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Caregiver coping with dementia: Relationships among patient characteristics, caregiver coping styles, and consequences of caregiving

Ramsey, Nina Sharp, Ph.D.

University of Washington, 1990

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**300 N. Zeeb Rd.
Ann Arbor, MI 48106**

**Caregiver Coping with Dementia:
Relationships among Patient Characteristics,
Caregiver Coping Styles, and Consequences of Caregiving**

by

Nina Sharp Ramsey

**A dissertation submitted in partial fulfillment
of the requirements for the degree of**

Doctor of Philosophy

University of Washington

1990

Approved by Nancy R. Hooyman
(Chairperson of the Supervisory Committee)

Program Authorized
to Offer Degree Social Welfare

Date September 24, 1990

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Doctoral Dissertation

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University of Washington

Abstract

**Caregiver Coping with Dementia:
Relationships among Patient Characteristics,
Caregiver Coping Styles, and Consequences of Caregiving**

by Nina Sharp Ramsey

Chairperson of the Supervisory Committee: Professor Nancy R. Hooyman
School of Social Work

Although little is known about how the changes that accompany Alzheimer's disease (DAT) affect caregiver coping, depression, and burden, interventions focused on improving caregiver coping with DAT are strategies widely used by gerontologists. This study reports relationships among DAT patient's need for assistance, supervision, or vigilance, rate of DAT patient decline in cognition, functional health, and physical health, and caregiver coping, depression, and burden. Data were drawn from a 1984 to 1987 longitudinal study of 59 DAT patients and their caregivers. Fourteen subjects were still caregiving and willing to be re-interviewed in 1989 in order to describe caregiver coping qualitatively, with special attention to the effectiveness and stability of their coping responses and religious coping activities. Although findings are descriptive in nature and limited by small sample size, results suggest patients' need for assistance is linked to increases in problem-focused coping ($p < .01$) and burden ($p < .001$) in caregivers. Patients' need for supervision is associated with increases in caregivers' problem-focused coping ($p < .001$) and burden ($p < .001$). Rapid patient functional health decline is associated with increases in caregivers' burden ($p < .01$). Results suggest it is the "here and now" DAT patient problems experienced by the caregiver, rather than rates of change in symptoms, that influence caregiver coping and burden, while caregivers' depression is unrelated to DAT patient characteristics. Relationships between coping styles and

depression and burden partially support previous caregiver coping studies. Caregivers' emotion-focused coping is associated with more depression ($p < .01$) and subjective burden ($p < .001$). Caregivers' problem-focused coping is related to more subjective burden ($p < .001$) and unrelated to depression. Qualitative results suggest that these caregivers cope in diverse ways. Their most frequently reported coping strategies are religious coping activities. These caregivers judge their coping strategies to be effective and stable over time. Caregivers' comments suggest that acceptance should be conceptualized as an outcome of successful adaptation rather than as a way of coping. Results are related to a suggested model of caregiver stress and coping. Implications for social welfare policy and practice, with suggestions for future study, are discussed.

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The research subjects who participated in this study responded to a lengthy interview that focused on very painful and catastrophic life experiences. They participated knowing that no immediate benefit to themselves would ensue. I am deeply grateful for the generous sharing of their experiences.

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Chapter One

Introduction

Improvements in the medical care of persons with chronic illnesses and infectious diseases over the past few decades have resulted in people living longer. A by-product of this longer life expectancy is an increase in the numbers of persons living beyond the age of 75. These persons, often referred to as the "old-old," suffer from a variety of chronic health conditions which require both acute and compensatory long-term care. A particularly prevalent condition of the old-old is progressive dementia of the Alzheimer's type (hereafter referred to as DAT), affecting from 20 to 30 percent of persons over the age of 80 (Heston & White, 1983; Terry & Katzman, 1983). DAT is characterized by progressive loss of the following cognitive functions: memory, judgment, the ability to assimilate new information, abstract thinking, and emotional responsiveness. These cognitive changes often produce inappropriate behavioral responses to other people and to the environment. The course of this illness is unpredictable. Some cases progress rapidly and others more slowly. There is no known cure for DAT and the cause of the illness is not yet known. The vast majority of persons with DAT reside in the community and are cared for by family members. Furthermore, because nearly half of all nursing home residents suffer from some form of dementia, caring for nursing home residents suffering from dementia comprises a significant portion of health care dollars spent on institutional long-term care.

DAT and Social Welfare Policy

Determining how to care for increasing numbers of older persons with DAT is a problem confronting social policy planners and affecting our social welfare system. What kind of a treatment environment is best for dementia patients--institutional or in the home? Who should provide the care and how will they be paid? How much unpaid care can be expected from family members? In this period of cost containment, it is increasingly difficult to justify large expenditures for managing older persons with incurable illnesses. Present social welfare policies are oriented towards institutional rather than community based, long-term care programs. However, as the costs of institutional care have risen, policy makers are considering the funding of specialized, compensatory services for the elderly in the community in order to delay or avoid placement into institutions (Horowitz, 1985). Policy proposals vary in their expectations of the role of family caregivers, with some expecting families to help more, and others concerned about relieving the burden family members carry. At present, 80 percent of all long-term care to the elderly in this country is provided, unpaid, by family members (Schorr, 1980). Thus, present policies already rely heavily on family care. Family caregivers are most often female, the wife, daughter, or daughter-in-law of the elder, in late middle age or old age, and experiencing their own health problems (Stone, Cafferata, & Sangl, 1987). This pattern of family caregiving makes the social welfare problem of developing long-term care policies even more important because demographic trends such as declining birth rates, increased divorce rates, and more women entering and staying in the labor force will produce a future shortage of family caregivers (Horowitz, 1985; Palley & Oktay, 1983).

Over the past five to ten years, the focus of interventions for patients with DAT has gradually shifted from direct interventions with the DAT patient to concern for the family caregiver. Many studies of dementia patients began to document the following negative effects on the caregiver of caring for a relative with dementia: depression, social withdrawal, health problems and financial strain (Chenoweth & Spencer, 1986; George & Gwyther, 1986; Haley, Levine, Brown, Berry, & Hughes, 1987; Zarit, Reever, & Bach-Peterson, 1980). Despite reports of such negative effects of caregiving, family caregivers providing home care continue to be viewed by both long-term care and social welfare systems as a low-cost alternative to institutional care. Thus, teaching the caregiver how to provide home care for the dementia patient, providing emotional support for the caregiver, and helping the caregiver cope so that home care can continue now form a major focus of treatment for DAT and a major area of gerontological and social welfare research.

Research Problem

This emphasis on caregivers of dementia patients as well as elderly persons with other chronic illness has spawned a body of research literature. This literature has further described the negative effects of caregiving, including a phenomenon which was labeled "caregiver burden," although groups of investigators began to use this term without agreement on a precise and specific definition of this concept (Deimling & Bass, 1986; Poulshock & Deimling, 1984; Zarit et al., 1980; Greene, Smith, Gardiner, & Timbury, 1982; Montgomery, Stull, & Borgatta, 1985). For the purposes of this discussion, "caregiver burden" will be conceptualized as the cumulative negative effects of caregiving across the domains of physical and mental health, social activities, family relationships, and

finances. This conceptualization comes closest to that put forth by Zarit et al. (1980), and measured by their Burden Interview, the most widely utilized instrument measuring burden.

The burden literature has sought to describe the incidence of burden as well as its correlates and consequences. Towards this end, relationships between patient characteristics and burden have been evaluated. It was assumed that, as symptoms became more severe and need for care increased, burden would increase. However, the patient's condition has not been found to correlate with the amount of cumulative burden experienced by a particular caregiver (Gilhooley, 1984; Zarit et al., 1980; George & Gwyther, 1986; Fitting, Rabins, Lucas, & Eastham, 1986). Other investigations suggest that specific types of patient impairments might differentially influence specific domains within a multi-dimensional concept of burden. For example, dependencies in activities of daily living (ADL) might have the direct effect of restricting the caregiver's social activities; symptoms generated by the patient's cognitive impairment such as failure to recognize family or inappropriate social behavior may have direct effects on the emotional health of the caregiver by producing depressive symptoms (Poulshock & Deimling, 1984; Montgomery, Gonyea, & Hooyman, 1985; Deimling & Bass, 1986).

The main consequence of caregiver burden for the DAT patient is hypothesized to be premature or inappropriate nursing home placement. Studies intended to identify variables associated with nursing home placement lend support for this hypothesis, as important variables influencing nursing home placement of dementia patients appear to be the caregiver's relationship to the patient and caregiver distress or burden (Colerick & George, 1986; Hirschfeld,

1983; Lund, Pett, & Caserta, 1985; Steinberg, 1985). Thus, interventions that reduce caregiver burden may directly influence where the DAT patient is cared for by avoiding premature or inappropriate nursing home placement. Of equal importance, and less often considered, is the possibility that although home care avoids costly institutional placement, the cost to the caregiver in terms of emotional distress, physical health problems, financial strain, and disturbed family relationships may be too high. It may be socially unjust to expect family members to bear these burdens.

Because objective aspects of the patient's condition, such as severity of dementia or number of behavior problems, do not correlate with burden, variables that mediate caregiver burden have been hypothesized. Two of the variables thought to be mediators of burden are social support and coping styles of the caregiver. It is hypothesized that improving social support to caregivers and altering the caregiver's coping styles towards "active" strategies such as problem solving will decrease burden and depression in caregivers and improve their well-being and life satisfaction. Although these relationships have only begun to be investigated, they form the rationale for such interventions as support and education groups for family caregivers. Evaluating the effects of support and education groups for family caregivers is one way of testing these assumptions. Empirical evaluations conducted to date have failed to support these hypotheses. Findings suggest that regardless of support group participation, burden and depression tend to decrease over time (Glosser & Wexler, 1985; Haley, Brown, & Levine, 1987; Lovett & Gallagher, 1988; Winogrand, Fist, Kirsling, & Keyes, 1987; Zarit, Anthony, & Boutsellis, 1987). These surprising findings imply that adaptation to caregiving, independent of

support group interventions, may occur over time for family members caring for a relative with DAT. Only two of these studies have measured coping styles, but neither has reported results that allow for an inference about direct effects of changes in coping on life satisfaction or depression (Haley, Brown, & Levine, 1987; Lovett & Gallagher, 1988).

Despite these reports, support and education groups continue to be offered, tested, and sought by caregivers. It is argued that the studies evaluating these treatments are methodologically flawed and so results should be interpreted with caution (Toseland & Rossiter, 1989; Zarit & Toseland, 1989). There may be some positive effects, and caregivers subjectively report these groups as helpful, yet altering coping and social support through group participation may not be sufficiently powerful to decrease the burden and depression experienced by family caregivers (Haley, 1989). It may also be premature to rely on treatments that depend upon assumptions that improved social support and altered coping decrease depression and burden. Not enough is known about how social support and coping styles influence caregiver well-being.

If interventions with the primary goal of altering the coping repertoires of caregivers continue to be advocated by mental health practitioners and gerontologists, it is critical that there be an empirical understanding of which types of coping strategies promote well-being and how this may differ from person to person and across situations. This is especially important because interventions intended to improve caregiver coping may produce unintended negative consequences such as low self-esteem in the caregiver, since they imply that if the caregiver could "cope better," then the negative effects of

caregiving would not occur. Also, emphasis is often placed on producing "active" coping such as problem solving. Other forms of coping which may be of benefit have not been as carefully studied. For example, little research has been completed that evaluates religious coping behaviors, despite findings suggesting that religion and prayer are activities frequently engaged in by older persons and subjectively judged to be "very important" in their lives (Manfredi & Pickett, 1987; Conway, 1985-86; Koenig, George, & Siegler, 1988).

For all these reasons, it is important to expand inquiries into the ways coping occurs as well as the mediating effects of coping in caregivers of DAT patients. Several avenues of inquiry emerge. Does coping with caring for a person with dementia differ from coping with other disabling chronic illness? Does coping with caregiving differ from coping with stressful life events experienced by non-caregiving elders? Are there age differences associated with coping? Are there particular types of coping styles that are used frequently by caregivers such as coping by engaging in religious activities? In what way do particular types of coping styles relate to depression or burden in family caregivers? How do coping styles relate to particular patient characteristics? What types of coping styles do caregivers judge as most effective? How does coping with caregiving change over time as adaptation to the caregiver role occurs? Exploration of these kinds of questions will help determine both the effects and the limitations of interventions intended to alter coping styles and may aid in the development of social policies that will support and fund the most effective interventional strategies for family caregivers of demented elders.

Purpose of the Study

The purpose of this descriptive study is to describe in depth the coping styles and consequences of caregiving for a sample of caregivers caring for relatives with a diagnosis of dementia of the Alzheimer's type (DAT), without additional complicating medical disorders. Two sources of data were used in this study: data from an existing longitudinal dataset and qualitative data collected by this investigator from caregivers who participated in the original study and were still available and willing to be interviewed. Both qualitative and quantitative research methods were used. The following specific patient characteristics are described as they relate to caregiver coping and to the consequences of caregiving that are operationalized as depression and burden: rate of cognitive, functional, and physical health decline; need for supervision/vigilance; and need for assistance in activities of daily living. Changes in caregiver coping, depression, and burden that occur over an 18-month period of time are described. Caregiver strategies, particularly religious coping behaviors, and the caregiver's perceptions of the stability and effectiveness of these coping behaviors are described in depth. It is expected that these detailed descriptions will produce hypotheses that can be subjected to testing in future research, and that they will also contribute to the building of conceptual models of the consequences to caregivers of caring for DAT patients with different rates of decline and needs for assistance or supervision.

Overview of the Dissertation

Chapters Two through Four comprise the literature review. Chapter Two reviews general theories of coping and adaptation, with emphasis on the ego process and the person-environment interaction models of coping. Chapter Two

also includes a review of the literature relevant to age changes in coping, gender differences in coping responses, and coping with chronic disease and disability. Chapter Three reviews religious coping and religiosity, with emphasis on what is known about how religious coping and religiosity may change with age. Chapter Four begins with a discussion of the negative effects of caregiving. This is followed by a review of the literature on caregiver coping. Chapter Four concludes with a discussion of a model of caregiver stress and coping. Chapter Five restates the purpose of this study and includes a discussion of how this study builds upon the current state of knowledge about caregiver coping. Chapter Six describes the research methods used in this study, including an overview of the study that generated the longitudinal dataset "Adaptation among Elderly with Alzheimer's Disease." Chapter Seven reports the results of the qualitative and quantitative analyses. The dissertation concludes with Chapter Eight, which discusses the limitations of this study, the results of this study in relation to the literature review, the implications of the results for social welfare policy and practice, and suggestions for future study.

Chapter Two

Coping and Adaptation

Introduction

This chapter begins with a discussion of the major theories of coping, including definitions, functions, determinants, dimensions, and criteria for assessing efficacy, followed by a statement of the conceptual framework for this study. Because the majority of family caregivers of DAT patients are older women with some health problems of their own (Stone et al., 1987), a brief review of the literature pertaining to age differences in coping, gender differences in coping, and coping with chronic illness will follow. This chapter will conclude with a discussion of how this literature relates to the literature on coping in caregivers of DAT patients and frail elderly persons.

Coping Theories

Coping strategies have a central role in contemporary theories of stress, yet relatively little is known about specific coping processes and how they influence adaptation. The study of coping is important for several reasons. The study of coping is relevant to clinicians because an understanding of coping processes and adaptation may promote empathy and helping behaviors that facilitate adaptation. Understanding coping may also help to predict future outcomes, for example, recovery from surgery or adaptation to major life events such as illness, job changes, or relocation. Understanding which coping responses lead to adaptation may help with the public health aim of preventing

maladaptation. Finally, the study of coping has implications for reducing maladaptation by effecting changes in coping responses.

Coping has generally been conceptualized as a process that occurs during adaptation to stress. Therefore, the study of coping behavior is bound to the conceptual domain of stress. An exact definition of the concept of stress has proved difficult within the stress literature, in part because of difficulty specifying the essential properties of stress. Definitions of stress include the following: all stimuli that upset people (Paykel, Prusoff & Uhlenhuth, 1971), that which requires people to adjust (Holmes & Rahe, 1967), or psychophysiological response patterns that occur as part of an individual's attempt to adapt to a stimulus or demand (Selye, 1950, 1976). Lazarus and Folkman (1984) define stress as a particular relationship between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being. Haan (1982) recommends that stress and coping research utilize the following definition of stress: either a bad event or a good event that did not come about. Stress is necessarily seen, then, through the eyes of the individual experiencing the event.

Coping behaviors can include all of the adaptive responses, both psychological and physiological, called into play by a stressful event. There have been two main conceptualizations of the coping process: an ego process approach that views coping primarily as a within person stable trait that is consistent across situations (Haan, 1977; Vaillant, 1977); and a person-environment interaction approach that views coping primarily as a fluid and situation-specific process (Lazarus, 1966; Pearlin and Schooler, 1978; Billings and Moos, 1981). Although the ego process models acknowledge that attributes

of the particular stressful event and the meaning of the stressful situation for the individual may influence coping, this fluid and situation-specific notion of coping comprises the major assumption underlying the latter approach.

Ego Process Models of Coping

The contributions of Haan (1977) and Vaillant (1977) are the most well known ego process models of coping. Haan's (1977) model integrates the Freudian ego process concepts and Piagetian developmental theories into a model of coping. Coping is defined as a normative, purposeful, flexible behavior that involves choice and is oriented toward both the future and the reality of the present situation. Coping as an ego process is different from a defense, in that coping means doing something about a problematic situation, whereas a defense implies some negation of reality. Developmentally, coping requires "process thinking" which includes Piaget's concrete and preconceptual thinking. In this model, coping functions to manage stress, "meter" disturbing affects, and allow various forms of affective satisfaction in an open, ordered and tempered way. Coping occurs as part of Piaget's concept of adaptation, which occurs whenever an interchange between the organism and the environment results in a modification of the organism that enhances its capacity for further interchange (Piaget, 1952, 1958). Thus, coping also functions to assimilate (the adjustment of an object to the structure of the organism), and accommodate (the adjustment of the organism to an object in the environment). Although coping is primarily determined by the developmental stage of the individual, Haan also hypothesizes that coping is influenced by the objective, external circumstances of the situation the individual is coping with, and the meaning of the situation to the individual.

For example, past experiences may influence the meaning of an individual's present experience, which in turn may affect that individual's future expectations. Interactions between the person, the situation, and the coping responses engaged in may produce or inhibit additional coping responses. Thus, despite the view that coping is primarily determined by within-person traits, Haan does see that interactions between an individual, the situation, and the individual's attempts at coping influence the process of adaptation.

Haan constructs several dimensions of coping, categorizing coping by ego process within which three levels of adaptive and/or maladaptive responses are specified: coping, defense, and fragmentation. Coping is categorized into these four dimensions: cognitive functions, reflective-intrceptive functions, attention-focusing functions, and affective-impulse regulations. In this taxonomy, coping was measured in two ways, by judges' ratings of interview data, and from item pools from the Minnesota Multiphasic Personality Inventory and the California Psychiatric Inventory. The effects or efficacy of coping are not seen as the removal of the stressful event, or even a decrease in the individual's experience of stress. Rather the criterion for "successful" coping are the individual's social-psychological functioning in terms of maintaining emotional and psychological equilibrium and preserving ego functions.

Vaillant's (1977) model of coping was developed as part of a longitudinal study of 55 white males, all graduates of Harvard. With psychoanalytic theory as the conceptual framework, the purpose of the study was to describe normative adult adaptation. Coping in this model is defined as an adaptive ego mechanism and is discussed as an ego defense. Coping is conceptualized primarily as an intrapsychic phenomenon; coping responses are described as dynamic,

reversible, unconscious, and either pathological or adaptive. Coping functions to manage instinct and affect. Vaillant hypothesizes that coping is determined primarily by the individual's developmental level and age, and influenced by the presence or absence of psychiatric illness. Thus, coping is seen as a person-specific, rather than a situation-specific process.

Rather than constructing dimensions of coping responses, Vaillant constructs a hierarchy of adaptive mechanisms, progressing from pathological to normative, consisting of the following four levels: 1) psychotic mechanisms, 2) immature mechanisms, 3) neurotic mechanisms, and 4) mature mechanisms. These levels were derived from the qualitative interview data from Vaillant's longitudinal study. In terms of outcome measures of the effectiveness of coping, the levels of coping mechanisms were tied to adjustment in the following five categories: career, social, psychological, medical illness or health, and overall adjustment. Therefore, even though in this model coping is conceptualized as primarily an intrapsychic phenomenon, the success of coping is measured in terms of adjustment in several areas of adult development, not solely in terms of emotional and psychological equilibrium. An additional limitation of Vaillant's work is the selection of a study sample comprised solely of white males.

One drawback to the ego process model of coping is the limitation of the concept of coping to the maintenance of psychological or emotional equilibrium. Therefore, this approach does not take into consideration either overt problem-solving behaviors directed towards changing the external stressor, or active attempts by the individual to avoid the external stressor. Despite this drawback, Haan (1977) and Vaillant (1977) have made major contributions to the understanding of intrapsychic coping processes and have helped in

conceptualizing and measuring these types of coping responses. However, the question of consistency of coping responses across situations remains.

Although there is evidence that coping responses across similar types of situations show consistency within individuals, research has revealed little empirical evidence of consistency in responses across dissimilar situations (Laux & Vossel, 1982). In addition, when coping responses have been conceptualized and measured as global and stable traits, regardless of the stressor, they have not been consistent predictors of actual coping behavior (Magnusson and Endler, 1977). An ongoing concern within this area of study is the construct validity of the hypothesized ego processes, which may limit the inferences that can be drawn about the effects of ego defense mechanisms. Despite these limitations, many aspects of the ego process models of coping have been built upon as conceptions of coping have been broadened. Theories that emphasize coping processes as fluid and dynamic have incorporated the ego process conceptions of intrapsychic coping processes.

