the study
contribute to the development of the nursing practice.

The use of the Adaptation theoretical framework and the possibility of the
cognator subsystem, as defined as coping mechanisms according to Lazarus and Folkman were affirmed in this study. The environmental stimuli that were affected by the coping processes included depression, hardiness and patient behaviors. These interrelationship were congruent with the Roy Adaptation model approach (Roy, 1976).

Implications for Nursing Practice and Education

The major findings of this study to the body of nursing knowledge is the confirmation that adaptation to the caregiving role can include some positive aspects for caregivers. The positive relationship between problem-solving coping and appraisal of the caregiving process was suggested by the data. The positive path between problem-focused coping, as compared with the negative direction of the path between emotion-focused coping and appraisal, suggests that interventions which promote problem-solving coping might assist the caregiver’s appraisal of the caregiving situation.

The study also highlighted the need for continued investigation of the caregiving situation, to clearly define possible stages of caregiving. The investigation of caregivers in similar stages of the caregiving experience might lead to more appropriate interventions.

The role of depression as directly influencing the caregivers’ problem-solving
ability, as well as depressions' direct negative path to appraisal might indicate that interventions which assist in relief of the depression of the caregiver might serve through multiple paths to relieve the stress of caregiving. When faced with the gradual loss of cognitive function of the loved one the caregiver might experience increasing depression with declines in cognitive performance and thus interventions might be needed at many stages of this illness.

The significant relationship between the patient behaviors, emotion-focused, and problems-focused coping, and appraisal of the situation suggests that both forms of coping assist the caregiver in dealing with behavioral patterns of the individual with dementia. The use of positive reappraisal, planful-problem solving, and self-control appeared to assist the caregivers in this study in dealing with the uncertainty of the caregiving situation. The limited use of distancing as a coping mechanism in this group of caregivers was significant, and needs to be investigated in other populations of caregivers. A knowledge of the patterns of coping mechanisms which assist caregivers to remain healthy and rewarded in the caregiving situation will assist those who care for the an individual with a dementing disorder.

The role of hardiness as it relates to the use of problem-focused coping was affirmed in this study. The qualities of hardiness: commitment, control and challenge, have been investigated in terms of a multifaceted personality type. If in dealing with caregivers an intervention could be designed, in which elements of these
three components were rewarded, a positive form of adaptation might be promoted.

The variable identified as having the most significant effect on appraisal of the caregiving role was the care recipients behavioral problems. This research suggested that interventions aimed at problem solving related to such behavioral problems would possibly serve to be the most effective in improving the caregiver's appraisal of their role.
Appendix A
Sample Letter to Caregivers

(Date)

Dear Caregiver:

I am a clinical nurse specialist and doctoral candidate at UCLA. For my doctoral dissertation I am conducting a study of stress and coping mechanisms of caregivers. The purpose of this study is to identify coping mechanisms which foster satisfaction or lead to distress in the caregiving role. By identifying such factors I hope to devise assistance for caregivers such as you.

If you are a woman, English speaking, are caring for a spouse or parent with Alzheimer or related disorder, and taking care of your spouse or parent at home, I would like to invite you to participate in this study. Involvement in this research involved completing a questionnaire which take approximately one hour of your time. I, or one of my research assistants, will bring the questions to your home and help you with its completion. These home visits will be scheduled at your convenience, you will be paid $10 upon completion of the questionnaire.

Please indicate on the enclosed postcard your willingness to participate in the study. If you would like further information, or clarification, I can be reached at --- ---- during the day or --- ---- ---- in the evenings. Thank you for your consideration and assistance. I look forward to meeting you.

Sincerely

Karen Jensen, RN, MN
Doctoral Candidate
Appendix B
Consent to Act as a Research Subject

Karen Jensen, MN, RN, a medical surgical clinical nurse specialist and doctoral candidate at UCLA is conducting a study to find out more about coping mechanisms of Alzheimer caregivers. I have been asked to take part because I am a caregiver to an individual with a dementing disorder.

If I agree to be in this study, I will be visited at home one by Ms. Jensen or her assistant. This visit will be scheduled at my convenience. During the visit I will complete a questionnaire requiring approximately one to two hours of my time.