Person-Environment Interaction Models of Coping

The work of three groups comprise the best known theories of coping emphasizing the interactive and situation-specific nature of coping responses: Lazarus and colleagues (1966, 1978, 1983, 1984) and Folkman and Lazarus (1980); Pearlin and Schooler (1978); and Billings and Moos (1981). Lazarus and Launier (1978) defined coping as "efforts, both action-oriented and intrapsychic, to manage (that is, master, tolerate, reduce, minimize) environmental and internal demands, and conflicts among them, which tax or exceed a person's resources." In this model, a stressful event must be perceived or experienced in order to

activate coping responses. Further, the coping response is shaped by the particular exigencies encompassed by the situation. There is some evidence that the functions performed by the coping response or the demand characteristics of the stressful situation may predict the coping method employed. For example, Folkman and Lazarus (1980) found that problem-focused coping was used when the goal was to change the stressor, whereas emotion-focused coping was used when the goal was to reduce aversive feelings evoked by the stressor. The meaning of the stressful event, or how the individual "appraises" the situation is a key determinant of coping (Lazarus, 1966). Appraisal is a cognitive process and refers to the way in which a person perceives the significance of an event for his or her well-being (Lazarus & DeLongis, 1983). Whether the stressor is perceived as positive (a challenge) or negative (a threat) plays a part in determining coping (Lazarus, 1966). Further, coping responses are affected by previous coping in an interactive fashion, e.g., if one responds to a stressful event with an emotion-focused response such as "getting upset," that particular coping response may evoke a problem-focused coping response such as taking some direct action to change the stressor (Lazarus & Launier, 1978).

Lazarus and colleagues initially categorized coping into four dimensions: 1) action-oriented behaviors, which include active avoidance, escape, attack and seeking allies, 2) cognitive or knowledge seeking behaviors, 3) wish-fulfilling fantasy, and 4) intra-psycho (defensive or accommodative strategies). This taxonomy was further refined into two categories: problem-focused and emotion-focused coping and the "Ways of Coping Checklist" developed to measure these coping responses (Folkman & Lazarus, 1980). The problem-focused category includes items that describe cognitive problem-solving efforts and behavioral

strategies for altering or managing the source of the problem, e.g., made a plan of action and followed it; stood your ground and fought for what you wanted. The emotion-focused category includes items that describe cognitive and behavioral efforts directed at reducing or managing emotional distress, e.g., tried to forget the whole thing; tried to look on the bright side. In this model, the efficacy of coping responses are assessed in terms of the reduction of emotional and physical discomfort that accompanies the stressful event.

Another person-environment interaction approach to coping has been proposed by Pearlin and Schooler (1978) who provide a sociological perspective to coping processes. In their model, coping must be examined in the context of the problems an individual is experiencing. Coping is defined as any response to external life strains that serves to prevent, avoid, or control emotional distress. Coping is inseparable from both the life strains an individual is experiencing and the inner emotional state of the individual. Coping functions to change the stressful situation, change the meaning of the stressful situation, control the stress itself after it has emerged, and anticipate or prevent future stressful events (Pearlin, Turner, & Semple, 1987). This latter function implies that coping can be "anticipatory," and has not been as well studied as the other functions. Pearlin and Schooler (1978) view the determinants of coping as the social resources available to the individual (their social network and how it functions), the psychological resources or personality characteristics of the individual (self-esteem, self-denigration, and sense of mastery or control), and the nature of the stressful situation.

Pearlin and Schooler (1978) categorized coping responses into three main categories and distinguished them from one another by the nature of their

function: 1) responses that change the situation out of which the stressful experience arises; 2) responses that control the meaning of the stressful situation after it occurs but before the emergence of stress; and 3) responses that function more for the control of stress itself after it has emerged. In their study of normative life strains in the areas of marriage, parenting, occupation, and household economics, Pearlin and Schooler (1978) developed a 17-item scale that measures these coping responses. Although not an exhaustive inventory of coping, the scale samples coping responses from each category. In terms of evaluating the efficacy of a coping response, they emphasize that this cannot be judged solely on whether or not an individual can remove the source of the stress, but rather how well the coping behavior prevents stressful events from resulting in emotional stress; how well the coping behavior attenuates stress in relation to life strains.

Billings & Moos (1981, 1984) do not differ from Lazarus and colleagues or Pearlin and Schooler in their definition of coping, and concur that coping is an intervening process that mediates the effect of life events on personal functioning. Their contribution to this literature is in further refining the measurement of coping and the dimensions of coping. They first developed a 19-item scale that categorized coping into three types of behaviors, active-cognitive, active-behavioral, and avoidance, within two categories of coping: problem-focused and emotion-focused coping (Billings & Moos, 1981). This classification scheme was further refined into a 32-item scale that categorized coping into appraisal-focused (logical attempts to understand the stressor and its consequences), problem-focused (either information seeking or problem solving), and emotion-focused (either regulation of stress-related emotions or

behavioral expressions of unpleasant emotions) (Billings and Moos, 1984). In terms of measuring the efficacy of coping responses, Billings and Moos (1984) utilize measures of physical health in addition to emotional health.

A major research problem within the person-environment interaction models of coping pertains to the situation-specific nature of coping, which implies that coping is best studied within the context of the specific stressful event. Thus, when differences in coping behaviors across different groups are studied, the subjects must be coping with very similar stressors. Appraised desirability of a stressor is also influenced more by the situation than the characteristics of the person. That is, most people agree on which events are positive and which are negative (Moos and Billings, 1982). How then, does one study coping across persons who are coping with similar or dissimilar situations? Is it possible to compare the coping responses of persons responding to different situations, and if so, how are control groups selected? Even if one compares persons coping with similar situations, their individual cognitive appraisal of the stressful situation is likely to vary.

Within this model of coping, several taxonomies of domains of coping have been developed, primarily through factor analytic techniques. Moos and Billings (1982) point out that these psychometric procedures may have only limited usefulness in evaluating the adequacy of measures of coping. These techniques assume positive inter-item covariation on similar coping responses, and the successful use of one response in a domain may effectively reduce stress and thus lessen the utilization of other responses within that domain. Despite these limitations, the person-environment interaction theorists have greatly expanded

the knowledge base related to coping and adaptation, as well as improved the methods used to measure coping responses.

Conceptual and Methodological Issues in the Study of Coping

There are several important conceptual and methodological issues inherent in the study of coping, regardless of whether one adheres to the ego process models or the person-environment interaction models of coping. First, the definition of the concept of coping is quite broad. This is both necessary and problematic. The concept of coping must be broad enough to encompass specific classifications of types of coping yet be detailed enough to include individual variations. The construct must be conceptually coherent and linked to observable conditions. It must be measurable and linked to relevant and meaningful outcome criterion that address adaptation in the short and the long run. All of these concerns are linked to the central problem of establishing construct validity, which is an ongoing problematic area of study within the field of stress and coping.

Second, questions relating to measurement methods and the development of measurement instruments for coping responses are areas of concern. Which methods of collecting data are most relevant? In much contemporary coping research, coping is assessed via interview or questionnaire; observational methods are underutilized, in part due the time, cost and difficulty involved with observational methodologies. Whenever subjective processes, such as intrapsychic coping, are studied, the reliability and validity of the measurement instruments must be carefully evaluated. An additional concern relating to the reliability and validity of data obtained via questionnaire and interview is whether

or not subject's self-reports of their coping in stressful situations correlate with their actual behavior. Many of the choices of coping responses on questionnaires may be appraised as socially desirable by respondents. Studies evaluating the relationship between self-report and observational data would be of use to clarify this point.

Most of the questionnaires measuring coping were developed with factor analytic techniques, which, as discussed earlier, may be problematic in terms of the statistical assumptions. Further, measures that have been developed to measure coping in one instance may not be appropriate in a different instance. Measures of coping as a trait or coping in general are not likely to be appropriate for the study of coping in specific situations, because some situations may evoke particular types of coping responses. For example, coping with a situation such as a terminal illness which is not likely to change with problem solving may evoke coping intended to manage feelings aroused by the situation. If coping is seen as fluid and situation-specific, then it is best studied vis-a-vis each situation. Although the person-environment interaction models hypothesize that coping is a constantly changing transaction, how best to operationalize and measure coping as a transaction presents extremely complicated conceptual and statistical issues for which there is no perfect solution (Moos, 1974; Lazarus & Launier, 1978; French, Rodgers & Cobb, 1974; Kulka, 1979). Thus, even when coping is studied in relation to a specific situation, it is usually measured as a static state of mind, rather than a constantly changing transaction.

Another difficult issue within this area of study is how to determine whether coping behavior is effective or adaptive. Judging the adaptiveness of a behavior is a relative question and is usually answered from a particular value base and

context. Adaptiveness can be assessed in a variety of domains: psychological, emotional, or social domains are just a few examples. Adaptiveness should be assessed in terms of the short term and the long run. A behavior that is adaptive in the short term might have the potential for being maladaptive in the long run. For example, denial may be effective in the short run for reducing anxiety for the person who has just learned of a serious illness, but may be maladaptive in the long run if it results in delays in seeking treatment. The fluid notion of coping implies that the effectiveness of any coping behavior can only be ascertained within the stressful situation producing the response, and generalizing about the effectiveness of a particular coping behavior to a different situation becomes problematic. This issue is related to the difficulty of comparing the outcomes of various coping responses across different studies. Finally, should the effectiveness of coping be evaluated in terms of intrapsychic processes such as emotional and psychological equilibrium and the absence of psychiatric illness, physiological measures such as health or the absence of physical illness, social or cultural adaptation such as socio-economic status, alterations in the actual stressful situation, or prevention of future stressful events? Logic argues for the inclusion of all of these possible outcome variables, particularly if coping is seen as a dynamic process, with influences beyond the maintenance of psychological and emotional equilibrium.

If coping is viewed as linked to particular conditions, how does one compare, or does one compare persons coping with different situations? Pearlin et al. (1987) suggest that even though coping may vary with the situation, the underlying functions of coping can form the basis of analysis and comparison of coping across situations. This concern arises when one wants to compare

caregivers with non-caregivers—is this an appropriate comparison when the stressful situations confronting caregivers are likely to be very different from those confronting non-caregivers? How would one choose the comparison group?

These conceptual and methodological concerns illustrate the complexity of conducting research in the area of coping. Contemporary coping research is in an early stage and much work remains to be done. Because coping processes have such a central role in adaptation, and relatively little is known about them, it is important to expand research efforts towards examining coping processes and their effects. Arriving at solutions for problems in research methods is part of this challenge. Enlarging the knowledge base relating to coping can have direct public health benefits in terms of promoting adaptation and preventing maladaptation. A more complete understanding of coping and adaptation has the potential for assisting professionals to become better helpers.

Conceptual Framework for this Study

The conceptual framework underlying most of the contemporary research on coping and aging, coping with chronic illness, and coping with caregiving is the person-environment interaction model of coping. Therefore, in order to be consistent with the current knowledge base relating to coping, the conceptual framework underlying this study is the person-environment interaction model of coping. An additional rationale for the choice of this model as a conceptual framework is the fact that the person-environment interaction model of coping provides the most comprehensive conceptualization of coping to date, taking into account person, environment, and situational variables as factors that influence coping strategy and coping effectiveness. In review, coping is

conceptualized as a process of adaptation and is defined as both action oriented and intrapsychic efforts to manage internal and environmental demands. It is fluid, dynamic, and functions to mediate the effects of stress and life strains upon the individual. Coping is determined by the particular exigencies encompassed in the stressful situation, the cognitive appraisal made by the individual, any previous experience the person has had with the stressful event, whether or not the stressful situation has been anticipated, and the presence or absence of a support system to call upon. Within this model, individual attributes such as physical health status and intrapsychic qualities such as values, aspirations, self-confidence and previous coping responses will interact to influence coping responses (Kiyak & Borson, in press).

Although several taxonomies of coping domains have been developed, the different domains overlap. The following dimensions of coping have been described most frequently: problem-focused, emotion-focused, intrapsychic, cognitive, and seeking social support (Pearlin & Schooler, 1978; Folkman & Lazarus, 1980; Billings & Moos, 1981, 1984; Felton & Revenson, 1984; Felton, Revenson, & Hinrichson, 1984; Vitaliano, Russo, Carr, Maiuro, & Becker, 1985). Problem-focused coping consists of seeking advice, changing the situation, seeking information, and behavioral or instrumental activities oriented on the problem. Examples of emotion-focused coping are affective expression, control of stress, control of feelings, and emotional expression. Intrapsychic coping is defined as defensive or accommodative strategies such as avoidance, escape, selectively ignoring, wishful thinking, or acceptance. Cognitive coping consists of changing the meaning of the situation and cognitive restructuring. In this study, coping is operationalized with an instrument derived from the work of Pearlin and

Schooler (1978), Lazarus and Folkman (1984), and Kahana, Kahana and Young (1985), and measures four dimensions of coping: problem-focused, emotion-focused, acceptance, and religious coping (Kiyak, 1988).

Age Differences in Coping

An important question that has not been extensively studied is whether there are differences in coping due to age. Unfortunately, the answer to this question has not been provided by current coping research, primarily because most of the observations relevant to this question have been cross-sectional rather than longitudinal, and secondarily, the state of the art in the measurement of stress and coping is in an early stage. Several relevant cross-sectional studies, as well as hypotheses based on clinical anecdotes, will be reviewed.

A common belief is that as people age, their coping becomes more restricted and limited. Based upon work with clinical populations, Pfeiffer (1977) views the stressors older persons are coping with primarily as losses in the areas of role, relationships, income, mobility, and health. He reports that while some older persons continue to use a wide range of coping and adaptive mechanisms, the majority of older persons return to the use of more primitive types of defense mechanisms, such as unmodified anxiety, depression-withdrawal, projection, somatization, and denial. Alternatively, Vaillant (1977) proposed that, from the period of early adulthood through middle adulthood, the use of immature mechanisms like hostile reactions and schizoid fantasy decreases and is replaced by mature mechanisms like humor and altruism.

Empirical studies have not consistently supported either Pfeiffer's regression hypothesis or Vaillant's growth and adult development model. Griffith (1983) interviewed a convenience sample of 579 women aged 25 to 65 in order

to describe how stress and coping styles differ by age. Age influenced both the types of stress experienced as well as the coping styles employed. Women over 55 reported that concerns with their general health and physical condition were their major stress area, while younger women reported personal time factors such as time to oneself and balance between work, family, leisure, home, and self as their major stress area. Personal success stress (defined as personal success in primary occupation or role, degree of recognition, and personal growth and development) was highest for younger women and decreased with age. These results support the notion that stressful events are determined in part by stages in adult growth and development. Coping styles differed by age with older women more likely than younger women to use working, religion, recreation, ignoring the problem, and taking drugs (the authors did not specify whether this referred to prescription drugs, recreational drugs, or both). For younger women, the most common coping styles were talking, exercise, alcohol consumption, and rest/relaxation. These coping differences do not reflect Vaillant's (1977) or Pfeiffer's (1977) ideas. However, these findings could reflect differences in stressors more than differences in coping styles.

McCrae (1982) reports the results of two cross-sectional studies which attempted to assess the influence of age on the use of coping mechanisms. The sample in the first study comprised 255 adults aged 24 through 91; the sample in the second study was 150 adults aged 21 to 90. Questionnaire data in response to specific life events provided data on the use and effectiveness of 28 different coping responses. Of these, 26 showed no age differences whatsoever, implying that older individuals cope in much the same way as younger persons.

The two ways of coping that did show differences were hostile reaction and escapist fantasy, and both of these mechanisms were used more often by persons under the age of 50 than those over the age of 50. Irion and Blanchard-Fields (1987), in their study of 96 persons aged adolescent through old age, report that older people tended to use more adaptive coping strategies and less escape-avoidance, hostility and self-blame. They suggest that as people age, they become better able to cope. The results of these two studies lend some support for Vaillant's hypothesis, and no support for Pfeiffer's model.

Other researchers have found no differences in coping due to age. Billings and Moos (1981), in a sample of 194 couples with mean ages of 45 years for the men and 43.5 years for the women, found that age was unrelated to either the method or focus of coping. Folkman and Lazarus (1980) in their study of 100 middle aged persons also found no relationship between age and scores on problem-focused or emotion-focused coping. Pearlin and Schooler (1978) studied 2,300 adults aged 18 to 65 and found that both young and old subjects were likely to employ coping mechanisms that support emotional well-being, despite differences in types of coping responses utilized. For example, younger persons were more likely than older persons to be self-denigrating, but they were also more likely than the older to feel a sense of mastery. Older people were more disposed to self-reliance and more likely to engage in controlled reflection and selective ignoring. These results do not support the idea that as people age, they become less effective in coping with life strains, but rather that both the young and old are equally effective in their coping responses.

A somewhat different pattern of results is reported by Folkman, Lazarus, Pimley, and Novacek (1987), who interviewed 75 younger (35 to 45 years of age) and 141 older (65 to 74 years of age) persons to determine whether and in what ways younger and older adults differ in their sources of daily stress and in their coping processes. They found that younger adults reported significantly more stress in the domains of finances, work, home maintenance, personal life, and family and friends than did their older counterparts. Older persons reported more stress associated with environmental and social issues, home maintenance, and health. These age differences may easily be interpreted in terms of role-related differences. Age differences in coping were significant and consistent. The younger adults used proportionately more active, interpersonal, problem-focused forms of coping than did the older respondents; they used proportionately fewer passive, intra-personal, emotion-focused forms of coping than did the elderly.

A question which remains unanswered is whether or not these results are due to differences in the stressful life events experienced by the two age groups, the particular developmental stages of the individuals, or cohort effects. A secondary question is whether or not the coping of older persons in this study can be judged as effective, as passive and emotion-focused coping styles are often assumed to be ineffective. Effective coping fits the possibilities or lack of possibilities for action in a specific context. Coping in a dynamic situation involves a greater use of problem-focused coping, whereas in an uncontrollable situation, effective coping involves a greater use of emotion-focused coping. It is logical to assume that older persons are coping with changes associated with aging that are appraised by the elder as unchangeable or uncontrollable, thereby

evoking passive and emotion-focused coping intended to manage feelings evoked by the stressor, rather than alter the stressor itself. Even so, some problem-focused coping could be expected, even if just to seek information about the unchangeable condition. For example, although adapting to a chronic health condition like arthritis might evoke more emotion-focused coping, some problem-focused coping in the form of seeking information and professional assistance could also be expected.

In recent longitudinal analyses, McCrae (1989) conducted cross-sectional, repeated measures, and sequential analyses on data collected in 1980 ($n = 405$) and in 1987 (191 of the original 405 subjects and 207 new subjects) in order to evaluate changes in coping due to maturation. This study provides an important contribution to this literature in that it attempts to more directly answer the question of whether there are changes in coping due to age alone. Findings suggest that if coping changes as people age, the changes are subtle in their influence. Cross-sectional analyses did show a significant association of age with many different coping mechanisms, but all associations were modest. The repeated measures and cross-sequential analyses failed to demonstrate support for the view that age differences in coping were due to maturation. McCrae's (1989) findings are consistent with other studies in that older individuals in this study used less interpersonal aggression in coping with stress, and age was negatively associated with the use of hostile reaction. Further, in analyzing the effects of types of stressors on coping responses, findings suggested that older persons used rational action when dealing with a challenge, and faith when dealing with threat and loss.

Another approach to describing coping and aging has been to study stress and coping in samples of elderly persons rather than compare the young and the old. George and Siegler (1982) interviewed 100 men and women ages 55 to 80 in order to describe the stresses currently being experienced, the types of coping responses used, and the perceived effectiveness of the coping. The types of stressors their sample experienced were categorized into five domains: self (feelings of boredom, fear of the future, loneliness, lack of time to devote to preferred activities), family (conflicts with spouse, children or grandchildren), health (chronic, limiting conditions, problems with diet or medications, complaints about lack of energy), work (excessive work pressures) and economics (general financial insecurity). These five domains of stress were further dichotomized into stress that was personal or interpersonal (experienced directly by the person, or experienced by close friends or family). By far the largest category for stress was the health category, followed by family, self, economics, and work. In this sample, direct-action coping responses were reported most frequently, followed by intrapsychic coping responses. Smaller and almost equal numbers of coping responses were classified as information-seeking and inhibition-of-action strategies. Most of the coping reported by the respondents had an instrumental orientation (i.e., intended to alleviate, modify, or eliminate the stressful event). However, those persons utilizing palliative coping strategies (i.e., intended to make the person feel better about the situation) perceived their coping as more effective than persons whose responses were limited to instrumental coping. Those persons who reported using both instrumental and palliative coping strategies reported the highest self-ratings of coping effectiveness.

In another study intended to describe stressors and coping of elderly persons, 51 adults ages 60 to 89 were interviewed by Manfredi and Pickett (1985). The types of stress these older adults were dealing with were categorized into loss (health, social, and economic) and conflict. The work of Lazarus and Folkman (1984) formed the conceptual framework for this study and coping responses were viewed as either emotion-focused or problem-focused. The most frequently reported coping responses in this sample were emotion-focused and included prayer, reminding oneself that things could be worse, maintaining pride, looking for the silver lining, and telling oneself things to feel better. The least frequently used response was "taking it out on other people." These findings are consistent with McCrae (1982), Irion and Blanchard-Fields (1987), and Pearlin and Schooler (1978), supporting the view that older people continue to display flexibility in the types of coping responses they use, as well as using less aggressive or hostile coping responses.

Rather than describing specific coping responses, other investigators have studied the "coping resources" of elderly persons. Simons and West (1984-85) examined the relationships between life events and health changes in the elderly, and the extent to which variables often cited in the literature as "coping resources" actually serve this function for the elderly. The following coping resources were examined: self-efficacy, religiosity, social resources, presence of a confidant, marital status, occupational status, and income. The sample was composed of 299 persons over the age of 65 (132 men and 167 women). They found that only income seemed to function as a coping resource in terms of providing a buffer to life changes. Contrary to what might be expected, for the elderly in this study, self-efficacy and high occupational status seemed to inhibit

coping during times of high life change. The authors suggest that high occupational status elderly may suffer greater loss of ego in the face of unavoidable life events that accompany old age (e.g., retirement), and thus have more difficulty with adaptation. They further suggest that feelings of self-efficacy may be dysfunctional for the elderly, since major life events experienced by the elderly involve changes that are uncontrollable, and a high expectation of personal mastery may be unrealistic and lead to frustrating attempts to modify situations over which they have little control. An additional unexpected finding was that neither social resources nor the presence of a confidant served to buffer against life change. In contrast, Clarke (1982), in a study of 1,841 persons over the age of 60 in Great Britain, found that coping behaviors were positively correlated to personal and social resources and concluded that the greater the availability of coping resources, the better able the elderly will be to cope with life stress.