There will be a $10 enumeration for my time and effort. Upon completion of the research, I may obtain a copy of the study. The benefit of this research is that investigator may learn factors which influence the care of demented individuals.

Ms. Jensen, or her assistant, has explained this study to me and answered my questions. If I have questions later, I can call Ms. Jensen at --- --- ---- or write her in care of UCLA School of Nursing, Los Angeles, CA 90024. If I have any other questions or research related problems, I may call Ms. Jensen’s sponsor at UCLA: Dr. Betty Chang - --- --- ----.

My participation in this research is entirely voluntary. I may refuse to participate or withdraw at any time without jeopardy to the medical care I or my loved one receive. Research records will be kept confidential. Only those directly involved in the study will have access to the information. Questionnaires will be identified by numbers only. Answers will be analyzed by groups rather than individually, so no one will ever know my specific answers.

I have received a copy of this consent document to keep. I agree to participate.

Subject’s Signature: ________________________________
Witness: _________________________________________
Date: ___________________________________________
Appendix C

1. What is your relationship to the person with alzheimer disease or related disorder?
   [ ] spouse [ ] daughter [ ] other

2. Are you the primary caregiver to the person with alzheimer disease or related disorder?
   [ ] yes [ ] no

3. Living arrangements: [ ] same household [ ] living apart

4. How long have you been providing care for the person with alzheimer disease or related disorder?
   ________ years ________ months (in months or years)

5. Average number of hours per day spent with the person with alzheimer disease of related disorder
   [ ] 0-6 [ ] 7-12 [ ] 13-18 [ ] 19-24

6a. Do you participate in any support groups for caregivers? [ ] yes [ ] no *If no skip to question 7

6b. If yes, how often do you participate? ______ times a week ______ times a month ______ once in a while

7. Would you rate your health as:
   [ ] excellent [ ] very good [ ] good [ ] fair [ ] poor

8. English speaking? [ ] yes [ ] no

9. What is your age? ________

10. What is your ethnicity?
    [ ] White [ ] Black [ ] Hispanic [ ] Asian **type** [ ] Other [ ]

11. Occupation (or occupation prior to retirement):
    Yours: __________________________________________________________________________
    Spouse’s: _______________________________________________________________________

12. Education: You: ________________ Spouse: ________________ 1st through 12th grade
    Your: ________________ Spouse: ________________ College (in years)

13. How important is religion to your life?
    [ ] extremely [ ] very [ ] moderately [ ] a little [ ] not

14. How important is religion to your health?
    [ ] extremely [ ] very [ ] moderately [ ] a little [ ] not

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### SECTION A

**Directions:** Below is a list of ways people cope with a wide variety of stressful events. Please indicate by checking the appropriate number how the strategies you are using in dealing with your member's illness.

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
<th>Does Not Apply</th>
<th>Used Somewhat</th>
<th>Used Quite a Bit</th>
<th>Used A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Just concentrate on what I have to do next - the next step</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>I try to analyze the problem in order to understand it better</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>Turn to work or substitute activity to take my mind off things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>I feel that time will make a difference - the only thing to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>Is wait.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>Bargain or compromise to get something positive from the situation.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>I'm doing something which I don't think will work, but at least I'm doing something.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>Try to analyze the problem in order to understand it better</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>I try to keep my feelings to myself</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>Go along with fate; sometimes I just have bad luck.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>I'm doing something which I don't think will work, but at least I'm doing something.</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>Turn to work or substitute activity to take my mind off things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
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<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>Try to get the person responsible to change his or her mind</td>
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<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
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<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31</td>
<td>Try to get the person responsible to change his or her mind</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Does Not Apply and/or Not Used</td>
<td>Used Somewhat</td>
<td>Used Quite a Bit</td>
<td>Used A Great Deal</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-------------------------------</td>
<td>--------------</td>
<td>-----------------</td>
<td>-----------------</td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>Take a big chance or do something risky.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34</td>
<td>Try not to act too hastily or follow my first hunch.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35</td>
<td>Try not to make myself feel better by eating, drinking, smoking, using drugs or medication, etc.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36</td>
<td>Maintain my pride and keep a stiff upper lip.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37</td>
<td>Rediscover what is important in life.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38</td>
<td>Avoid being with people in general.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39</td>
<td>Don't let it get to me; refuse to think too much about it.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40</td>
<td>Ask a relative or friend I respect for advice.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>41</td>
<td>Keep others from knowing how bad things are.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>42</td>
<td>Make light of the situation; refuse to get too serious about it.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>43</td>
<td>Take it out on other people.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>44</td>
<td>Draw on my past experiences; I was in a similar situation before.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>45</td>
<td>Know what has to be done, so I am doubling my efforts to make things work.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>46</td>
<td>Accept it, since nothing can be done.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>47</td>
<td>Face it.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>48</td>
<td>Adapt some of my actions to the problem.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>49</td>
<td>Change something about myself.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>50</td>
<td>Change something about others.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>51</td>
<td>Try to make my feelings from interfering with other things better.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>52</td>
<td>Wish that I can change what is happening or how I feel.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>53</td>
<td>Imagine a better time or place than the one I am in.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>54</td>
<td>Wish that the situation would go away or somehow be easier.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>55</td>
<td>I dream or imagine a better time or place than the one I am in.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>56</td>
<td>I am in a similar situation.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>57</td>
<td>I am in a similar situation.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>58</td>
<td>I have fantasies or wishes about how things might turn out.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>59</td>
<td>I prepare myself for the worst.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>60</td>
<td>I prepare myself for the worst.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>61</td>
<td>I go over in my mind what I will do or say.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>62</td>
<td>I think about how a person I admire would handle this situation and use that as a model.</td>
<td>O</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
**SECTION A (cont.)**