Okun, Melichar, and Hill (1990) evaluated social support as a coping resource in a sample of 110 persons aged 60 to 89. They found that positive social ties were inversely associated with psychological distress, and that both negative daily events and negative social ties were associated with increased psychological distress. They also found that as positive social ties increased, the influence of negative daily events on psychological distress decreased. This finding is consistent with the buffering hypothesis of social support, and reinforces the importance of positive social ties as a coping resource for the elderly.

In a study evaluating the effect of role loss on coping resources among the elderly, Elwell and Maltbie-Crannel (1981) used path analysis to assess the

effects of personal characteristics (age, race, education, role loss), personal resources (income and health) and social support (from family, formal and informal networks) on life satisfaction in a sample of 1,660 men and women over age 50 drawn from the National Opinion Research Center General Social Surveys of 1974, 1975, and 1977. They found that role loss was associated with decreased income. They also found different coping resource patterns for men and women in that financial security was more important as a coping resource for men while social participation was more important for women. Of interest is their finding that age itself can be considered a coping resource. Age was associated with both personal and social coping resources, such that as age increased, personal and social coping resources decreased. This finding implies that people may become less able to cope as they age, because of having fewer personal and social resources to call upon.

Religious activities and religious coping (turning to prayer; hoping for a miracle) have been conceptualized as both emotion-focused and intrapsychic coping. Little research has been conducted that evaluates religious coping behaviors, despite findings that suggest religion and prayer are activities frequently engaged in by older persons and subjectively judged to be "very important" (Koenig, George, & Siegler, 1988). The literature describing religious coping behaviors of older adults will be the subject of Chapter Three.

In summary, although one belief about change in coping associated with age predicts that as people age they become more regressive, rigid, and less adaptive in their coping responses, this hypothesis is not supported empirically. The model predicting change in coping brought about by age related changes due to normal adult growth and development is somewhat supported in the

literature, but not consistently. The literature suggests that older people are often coping with stressful life events that are negative and uncontrollable such as health changes and role loss, and that older people frequently experience decreases in such "coping resources" as income, health, and social support. Although these changes might predict restricted coping repertoires, instead studies suggest that as people age, they continue to display the capacity for a flexible and diverse range of coping responses. Other studies suggest that as people age, they become better able to cope in terms of using more mature coping responses and less aggression or hostility. The results of these studies may not be generalizable to minority elders as none of them had a sample with meaningful representation of ethnic or racial minorities. Finally, it must be stated that none of these studies support conclusions about change in coping due to age alone, but instead changes in coping are associated with changes in the context of coping. In order to determine the effect of age alone, sampling different age cohorts and studying them longitudinally would be required, so that the effects of age could be differentiated from cohort or history effects. Only one of the studies reviewed made use of longitudinal analyses, utilizing cross-sequential analyses to determine the degree to which maturation influenced coping, but could not speak to the issue of cohort effects, since different age cohorts weren't sampled (McCrae, 1989).

Gender Differences in Coping

Because the meaning and appraisal of any significant event is embedded in an individual's personal and social experiences, one might expect that there would be gender differences in coping. Given our cultural stereotypes gender differences would be expected. Men are socialized to be analytic, active,

problem-solvers while women are socialized to be more emotionally sensitive, expressive, and dependent than men. Therefore, men would be expected to use more problem-solving coping and women more emotion-focused coping. However, studies in this area report conflicting findings. Billings and Moos (1981) found statistically significant (t tests) gender differences in coping responses but caution that the magnitude of the difference was quite small. In their sample of 192 men and women, men reported less frequent use of active-behavioral ($p < .05$), avoidance ($p < .01$), and emotion-focused coping ($p < .01$) than did women. However, partial correlations indicated that persons with more education were more likely to use active-cognitive and problem-focused coping and less likely to use avoidance coping. Amount of income was also positively related to active-behavioral, active-cognitive, and problem-focused coping. There were no differences between men and women in their perceptions of the severity of the stressful events with which they coped, although men were more likely to report coping with financial stress, while women were more likely to report stressful events due to illness (self or other) and children. These investigators found that illness related stressful events elicited more active-behavioral and problem-focused coping than did most other categories of stress. There were no significant gender differences in type of stressful event experienced.

A similar pattern of results is reported by Billings and Moos (1984). In a study of 424 men and women with depression, women used more emotional-discharge coping than men, which was linked to greater dysfunction. Coping responses directed toward problem solving and affective regulation were associated with less severe dysfunction. Viney and Westbrook (1982), in their

study of 89 men and women coping with chronic illness also found that women used more "escape" coping strategies (reduce tension by emotional expression or distraction), than men. Taken together, the reports by Billings and Moos (1981, 1984) and Viney and Westbrook (1982) do lend support to predictions based on cultural stereotypes.

Folkman and Lazarus (1980) studied types of stressors, cognitive appraisal, and coping responses in a sample of 100 adults aged 45 to 64, (48 men and 52 women). In their study, women reported more stressful events related to health and family than men. Men reported more stressful events related to work than women. However, men and women differed little in how they appraised events. In terms of coping responses, there were relatively few differences between men and women. Men did use more problem-focused coping than women, but only at work and in situations appraised as requiring acceptance and more information. No gender differences were found in the use of emotion-focused coping. Further, Folkman and Lazarus (1980) suggest that the gender differences in problem-focused coping in the work context reflect gender differences in jobs rather than a general disposition on the part of males to use more problem-focused coping. These investigators stress the importance of comparing coping within the source of stress, and not just coping responses, because differences may be due to the source of the stress and not gender per se. For example, men and women do not differ in their use of emotion-focused coping within similar contexts of living but they do differ in the contexts in which their stressful encounters occur.

Pearlin and Schooler (1978), in their study of 2,300 men and women experiencing life strains in the areas of marriage, parenting, home finances and

occupation, found significant patterns of gender differences. Women tended to use more selective ignoring within all of the life strain contexts. Within the marriage context, women used more self-assertion and negotiation than men. Finally, within the household economic context, women tended to cope by devaluing money more than men did. These investigators also point out that use of selective ignoring as a coping response within the contexts of marriage and parenting actually serves to exacerbate stress. They conclude that men more often possess psychological attributes or employ coping responses that inhibit stressful outcomes of life strains, whereas women may be socialized in a way that less adequately equips them with effective coping patterns.

Rather than compare coping across gender, other investigators have studied samples of women in order to describe stress and coping experienced by women. Griffith (1983) studied 579 women who were coping with stress in the categories of love relationships, parent-child relationships, personal success, personal time, physical health, and social relationships. She found that the six most frequently used coping responses were talking (48%), working (38%), religion (31%), consumption (29%), rest/relaxation (15%) and exercise (12%). In another study, the coping responses of 40 female spouses of myocardial infarction patients were described as either behavioral, cognitive, or intrapsychic (Nyamathi, 1987). Behavioral responses such as seeking assistance and support were used by 100% of the women. Cognitive responses such as focusing on the problem at hand, considering available options and resources, and minimizing threat by consciously controlling fearful thoughts and planning for the future were used by 91% of the women in this study. Intrapsychic coping responses were used by 38% of the women in an effort to deny/avoid, rationalize,

and fantasize about various aspects related to their husband's heart attack. These two studies suggest that women cope in diverse ways, and do not support the idea that women cope primarily with emotion-focused responses.

In summary, there is little evidence strongly supportive of predictions about differences in the coping strategies of men and women based on cultural stereotypes. There is conflicting evidence relating to whether or not women use more emotion-focused coping than men. It may be much more important to evaluate the stressful events evoking coping responses, than the coping responses themselves. These events do differ between the sexes, as women are coping with events related to health, interpersonal relationships and family more often than men, whereas men are more often coping with stresses related to work and finances. Studies evaluating gender differences in coping must compare men and women coping with the same stressors in order to draw conclusions about sex differences in coping.

Coping with Chronic Illness

Historically, much of the stress and coping research has evaluated coping with physical threats such as acute illness, surgical interventions, and chronic disease. The relevant literature to be reviewed in this section will be limited to coping with chronic illness, as chronic conditions comprise the majority of the health problems experienced by older adults. Cohen and Lazarus (1979) synthesized several investigators' efforts to summarize threats associated with physical illness and described them as: threats to life and fears of dying, threats to bodily integrity and comfort, threats to one's self-concept and future plans, threats to one's emotional equilibrium, threats to the fulfillment of customary social roles and activities, and threats involving the need to adjust to a new

physical or social environment. Threats to bodily integrity and life are experienced more often with acute illness, whereas threats to self-concept, future plans, emotional equilibrium, social and occupational roles, and values are more likely to occur with chronic illness. Thus, an older person adapting to a chronic illness may be judged as stable by health care providers since threat to bodily integrity or life are minimal, yet that individual may still be putting forth extensive coping efforts.

There is evidence in the literature that coping changes as an individual adapts to a chronic illness. For example, in an early descriptive study of burn patients, coping strategies used in the acute phase of the illness were denial, avoidance, emotional constriction, and withdrawal from interpersonal contacts. During the rehabilitation phase of treatment, the burn patients' coping changed to hope, pride, restoration of interpersonal relationships and self-esteem, as well as attempts to regain active participation in treatment (Hamburg, Hamburg and deGoza, 1953). Another early study described a similar pattern in polio patients, in that during the acute phase of the illness, patients coped primarily with denial and avoidance, whereas in the chronic phase, coping strategies used more were religiosity, projection of concern, "bargaining," emotional constriction, setting intermediate goals, testing hospital staff and family, and efforts to be physically active (Visotsky, Hamburg, Goss, & Lebovitz, 1962). These authors also emphasized the sequencing of coping responses, hypothesizing that, at first, individuals cope by denial and avoidance in order to minimize the impact of the trauma or illness. Gradually, as patients begin to seek information about their condition, emotions including depression increase. Finally, recognition and acceptance of the reality of the chronic condition takes place, and that coping by

using hope, religiosity, and emotional support from others occurs. Several subsequent descriptive studies support these earlier findings (Cohen & Lazarus, 1979). This evidence suggests that in early stages of chronic illness, emotion-focused coping is prevalent (denial, avoidance, emotional restriction) and as adaptation to the illness proceeds, more problem-focused coping strategies such as seeking information occur.

Further evidence of how coping responses progress during stages of illness is provided by two studies of patients on chronic renal dialysis. Streltzer, Moe, Yanagida, and Siemsen (1983-84) described the coping of 25 chronic renal disease patients confronted with transplant failure, an acute condition. In their sample, patients coped in two ways, either with denial, or by experiencing a "grief reaction," which involved emotional expression comparable to emotion-focused types of coping. The group of "deniers" seemed to have more positive reactions to returning to dialysis than "grievers." Therefore, the authors recommended that health care providers support the use of denial as a means of coping with transplant failure. These results suggest that persons faced with acute illness events cope with denial, even when the acute events occur during the course of a chronic illness. Results also provide evidence that emotion-focused types of coping with illness may have adverse outcomes in terms of adaptation to a chronic condition. Baldree, Murphy and Powers (1982) evaluated the perceived stresses and coping responses of 35 patients on chronic renal dialysis and found that problem-oriented coping methods were used more often than affective-oriented coping. Optimism and controlling the situation were the two most common coping responses, while putting the problem out of one's mind and blaming someone else were the least used ways of coping. These results are

consistent with the hypothesis that as adjustment to chronic illness occurs, coping becomes more problem-focused and less avoidant and emotion-focused.

Viney and Westbrook (1982) studied coping in 89 adults who were chronically ill (defined as ill for six months or longer), but hospitalized for an acute exacerbation of their illness. Although they were asking respondents to discuss coping with their chronic illness, data were collected during an acute phase of illness. Six coping styles were identified: action strategies (finding the cause of the problem; taking positive action), control strategies (controlling feelings, compromising), escape strategies (reduce tension with emotional expression, distraction), fatalism strategies (expect the worst, accept that life is difficult), optimism strategies (every cloud has a silver lining, don't worry), and interpersonal coping (ask for help, talk with friends). The most frequently used coping strategies in their sample were action, followed by control, escape and fatalism. Patients with less disability tended to use more control strategies. Patient's perceptions of their handicaps were associated with fatalism, optimism and control in that the fatalism coping strategy was associated with more perceived handicaps in interpersonal relationships, mobility, and self-care; the optimism coping strategy was associated with more perceived handicaps in leisure activities; and the control coping strategy was associated with less perceived handicaps in mobility. Finally, control coping strategies were associated with perceived achievement of rehabilitation goals, while fatalism coping strategies were associated with less perceived success in rehabilitation. These findings indicate that positive outcomes are associated with action-oriented and problem-focused types of coping.

The effects of coping on psychological adjustment and the utility of the stress buffering hypothesis were tested in a longitudinal study of 170 middle-aged and elderly adults suffering from one of four chronic diseases: hypertension, diabetes, cancer, and rheumatoid arthritis (Felton et al., 1984). Coping was assessed with a scale derived from the "Ways of Coping Checklist" developed by Folkman and Lazarus (1980). In terms of differences in types of coping by illness category, only one difference emerged in that patients with rheumatoid arthritis used more wish-fulfilling fantasy. In a regression analysis, coping was found to add only minimally to the explanation of variance in the following outcome measures of psychological adjustment: acceptance of illness, self-esteem, and positive and negative affect. The authors also found that cognitive strategies, including information seeking, were related to positive affect, while emotional strategies, such as avoidance, blame and emotional ventilation, were related to negative affect.

In additional analyses of the same data, Felton and Revenson (1984) looked at how coping may differ depending upon the controllability of the illness, with cancer and rheumatoid arthritis conceptualized as diseases that offer few opportunities for control, and hypertension and diabetes as diseases more amenable to efforts at control. Results showed that information seeking was associated with decreased negative affect while wish-fulfilling fantasy had deleterious effects on psychological adjustment. However, neither of these coping strategies' effects were modified by illness controllability. Felton and Revenson (1987) report analyses of the correlation between age and coping strategies from the same dataset. In this analysis, they found that as age increases, there is a decrease in the use of information seeking, emotional

expression, and self-blame. They also looked at the effects of perceived seriousness of the illness on coping, and found that perceived seriousness seemed to amplify the relationships between age and coping style, such that those subjects who were both older and perceived their illness as serious coped through less active, more submissive and pessimistic means.

In a study of the relationships of coping responses to physical health status and life satisfactions in 281 older women, Lohr, Essex, and Klein (1988) report similar relationships. They found that passive-cognitive coping was associated with more reported functional impairments, regardless of the number of physical conditions; while positive cognitive coping (such as information seeking) was associated with lower reported levels of impairment. The relationship of passivity to poor health status is of interest because this implies that avoidance coping (included in this study as a passive cognitive coping style), may be detrimental in coping with a chronic condition, supporting the notion that if a switch to a more active coping strategy does not occur during adaptation to a chronic illness, there may be negative consequences to the individual, in this case, poorer health status.

Two of the studies discussed in previous sections also looked at the relationships among types of coping responses and health, although it is not clear in either study what type of health condition, acute or chronic, was being adjusted to. Folkman and Lazarus (1980) found that more emotion-focused coping was associated with health problems, although problem-focused coping was also used. Billings and Moos (1981) report that those persons in their study who were coping with illness (either in self or others), used more active-behavioral and problem-focused coping strategies compared to those coping

with their other stressful event categories (death, economic events). Further, their findings support the association between active-behavioral coping and decreased stress.

In a longitudinal study, Kahana et al. (1985) examined the relationships between coping strategies and well-being among 253 chronically ill older adults adjusting to nursing home placement. Coping was assessed with a scale measuring three dimensions of coping: instrumental coping (active behaviors or preparing for action), affective coping (affective expression or helpless resignation) and escape coping (actions that involved physically leaving or cognitive restructuring of the situation). Outcome variables were mental status, morale, self-esteem, health, and mortality. Of interest are findings that coping responses appeared to be stable over time, lending some support for a trait approach to the study of coping. They found that affective coping was predictive of low morale, low self-esteem, poor health, and mortality prior to their three year follow-up. Those respondents using escape coping at the start of the study reported poor health and had higher mortality rates over the three year course of the study. Instrumental coping was shown to be an important predictor of health, survival, and mental status. These findings are consistent with Felton et al. (1984), Felton and Revenson (1984), and Lorh et al. (1988).

In a study of 80 low income urban elderly women coping with the stresses of health problems, Conway (1985-85) described racial differences in coping styles between African American and white respondents. This study is important in that it addresses the understudied area of coping by racial minorities. In this sample, medical problems were the most frequently experienced stressful event, and subjects rated their health problems as very difficult. Affective responses to

these health problems included anxiousness, depression, feeling unsure about the future, and feeling tense. Coping responses were conceptualized as active strategies, cognitive strategies, and obtaining social support. A variety of coping responses, both action oriented and cognitive were used by this sample. The most frequently used active coping response was prayer; the only significant difference between African American and white respondents in active coping responses was that African Americans tended to use more non-prescription drugs. The two most frequently used cognitive coping responses were telling oneself that "I'm better off than a lot of people," and thinking of God or religious beliefs. The latter coping response varied by race in that African American respondents were more likely to cope by thinking of religion. Finally, there were racial differences in the use of support, in that African Americans reported that friends instrumentally helped them more often than whites reported. Also, African Americans reported a larger support system than whites. Unfortunately, this study did not link coping to outcome so no inference is drawn about the effectiveness of types of coping. These findings are consistent with the literature on how older persons cope, but is not consistent with the speculation that women use more emotion-focused coping, even though subjects in this study acknowledged experiencing a number of affective responses to their health problems.

In summary, the results of the studies reviewed support the hypothesis that there is a sequencing of coping responses as adaptation to chronic illness occurs. In early stages of chronic illness, emotion-focused coping is prevalent (denial, avoidance, emotional restriction) and as adaptation to the illness proceeds, more problem-focused coping strategies such as seeking information

and active participation in treatment occur. There is also some evidence that during an acute illness episode, coping with denial and avoidance is adaptive and associated with positive outcomes, such as adjustment to limitations due to illness. In chronic conditions, the use of action-oriented and problem-focused coping strategies are linked to decreased stress, increased positive affect, health, and self-esteem. Emotion-focused coping, affective coping, and passive cognitive coping are linked to low morale, decreased self-esteem, and increases in perceptions of functional impairment. These findings imply that as one adapts to chronic illness, there may be deleterious outcomes if the individual does not make the transition from emotion-focused coping strategies to action-oriented and problem-focused methods of coping.

Summary

In what ways are these bodies of knowledge--age and gender differences in coping, and coping with chronic disease--relevant to the study of coping in caregivers of DAT patients? As stated in Chapter One, the majority of family caregivers of elderly persons (both DAT patients and frail elderly persons with other chronic conditions) are older women who are experiencing their own health problems as well as adapting to the progression of their family member's illness (Stone et al., 1987). Consistent with the person-environment interaction model of coping which is the underlying conceptual framework for this study, age, gender, and presence of health problems can be considered variables that affect the coping resources of an individual as well as variables that represent factors influencing the internal disposition of an individual. They are therefore important to consider in understanding caregiver coping with DAT.

First, age alone is unlikely to influence a caregiver's coping. Studies suggest that as people age, they continue to display the capacity for flexibility and a diverse range of coping responses, but that there may be slight increases in passive coping styles such as cognitive restructuring and acceptance, and less of the emotion-focused responses of hostility or aggression. Thus, caregivers can be expected to cope in diverse and flexible ways. However, coping with DAT in a loved one may be experienced by the caregiver as a loss, which might evoke more coping through faith or religion (McCrae, 1989). The caregiver may also perceive DAT as an uncontrollable stress, in which case more emotion-focused coping responses could be expected. Further, those caregivers who are using both instrumental and palliative coping strategies may perceive their coping as most effective (George and Siegler, 1982). Second, the only gender difference observed is the presence of more emotion-focused coping responses among women. Therefore, women caregivers might report more emotion-focused coping compared to their male counterparts. Finally, caregivers who are coping with their own chronic illness may report more action-oriented and problem-focused coping responses, but those who report more emotion-focused and passive cognitive coping might experience more of the negative affect associated with caregiving, such as burden and depression. Although caregivers are coping with and adapting to a chronic illness in their family member, DAT is an illness that generally progresses in stages such that, at times, caregivers are coping with acute changes in the DAT patient's behavior, affect, cognition and functional ability. During times of acute or rapid change in the DAT patient's condition, the caregiver may cope with denial, avoidance, or other emotion-focused coping strategies. This may be seen as adaptive and

appropriate to the stage of the illness, and might not necessarily be associated with a detrimental outcome in terms of the caregiver's well-being.

Chapter Three

Religious Coping

Introduction

A majority of U.S. adults (56%) say religion is "very important" in their lives and the value placed on religion appears to rise with age as 73% of persons over the age of 65 regard religion as "very important" in their lives (Princeton Religion Research Center, 1985). Although religiosity and religious coping activities comprise frequently reported coping strategies used by older individuals under stress, few studies on religious coping have been completed. Further, research on the well-being of older adults rarely considers the relationship of religion to well-being (Larson, 1978). In clinical practice, the patient's religious beliefs and practices are often ignored, particularly by mental health professionals (Kroll & Sheehan, 1989). The importance of religion in people's lives has been understudied, and perhaps embodies an underutilized source of help for individuals of all ages experiencing stress.

This chapter will focus on religious coping. First, the function of religion and its relationship to well-being and health will be reviewed. Religiosity will then be defined. Next, what is known about religiosity and religious activities of older adults, and how these activities might change over the life span will be reviewed. This discussion will be followed by a review of the literature relating to religious activities that are conceptualized and studied as coping responses. The chapter will conclude with a summary of how religious coping behavior may relate to coping in caregivers of DAT patients.

Religiosity and Aging

Religion seems to give hope, meaning, optimism, and security to individuals and appears to be linked to well-being. In a study synthesizing the work of many investigators through meta-analysis, Witter, Stock, Okun and Haring (1985) report that religion accounts for between two and six percent of the variance in adult subjective well-being. Compared to 16 other predictors of subjective well-being, religion was as potent a predictor of well-being as education, socioeconomic status, marital status, work status, and social activity, and a better predictor than age, gender and race. Although it has been reported that women are more religious than men (Kivett, 1979), this was not supported by the meta-analysis. Recent reports suggest that strong commitment to religious faith improves one's chances for good health, and this pattern appears to hold for physical illness such as cancer and heart disease, and psychiatric illness like depression (Larson, 1989; Meador, Turnball, Hughes, Blazer, & George, 1989; Williams & Jackson, 1989).