<table>
<thead>
<tr>
<th>Item</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite a Bit</th>
<th>Most of the Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>83</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>84</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>85</td>
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</tr>
<tr>
<td>86</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**SECTION B**

Directions: The following statements reflect how people sometimes feel when taking care of another person. Read each statement and circle the appropriate number for how often you feel that way. Remember, there are no right or wrong answers.

<table>
<thead>
<tr>
<th>How often do you feel ...</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite a Bit</th>
<th>Nearly Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. That he asks for more help than he needs?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. That because of the time you spend with him, you don’t have enough time for yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. You really enjoy being with him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Angry when you are around him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. That he shows some appreciation of what you do for him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. That he currently affects your relationship with other family members in a negative way?</td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. Your health has suffered because of the care you must give him?</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>8. That his pleasure over some little thing gives you pleasure?</td>
<td></td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. That caring for him doesn’t allow you as much privacy as you would like?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Taking responsibility for him gives your self esteem a boost?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Your social life has suffered because you are caring for him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Uncomfortable about having friends over because of him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Helping him has made you feel closer to him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Uncertain about what to do about him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Relieved knowing that as long as you are helping him, he is getting proper care?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Related and alone as a result of caring for him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. That you should be doing more for him?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. That you will be unable to care for him much longer?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. That you have lost control of your life since his illness?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Caring for him has interfered with your use of space in your home?</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>
SECTION B (cont.)

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Quite</th>
<th>Nearly</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. Do you feel able to handle most problems in care for him?</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
<td>R</td>
</tr>
<tr>
<td>22. Very tired as a result of caring for him?</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
<td>R</td>
</tr>
</tbody>
</table>

Directions: Here is another group of statements. For each one circle the response that best describes how you feel.

<table>
<thead>
<tr>
<th>Disagree</th>
<th>A little</th>
<th>Neither</th>
<th>Agree</th>
<th>A little</th>
<th>Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>23. In general, I feel able to handle most problems in the care of him.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. I can fit in most of the things I need to do in spite of the time taken by caring for him.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>25. It's hard to plan things ahead when his needs are unpredictable.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>26. It's mostly his needs that determine how my days are spent.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>27. I am pretty good at figuring out what he needs.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>R</td>
<td></td>
</tr>
<tr>
<td>28. Taking care of him gives me a trapped feeling.</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td></td>
</tr>
</tbody>
</table>

SECTION C

Directions: For each of the behaviors listed below, please circle the most accurate number for its frequency of occurrence, and your level of distress when it occurs.

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Frequency</th>
<th>Distress</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wandering or getting lost</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>2. Asking the same question over and over again</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>3. Hitting things (e.g., jewelry, money)</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>4. Being suspicious or accusatory</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>5. Losing or misplacing things</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>6. Not recognizing familiar people</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>7. Forgetting what day it is</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>8. Starting, but not finishing things</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>9. Destroying property</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>10. Doing things that embarrass you</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>11. Waking you up at night</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>12. Being constantly restless</td>
<td>0 1 2 3 4 5</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

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SECTION A - Part 1

**KEY:**

**Emergency Rating:**

Does this problem occur?

If so, how often?

- 0 never occurred
- 1 has occurred, but not in the past week
- 2 has occurred once or twice in the past week
- 3 has occurred 3 to 6 times in the past week
- 4 occurs daily or more often
- 5 would occur if not supervised

**Difficulty Rating:**

How much does it bother or upset you when this occurs?

- 0 not at all
- 1 a little bit
- 2 moderately
- 3 very much
- 4 extremely

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Emergency</th>
<th>Difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Being constantly talkative</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>14. Talking little or not at all</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15. Engaging in behavior that is potentially dangerous to self or others</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>18. Dying situations from the past</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17. Seeing or hearing things that are not there (hallucinations or illusions)</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. Unable to dress self (partly or totally)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>19. Unable to feed self</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>20. Unable to bathe or shower by self</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>21. Unable to put on make up or shave by self</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>22. Handicapped of bowel or bladder</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>23. Unable to prepare meals</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>24. Unable to use phone</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>25. Unable to handle money (e.g., to make a purchase)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>26. Unable to clean the house</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>27. Unable to shop</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>28. Unable to do other simple tasks (e.g., simple repairs, put groceries away)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>29. Unable to stay alone by self</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>30. Other problems</td>
<td>3</td>
<td>3</td>
</tr>
</tbody>
</table>

SECTION B

Directions: Please circle the response that best reflects the number of times the following things have occurred in the past 6 months, including today.

<table>
<thead>
<tr>
<th>Question</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. You were bothered by things that usually don't bother you</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7. You did not feel the eating; your appetite was poor</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>3. You felt that you could not shake off the blues even with help</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>4. You felt that you were just as good as other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>5. You had trouble keeping your mind on what you were doing</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

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**SECTION B (cont.)**

<table>
<thead>
<tr>
<th>Number</th>
<th>Sentence</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>You felt depressed</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>7</td>
<td>You felt every other you did was an effort</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>8</td>
<td>You felt hopeful about the future</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>9</td>
<td>You thought your life had been a failure</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>10</td>
<td>You felt treated</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>11</td>
<td>Your sleep was restless</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>12</td>
<td>You were happy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>13</td>
<td>You talked less than usual</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>14</td>
<td>You felt lonely</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>15</td>
<td>People were unfriendly</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>16</td>
<td>You enjoyed life</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>17</td>
<td>You had crying spells</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>18</td>
<td>You felt sad</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>19</td>
<td>You felt that people disliked you</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>20</td>
<td>You could not get 'going'</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>

**SECTION F**

Directions: Below are some items that you may agree or disagree with. Please indicate how you feel about each one by checking a number 1 to 4 in the space provided. A one indicates that you feel the statement is not at all true; checking a four means that you feel the statement is completely true. As you will see many of the items are worded very strongly. This is to help you decide the extent to which you agree or disagree. Please read all the items carefully. Be sure to answer all the items true or false (true or not at all true) and not to think too much time on any one item.