Religiosity encompasses institutional activity such as church attendance (organized or formal religious activity), personal activity like prayer or reading religious materials (non-organized or informal religious activity), the subjective value or importance one places on religious beliefs and attitudes, and one's commitment to religious beliefs. Although religiosity is clearly a multi-dimensional concept, it is often measured in one item questions, such as church attendance or membership, which may confound religion with social support activities. Further, each dimension of religiosity may have different influences upon various aspects of well-being. For example, Peterson and Roy (1985) report church attendance to have a direct effect on reducing anxiety,

whereas religious salience (the importance of religion to the individual) had a direct effect on the individual's sense of meaning and purpose in life. Witter et al. (1985) found the relation between religion and subjective well-being to be stronger for religious activity than for measures of religious value or importance. In a study examining the extent to which relationships with "divine others" affect psychological well-being, Pollner (1989) found that after the effects of sociodemographic variables and church attendance were controlled, divine relations explained a significant amount of the variance in global happiness, life satisfaction and life excitement. When considering the role of religion, it is thus important to operationalize and measure the concept in a multi-dimensional manner, so that the influences of different aspects of religiosity can be determined.

The role religion plays in daily life is thought to increase as people age (Moberg, 1983). This is thought to be true for a variety of reasons. Older adults may look to religion to alleviate the fear of death. Physical and psychological healing as well as spiritual strength may be found in prayer or through religious teachings and ritual (Moberg, 1983). Elderly persons are more likely to find personal friendship and other social resources in the church than in any other institution outside the family (Kivett, 1979). Thus, for the elderly, religion may function as a coping response to illness or death and as a source of social support. Additionally, many elderly persons receive church-sponsored volunteer services, institutional care, and welfare programs. Receiving these services may increase the religious activities of an older individual. Finally, many older persons fill responsible positions of service within the church, and although these activities represent religious behavior, they may also portray the

need to serve or be needed or function as a replacement for paid employment. Therefore, service to a religious institution may imply a process other than religious commitment.

A popular belief is that religious faith and religious activities increase with age. Is there empirical evidence to support this assumption? Blazer and Palmore (1976) analyzed the religious activities and attitudes in a longitudinal panel of 272 persons. Data were from the Duke Longitudinal Study of Aging (Palmore, 1970, 1974). At the time of the first round of interviews (1955-1959), the age range of subjects was 60 to 94 years with a median age of 70.8. The sample contained African Americans and whites and both genders in proportions that approximated the race and sex distribution of the community from which the sample was drawn. Findings suggest that attitudes toward religion (e.g., subject agreement/disagreement with such statements as "religion is a great comfort to me" and "religion is the most important thing to me") remain stable across the life span, but religious activities decline with age. Religious activities included both organized activities such as church attendance, and non-organized activities like prayer or reading religious books or magazines. Both types of religious activities were more strongly associated with happiness, usefulness, and adjustment than a positive attitude towards religion, and these relationships became stronger over time. This finding implies that religious behaviors, and not one's religiosity, represented by a positive attitude toward religion, influence well-being. Women were significantly more religious, in both their attitude towards religion and religious activities, compared to male respondents. Religious activities remained significantly higher for women over time, but showed the same pattern of decline as men.

In a secondary analysis of data drawn from the National Opinion Research Center's General Social Survey, the relationship between religiosity and well-being was evaluated (Steinitz, 1980). Responses from 1,493 persons over the age of 65 were analyzed. Religiosity was measured by four items: frequency of church attendance, strength of affiliation, belief in life after death, and confidence in organized religion. Similar to the findings of Blazer and Palmore (1976) and Witter et al. (1985), church attendance, and not strength of religious affiliation or confidence in organized religion, was consistently associated with well-being. This result also supports the idea that the positive relationship between religious activity and well-being is produced via social support functions. It should be noted that although the sample size in this study was quite large, the measure of religiosity was inadequate in that it was comprised of only four items. Secondary analysis suffers from limitations incurred by the use of measures and methods for purposes different from what was originally planned when the study was designed.

In a cross-sectional survey of 106 elderly persons, Mindel and Vaughan (1978) evaluated organized and non-organized religious activities and the relationship of these religious activities to health and other forms of social activity. The authors hypothesized that declines in organized religious activity (formal activities such as attending church services) make elders appear "disengaged;" however, this may be a fallacious assumption, and should be assessed in conjunction with the elders' participation in non-organized religious activities (informal activities such as praying alone or with family, listening to religious radio/watching religious television). If elders were truly disengaged from their religious role, this would be reflected in both organized and non-

organized religious activity. A little more than half of the subjects (55%) did not attend church services, whereas 62% reported engaging in non-organized religious activities. Elders were not consistently "disengaged" from both types of religious activities in that often persons who scored low on organized activity scored high on non-organized religious activity. Although poor health has been suggested as the reason religious activity declines with age, in this study, health or physical impairment had no relationship to participation in organized religious activity. However, those subjects who reported poor health engaged in more non-organized religious activities than their healthier counterparts. Those elders with low organized religious participation rates also had low rates of participation in other forms of social activity, suggesting that for older persons, the same variables influencing participation in organized religious activities may influence participation in other social activities.

The relationships among age, church attendance, and health were assessed in a study of 1,170 elderly (Guy, 1982). As in the study described above, by Mindel and Vaughan (1978), it was hypothesized that poor health would account for declining church attendance as persons grow older, and that church attendance would be related to life satisfaction. Life satisfaction was greatest for those elders who reported an increase in church attendance over the previous fifteen years, but was also high for persons whose church attendance had been stable for the previous fifteen years. Results revealed that church attendance declined with increasing age. Age and physical activity limitations were also related in that physical limitation increased with increasing age. The data indicated that as age increases, proportionately more individuals with limited physical activity never attend church or attend church less

frequently. This is contrary to the findings reported by Mindel and Vaughan (1978).

Devine (1980) interviewed 121 elderly individuals in order to describe how religious attitudes and activities (both formal and informal religious activities) changed after retirement and the role religion plays in the lives of older persons. The majority of the subjects (86%) reported that there was no change in their religious attitude after retirement. Only 31% of the subjects stated that their religious activities had changed after retirement. Of these, nine people reported an increase in activities, primarily due to an increase in time for religion after retirement, and 27 respondents stated their church activities declined, attributing this to failing health, lack of transportation, and statements indicating that their church "had changed." Overall, only 22.3% of the subjects reported a decline in religious activities. This finding is somewhat less than what might be expected based on previous studies, and may be due to combining formal and informal religious activities in one measure of religious activities. When asked what religion does for them, most of the subjects indicated that religion provided them with support and strength in dealing with their health and the health of others. These results suggest that for most elders, religious activities and attitudes remain stable after retirement. Religion appears to function as a coping mechanism and a source of social support.

In a study focused on exploring how religion constructs meaning and guidance in life, Tellis-Nayak (1982) analyzed survey data from 259 rural elderly. The relationships between religiosity and the following variables were explored: sex, age, marital status, health, loneliness, death anxiety, meaning in life, and psychic well-being. In this study, religiosity was a summary measure which

included religious ideology, ritual, experience, and consequence. Women appeared slightly more religious than men in this sample, and religiosity tended to increase with age. In contrast to recent reports, health was unrelated to religiosity. There were weak relationships between religiosity and death anxiety and psychic well-being such that less death anxiety and higher well-being correlated with religiosity. However, religiosity was found to be highly positively correlated with meaning and purpose in life. These findings tend to support the hypothesis that religion functions to enhance well-being through providing meaning and purpose in life.

Hunsberger (1985) interviewed 85 persons between the ages of 65 and 88 years in order to explore the extent to which religiousness is related to age and life satisfaction. In this study, religiousness was assessed with a summary scale with items pertaining to religious activities (organized or formal activities only) and religious value. Additionally, subjects were asked about the stability of their religious beliefs over the course of their life. In general, there was a trend towards religion becoming more important as people age. However, when this was analyzed by degree of religious orthodoxy, it was apparent that it was the high orthodoxy group that became more religious with age. This finding suggests that samples of highly religious older persons may be biased towards demonstrating an increase in religiosity with age. In this study, all of the religious orientation items were positively correlated with life satisfaction, and importance of religious belief had a stronger relation than church attendance. These results imply that the positive association between religion and well-being comes about more because religion provides a sense of meaning and purpose,

and that the social support functions of church participation are less important in relation to well-being.

Koenig, Kvale and Ferrel (1988) studied 836 older adults, operationalizing religiosity by measuring participation in organized religious activities, non-organized religious activities, and intrinsic religiosity, which is a measure of one's cognitive commitment to religious beliefs. The relationships among religiosity, health, and morale were assessed. Respondents were also asked to rate how well they felt they were coping by responding to a single item that asked for agreement/disagreement regarding the statement "I handle tension in my life very well." Sampling was purposive in order to obtain a group of elders who were heterogeneous in relation to religiosity. The age range of the sample was 55 to 94 years (mean age was 73.4) and women predominated. In terms of the relationship between the religiosity measures and sociodemographic variables, women and subjects over age 75 reported more religiosity. This is consistent with other reports. However, none of the religiosity measures correlated with health. Subjects who reported that they were coping well also scored high on the three religiosity measures, with both types of religious activity demonstrating a somewhat stronger relationship to subjective coping compared to intrinsic religiosity. Overall, all of the religiosity measures were positively correlated with morale, with slightly stronger correlations for organized religious activity. In evaluating the relationship between religiosity and morale for subgroups of the sample, results suggest that for those elders in poor health, organized religious activity was a particularly strong correlate of morale, whereas for those in good health, the relationship between intrinsic religiosity and morale was stronger.

Chatters and Taylor (1989) analyzed the responses of 2,107 adults from the National Survey of Black Americans in order to describe age differences in the religious activities of African American adults. The sample was comprised of African American aged 18 and older; 11% were aged 65 to 74, 5% were over age 74. Women made up slightly less than two thirds of this sample, and nearly half the sample had less than a high school diploma. Seven indicators of religiosity were available in the dataset: church attendance, church membership, reading religious materials, watching/listening to religious programs, frequency of prayer, requests for prayer, and subjective religiosity. Results indicate that African American adults of all ages manifest high levels of organized religious participation and involvement in private, non-organized religious pursuits. Additionally, gender differences emerged in that women reported more religious involvement than men. Age was positively associated with both organizational and non-organizational religious behaviors and activities, as well as attitudinal measures of religious involvement. These patterns persisted even after demographic and health factors were controlled, suggesting that age exerts an independent effect on religiosity. In terms of particular religious activities, frequency of church attendance, reading religious material, and requesting prayer were lower for respondents over age 75 compared to persons age 65 to 74. These findings are similar to what has been reported for elderly whites by Blazer and Palmore (1976).

In summary, results from these studies generally find that older women tend to be more religiously involved than older men. However, it is less clear that religiosity increases as people age. Positive correlations between age and religiosity might be a cohort effect. Some older persons may be more religious

because their generation was more religious. If so, then they were probably very religious as younger persons, too, rather than becoming more religious with age. When different dimensions of religiosity are evaluated, different and somewhat conflicting patterns arise. The best evidence of change due to age is that provided by Blazer and Palmore (1976), who find in their longitudinal study that religious attitudes remain stable over time, while religious activities tend to decrease. What is clear is that in cross-sectional studies, older people indicate that religion is very important in their lives. Religiosity does appear to be related to well-being, particularly organized religious activities, which implies that it may be the social support functions of religiosity that contribute to well-being (Blazer & Palmore, 1976; Devine, 1980; Steinitz, 1980; Koenig, Kvale & Ferrel, 1988). However, non-organized religious activities and religious commitment also appear related to well-being, but somewhat less so, indicating that provision of meaning and purpose in life through religious belief and ritual may also contribute to well-being in older individuals (Tellis-Nayak, 1982; Hunsberger, 1985). When religious activities do decline with age, it is not clear whether this is a function of declines in health or some other factor (Mindel & Vaughan, 1978; Guy, 1982).

There is much room for additional research into questions relating to how religiosity changes as people age, and the relationships among different dimensions of religiosity, health and well-being. More longitudinal studies need to be conducted. Also, datasets from longitudinal studies that include religious activity items may be available and could be analyzed to determine in what way religiosity changes as people age. In addition to the importance of measuring and analyzing religiosity as a multi-dimensional construct, another problem in

the study of religiosity has to do with the social desirability of many religiosity and religious activity questionnaire items. It is important to obtain samples that are heterogeneous in regards to religious orthodoxy and religiosity, as samples comprised of highly religious persons may bias results. Studies that include samples representative of ethnic and racial minorities also need to be conducted.

Religious Activity as a Coping Response

Conceptualizing and Measuring Religious Coping

Items describing religious behaviors are included in several instruments measuring ways of coping. Examples include "turning to prayer," "asking for help from clergy," and "finding new faith." These responses are considered to be both problem-focused coping (intended to manage the problem situation) and emotion-focused coping (intended to manage the feelings aroused by the difficult situation). For example, the instrument used by Billings and Moos (1981) to measure coping included two religious behaviors. "Prayed for guidance" was considered an active cognitive coping method which was emotion-focused. A second item, "talked to a professional person (clergy, doctor, etc.) about the situation" was categorized as an active behavioral coping response that was problem-focused. In a later study, Billings and Moos (1984) classified these same responses somewhat differently in that both of these items were considered to be problem-focused coping in a classification scheme that included three types of coping: problem-focused, emotion-focused, and appraisal-focused.

Felton et al. (1984) used an instrument to measure coping responses that also included two religious items: "found new faith or some truth about life" and

"religion became more important." These items were in the coping dimension they labeled cognitive restructuring. Lohr et al. (1988) utilized a coping measure that included one religious response, "turned to religion, prayer, or meditation;" this item was considered passive cognitive coping. The coping measure used by Jalowiec and Powers (1981) included one religious item, "pray; trust in God," and the investigators considered this to be affective-oriented coping. Rather than a specific coping response, religiosity, defined as the extent to which a person was committed to a set of religious beliefs and religious activities, was seen as a "coping resource" by Simons and West (1985).

It is difficult to synthesize results from these studies to find clear relationships between religious coping and well-being because these different dimensions of coping have also demonstrated somewhat different patterns in terms of associations with well-being measures. For example, passive cognitive coping was found to be linked to poor perceived health in older women (Lohr et al., 1988). Felton et al. (1984) report that cognitive restructuring was associated with positive affect in chronically ill adults. And Billings and Moos (1984) found that problem-focused coping was associated with less severe dysfunction in adults with unipolar depression. Simons and West (1985) found that religiosity did not appear to function as a coping resource. What does seem to be consistent in the literature is that religious coping behaviors, depending upon the particular item, can be conceptualized as emotion-focused coping, problem-focused coping, cognitive restructuring, or as passive cognitive coping.

Frequency of Religious Coping

Most of the studies of religious coping are descriptive in nature and do not

link religious coping to outcome measures such as well-being or life satisfaction. Jalowiec and Powers (1981) report that prayer was among the top five coping responses reported by 25 newly diagnosed hypertension patients. Baldree et al. (1982) found coping through prayer to be the third most frequently reported coping response in a sample of 35 patients on hemodialysis. Griffith (1983) reports religious coping to be the third most frequently reported coping strategy in a sample of 579 women aged 25 to 65. In this study, comparisons across age groups were made, and the women over age 45 reported significantly more religious coping compared to women under the age of 45.

Soderstrom and Martinson (1987) studied the spiritual coping strategies of 25 cancer patients and their nurse's awareness of these strategies. These investigators examined several religious behaviors and similar to other reports, found prayer (84%) and prayer activities with others (64%) to be the most frequently reported spiritual coping strategies. The next most frequently reported activity was the use of religious objects or music, followed by watching religious TV/listening to religious radio, reading the Bible, attending church, reading other religious books, memorizing Bible verses, and requesting communion. This sample of terminally ill cancer patients saw family members as their primary spiritual resource persons, followed by clergy, friends, nurses and doctors. Given the reported neglect of patient's religious beliefs and practices on the part of health care providers (Kroll and Sheehan, 1989), it is of interest to note that over half of the nurses (56%) in this study could not correctly identify their patient's religious faith, and their ability to identify patient's use of spiritual coping strategies varied. Sixty percent of the nurses were able

to identify their patient's use of religious objects or music (60%) while only 40% identified their patient's use of prayer. Given the importance the patients placed on religious coping, these figures do not reflect a high level of understanding on the nurses' part, and may make the nurses in this study less able to facilitate the patient's use of religious coping. Further, results clearly demonstrate the role nurses and other health care providers can take in supporting their patient's spiritual coping: nineteen of the patient respondents wanted the nurse to talk with them about their feelings about God; fourteen wanted to be referred to clergy for prayer or communion; thirteen wanted privacy provided for prayer; and eleven wanted respect for their beliefs and assistance with Bible reading.

The frequency of religious coping responses is similar when samples of elderly persons are studied. Conway (1985-86) studied the coping responses of 46 elderly African American women and 34 elderly white women, all of whom identified a health problem as their major stress. Prayer was considered action oriented coping and was the most frequently reported coping response in this sample with 90% of the subjects using prayer. "I think of religion" was conceptualized as a cognitive oriented coping response and was reported by 86% of the sample. On this item, however, there were racial differences in that African American women reported using this coping strategy more frequently than white women. Subjects in this study were also asked to report who assisted them when faced with stressful medical problems. Eighty-five percent reported they turned to God, and this was more frequently reported by African Americans than by whites. In contrast, only 27% reported seeking assistance from their minister, and no racial differences were detected on this item.

In a descriptive study of the stresses and coping in 51 individuals over age 60, Manfredi and Picket (1987) also found prayer to be the most frequently reported coping response. The subjects in this study reported loss of physical health as their main source of stress. These authors measured coping with the Ways of Coping Checklist, which includes "prayer" and "finding new faith" as emotion-focused coping strategies. However, the latter response, "finding new faith," was one of the least frequently used coping strategies reported by this sample. These elders may have perceived their religious commitment or faith to be a stable attribute, and therefore not "new." Koenig, George and Siegler (1988) also found religious coping behaviors to be the most frequently mentioned coping strategy used by older adults during stressful experiences. In this study, 100 respondents aged 55 to 80 were interviewed about how they had coped with stressful experiences in the present, in the past ten years, and over the course of their whole life. To reduce bias that may have been introduced by the interviewer, only those coping responses mentioned spontaneously by the respondents were counted in the analysis. Although a great variety of coping responses were mentioned by this sample, religious behaviors were mentioned most frequently. Of these religious behaviors, 74% consisted of placing trust and faith in God, praying, and obtaining help and strength from God, while church related or religious social activities were seldom noted apart from religious cognitions. Consistent with Peterson and Roy (1985), Tellis-Nayak (1982), and Hunsberger (1985), these findings imply that it is the provision of meaning and purpose, and not the social support functions of religion, that may be most helpful in terms of coping with stress.

Bearon and Koenig (1990) further described the role of religious cognitions and the use of prayer in health and illness in a sample of 40 adults aged 65 to 74. The sample was composed of roughly half African Americans and half whites, with even gender distribution. Subjects were interviewed about their beliefs as to cause and effect in health and the frequency of prayer, particularly over recently suffered physical symptoms. The authors hypothesized that people most likely to pray would be less educated, African American, and from a conservative religious denomination and that the symptoms most likely to be prayed about would be those over which people felt no personal control. In terms of beliefs about cause and effect in health, this sample agreed with the statements "there is no guarantee of health as a reward for good behavior" and "health is a blessing or a gift from God." Subjects did not believe illness was a test by God or a punishment for sin. Thirty-six of the 40 subjects reported at least one recent physical symptom, and of those reporting symptoms, most felt there was nothing that could be done about their symptom. Nineteen (53%) of the symptomatic respondents reported praying about at least one symptom the last time they experienced it. People with multiple symptoms tended to pray for more than one of their symptoms. The use of prayer in this sample was found to be associated with less education and membership in a conservative denomination. African Americans were slightly but not significantly more likely than whites to report having prayed about a symptom. Additionally, symptoms that respondents felt could be treated medically were no more likely to be prayed about than those about which the respondents felt nothing could be done. This finding does not support the

hypothesis that prayer functions to provide a sense of control or mastery over a stressful event.

Religious Coping and Stress Reduction

The studies reviewed thus far have been limited to describing the frequency of religious coping responses. Although it is not clear whether older adults cope with religious activities more often than their younger counterparts, these studies provide strong documentation that religious activity, particularly prayer, is a frequently used coping response of individuals under stress. Krause and Van Tran (1989) expanded the knowledge about the process by which religiosity influences well-being by using structural equation modeling to evaluate the role of religious involvement in attenuating stress in a sample of older African Americans. The sample size ranged from 486 to 511, depending upon response sizes available for particular analyses. Religiosity was measured in terms of organizational religious activity and non-organizational subjective religiosity. Outcome measures were self-esteem and mastery. Respondents were asked about their experience with stressful life events in the recent past so that a simple summary score on amount of recent stress could be produced.

In this study, three models of the role of religion were tested: the moderator model, the suppressor model, and the counterbalancing model. The moderator model assumes that there are no direct effects of religiosity on self-esteem and mastery in the absence of stress, and that the stress buffering effects of religiosity are non-additive. Religious involvement is seen as progressively more effective in reducing the effects of stress, and the maximum buffering effects occur at high levels of stress. The suppressor model assumes

that the relationships among stress, religious involvement, and the outcome measures are additive. Level of religious involvement is dependent upon the amount of stress present such that as stress increases, individuals are motivated to increase their religious involvement, which tends to bolster self-esteem and mastery, thereby diminishing the overall negative effects of life stress. The counterbalancing model assumes that stress and religiosity exert direct additive effects on mastery and self-esteem, but there is no relationship between stress and religiosity. The impact of stress on self-esteem and mastery is not contingent on the current level of religious involvement, nor does greater exposure to life stress increase religiosity.

Krause and Van Tran (1989) tested these models after controlling for the effects of age, sex, marital status, and education. Their analyses failed to support either the suppressor or the moderator model; instead, their findings tended to support the counterbalancing model. Findings revealed that while stress tends to erode feelings of mastery and self-esteem, these negative effects are offset or counterbalanced by religious involvement. Both organizational religious activity and non-organizational subjective religiosity offset the negative effects of stress. Consistent with the literature that suggests religiosity is a fairly stable characteristic, the authors found that religious involvement was not affected by the amount of stress experienced by study participants. More studies utilizing large samples to test complex statistical models would be of benefit in continuing to test and define the role religiosity and religious coping behaviors play in maintaining well-being and as a response to stress.

Summary

It is not clear that religiosity or religious coping behaviors increase with age. It may be that religious values and attitudes remain stable over the life span, while organized religious activity decreases with age. Religiosity is a multi-dimensional construct and there is conflicting evidence relating to which dimensions of religiosity influence well-being. Further, it is not clear how religiosity functions to influence well-being. The two major hypotheses are 1) religion functions to provide social support and 2) religion provides a sense of meaning and purpose, and thereby control. There does appear to be gender and racial differences in religiosity, as women and African Americans tend to be somewhat more religiously involved. Very strong evidence that people of all ages use religion, particularly prayer, as a coping response is provided in the literature. But because these studies are all cross-sectional, it is not clear whether prayer is evoked as a response to stress, or if it is a stable behavior. The findings of Krause and Van Tran (1989) tend to support the view that religiosity is stable and unrelated to the amount of stress an individual experiences.

Since religious coping behaviors are so frequently reported, more studies describing the components of religious coping behaviors and evaluating the effects of religious coping could be of benefit in helping health care providers support and facilitate their patients' coping strategies. Caregivers of DAT patients, perhaps more than other populations, could be expected to be utilizing religious coping behaviors as they adapt to caregiving and the progression of DAT. This is because the majority of DAT caregivers are women who may already have high religious involvement as a function of gender (Blazer &

Palmore, 1976; Kivett, 1979). Also, much religious coping is conceptualized as emotion-focused in that it functions to manage feelings aroused by the stressor, rather than change the stressful situation. The problems associated with DAT may be unlikely to respond to problem-focused coping intended to directly manage or change them, and so caregivers may use more emotion-focused coping. Further, if the diagnosis of DAT in a loved one is perceived by the caregiver as a loss, religious coping might be evoked (McCrae, 1989). Religion might also operate to provide meaning and purpose, and to help caregivers continue to provide care despite suffering negative consequences from caregiving, such as depression or burden. Gathering data about the religious coping behaviors of DAT caregivers could help clarify these questions and provide information that could guide health care providers in promoting the well-being of the DAT patient's caregiver.

Chapter Four

Coping in DAT Caregivers

Introduction

This chapter will review the relevant literature on coping in caregivers of dementia patients. Because it is assumed that coping processes mediate the impact of negative outcomes associated with caregiving, the discussion of coping will be preceded by a review of the literature pertinent to these negative outcomes. First, the negative effects of caregiving will be reviewed, with a discussion of the correlates of these outcomes and the potential differences between caring for a DAT patient versus persons suffering from chronic conditions with less mental impairment. Next, the coping strategies of DAT caregivers will be discussed, including an elaboration of the mediating effects of coping on caregiver well-being. A critique of the caregiver coping literature will be presented. The chapter will conclude with a discussion of the components of a proposed model of caregiver stress and coping and how this model relates to the purpose of this study.

The Negative Effects of Caregiving

The negative effects of providing care to persons with DAT or persons with other chronic conditions requiring care (often referred to as the "frail elderly") are well documented and have been described in terms of caregiver stress, burden, depression, health problems, decreased social activities and financial strain. In addition, research has demonstrated a link between

institutional placement of DAT patients and depression or burden in their caregivers (Colerick & George, 1986; Lund et al., 1985). Therefore, identifying variables associated with caregiver stress so that interventions can be planned to alleviate these negative effects have comprised the focus of much gerontological research during the past ten years. Many of these studies have been descriptive and limited by small non-representative samples. Caregivers are rarely compared with non-caregiving controls. Nevertheless, the pattern of results of both descriptive studies and studies with larger samples and normal controls are consistent in that there appears to be significantly more depression and lower well-being in caregiving samples compared to non-caregiving controls, and a cumulative or global caregiver burden score does not appear to have clear relationships to patient characteristics or to the particular caregiving tasks demanded.

This section of Chapter Four will first review the descriptive studies of caregiving. Included will be a discussion of global versus multi-dimensional measures of burden, the use of depression as an outcome variable, and how caring for a non-demented elder may be different from or similar to caring for an elder with DAT. Next, the studies that compare caregivers to non-caregivers or "normals" will be reviewed. Although few studies to date have utilized designs that allow such comparisons, these studies are of particular importance in relation to validating descriptive reports of the negative effects of caregiving. This section of Chapter Four will conclude with a summary of what is known about the negative effects from caregiving, taking into consideration the limitations of these studies.

Descriptive Studies of Caregiving

One of the earliest studies in this area examined 29 DAT caregivers and measured caregiver "burden" by an inventory developed from the investigators' clinical experience with caregivers, and covered deficits in the areas of health, psychological well-being, finances, social life, and the relationship between the caregiver and the patient (Zarit et al., 1980). This instrument became known as the "Burden Interview," and to date is the most widely used instrument measuring burden. It provides a cumulative burden score across several domains affected by caregiving. This early study also evaluated the impact of patient characteristics (memory and behavior problems, duration of illness) and caregiver characteristics (social support, relationship to patient) on caregiver burden. The only significant correlation found was that patients who reported more visits from family other than the primary caregiver had caregivers who reported less burden, implying that the presence of social support may influence burden in the caregiver.

Chenoweth and Spencer (1986) surveyed 289 family caregivers of dementia patients and asked them to report their experiences with seeking help for the DAT symptoms, the difficulties in day-to-day care, and the problems they were experiencing as a result of caregiving. These caregivers reported their most frequent problems as patient requirements for complete care or constant supervision, physical and emotional strain, being unable to get away from the caregiving, and concern about finances. Of note are results indicating little help or support from professionals—only 16% of the respondents reported receiving specific instruction about managing DAT symptoms and no one reported being given information about home services or help for the caregiver. Further, many

caregivers reported that the way the diagnosis was presented to them served to increase their stress, in that little explanation about the disease was given and the hopeless nature of the illness was emphasized. These findings suggest that the manner in which professionals communicate the diagnosis of DAT and whether information is given early on about management of DAT patient symptoms may significantly influence the caregiver's stress.

In a study describing changes over time in caregiver burden (measured by the Burden Interview) and the differences in burden between husbands and wives, Zarit, Todd, and Zarit (1986) report that burden scores tended to decrease over the two year time frame of their study of 64 spouse caregivers of DAT patients, regardless of the condition of the patient. This finding may reflect adaptation to the stress of caring for a DAT patient. Women had higher burden scores than men at time one and tended to report a greater decrease in burden at time two such that gender differences in burden were no longer present at time two. No other differences between husbands and wives were detected. Similar results are reported by Fitting et al. (1986) in their study of 54 spouse caregivers of DAT patients. No differences between husbands and wives in burden (measured by the Burden Interview) or family relationships and family environment are reported. However, women reported significantly more depression than men, as measured by the depression subscale from the Minnesota Multiphasic Personality Inventory. This result could be interpreted as a gender effect independent of caregiving, since depression has been found to be more prevalent in women (American Psychiatric Association, 1987). Again, patient characteristics did not seem to relate clearly to burden; only the severity

of the patient's illness was associated with higher perceived burden in younger wives and older husbands.

In another study describing gender differences in burden and stress associated with caregiving, Barusch and Spaid (1989) surveyed 131 spouse caregivers of frail elderly persons (51% of the care receivers had a primary diagnosis of dementia). They found that women, who comprised 70% of their sample, reported significantly more burden (measured by the Burden Interview) than men. However, in a linear regression model, more memory and behavior problems in the patient, increased caregiver age, and increased number of caregiver adverse social contacts were better predictors of burden than was gender. The finding that more frequent memory and behavior problems predicted caregiver burden suggests that coping with problems associated with dementia might engender more burden in the caregiver.

Barusch and Spaid (1989) also explored gender differences in the use of formal and informal support. Few differences between men and women were found. Male caregivers used somewhat more formal support services (the use of congregate and home delivered meals, legal services, case management, transportation, senior center activities, home health aide, visiting nurse, and counseling) than their female counterparts in that they made use of more meal services. There were no significant differences in the use of informal social supports (amount of emotional support received, and measures of positive and negative social contacts). These findings are contrary to what would be expected based on the social support literature, which has found that older women generally have more confidantes than older men (Lowenthal, Thurnher, Chiriboga, & Associates, 1975), but men receive more help from kin and other

informal sources (Noelker and Wallace, 1985). Gender differences in the use of formal support services have been documented, with women making greater use of physicians, support groups, and counseling, while men use more help with home nursing and housework (Wylie, 1984; Snyder & Keefe, 1985). Additionally, Barusch and Spaid (1989) found that social support did not seem to lower caregiver's perceived burden.

Economic strain and job performance problems are two additional difficulties caregivers face. These areas have only recently been described in detail. In a study of 286 DAT caregivers, Enright and Friss (1987) reported that 47% of caregivers under the age of 65 quit their jobs in order to provide care, and that two-thirds of the "not employed" daughter caregivers indicated that they would be working if they were not caregiving. These caregivers estimated their lost wages at \$1,700.00 per month. One-half of the caregivers still employed full-time indicated that they missed work due to caregiving; 58% of this group report decreased work productivity due to worry about the care receiver. Caregiving was found to deter labor force participation for wives only. These results suggest that caregiving has a measurable impact upon employment, and that this impact is not felt equally by all caregivers.

Even stronger evidence of how caregiving affects job performance is provided by an employee survey ($n = 3,658$) conducted by Scharlach and Boyd (1989). Of the respondents in this survey, 28% (1,989) were assisting an elderly person. Results revealed that these care providers, when compared to other employees, were more likely to miss work due to caregiving, had decreased work performance because of fatigue related to caregiving, and had taken leaves from work in order to provide care. Caregivers of elderly persons

and caregivers of children, however, reported approximately the same amount of interference between job and family, and approximately the same number of absences due to caregiving. Interference between job and family was greatest for those employees with both eldercare and childcare responsibilities. The considerable number of employees providing eldercare in this sample illustrates the need for special services such as flexible schedules for family caregivers in existing employee assistance and benefit programs. Results also suggest there are considerable economic costs of caregiving in terms of lost wages for caregivers and lost productivity for business.

In summary, the results of these studies provide descriptive evidence of burden and depression in caregivers, but fail to support claims that specific types of patient problems or caregiving demands correlate with caregiver burden or depression (Zarit et al., 1980; Zarit et al., 1986; Fitting et al., 1986). Further, Zarit et al. (1986) report that caregiver burden decreases over time regardless of the condition of the DAT patient. Only Barusch and Spaid (1989) find increases in the frequency of memory and behavior problems in the DAT patient to be linked to increases in caregiver burden. Caregivers report their most frequent caregiving problems to be providing care for a DAT patient in need of constant supervision or complete care, and being unable to have respite from caregiving (Chenoweth & Spencer, 1986). Results relating to the effects of social support on burden are conflicting. Zarit et al. (1980) suggest that social support may decrease burden, while Barusch and Spaid (1989) find no relationship between burden and social support. There is also conflicting evidence regarding whether gender plays a role in caregiver depression and burden. For example, Barusch and Spaid (1989) found that women caregivers

reported significantly more burden compared to their male counterparts, while Fitting et al. (1986) found no gender differences in burden. Women caregivers, however, report more depression than male caregivers (Fitting et al., 1986). Finally, caregiving does appear to deter labor force participation for women and lessen productivity on the job for both genders (Enright & Friss, 1987; Scharlach and Boyd, 1989).

Global versus multi-dimensional measures of burden. Clinical anecdotes provided by practitioners working with caregivers, as well as common sense, lead to an expectation that burden and depression in the caregiver vary with the type and severity of DAT patient problems and caregiver variables such as relationship to patient or competing role responsibilities. Yet these hypotheses are not supported by the results of the descriptive studies reviewed thus far. This may in part be due to the use of a global or cumulative burden score, and to some extent, a global depression score, which may be poorly correlated to specific patient and caregiver characteristics. Several subsequent researchers have developed multi-dimensional instruments for the burden concept. When specific dimensions of burden are assessed individually, correlates of burden have been more readily identified. For example, Montgomery, Gonyea, and Hooyman (1985) conceptualized burden as "objective"--which includes changes in amount of time, privacy, freedom, and vacations due to caregiving; and "subjective"--the deficits in emotional health, physical health, and relationships with family that result from caregiving. In their study of 80 family caregivers of frail elderly persons, the presence or absence of chore services was found to be unrelated to objective or subjective burden. Types of caregiving tasks performed were better predictors of objective burden than frequency of

caregiving tasks or length of time in the caregiving role. For example, personal care or body contact tasks were associated with higher objective burden, but unrelated to subjective burden. However, younger caregivers experienced more subjective burden. Results in this study may not generalize well because this sample was comprised of non-spouse caregivers, and their perceptions of burden associated with specific caregiving tasks may be different from those of a spouse. These findings suggest that there are two sets of correlates for the two types of burden, implying that there are different causes and consequences, and therefore different remedies for these two types of burden.

Poulshock and Deimling (1984) and Deimling and Bass (1986) hypothesized a model of "impacts of caregiving," which were specified as negative impact on family relationships, caregiver social activity restrictions, and caregiver depression (measured by the Zung Depression Scale). Burden was conceptualized as the caregiver's subjective experience of strain associated with particular elder impairments such as impaired social functioning, disruptive behavior, and impaired ADL functioning. Burden in their model was seen as antecedent to impact. Results from analyses of data collected from 614 caregivers of dementia patients suggest that disruptive behavior and impaired social functioning in the DAT patient have direct effects on family relationship, social activity, and depression in the caregiver. Cognitive incapacity in the DAT patient exerted indirect effects on family relationships, social activity and depression in the caregiver through the effects of disruptive behavior and impaired social functioning in the DAT patient, which were conceptualized as problems that occur as a result of DAT patient cognitive incapacity (Deimling & Bass, 1986). The authors found that ADL impairment and its associated burden

were highly correlated with restrictions in caregiver social activities; mental impairment and its associated burden were substantially correlated with negative impact on family relationships. Depression in the caregiver seemed to be related both to negative impact in family relationships and disruptive patient behaviors, such that depression could be viewed as an effect of caregiving, as in previous studies, or as an antecedent influence on the caregivers' perceptions of burden and the impact that caregiving has on their lives (Poulshock & Deimling, 1984). These two reports demonstrate the usefulness of looking at specific dimensions of patient problems as well as impacts of caregiving, rather than global and general measures of these variables, in order to identify relationships among these complex variables.

Similar to the approach taken by Poulshock and Deimling (1984), Kinney and Stephens (1989) conceptualized a "Caregiving Hassles" scale by asking 60 DAT caregivers to report how "hassled" they felt by caregiving demands related to basic ADL's, instrumental ADL's, cognitive impairment, behavioral disturbances, and social network restrictions. These caregiving hassles were related to impacts of caregiving by correlating these caregivers' responses with scales measuring social activity restrictions, negative family relationships, and a symptom checklist measuring anxiety, hostility, depression and somatization in the caregiver. Hassles related to basic ADL's and instrumental ADL's were unrelated to the measures of caregiver well-being, suggesting that ADL impairments are less stressful to the caregiver than cognitive impairments. Cognitive, behavioral, and social network hassles had a direct relationship to negative family relations, anxiety, and depression; cognitive and behavioral hassles had a direct association with hostility; while behavioral and social

network hassles had a direct link with somatization. Although the small sample size limits the interpretation of these data, results further illustrate the importance of specifying particular types of burden rather than a cumulative score in order to evaluate relationships among variables influencing burden.

Novak and Guest (1989), in a study of 107 caregivers of mentally impaired adults, constructed a 24 item multi-dimensional burden scale, called the Caregiver Burden Inventory, which measured the following five dimensions of caregiving: 1) time, that is, the burden due to restrictions on the caregiver's time, 2) developmental burden, or burden associated with feeling "off-time" developmentally, 3) physical burden, 4) social burden, and 5) emotional burden. Although this study did not make use of quantitative outcome measures of the caregiving situation, the authors did relate qualitative interview data from caregivers to their scale. Their results suggest that caregivers with the same total burden score have very different needs for interventions based on their subscale scores. For example, caregivers with the same total score may have different scores on the social subscale and the time subscale, which would imply different interventions. This study also illustrates a common problem in scale development in this literature: the use of factor analytic techniques without sample sizes that are adequate to ensure stability of the estimates of the factor structures produced.

In a study of 127 DAT caregivers, Kosberg, Cairl and Keller (1990) assessed variables associated with burden as measured by the Cost of Care Index (CCI). This instrument measures the following five dimensions of burden: personal and social restrictions, physical and emotional problems, economic costs, value investment in caregiving, and the perception of the care receiver as

a provocateur. Their analyses are somewhat problematic in that five regression analyses were run with 18 independent variables in each equation, which, with a sample size of 127, tends to make the slope estimates unstable. However, they found that the following variables predicted overall burden measured by the total score on the CCI: female caregiver, caregiver's self-reported mental and physical health problems, caregiver's score on the Short Psychiatric Evaluation Schedule (SPES), which is a measure of psychiatric symptoms, caregiver functional health problems, decreased tolerance for patient behavior, and behavioral impairment in the patient. However, different patterns emerge when the subscales are evaluated separately. For example, burden in terms of economic costs was predicted only by patient behavioral problems. Burden in terms of personal and social restriction was primarily predicted by living with the patient, poor caregiver mental and physical health, caregiver ADL impairments, and low tolerance for patient behavior. Burden in the provocateur dimension was primarily predicted by female caregiver, low tolerance for patient behaviors, and patient behavioral impairment. Burden in the health dimension was predicted primarily by the caregiver's self report of emotional and health problems; however, the outcome and predictor variables in this equation probably represent the same concept, since the dependent variable was physical and emotional problems in the caregiver. The value burden domain was weakly predicted by female caregiver and unemployment. Of interest is the fact that neither of the two measures representing formal and informal support were related to overall burden or to any one of the burden subscales.

Taken together, these studies imply that particular types of patient problems may have effects upon different dimensions of caregiver burden. ADL

impairments in the DAT patient may produce caregiver social activity restrictions, but have fewer deleterious effects on caregiver mental health than DAT patient cognitive impairment (Deimling & Bass, 1986; Poulshock & Deimling, 1984; Kinney & Stephens, 1989). Montgomery, Gonyea and Hooyman (1985) report caregiving tasks to be related to objective burden, but not subjective burden. DAT patient's cognitive and behavioral problems are associated with negative impact on family relationships and caregiver depression, burden and anxiety (Deimling & Bass, 1986; Poulshock & Deimling, 1984; Kinney & Stephens, 1989). Finally, Kosberg et al. (1990) found that caregiver personal and social restrictions were related to living with the DAT patient and having a low tolerance for DAT patient behavioral problems.

The results of these studies demonstrate the need for multi-dimensional measures of burden, in that specific patient and caregiver variables are associated with particular types of burden. Thus, multi-dimensional measures are important to use when the purpose of the research is to identify correlates of burden so that interventive approaches for particular types of burden can be devised or to specify further the complex relationships among patient and caregiver variables. Cumulative measures of burden are best used when the purpose of the research is to describe cumulative burden across dimensions or present a summary "distress" level. It is important to note that the development of multi-dimensional burden instruments is still in an early phase, and the instruments utilized in these studies need to be refined and tested in larger groups of subjects, with on-going attention to the construct validation of burden.

Depression as an outcome variable. Depression has been reported by several investigators as a negative effect of caregiving, particularly when the

care receiver has mental impairments, as is the case with DAT patients. Cohen and Eisdorfer (1988) report that 55% of their sample of 46 caregivers (primarily spouses) of DAT patients experienced clinical depression based on scores from the Beck Depression Inventory. Haley, Levine, Brown, Berry, and Hughes (1987) in a study of 44 caregivers of dementia patients and 44 matched non-caregiving controls report that the caregivers endorsed significantly more depressive symptoms on the Beck Depression Inventory compared to non-caregivers. A smaller percentage of depressed caregivers has been reported in previous studies; Coppel, Burton, Becker and Fiore (1985) report that 28% of their sample of 68 spouse caregivers of DAT patients met Research Diagnostic Criteria (RDC) for minor depression or intermittent depressive disorder while 25% met RDC criteria for a depressive disorder during an earlier phase of their relative's dementia. On the other hand, severity of the cognitive loss may be unrelated to caregiver depression in the same way that severity of patient symptoms has failed to correlate with caregiver burden. Pagel, Becker and Coppel (1985), reporting additional analyses from this same study of spouse caregivers of DAT patients, found severity of patient illness to be unrelated to caregiver depression.

Pruchno and Resch (1989) studied 262 spouse caregivers of DAT patients in order to evaluate the mental health effects of providing care for DAT patients with forgetful, asocial, and disoriented behaviors. The mental health outcome variables were comprised of depression, measured by the Center for Epidemiologic Studies Depression Index (CES-D), decreased social activity, a "consequences of caregiving" composite index which included social and emotional effects from caregiving, and a self-reported global rating of total

"burden." In terms of depression, the caregivers in this study reported moderate depressive symptoms, with a mean CES-D score of 17.2 which is in the low end of this scale (the range possible for the CES-D is 0-no depression to 60-severe depression).

These investigators report that asocial patient behaviors were associated with more depression, burden, consequences of caregiving and restrictions in social activities in the caregiver. Disoriented patient behaviors were associated with more burden, consequences of caregiving, and restrictions in social activities in the caregiver, but not with caregiver depression. Forgetful patient behaviors, however, showed curvilinear relationships in that caregivers experiencing either none/few or severe levels of forgetful patient behaviors show similar levels of stress, whereas in caregiving situations with moderate amounts of forgetful patient behaviors, there is an increase in caregiver stress. The authors interpret these results in terms of the progression of DAT, e.g., forgetful behaviors increase linearly as DAT progresses, resulting in the patient becoming passive, vegetative, and behaviorally more predictable, with caregiving demands revolving around providing for basic needs, which are assumed to be less stressful than caregiving for asocial and patient disoriented behaviors.