<table>
<thead>
<tr>
<th>Number</th>
<th>A Little True</th>
<th>Quite A Bit True</th>
<th>Completely True</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Not True</td>
<td>A Little True</td>
<td>Quite A Bit True</td>
<td>Completely True</td>
</tr>
<tr>
<td>----------</td>
<td>---------------</td>
<td>------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>13. When you marry and have children you have lost your freedom of choice</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14. No matter how hard you work, you never really seem to reach your goals</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>15. A person whose mind seldom changes can usually be depended on to have reliable judgment</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>16. I believe most of what happens in life is just meant to happen</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>17. It doesn't matter if you work hard at your job, since only the boss really profits from it anyway</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>18. I don't like conversations when others are confused about what they mean to say</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>19. Most of the time it just doesn't pay to try hard, since things never turn out right anyway</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>20. The most exciting thing for me is my own fantasies</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>21. I won't answer a person's questions until I am very clear as to what he is asking</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22. When I make plans I'm certain I can make them work</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23. I really look forward to my work</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24. It doesn't bother me to step aside for a while from something I'm involved in, if I'm asked to do something else</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25. When performing a difficult task at work, I know when I need to ask for help</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26. It's exciting for me to learn something about myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27. I enjoy being with people who are unpredictable</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28. I find it's usually very hard to change a friend's mind about something</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29. Thinking of yourself as a free person just makes you feel frustrated and unhappy</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30. It bothers me when something unexpected interrupts my daily routine</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31. When I make a mistake, there's very little I can do to make things right again</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32. I feel no need to try my best at work, since it makes no difference anyway</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33. I respect rules because they guide me</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34. One of the best ways to handle most problems is just not to think about them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35. I believe that most athletes are just born good at sports</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36. I don't like things to be uncertain or unpredictable</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37. People who do their best should get full financial support from society</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38. Most of my life gets wasted doing things that don't mean anything</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39. Lots of times I don't really know my own mind</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
SECTION E (cont.)

Not True
A Little True
Quite A Bit True
Completely True

40. I have no use for theories that are not closely tied to the facts .......... 1
41. Ordinary work is just too boring to be worth doing ........................................ 1
42. When other people get angry at me, it's usually for no good reason . 1
43. Changes in routine bother me ................................................................. 1
44. I find it hard to believe people who tell me that the work they do .... 1
45. I feel that if someone tries to hurt me, there's usually not much ...... 1
46. I can do it by try and stop him ................................. 1
47. When other people get angry at me, it's usually for no good reason 1
48. Most days, life just isn't very exciting for me .............................................. 1
49. I think people believe in individuality only to impress others .......... 1
50. When I'm reprimanded at work, it usually seems to be unjustified .... 1
51. I think people believe in individuality only to impress others .......... 1
52. M ost days, life just isn't very exciting for me ......................................... 1
53. I think people believe in individuality only to impress others .......... 1
54. When I'm reprimanded at work, it usually seems to be unjustified .... 1
55. I think people believe in individuality only to impress others .......... 1
56. When I'm reprimanded at work, it usually seems to be unjustified .... 1

SECTION F
Directions: Please mark the most appropriate answer

FAMILY NETWORKS

1. How many relatives do you see or hear from at least once a month?
   | 1 0 | 1 1 | 1 2 | 1 3 4 | 1 5 6 | 1 9 or more

2. Tell me about the relative with whom you have the most contact. How often do you see or hear from this person?
   | I | less than monthly | | monthly | | a few times a month | | weekly | | a few times a week | | daily

3. How many relatives do you feel close to? That is, how many of them do you feel at ease with, can talk about private matters, call on for help?
   | 1 0 | 1 1 | 1 2 | 1 3 4 | 1 5 6 | 1 9 or more

FRIEND NETWORKS

4. Do you have any close friends? That is, do you have any friends with whom you feel at ease, can talk about private matters, call on for help? If so, how many?
   | 1 0 | 1 1 | 1 2 | 1 3 4 | 1 5 6 | 1 9 or more

5. How many of these friends do you see or hear from at least once a month?
   | 1 0 | 1 1 | 1 2 | 1 3 4 | 1 5 6 | 1 9 or more

6. Tell me about the friend with whom you have the most contact. How often do you see or hear from this person?
   | | less than monthly | | monthly | | a few times a month | | weekly | | a few times a week | | daily

CONFIDENTIAL RELATIONSHIPS

7. When you have an important decision to make do you have someone you can talk to about it?
   | | always | | very often | | often | | sometimes | | seldom | | never

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SECTION F (cont.)

8. When other people you know have an important decision to make, do they talk to you about it?

I I always I I very often I I often I I sometimes I I seldom I I never

HELPING OTHERS

9a. Does anybody rely on you to do something for them each day? For example: shopping, cooking dinner, doing repairs, providing child care, etc.

I I yes *If yes, skip to question 10 I I no *If no, go on to question 9b

9b. Do you help anybody with things like shopping, filling out forms, doing repairs, providing child care, etc.?