In a study of 318 caregiving dyads, Moritz, Kasl and Berkman (1989) investigated depressive symptoms and social functioning in spouse caregivers. This study is of interest in that the sample was comprised of equal numbers of men and women, rather than primarily women, as in previous studies. Furthermore, the care receivers had mental impairments ranging from minimal to severe, and the caregiver dyads were identified through a representative

survey. In contrast to other studies, women did not report higher levels of depression (measured by the CES-D), and there was a significant relationship detected between presence of cognitive impairment in the wife and depression in the caregiving husband (but not in the converse situation). The caregiving demands in terms of household responsibilities and amount of care receiver functional deficits did not account for the presence of depression, yet presence of financial problems was related to depression. Most of the scores on the CES-D reported in this study did not reach the level necessary for a diagnosis of major depression.

One problem in the use of depression scales as an outcome variable in the study of caregiving has to do with the validity of these scales in the caregiving context. The instruments most often used (CES-D, Zung Depression Scale, Beck Depression Inventory, SADS) do not include a way to adjust scores when depressive symptoms might be directly due to caregiving demands, and not indicative of psychopathology. For example, low energy and sleep disturbance might be due to caring for a DAT patient who is up several times during the night, rather than due to depression. Thus, the incidence of depression as a consequence of caregiving may be overestimated. Further, there is considerable agreement among experts in psychopathology that severe, chronic, or acute stressors are unlikely to precipitate a major depression except in persons predisposed to depression, as evidenced by a prior history of depression, and/or a family history that is positive for affective illness to the extent that genetic loading could be assumed (Hirschfeld, Klerman, Andreasen, Clayton, and Keller, 1985; Akiskal et al., 1979). Becker and Morrissey (1988) suggest that many of the depressive-like reactions reported in caregivers are

not due to the psychopathology of major depression but are instead a result of exposure to chronic stress.

Gallagher, Rose, Rivera, Lovett, and Thompson (1989) addressed the possible overestimation of depression in a study of 158 caregivers of frail elderly who were seeking help from a support group and 58 DAT caregivers who were not help-seekers. Depression was measured with the Schedule for Affective Disorders and Schizophrenia (SADS), a structured clinical interview used to classify psychiatric diagnoses within the Research Diagnostic Criteria (RDC). However, items that the caregiver attributed directly to the caregiving demands were excluded from the score. Although prevalence of depressive disorders in this sample was not compared to norms, it would appear that even with this adjustment, many depressive symptoms are experienced by caregivers. Within the help seeking group (which included caregivers of DAT patients and frail elderly), 26% met criteria for major depression, 18% had minor depression; 2% had intermittent depression; 22% had depressive features, while 32% reported an absence of depressive symptoms. In the non-help seeking group (comprised entirely of DAT caregivers) 10% experienced major depression; 8% had minor depression; 18% reported depressive features; and 64% reported the absence of depressive symptoms. These results suggest that non-help seeking DAT caregivers are far less likely to be depressed compared to help-seeking caregivers of frail elderly persons. In order to determine whether this finding was due to differences in caring for a DAT patient versus a patient with some other health problem, chi squares were computed comparing caregivers of non-cognitively impaired elders to DAT caregivers in terms of caregiver depression. No differences were detected, suggesting that differences in

caregiver depression were due to help-seekers asking for help, perhaps because they were feeling more stressed or depressed, and not a result of caring for a demented elder. This is an important finding because nearly all of the studies evaluating the negative effects of caregiving are comprised of "help-seekers," since research subjects were members of self-help or support groups for caregivers. Therefore, one cannot conclude that caregiving per se results in depression.

As a whole, although estimates vary, these studies do support a high incidence of depression in family caregivers, even when depression scores are adjusted for direct effects from caregiving that may be confounded with depressive symptoms (Gallagher et al., 1989). The findings reported by Gallagher et al. (1989) also suggest the high incidence of depressive disorders in caregivers may be a design effect in that caregivers in many studies are "help-seeking," and those caregivers who are seeking formal support may be experiencing more depression than non-help seeking caregivers. Similar to the studies looking at correlates of burden, the severity of DAT patient symptoms do not appear to be related to caregiver depression (Cohen & Eisdorfer, 1988; Coppel et al., 1985; Haley, Levine, Brown, Berry, & Hughes, 1987, Pruchno & Resch, 1989). However, Moritz et al. (1989) found that financial problems were associated with depression; Pruchno and Resch (1989) report that asocial DAT patient behaviors were associated with caregiver depression, while disoriented or forgetful DAT patient behaviors were not associated with depression in the caregiver.

A more precise definition of what researchers in this area mean by "depression" would help clarify the experience of family caregivers, and lead to

more appropriate treatments for their depressive symptoms. Are investigators identifying episodes of major depression? Some depressive symptoms being measured are likely the direct result of caregiving demands, and not neurophysiological changes due to major depression. Even when scores on depression scales are adjusted for the direct effects of caregiving demands, caregivers still appear to experience a significant number of depressive symptoms. The affective symptoms being measured, however, may also be the result of exposure to the chronic stress of caregiving. Little is known about the effects of exposure to chronic stress, and how they may be similar to or different from mood disorders. The suggestion made by Becker and Morrissey (1988), that the experience of caring for a relative with DAT is a paradigm for the study of exposure to chronic stress, would be a useful approach to adopt.

Caregivers of non-demented elders. An intuitive assumption often made by gerontologists is that caring for a mentally impaired elder is somehow more emotionally detrimental than caring for a person with other types of impairments. The descriptive studies reviewed thus far have focused primarily on the care of DAT patients. Exceptions to this are Barusch and Spaid (1989), whose results suggest that higher burden scores are associated with caring for patients experiencing more memory and behavior problems, and Gallagher et al. (1989), whose results do not support this assumption. Although there is a body of knowledge describing the effects of caring for a family member with a chronic mental disorder such as schizophrenia, most of the literature describing caregiving has focused primarily on caring for patients with dementia, and few studies have described the impact on the caregiver of caring for patients with stroke, hip fractures, heart disease, or cancer. In a literature review of stroke

caregivers, Silliman and Sternberg (1988) found reported rates of anxiety and depression in caregivers of stroke patients to be approximately 11-12%, which is considerably less than what is reported for caregivers of DAT patients.

Although stroke patients often have mental deficits, these sometimes improve in the first year post-stroke and are generally not progressive. However, stroke patients often have sensory-motor impairments and may have more needs for physical assistance than persons with DAT. A valid question is whether the lower rates of anxiety and depression in stroke caregivers might be due to providing physical assistance, rather than supervision for memory impairment.

In a survey of 89 stroke caregivers, Silliman, Fletcher, Earp, and Wagner (1986) report that roughly one quarter of caregivers noted deteriorating physical health in the first year of caregiving and 40% scored in the "ill" range on the General Health Questionnaire, an instrument designed for screening emotional ill-health. The prevalence of scores in the "ill" range in this sample is nearly twice the prevalence rate reported in community samples. These findings suggest that the care receiver's needs for physical assistance might be closely related to caregiver physical illness, and contrary to the Silliman and Sternberg (1988) literature review, stroke caregivers may also be experiencing significant emotional distress. Silliman et al. (1986) found that increased functional dependency in patients was associated with decreased caregiver social activities and increased emotional ill health, whereas none of the patient or caregiver variables were associated with the caregiver's general perception of ill health. They also compared home caregivers to "potential caregivers," defined as relatives of stroke patients placed into nursing homes, and found no

significant differences between these two groups. These latter findings are consistent with studies describing DAT caregivers.

Young and Kahana (1989) interviewed 183 family caregivers of heart attack patients, six weeks after hospital discharge. These caregivers were experiencing considerable deleterious effects on their health, mental health, and social activities, yet objective aspects of the caregiving effort were unrelated to burden, measured by the Burden Interview. Although spouse caregivers and children caregivers experienced similar caregiving demands, child caregivers reported significantly more burden and role conflict. Female caregivers, who comprised 80% of the sample, reported more burden, poor physical health, and psychiatric symptoms than their male counterparts. When caregiving effort and caregiving effects were assessed by relationship to the patient, there was a trend toward greater caregiving effort by wives and daughters. In terms of specific caregiving tasks, wives and daughters performed more cooking and laundry, husbands performed more handiwork, and daughters provided more transportation. There were no sons in this sample. Although the negative effects of caregiving were significantly greater among the daughters and wives, more severe effects were reported by daughters. The results of this study of cardiac patient caregivers is consistent with the literature describing the effects of caring for a patient with DAT, and do not support the assumption that more burden results from caring for a family member with mental impairment.

In an exploratory study, Liptzin, Grob and Eisen (1988) compared 11 family caregivers of dementia patients to 27 family caregivers of patients with depression on the Burden Interview and the Memory and Behavior Problems Checklist. All of the patients were disturbed enough to require in-patient

psychiatric hospitalization and did not differ in their socio-demographic characteristics. The authors found no differences in burden between caregivers of dementia or depressed patients, either at the time of admission to the hospital or four months after discharge. Despite improvement in the depressed patients, there was no reduction in their caregivers' burden scores. Although these results must be interpreted with caution because of the small sample size, they do suggest that caregivers of depressed patients experience as much burden as DAT caregivers. Similarly, Gallagher et al. (1989) found no difference in caregiver depressive symptoms when comparing dementia caregivers to caregivers of frail elderly persons. Taken together, the results from the work of Silliman et al. (1986), Young and Kahana (1989) and Liptzin et al. (1988) suggest that in terms of cumulative measures of strain and burden, caregivers of non-demented elders experience similar levels of burden compared with DAT caregivers. However, there is a need for more studies examining caregiving in non-dementing chronic conditions as well as studies comparing the effects of caregiving across different chronic conditions.

Studies Comparing Caregivers to "Normals"

Although the descriptive studies reviewed provide convincing data about the experience of caregivers, the negative outcomes described cannot be attributed solely to caregiving unless comparisons are made to non-caregiving groups. Studies comparing caregivers to non-caregivers are important to conduct, particularly if one wants to argue for special programs and social policies geared towards helping caregivers. Therefore, measures of well-being

that can be compared to normal populations must be used, instead of measures of caregiver burden. Although only three studies to date have made use of normal comparisons while assessing the effects of caregiving, the results of those studies provide very strong evidence of the detrimental effects of caregiving and are consistent with the descriptive studies. Haley, Levine, Brown, Berry and Hughes (1987) compared 44 DAT caregivers with 44 matched non-caregiving controls on several psychological, health and social outcome variables. Even in this small sample, several significant differences were detected. Caregivers reported significantly more depression (measured by the Beck Depression Inventory), lower life satisfaction, more negative family relationships, less social network satisfaction, more restricted activities with friends, less church attendance, fewer planned vacations, worse self-rated health with more chronic conditions, more prescription drug use, and more recent visits to their physician.

George and Gwyther (1986) surveyed 510 DAT caregivers in order to gather information about the caregiving situations, patient illness, and caregiver well-being, measured with instruments representing health, psychiatric symptoms, income, social participation, and satisfaction with social participation. Normative data were available on all these well-being measures with the exception of the satisfaction with social participation measure. Contrary to what would be expected, results suggest that caregivers are no different from other populations in their physical health. In contrast to other studies describing financial burden, these caregivers were actually better off than other populations. However, the mental health indicators showed that these caregivers used more psychotropic drugs and had three times the amount of

stress symptoms of other populations, suggesting that deficits in mental health indicators may be the result of caregiving. Caregivers also reported significantly fewer social activities compared to other populations. Further, lower levels of caregiver well-being were associated with being the spouse of the patient, and persisted after controlling for age. Patient characteristics were found to be unrelated to caregiver well-being, suggesting that it is the context of the caregiving situation and not objective aspects of the patient's condition that influence negative effects from caregiving.

A similar design was used by Anthony-Bergstone, Zarit and Gatz (1988) in a study of 184 DAT caregivers. Nine subscales of the Brief Symptom Inventory (BSI) were examined for these caregivers, who were then divided into groups on the basis of age and gender so that their scores could be compared to aged-matched norms. Older female caregivers had significantly more obsessive-compulsive symptoms, depression, anxiety, hostility and psychoticism than other populations. Older male caregivers, in contrast, had only one significant difference in that they reported more hostility than other populations. Younger female caregivers reported significantly more anxiety, hostility and obsessive-compulsive symptoms than other populations, whereas younger male caregivers were not significantly different than other populations. These results suggest that older women caregivers are at highest risk for deleterious effects from caregiving. However, when older women were categorized by relationship to DAT patient, and then compared to other caregivers, they were no longer significantly more impaired on the BSI, but the directions of the differences suggested that wife caregivers were more impaired.

Consistent with other reports, caregiver scores on the BSI were unrelated to DAT patient symptoms.

The results from these three studies are consistent and serve to validate clinical anecdotes from practitioners about the stress that caregivers experience as well as the results from the descriptive studies reviewed. Caregivers clearly suffer more mental health and life satisfaction deficits compared to non-caregiving controls (Anthony-Bergstone et al., 1988; George and Gwyther, 1986; Haley, Levine, Brown, Berry and Hughes, 1987). These deficits appear to be unrelated to DAT patient symptoms. Of note are the findings reported by George and Gwyther (1986) indicating that caregivers in their study were no different from non-caregivers in terms of their physical health, and reported higher incomes than non-caregivers. This finding could be a result of sampling and geographic location, and may not generalize.

Summary

The literature describing negative effects from caregiving and relationships among patient and caregiver variables suffers from several limitations. First, samples are often small and comprised of primarily white middle class persons. The small sample sizes may make estimates of depression and burden unstable. Further, sociodemographic variables may influence perceptions of the caregiving experience in ways that cannot be determined from studies of middle class caregivers. Little is known about how caregiving is experienced by ethnic or racial minorities and because the current measures of caregiver burden have been developed and tested primarily in samples of Caucasians, they may not be valid for use with racial or ethnic minorities. Caregiver research

subjects are mostly obtained through self-help and support groups for caregivers, such as the Alzheimer's Disease and Related Disorders Association (ADRC). Thus, research subjects are "help-seekers," and may be different in terms of burden, depression, and strain from caregivers who are not actively seeking help or support. The findings reported by Gallagher et al. (1989) suggest that help-seeking caregivers may experience more depression compared to those who are not. Samples often include several levels of caregiver, in that "caregiver" has been broadly defined to include persons who live with the patient as well as caregivers whose relatives live in nursing homes or other institutions. Samples are also comprised of larger proportions of women than men, which may produce results suggestive of higher rates of depression and burden in female caregivers. Outcome variables such as burden and depression warrant further definition and refinement. Cumulative burden may not be the best type of measure when evaluating correlates of burden; global measures of depression, if not adjusted for direct effects of caregiving demands, may tend to overestimate major depression in caregiver samples.

Despite these limitations, descriptive studies provide convincing data describing the negative effects of caregiving, particularly in terms of cumulative burden and depression. These results are replicated in the studies comparing caregivers to non-caregivers. Cumulative burden, and to some extent depression, appear unrelated to patient characteristics or objective demands of the caregiving situation. Different patterns emerge when particular dimensions of burden are evaluated separately. For example, decreased caregiver social activity appears to be linked to the care receiver's needs for functional

assistance. There is little evidence that the presence of social support influences cumulative burden. There is some evidence that women experience more cumulative burden and depression, but it is not clear which women are at higher risk: older women, wives, or daughters. Although it has been suggested that caring for a mentally impaired elder engenders more burden, the studies reviewed that are pertinent to this question do not support this hypothesis.

Given that there are negative mental health effects such as depression and burden from caregiving, what do these symptoms and mood states represent? Are caregivers suffering from formal psychiatric disorders, transient stress symptoms, or distress due to caregiving as a normative life experience? Little is known about normative and maladaptive responses to chronic stress. The literature pertaining to coping and adaptation has focused primarily on acute stressors and normative life strains (Pearlin and Schooler, 1978; Folkman and Lazarus, 1980; Billings and Moos, 1981). In terms of coping with the chronic stress inherent in the caregiving experience, it is not known what comprises normal, maladaptive, or pathological responses. This is an important area to study, since different caregiver responses to the chronic stress of caregiving may require different interventive strategies. For example, for those caregivers experiencing normal distress, informal support may be all that is required; those experiencing maladaptive responses might require formal support and education programs; and those caregivers experiencing pathological responses would likely require help from psychiatric-mental health specialists. The caregiving experience might best be studied as a paradigm for the study of exposure to chronic stress.

Coping in DAT Caregivers

In contrast to the large body of literature describing the negative outcomes associated with caregiving, relatively few studies have been conducted that describe the coping repertoires of caregivers or their mediating functions. As report after report found no relationship between negative outcomes such as burden and the objective aspects of the caregiving situation, mediating variables such as coping and social support were suggested as potential modifiers of caregiver burden or depression. At about the same time and despite the limited knowledge base relating to caregiver coping, support and education groups emphasizing caregiver coping became a widely used intervention for caregivers of DAT patients. Thus, although the size of this literature is small at present, it will expand as research into the caregiving experience evolves.

A brief restatement of the conceptual framework underlying this study and the results from the larger bodies of literature pertaining to coping and aging, gender differences in coping, coping with chronic illness and religious coping will help focus the review of the caregiver coping literature. First, the person-environment interaction model of coping predicts that the situational characteristics of the caregiving context, and the caregiver's appraisal of the stressful caregiving events will be the primary determinants of caregiver coping responses (Lazarus et al., 1966, 1974, 1978; Folkman & Lazarus, 1980; Pearlin & Schooler, 1978; Billings & Moos, 1981). Thus, caregivers coping with DAT patient problems that are not amenable to problem-solving will likely cope with emotion-focused responses or passive responses such as acceptance or cognitive restructuring. The individual caregiver's coping resources will also

interact to influence coping. For example, caregivers who are experiencing poor health may have fewer coping resources, and may be more vulnerable to the deleterious effects of caregiving (Okun et al., 1990; Elwell & Maltbie-Crannel, 1981). The broader coping literature suggests that coping with emotion-focused responses and passive cognitive coping may engender depression, while problem-focused coping may promote well-being (Billings & Moos, 1981, 1984; Folkman et al, 1987; Pearlin & Schooler, 1978).

Results from the broader coping literature suggest that caregivers, who are primarily older women, will cope in diverse ways, but may evidence slightly more passive coping styles, such as cognitive restructuring and acceptance, and less of the emotion-focused coping responses of hostility or aggression (McCrae, 1982, 1989; Irion & Blanchard-Fields, 1987; Pearlin and Schooler, 1978; Folkman et al., 1987). Women caregivers may report more emotion-focused coping compared to their male counterparts (Billings & Moos, 1981, 1984; Pearlin & Schooler, 1978). Similar to adaptation to other chronic diseases, the process of adaptation by caregivers to DAT may initially involve mostly emotion-focused coping responses, which progress over time to more problem-focused and behavioral coping responses (Hamburg et al., 1953; Visotsky et al., 1962; Streitzer et al., 1983-84; Baldree et al, 1982). Finally, caregivers of DAT patients may be using more religious coping, in part because they are primarily older women who may already have high religious involvement (Blazer & Palmore, 1976; Kivett, 1979). Also, if DAT in a loved one is experienced by the caregiver as a loss, more religious coping responses might ensue (McCrae, 1989).

Pratt, Schmall, Wright and Cleland (1985) studied 240 DAT caregivers and described their coping strategies in relation to burden, measured by Zarit's Burden Interview. In this study, coping was conceptualized as occurring in the context of the family and larger social environment and was measured by the F-COPES scale which describes eight coping strategies: three internal strategies (cognitive reframing, confidence in problem-solving, and passivity or avoidance) and five external strategies reflecting the use of social resources (spiritual support, extended family support, support from friends, neighbors, and community services). The caregivers in this sample were primarily female (78%), their average age was 61 years, the average length of time caregiving was four years, 61% were members of Alzheimer's disease support groups, and 62% of the DAT patients resided in the community while 38% were institutionalized. Results suggest that not all types of social support are helpful in terms of reducing burden; only spiritual support and extended family support were correlated with decreased burden. The coping responses "confidence in problem solving" and cognitive reframing were associated with decreased burden as well. Consistent with the coping literature, passivity or avoidance coping was related to increased burden. Of interest is the relationship of poor caregiver health to coping. For both caregivers of home DAT patients and institutionalized DAT patients, and controlling for the effect of age, caregivers who reported their current health status to be poor had significantly higher passivity scores than those caregivers who reported their health as fair to excellent. This finding supports the notion that health may operate as a coping resource and therefore is a variable that should be evaluated in assessing

caregiver coping. There were no other differences on coping scores (Pratt, Wright, and Schmall, 1987).

Coppel et al. (1985) focused specifically on cognitive coping and its relationship to depression in 68 spouse caregivers of DAT patients. The purpose of this study was to test the reformulated learned helplessness theory of depression. Therefore, cognitive coping was comprised of the caregivers' attribution-related cognitions concerning two situations: 1) an unpredictable upsetting behavior by the DAT patient and 2) significant life change experienced by the caregiver as a result of his/her spouse's DAT. These coping responses were then correlated with the Beck Depression Inventory. The caregivers were comprised of 43 women and 25 men, ages 37 to 85, referred to the study through physicians, medical clinics, and the local Alzheimer's support group. Twenty-one of the DAT patients were nursing home residents while 47 lived at home with their spouse. No significant differences in demographics, coping responses or depression were detected between caregivers with spouses at home and those with institutionalized spouses.

In this study, the following types of cognitions (what the caregiver told his/herself in order to cope) about unpredictable DAT patient behavior were related to increased depression: important to handle successfully, upset about behavior, unprepared for behavior, and no control over DAT patient behavior. These results are consistent with the coping literature in that cognitions emphasizing emotion (upset) and uncontrollability are likely to be linked to increased depression. The cognition relating to the importance of handling the situation successfully may represent the importance of the event to the caregiver as well as the perception of the event as a threat or challenge. If the

situation is perceived as a threat, unsuccessful coping may produce depressive symptoms. Coppel et al., (1985) suggest that in order for a depressive reaction to ensue, an event must be appraised as important and aversive. Cognitive coping with life change as a result of caring for the DAT patient produced a slightly different pattern. The following coping cognitions were related to increased depression: upset about life events, unsuccessful in coping now, dissatisfied with coping now, and will cope poorly in future. Even though this study cannot address the direction of these relationships in terms of causality, the theory being tested assumes that the cognitions produce the depression. All of these cognitions could be considered negative or depressogenic, and could be produced and maintained by the caregiver's depression, rather than the other way around. Nevertheless, these results are similar to what is reported in the coping literature.

In another study of what can be conceptualized as cognitive coping, the relationship between self-efficacy and caregiver depression, morale and stress was assessed in 107 caregivers of disabled elderly persons (Zeiss, Gallagher, Lovett, & Rose, 1987; Lovett & Gallagher, 1988). Self-efficacy is defined as the personal judgment that one is capable of performing a specific behavior because one has the requisite skills, talents or physical capacity; it is the specific self-expectations about one's ability to perform (Bandura, 1977, 1982). As originally conceptualized, self-efficacy determines whether coping behaviors will be initiated, how much effort will be expended, and how long they will be sustained in the face of an aversive experience. Self-efficacy as used in this study is similar to the cognitive coping studied by Coppel et al., (1985). Self-efficacy was measured specific to the caregiver's perception of ability to use a

systematic problem solving strategy when confronted with DAT patient problems, and in this way is similar to the caregiver's expectation of success in problem solving coping. Caregiver outcomes were as follows: depression measured by the Beck Depression Inventory (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), morale measured by the Philadelphia Geriatric Center Morale Scale (Lawton, 1975), and psychological stress measured by the Perceived Stress Scale (Cohen, Kamarck and Mermelstein, 1983). The primary purpose of this study was to evaluate the effectiveness of psychoeducational group interventions for caregivers, and the self-efficacy data were reported as part of the pre-intervention data analysis.

The caregivers in this study were predominantly women (83%) who were caring for an impaired spouse (55%) or older parent/parent-in-law (41%). The average caregiver age was 59.3 years; the average amount of education was 14 years, and the median length of time in the caregiver role was 30 months. The caregivers were referred to the research project through adult daycare, day health, or overnight respite programs. The average patient age was 73 years and 40% suffered from a dementing illness. The investigators found high scores on problem solving self-efficacy to be associated with high levels of morale and low levels of depression. Problem solving self-efficacy scores tended to be lower among those caregivers with higher perceived stress. These results suggest that expectation to succeed in problem solving, or positive cognitive coping is linked to positive well-being in caregivers.

Wright, Lund, Pratt and Caserta (1987) described coping in 597 middle-class caregivers of community dwelling DAT patients. These caregivers were primarily women (73%) who were caring for spouses (57%) or an older parent

(27%). The average caregiver age was 60; the average time in the caregiving role was four years, and half of these caregivers reported caring for the DAT patient at least 16 hours per day. All of the caregivers were approached to participate in this study through mailing lists of Alzheimer's support and self-help groups. Coping was measured by the Jalowiec Coping Scale, which produces four coping subscales: problem-solving coping, avoidant-evasive coping, regressive coping, and support-related coping (Jalowiec, Murphy, & Powers, 1984). In this caregiver sample, however, this coping scale produced a somewhat different factor structure, again producing four subscales of coping, but rather than a support-related coping subscale, a reframing coping subscale was identified. These ways of coping were used to predict burden measured by the Burden Interview (Zarit et al., 1980) and life satisfaction measured by the Life Satisfaction Index-Z (Wood, Wylie, & Sheafor, 1969).

The findings reported by Wright et al. (1987) are quite consistent with what would be expected from the coping literature. Regressive coping predicted higher burden scores and lower life satisfaction. Problem-focused coping predicted higher life satisfaction, as did reframing coping. Avoidant-evasive coping predicted higher burden and lower life satisfaction, and was by far the most important predictor. In the avoidant-evasive subscale, many of the items are similar to items related to emotion-focused coping, e.g., worry, expect the worst, get nervous, or resign/hopeless. Particularly noteworthy, are the top ten coping responses ranked by the caregivers in order of frequency of use. All of them, with the exception of one, represent problem-focused coping responses. Thus, despite the frequency with which problem solving coping was used by the caregivers, burden was not lowered, suggesting that a feeling of controllability

or active manipulation of the situation does not always result in decreased stress. These findings also imply that counseling caregivers by exploring alternatives to the use of avoidant-evasive coping may be of help in reducing burden.

Myers and Pruchno (1987) studied the coping responses of 315 spouse caregivers of community dwelling DAT patients. These caregivers were selected through support groups, churches, and hospitals. The sample was 67% female, with an average age of 70 years, and had been caregiving for an average of 2.9 years. Coping was measured using the 34-item version of the coping instrument developed by Kiyak, Montgomery, Borson and Teri (1985), which is conceptually linked to Lazarus and Folkman (1984) and Pearlin and Schooler (1978), and produces four coping subscales: problem-focused, emotion-focused, acceptance and intrapsychic coping. First, the investigators explored the relationships among ways of coping, caregiver characteristics such as age, gender and health, and "demand" characteristics of the caregiving situation such as burden (the authors do not report how this was measured), time in caregiver role, and degree of aberrant, forgetful, socially inappropriate, and psychotic behaviors exhibited by the DAT patient. Several interesting patterns emerge. Emotion-focused coping was used more often by younger women, caregivers with self-reported poorer health, caregivers experiencing more burden, caregivers in the caregiving role less than one year, and caregivers coping with socially inappropriate patient behaviors. Problem-focused coping was used more often by younger caregivers, and caregivers coping with forgetful DAT patient behaviors. Acceptance coping was more likely to be used by male caregivers, caregivers experiencing less burden, and

caregivers in the caregiver role for less than one year. Younger caregivers, those experiencing poorer health, caregivers with higher levels of burden, and caregivers coping with forgetful DAT patient behaviors used more intrapsychic coping. It is interesting to note that younger caregiver age predicted three of the four types of coping responses. These findings suggest that adaptation to the caregiver role and to a spouse with DAT may initially engender more emotion-focused and acceptance coping. The impact of poor physical health in the caregiver on coping is also consistent with previous studies.

In order to link their coping variables, caregiver characteristics, and demand characteristics of the caregiving situation to mental health outcomes, Myers and Pruchno (1987) used regression analysis to predict depression as measured by the CES-D and "positive affect" as measured by the Positive Affect Balance scale onto these variables. Poor caregiver health, forgetful and socially inappropriate DAT patient behaviors, emotion-focused coping, and intrapsychic coping predicted depression in these caregivers. Female gender and the use of problem-focused coping predicted positive affect. This is in contrast to previously reviewed studies which found women to be more depressed (Fitting et al., 1986; Young & Kahana, 1989). Consistent with the person-environment interaction model of coping, these findings suggest that coping strategies vary with both characteristics of the caregiver and characteristics of the particular caregiving situation. Again, as with most other studies of caregiver coping, assumptions about causal directions must be made with caution. It is possible that coping styles predict levels of depression and that certain styles of coping can lead to greater dysfunction than others, or that levels of depression predict styles of coping. An even more feasible explanation, particularly given the

interactive nature of coping processes, is that ineffective coping may lead to poor mental health outcomes, which in turn lead to even less effective modes of coping.

Quayhagen and Quayhagen (1988) described the coping responses and well-being of 58 caregivers of DAT patients and compared husbands, wives, and daughters. In this study, coping was conceptualized in accordance with the work of Pearlin and Schooler (1978). A coping inventory developed by the authors measured six ways of coping, categorized by the functions they are intended to serve. Problem solving coping and help seeking coping function to modify the stressful situation. Existential growth (composed of cognitive restructuring) and minimizing threat through diversionary activities function to control the meaning of the situation. Coping through fantasy and self-blame function to alter the stress experienced because of the situation. Well-being was measured with the Life Satisfaction Index-Z, and global self-rated physical health and emotional health (poor to excellent). These three measures were combined to form a composite score representing well-being. The authors also measured stress associated with DAT patient problems with the Memory and Behavior Problems Checklist, which produces a score representing the amount of stress the caregiver feels in relation to specific DAT patient problems.

This sample was drawn from members of Alzheimer's self-help groups and was comprised of 17 husbands, 26 wives and 15 daughters. As could be expected, the group of daughters were younger in age than the spouses, by an average of 12 years. There were no differences among these three caregiver groups in terms of years of education (average 13.9), years of DAT patient memory loss (average 6.9), or scores on the frequency of problem patient

behaviors measured by the Memory and Behavior Problems Checklist (average score 73.4). Results of this study are consistent with the larger coping literature. For the total caregiver group, help seeking and existential growth coping were associated with higher well-being, while coping through fantasy and self-blame was associated with lower well-being. Caregiver stress was higher in caregivers coping with self-blame.

However, when coping responses were correlated with well-being by caregiver group, slightly different patterns emerge and because these are small groups, the correlation coefficients may be less stable. For caregiving husbands, coping through fantasy and self-blame was associated with lower well-being. For caregiving wives, coping through problem solving, help seeking, and existential growth correlated with higher well-being. Caregiving daughters who coped through fantasy had lower well-being. Contrary to what might be expected in terms of gender differences in coping, no differences were detected in the coping responses used by the different caregiver groups. Further, the three groups of caregivers did not differ in terms of the well-being measure. Again, this is contrary to what might be expected based on the literature describing the negative effects of caregiving. These results might be explained by inadequate statistical power to detect differences in well-being or ways of coping.

Barusch and Spaid (1989) in their study of 131 caregivers of disabled elderly persons, used a different method of assessing caregiver coping. Caregivers were asked if they had encountered specific problem situations and if they had, were asked to describe how they had coped. Coping effectiveness was conceptualized somewhat narrowly in that it was defined as solving the

problem, and not in terms of decreasing the caregiver's perception of stress. The caregiver's descriptive comments were coded into Lazarus & Folkman's (1984) taxonomy of ways of coping and described by the following categories: inhibition of action, information seeking, partial action to manage the situation, cognitive restructuring, seeking help to change the situation, and doing something alone to change the situation. The primary purpose of this study was to assess gender differences in burden, measured by the Burden Interview, coping responses and coping effectiveness.

The caregivers in this study were recruited from a variety of community sources and fit the expected demographic picture as they were primarily female (70%), the average caregiver age was 69 years, they were middle to lower class, and their average length of time in the caregiving role was 66 months. The care receivers had an average age of 71 years and roughly half of these patients suffered from dementia while the rest had stroke, lung disease, and general frailty. The results reported by Barusch and Spaid (1989) are consistent with the reports found in the coping literature relating to gender differences in that it is not clear that there are specific gender differences in coping. Overall, there were no differences found between men and women in the types of coping responses used. However, women tended to use more diverse types of coping compared to men. When men and women were compared as to how they coped with the same stressful situation, some gender differences emerged. When caregivers were coping with feeling angry, having arguments with one's spouse, or worrying about future finances, women tended to perceive their coping as ineffective, whereas men either took action to change the situation or used cognitive restructuring to reduce its negative impact. Only one gender

difference was detected in ratings of global coping effectiveness: when coping with the interpersonal relationship with one's spouse, men reported coping more effectively than women. A model predicting caregiver burden was developed as part of this study. The measure of coping effectiveness was included in a regression equation predicting caregiver burden, but with a significance level of just $p = .10$.

The studies reviewed thus far have, with the exception of Lovett et al. (1987) and Barusch and Spaid (1989) focused specifically on caregivers of DAT patients. Two additional studies merit a brief review, in that they assess caregiver coping with two different disablements: stroke and heart attack. These reports are relevant because coping responses may vary as a result of adaptation to different symptoms or illness states. Stephens, Norris, Kinney, Ritchie and Grotz (1988) studied the coping of 58 family caregivers of patients recently discharged from an in-patient setting after treatment for stroke. Coping was measured with the revised Ways of Coping Checklist (Lazarus and Folkman, 1984); caregiver well-being was represented by the Bradburn Affect Balance Scale (Bradburn, 1966), which produces measures of positive and negative affect. After controlling for the effects of the patient's impairment level, analyses indicated that caregivers using more escape-avoidance coping had more negative affect while caregivers using positive reappraisal, which involves redefining the event to derive inspiration or personal growth, reported more positive affect. Younger caregivers, many of whom were women, used more avoidance coping strategies. These findings are similar to what is reported in the DAT caregiver coping literature.

in an exploratory field study, Nyamathi (1987) described the coping responses of 40 wives of patients with myocardial infarction over the course of one year. Coping responses at three points in time were assessed: during hospitalization, the first month after hospital discharge, and five weeks to one year after hospital discharge. Coping responses were described after the work of Lazarus and Folkman (1984) as behavioral, cognitive, or intrapsychic. Differences in coping mechanisms used during the acute and convalescent phases of illness were noted. During the acute period, wives used illness-focused assessment, controlling/taking charge, physical and emotional help-seeking, and avoidance strategies to prevent or reduce their stress. These coping strategies are primarily cognitive and behavioral. During the convalescence, the coping responses changed toward monitoring and controlling their partner's activities, which are primarily behavioral coping responses. Seeking emotional support and coping through denial or avoidance were greatly reduced. These findings are similar to what is reported about how patients adapt to chronic illness, in that as adaptation proceeds, there is less denial/avoidance, and more active behavioral coping.

In summary, the studies of caregiver coping reviewed support the findings from the broader coping literature. Generally, use of the following coping strategies is associated with more negative caregiver outcomes such as depression and deficits in well-being: escape/avoidance coping, emotion-focused coping, passive/avoidant coping and regressive coping. Problem solving coping is associated with well-being in caregivers, but does not result in less burden. It is unclear what effect caregiver relationship to the patient has upon coping and outcome. Contrary to what would be expected based on the

situation specific nature of coping, it does not appear that there are differences in coping responses of home care DAT caregivers versus those caregivers whose relative is in a nursing home. Along these same lines, the results of a study of coping in stroke caregivers were very similar to the DAT caregiver studies. Finally, caregiver poor health emerges as an important variable affecting both coping responses and negative caregiver outcomes.

The results from these studies must be interpreted in view of their limitations. First, sampling and subject selection are problematic in that many of the subjects are drawn from self-help groups, and are already engaged in a process of coping by "help-seeking." Also, many family caregivers and DAT patients consent to participate in research projects as a way of giving meaning to their suffering, and this behavior could be considered a form of cognitive reframing or behavioral coping. Like the literature describing the negative effects from caregiving, subjects in these studies are mostly Caucasian, and samples lack significant minority representation. Thus, samples may be biased towards white caregivers and caregivers who are already using specific coping strategies such as help-seeking, information seeking, and cognitive reframing. Interventions designed for caregivers that are based on this literature may not be effective for non-help seekers or racial and ethnic minorities. Although many of the studies cited have large sample sizes, the studies evaluating differences in coping and outcome by relationship to the patient, or gender, had smaller samples and may not have had adequate statistical power to detect differences.

An additional design problem is the multiple ways used to label and measure coping responses. For example, Zeiss et al. (1987) used self-efficacy which could be considered a form of cognitive coping or cognitive reframing;

passive/avoidance coping may be similar to intrapsychic coping; Coppel et al.'s (1985) cognitive coping contains items similar to emotion-focused coping and cognitive reframing. Thus, it is important to review items on subscales that describe ways of coping so that comparisons may be made across studies and results can be synthesized. Most studies make use of multivariate correlational or regression analyses. Although these techniques cannot address the temporal order of the variables, the theories underlying these studies assume that particular stressful events evoke specific coping which mediates the impact of the stress. When well-being or depression are the outcome variables, it is just as likely that those outcomes maintain or produce certain types of coping. And similar to the literature on negative effects from coping, a global measure of burden may be too general and may not correlate with ways of coping.

A Model of Caregiver Stress and Coping

The relationships among DAT patient characteristics, caregiver characteristics and caregiver coping resources, caregiver coping responses, and negative caregiver outcomes need further clarification. This will be a complex process because these are not well-defined and clearly operationalized variables, and they probably exert interactional and feedback effects. These effects may occur either at the categorical level of variable, or within each variable set. Although the study of caregiver coping is in an early stage, a model of caregiver stress and coping can be suggested, based upon this small and emerging body of knowledge. Figure 4.1 illustrates the components of such a model of caregiver stress and coping. DAT patient characteristics include cognitive function, ADL function or need for assistance,

behavioral problems or need for supervision, pattern of decline, e.g., rapid versus slow, the presence of co-morbid health conditions, and residence (community versus institution). These DAT patient characteristics produce caregiver coping responses, which are described in this model as problem-focused, emotion-focused, acceptance, and religious coping. Although unidirectional in this model, it is possible that particular caregiver coping may have feedback effects which further influence DAT patient characteristics. For example, coping with problem solving may alter the DAT patient's need for assistance if the caregiver finds solutions to managing functional health problems experienced by the DAT patient. The DAT patient characteristics may also exert direct effects on negative caregiver outcomes. The literature supports such relationships when specific and multi-dimensional measures of caregiver burden are used, but not when burden is conceptualized and measured as global and cumulative. Therefore, the term "burden" is not included as a negative caregiver outcome in this proposed model.

Although support in the literature is limited, caregiver coping may be affected by the following caregiver characteristics and coping resources as shown in Figure 4.1: gender, age, health, relationship to patient, length of time in caregiving role, meaning of and values pertaining to caregiving, and the presence of and satisfaction with social support. These relationships are proposed, despite weak and sometimes conflicting support in the literature, because there is a possibility that results have been limited by research methodology that have led to type II errors. Age is included as a factor with potential effects on coping, but these effects are likely produced indirectly

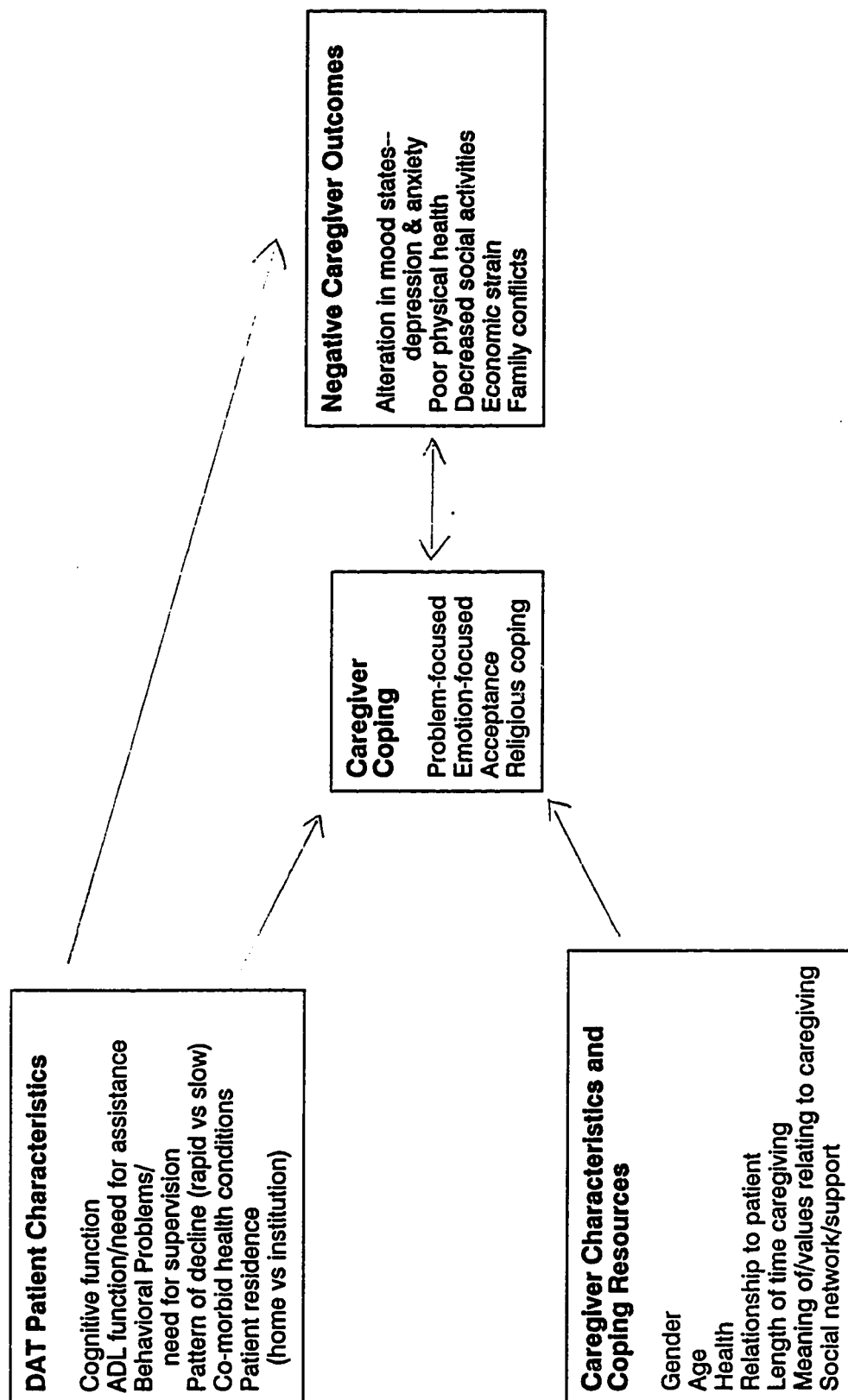


Figure 4.1 Components of a Model of Caregiver Stress and Coping

through the variables health and social support. Caregiver health and social support are variables with empirical support in the literature as potential modifiers of coping. Again, even though a unidirectional influence is specified in this model, particular coping responses may have feedback effects on caregiver coping resources. For example, the use of religious coping might alter the meaning of the caregiving experience. The use of problem-focused coping might influence the presence of social support, e.g., support and education group attendance. Finally, there would be mutual influences between caregiver coping and the following negative caregiver outcomes: alterations in mood states such as anxiety and depression, poor physical health, decreased social activity, economic strain, and family conflicts.

Further studies about the complex relationships among these variables are needed to clarify and refine this model. Large sample studies with adequate statistical power to test this model through path analysis or structural equation modeling are recommended. Additionally, studies of these potential relationships utilizing qualitative designs may help to describe further the processes involved in caregiver coping and suggest new variables to represent outcomes of caregiving and the coping responses of caregivers.