I I very often I I often I I sometimes I I seldom I I never

LIVING ARRANGEMENTS

10. Do you live alone or with other people (include in-laws with relatives)

I I live with spouse I I live with other relatives or friends I I live with other unrelated individual (e.g., paid help)
SECTION II
PAID HELP IN THE HOME

1. Has someone been coming in (e.g., housekeeper, aide, caregiver) to assist you?  [ ] yes  [ ] no
   If "yes" is it difficult for you to have someone come into your home to take care of your relative?
   If "no" would it be difficult for you to have someone come into your home to take care of your relative?
   Difficulty Level:
   Not at all 0 ______
   A little 1 ______
   Moderately 2 ______
   Very Much 3 ______
   Extremely 4 ______

2. Uses Meals on Wheels:  [ ] yes  [ ] no
   If "yes" how difficult is it for you to use a service such as Meals on Wheels?
   If "no" would it be difficult for you to use Meals on Wheels for some of your meals?
   Difficulty Level:
   Not at all 0 ______
   A little 1 ______
   Moderately 2 ______
   Very Much 3 ______
   Extremely 4 ______

3. Is there assistance to take the patient out?  [ ] yes  [ ] no
   If "yes" how difficult is it for you to have someone else take the patient out?
   If "no" how difficult is it for you to find someone to help to take the patient out?
   Difficulty Level:
   Not at all 0 ______
   A little 1 ______
   Moderately 2 ______
   Very Much 3 ______
   Extremely 4 ______

UNPAID HELP IN THE HOME

4. Is there someone to turn the care of the patient over to for a few hours?  [ ] yes  [ ] no
   If "yes" how difficult is it for you to turn the care of your relative over to this person?
   If "no" would it be difficult to turn the care of your relative over to a relative or friend for a few hours?
   Difficulty Level:
   Not at all 0 ______
   A little 1 ______
   Moderately 2 ______
   Very Much 3 ______
   Extremely 4 ______

5. Is there a relative or friend to take the patient out?  [ ] yes  [ ] no
   If "yes" how difficult is it for you to have someone help you do the day to day errands and shopping?
   If "no" would it be difficult for you to have someone help you with day to day errands and shopping?
   Difficulty Level:
   Not at all 0 ______
   A little 1 ______
   Moderately 2 ______
   Very Much 3 ______
   Extremely 4 ______

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SECTION H (cont.)

FORMAL SIT OFFERING SUPERVISION

6. Do you use day care?  |  | yes  |  | no
If "yes" is it difficult for you to take your relative to day care?
If "no" would it be difficult for you to use senior day care for your relative?

Difficulty Level:
- Not at all 0  
- A little 1  
- Moderately 2  
- Very Much 3  
- Extremely 4  

RESPITE CARE

7. Is respite care (paid short term care of the patient in a formal setting) available to you?  |  | yes  |  | no
If it were available, how difficult would it be for you to use respite care?

Difficulty Level:
- Not at all 0  
- A little 1  
- Moderately 2  
- Very Much 3  
- Extremely 4  

EMOTIONAL SUPPORT

8. Do you belong to a support group?  |  | yes  |  | no
If "yes" how much help do you feel you are getting?
If "no" how much do you think you would like to be in one?

Not at all 0  
A little 1  
Moderately 2  
Very Much 3  
Extremely 4  

PROFESSIONAL COUNSELLING

9. Are you receiving professional counselling regarding your caregiver role?  |  | yes  |  | no
If "yes" how much help do your feel you are getting?
If "no" how much do you think you would like to be receiving counselling?

Not at all 0  
A little 1  
Moderately 2  
Very Much 3  
Extremely 4  

SOMEONE TO TALK TO

10. Do you have someone to talk to when you are upset?  |  | yes  |  | no
If "yes" how difficult is it for you to talk to this person when you are upset?
If "no" how difficult is it for you to have someone to talk to when you are upset?

Not at all 0  
A little 1  
Moderately 2  
Very Much 3  
Extremely 4  

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SECTION H (cont.)
FRIENDS OR FAMILY VISITS

11. Do you have friends or family visit you or are you able to call them?  [ ] yes  [ ] no

How often do you have them visiting?

- Not at all/few times a year  0 _____
- Once every few months  1 _____
- Once or twice a month  2 _____
- Every week  3 _____
- Several times a week/ every day 4 _____

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Appendix D

Means and Standard Deviations for variables

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## Appendix E

### Correlation Matrix for SEM

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