Although this study did not have a sample size adequate to test the model of caregiver stress and coping proposed in Figure 4.1 with path analytic techniques or structural equation modeling, selected components of this model were addressed in this study. This study utilized an existing dataset to perform correlational analyses in order to describe the relationships among DAT patient needs for assistance, supervision/vigilance, and rates of decline in cognition, physical health and functional health and caregiver coping, depression and

burden. Qualitative data collected from those caregivers who participated in the original study and were still available and willing to be interviewed will be drawn upon to describe in depth the the process of coping experienced by these caregivers, with special emphasis on their perceptions of the stability and effectiveness of their coping responses and on religious coping. Patterns in the qualitative data that support the hypothesized relationships among the variables in the proposed model of caregiver stress and coping will be described.

Chapter Five

Purpose of the Study

This study builds on the existing literature on coping in caregivers of DAT patients by describing their coping responses to very specific DAT patient characteristics. Studies of DAT caregiver coping have focused primarily on linking coping responses to outcomes such as burden, depression and well-being (Pratt et al., 1985, 1987; Coppel et al., 1985; Zeiss et al., 1987; Lovett & Gallagher, 1988; Wright et al., 1987; Quayhagen & Quayhagen, 1988). Only Myers and Pruchno (1987) linked coping responses to the context within which the caregiving occurred, including DAT patient behaviors. None of the studies describing DAT caregiver coping or negative effects from caregiving have assessed the differential effects of caregiving demands such as the DAT patient's needs for assistance and supervision. Patient symptoms have most often been described in terms of their frequency or severity, combining memory and behavior problems into one measure (Zarit et al., 1980; Barusch & Spaid, 1989). However, several studies suggest that there may be differential effects on the caregiver when caring for a DAT patient requiring constant supervision versus functional assistance (Chenoweth & Spencer, 1986; Kinney & Stephens, 1989; Poulshock & Deimling, 1984; Deimling & Bass, 1986; Moritz et al., 1989). The specific patient needs for supervision and assistance are variables that have not been described in relation to caregiver coping and caregiver depression and burden. This study describes these relationships.

The rates of decline in DAT patient physical health, cognition, and ADL functioning have not been explored as variables that may differentially affect caregiver coping, depression or burden. Only one longitudinal study of DAT patients and their caregivers has been completed recently, and the effects of the rate of DAT patient decline on the caregiver were not described (Zarit et al., 1986). Thus, there is little information in the literature on how caregiver coping, caregiver depression, and caregiver burden change as DAT progresses. Because this study makes use of an existing longitudinal dataset, patterns of change in caregiver coping, depression and burden that occur over time are identified. In addition, the effect of rates of decline in DAT patient physical health, functional health, and cognition on the caregiver are described.

Although the coping responses of DAT caregivers are described in depth, particular attention is focused on contributing to the body of knowledge relating to religious coping. Religion appears to be very important in older people's lives (Princeton Religion Research Center, 1985; Blazer & Palmore, 1976) and religious coping behaviors are a frequently reported coping method used by older individuals (Jalowiec & Powers, 1981; Baldree et al, 1982; Griffith, 1983; Soderstrom & Martinson, 1987; Conway, 1985-86; Manfredi & Pickett; Bearon & Koenig, 1990). However, the religious coping behaviors of DAT caregivers have not been described. Further, it is unclear whether religious coping functions as a form of social support (Witter et al., 1985; Steinitz, 1980; Devine, 1980; Peterson & Roy, 1985), or through providing a sense of meaning (Tellis-Nayak, 1982; Hunsberger, 1985). Krause and Van Tran (1989) linked religious coping to stress reduction and found that religious attitudes and behaviors were stable and unrelated to the amount of stress an individual experienced, which is

contrary to what would be expected based on the person-environment interaction model of coping. This study describes the religious coping responses of DAT caregivers. In-depth, qualitative data regarding DAT caregiver coping responses, the stability of those responses, and perceived effectiveness of those coping responses in terms of decreasing stress, were gathered from DAT caregivers who participated in the original study and were still available and willing to be interviewed. It was hypothesized that religious coping would emerge as a major coping strategy of DAT caregivers.

The following caregiver coping responses are also described in depth: problem-focused, emotion-focused, and acceptance coping; and coping through wishful thinking, self-talk, or support group attendance. These coping responses are discussed in relation to the broader coping literature, which suggests that caregivers, who are primarily older women, cope in diverse ways, but may evidence slightly more passive coping styles, such as cognitive restructuring and acceptance, and less hostility or aggression, which are emotion-focused responses (McCrae, 1982, 1989; Irion & Blanchard-Fields, 1987; Pearlin & Schooler, 1978; Folkman et al., 1987). In general, women caregivers may report more emotion-focused coping compared to their male counterparts (Billings & Moos, 1981, 1984; Pearlin & Schooler, 1978). In addition, caregivers who perceive their health to be poor may use more emotion-focused coping responses (Pratt et al., 1985, 1987; Felton et al. 1984; Felton & Revenson, 1984, 1987).

Therefore, the purpose of this study is to describe in depth the coping styles and consequences of caregiving for a sample of caregivers caring for relatives who have a diagnosis of dementia of the Alzheimer's type (DAT),

without additional complicating medical disorders. Two sources of data were utilized in this study: data from an existing longitudinal dataset and qualitative data collected by this investigator from caregivers who participated in the original study and were still available and willing to be interviewed. The individual patient's rate of cognitive, functional, and physical health decline, need for supervision/vigilance, and need for assistance will be described as it relates to caregiver coping and consequences of caregiving that are operationalized as depression and burden. Changes in caregiver coping, depression, and burden that occur over 18 months are identified. Caregiver coping strategies, particularly religious coping behaviors, and the caregiver's perceptions of the stability and effectiveness of these coping behaviors are described in depth. It is expected that these detailed descriptions will produce hypotheses that can be subjected to testing in future research, as well as contribute to the building of conceptual models of the consequences to caregivers of caring for DAT patients with different rates of decline and needs for assistance or supervision.

Study Hypotheses

Although this was a descriptive study and confidence in hypothesis testing was limited by the small response size in the existing dataset, efforts were made to detect patterns of relationships among variables that support the following hypotheses:

h_1 : Rapid rates of decline in DAT patient's cognitive, functional and physical health will be positively correlated with caregiver depression, burden, and emotion-focused coping.

Rationale. DAT patients who are rapidly deteriorating are likely to exhibit behaviors not amenable to problem-focused coping or coping that functions to change or control their symptoms. Therefore, caregivers are more likely to use emotion-focused coping (coping that functions to manage the feelings aroused by the DAT symptoms and the stress effects associated with the DAT symptoms). The literature review supports the relationship between emotion-focused coping and depression and burden. Thus, rapid rates of decline in DAT patients may also be associated with increasing depression and burden in the caregiver.

h_2 : DAT patient need for supervision/vigilance will be positively correlated with caregiver depression, burden and emotion-focused coping.

Rationale. The rationale for this hypothesis is the same as for the first hypothesis. The more a DAT patient requires supervision, the more unpredictable the symptoms are likely to be and the less likely they would be amenable to coping that functions to change or control the symptoms. Thus, the caregiver will use more emotion-focused coping and experience more depression and burden.

h_3 : DAT patients' need for assistance will be positively correlated with problem-focused coping and caregiver depression and burden.

Rationale. Coping with a DAT patient who needs functional assistance may evoke more problem-focused coping as the symptoms the DAT patient has may be amenable to direct attempts to manage the behavior. Although the literature supports a relationship between decreased depression and problem-focused coping, this is not an expected finding in this sample because one type

of patient behavior that evokes more problem-focused coping is unlikely to be sufficient to reduce caregiver depression and burden.

Chapter Six

Research Methods

Two different research approaches were taken in this study: 1) a secondary analysis of an existing dataset was conducted and 2) follow-up interviews were conducted with subjects who participated in the original study to obtain qualitative data related to caregiving coping. This chapter will describe these research methods. First, the study that generated the data will be reviewed, including the purpose of the original study, a description of the DAT patient sample, the data collection method, and the instruments used. Next, data analysis procedures utilized for the secondary analysis will be described. Finally, procedures for the follow-up interviews will be reviewed, including the purpose of the interview, how subjects were approached to participate, a description of those subjects who did consent to the interview, and a description of the interview procedure.

The Original Study:

Adaptation Among Elderly with Alzheimer's Disease

Purpose and Design

The original study, "Adaptation Among Elderly with Alzheimer's Disease" described changes in DAT patients and their caregivers, compared to a sample of normal controls matched on age and sex of the DAT patient, over a period of 30 months (Kiyak, 1988). Subjects entered the study between 1984 and 1985. Six waves of data were collected as subjects were interviewed twice yearly until

1988. The primary purpose of the study was to evaluate changes in the DAT patient, therefore most of the data collected from subjects related to the effect of DAT on the patient, rather than the caregiver. The study also served to help refine instruments measuring the physical environment, architectural activities of daily living, coping responses, and behavioral symptoms. The last three waves of data collection included measures intended to assess the caregiver's adaptation to the patient's illness, including asking specifically how the caregiver was coping with the increasing memory problems and disorientation of the DAT patient, as well as negative effects of caregiving such as depression and burden.

Sample

The sample was comprised of non-institutionalized DAT patients who were assessed to be moderately demented and had a caregiver. DAT patient subjects were selected from the files of the Geriatric and Family Services Clinic of the Hospital at the University of Washington's Medical School and the Seattle Veteran's Administration Medical Center's Geriatric Research, Education and Clinical Center. Subjects were also referred to the study after completing other DAT research projects. Criteria for inclusion in the study included a Mini Mental Status score greater than or equal to 16, a strong presumptive diagnosis of DAT based on a complete evaluation by the medical team at each site, age over 55, and residence in the community with a primary family member or a close friend. A normal control, matched on the age and sex of the DAT patient, and their primary family member were also included in the study. However, data provided by the normal controls were not utilized in the secondary analyses.

Sixty-six patients were screened for entry into the study. Of these, three refused the study, three subjects had Coblenz Dementia Rating Scale scores that were too low, indicating marked cognitive impairment, and one subject's caregiver died before beginning the study. Fifty-nine DAT patients and their caregivers entered the study between 1984 and 1985 and were interviewed twice yearly (a total of six times) until 1988. Demographic characteristics of the caregivers were not collected. The mean age of the DAT patient at entry into the study was 71 years (*SD* 6.3); they had completed a mean of 14.3 years of education (*SD* 3.1); with a median family income of \$30,000, and nearly two-thirds were male. The subjects were Caucasian with the exception of one Chinese-American couple. Over the 30 month course of the study, 3 patient subjects were dropped from the study due to medical problems calling into question the original diagnosis of DAT, 3 patient subjects were placed into adult family homes, 4 patient subjects died, and 10 patient subjects were placed into nursing homes. After entry into the study, two caregiving dyads refused to continue the study. One couple dropped out after the first wave of data collection and the second couple dropped out after completing the first two waves of data collection. Demographic characteristics of the DAT patient sample at the start of the study, excluding the three subjects with questionable diagnoses of DAT, are summarized in Table 6.1.

Much of the secondary analyses is on data from time four (18 month assessments); rate of change variables were based on changes from time one through time four. Caregiver variables were taken from time four through time six, in part because some instruments relating to the caregiver were not collected in the earlier waves of data collection. In addition, the rationale for

Table 6.1

Demographic Characteristics of the DAT Patient Sample at Time 1 ($n = 56$)

Age	\bar{x} (sd)	71 (6.3)
Gender	Men	32 (57%)
	Women	24 (43%)
Educational level	< 8th grade	4 (7%)
	Some HS	5 (9%)
	HS graduate	9 (16%)
	Some college	13 (23%)
	College graduate	15 (27%)
	Advanced degree	6 (11%)
	Unknown	4 (7%)
Annual income	Median	\$30,000
Marital status	Married	47 (84%)
	Widowed	9 (16%)
Caregiver respondent	Spouse	47 (84%)
	Daughter/daughter-in-law	6 (11%)
	Friend	3 (5%)

selecting variables from particular waves of data was to obtain an adequate sample size to satisfy assumptions for statistical tests, while at the same time using data that were not outdated to relate to qualitative data collected by this investigator from the same research subjects during follow-up interviews. At time four, 47 community dwelling DAT patients and their caregivers were still participating in the study. However, the response sizes to different variables in the dataset varied quite a bit. For example, 47 caregivers gave complete information on the patient's functional status, whereas only 33 caregivers gave complete responses on the instrument measuring caregiver burden. The sample size for caregivers completing all six waves of data collection ranged from 17 to 25, again depending upon response sizes to particular instruments. This attrition was partly due to the period of grant funding coming to an end such that those subjects who had not completed time 6 could not be re-interviewed past the end of the funding period. Attrition was also due to deaths and nursing home placement of DAT patient subjects. Four DAT patients died over the course of the study. Ten DAT patients were placed into nursing homes, and in two cases, placement occurred because the caregiver died, rather than because of declines in DAT patient health.

Data Collection

Data were collected during a structured interview. All of the interviews with the DAT patients and their caregivers took place in the patient's home, and were conducted by the principal investigator and trained research assistants. All of the information relating to the DAT patient utilized in the secondary analysis was reported by the DAT patient's caregiver, with the exception of one instrument

assessing cognitive functioning, the Coblenz Dementia Rating Scale, which was administered to the patient by a research assistant trained in psychometry.

Instruments

This section will describe the instruments used to measure the variables that were included in the secondary analysis. Each variable will first be described conceptually, followed by a description of the instrument that was used to operationalize each variable. Copies of the instruments are included in Appendix A.

DAT patient demographics. DAT patient demographic information included age, education, lifetime work, marital status, and family income. DAT patient demographics were collected at time one.

DAT patient physical health. Physical health status was conceptualized as the caregiver's subjective judgement of the DAT patient's physical health. It was operationalized by asking the caregiver to give Likert type ratings on the DAT patient's health status as compared to other persons the same age: 1 (much better than others his/her age), 2 (somewhat better than others his/her age), 3 (about average, ok), 4 (not as good as others), and 5 (much worse than others). The test-retest reliability for this item ranged from .41 to .74. In addition, caregivers were asked to report the DAT patient's number of days in hospital, number of physician office visits, and number of days at home in bed due to any illness over the previous six months. Since the test-retest reliabilities for these items were quite poor, they were not included in the secondary analysis. Even though subjective health assessments have been shown to be moderately correlated with physicians' ratings and more objective self-report

measures such as number of chronic health conditions (Ferraro, 1980; LaRue, Bank, Jarvik, & Hetland, 1979), they are not equivalent measures. Therefore, these single item subjective health measures should be interpreted with caution since they may have poor reliability and validity.

DAT patient functional health. Functional health was defined as the extent to which an individual can carry out usual daily activities without assistance from others. Functional health was operationalized by a modified version of the Older Americans Resources and Services Methodology (OARS), which measures ability to perform activities of daily living (ADL) independently (Pfeiffer, 1975). Additional items were developed to reflect functional health vis-a-vis the physical features of the environment. Included was the caregiver's report of the DAT patient's ability to perform 8 instrumental ADL's (e.g., shopping, preparing own meals, handling own money, etc.), 4 self-care ADL's (e.g., eat, dress/undress, groom, etc.), and 8 architectural ADL's (e.g., getting in and out of chairs, using stairs and ramps, reaching into high closets or under beds and chairs, etc.). Similar to the OARS system, each item was scored 0 (unable), 1 (needs help) or 2 (independent) producing a total ADL score with a range of 0 (completely unable) to 40 (completely independent). Internal consistency (Chronbach's alpha) reliability estimates for the total ADL score in this sample ranged from .82 to .94. Test-retest reliability estimates for the total ADL score in this sample ranged from .79 to .82. DAT caregivers were also asked to report the number of DAT patient cognitive/self-care problems and the number of DAT patient motor/physical problems.

DAT patient cognitive function. Cognitive functions were defined as the mental processes of comprehension, judgement, memory and reasoning.

Cognitive functioning was operationalized by total scores on the Coblentz Dementia Rating Scale (DRS), which is a brief measure of cognitive impairment and taps many of the domains identified as critical to cognitive functioning in DAT (Coblentz et al., 1973; McKhann et al., 1984). The DRS has a possible range of 0 (completely impaired) to 144 (normal functioning). When subjects became too impaired to be tested, they were given a score of zero. The DRS has been shown to have good discriminant validity between normal and cognitively impaired groups, good overall reliability and a strong correlation with overall patient functioning (Vitaliano et al., 1984; Prinz et al., 1983; Mattis, 1976). Internal consistency reliability estimates were not computed on the total score for the DRS because the DRS is comprised of several subscales. Even so, the total score is used as an overall measure of cognitive function.¹ Test-retest reliability estimates in this sample ranged from .75 to .96. The DRS was administered to DAT patient subjects by trained research assistants.

DAT patient behavioral symptoms. Behavioral symptoms were defined as behaviors that represent both cognitive and affective disturbances. Behavioral symptoms were measured by the Behavioral Symptoms Checklist (BSC), a 75 item scale developed over the course of the study which asked caregivers to report the frequency of several behavioral symptoms with ratings scored as 0 (never), 1 (seldom--1 or 2 times), 2 (sometimes--1 or 2 times per week), 3 (often--every day), or 4 (always--several times per day). The final form of the BSC was collected beginning with time four. The BSC taps all major dimensions of cognitive, emotional, behavioral and psychiatric disturbance. It

¹Personal communication with Linda Teri, Ph.D., Associate Professor, Psychiatry and Behavioral Sciences, University of Washington, Seattle, Washington.

demonstrated high test-retest reliability over the course of the study ($r > .90$). Cluster analysis was used to identify twelve subscales: simple cognitive failure, complex cognitive failure, sleep disorder, decreased appetite, disinhibition, retardation, passivity/self-care/motor dysfunction, psychosis/aggression, anxiety, anxious depression, loss/self-blame, and a composite severity scale (Borson, Yamagishi, Teri, and Kiyak, 1988). Three BSC subscales from time four only were used in the secondary analysis: psychosis with aggression, sleep disorder, and disinhibition. Internal consistency reliability estimates (Chronbach's alpha) for these scales at time four were psychosis with aggression .80, disinhibition .74 and sleep disorder .83.

Caregiver coping. Coping was defined as the adaptive cognitive, behavioral, and emotional responses that are evoked by a stressor, which in this case was the increasing memory problems and disorientation of the DAT patient. For the purposes of this study, coping did not include physiological responses. Coping was operationalized by asking caregivers to rate their coping with the memory problems and disorientation of the DAT patient by responding to a 26 item coping questionnaire developed by Kiyak (1988). The scale was derived from the work of Pearlin and Schooler (1978), Lazarus and Folkman (1984), and Kahana et al. (1985), and measured four dimensions of coping: problem-focused coping, emotion-focused coping, acceptance, and religious coping. This instrument was administered to caregivers at time four through time six. For each coping response, caregivers were asked to give a yes/no response; the score given for each coping subscale represents the proportion of items checked yes for that particular subscale. The specific items comprising each subscale are reported in Appendix A. Internal consistency

reliability estimates (Chronbach's alpha) for each subscale at time four were: emotion-focused coping .58, problem-focused coping .72, acceptance coping .47, and religious coping .91. Test-retest reliability estimates for each subscale for time four through time five should be considered quite unstable, primarily because the sample size at the end of the study is quite small. Test-retest reliability estimates for each subscale are as follows: emotion-focused coping .58 to .88, problem-focused coping .58 to .67, acceptance coping .03 to .42, and religious coping .53 to .98.

Caregiver burden. Caregiver burden was defined as the caregiver's subjective report of the effects caregiving has had on their emotions and relationship with the care-receiver, and on objective aspects of lifestyle such as time to oneself and time for recreation. Caregiver burden was measured with a revision of the Subjective Burden and Objective Burden scales developed by Montgomery, Gonyea and Hooyman (1985). Caregiver burden was collected at time four through time six. This instrument asks the caregiver to rate on a scale of 1 "very much" to 5 "not at all" the effect caregiving has had on items such as time you have to yourself, personal privacy, time for recreation and vacations, time for own work and chores, time for friends and other relatives (objective burden); and stress in the relationship with the patient, attempts by the patient to manipulate, nervousness and depression about the relationship with the patient, and demands made by the patient that are more than he/she needs (subjective burden). Although the purpose of this instrument is to produce a cumulative score across both subjective and objective aspects of burden, the literature review suggests that looking at dimensions of burden separately may be useful, particularly when correlates of burden are being assessed.

Therefore, the range and reliability of the total score and the objective and subjective burden subscores will be described. The total score represents the cumulative effects from caregiving on the caregiver's life and has a range of 10 to 50, with a lower score indicating more effects from caregiving. Objective burden consists of six items and produces a score that has a range of 6 to 30; subjective burden consists of 4 items and produces a score with a range of 4 to 20. Internal consistency reliability (Chronbach's alpha) and test-retest reliability were computed for the total score, for objective burden, and for subjective burden for time four through time six. These estimates must be interpreted with caution and considered unstable because of the small sample sizes for time four through time six. Chronbach's alpha for the total burden score ranged from .82 to .88 with test-retest reliability ranging from .47 to .83. For objective burden, Chronbach's alpha ranged from .80 to .85, with test-retest reliability from .13 to .62. Subjective burden produced Chronbach's alpha estimates from .66 to .76, with test-retest reliability from .58 to .76.

Caregiver depression. Depression was defined as dysphoric mood and affective disturbances such as crying. It was measured with the Center for Epidemiological Studies Depression Scale (CES-D). The CES-D was administered to caregivers at time four through time six. This is a 20 item scale that asks caregivers to report the frequency with which they have experienced the occurrence of depressive symptoms during the past week. Ratings of 1 (less than one day) to 4 (5 to 7 days) are given, producing a score with a range of 20 to 80, with higher scores indicating more depression. Internal consistency reliability estimates (Chronbach's alpha) in this sample ranged from .68 to .87

for time four through time six. Test-retest reliability ranged from .38 to .63 for time four through time six.

Caregiver's social support. Social support was defined as the presence of people available to provide support, but did not include satisfaction with support given or frequency of requests for support. Social support was measured with the Social Support Questionnaire derived from the work of Sarason, Levine, Basham, and Sarason (1983). This instrument asks the caregiver to report whether they have people available to provide them with six types of support (e.g., acceptance, distraction from worries, someone to count on, etc.). If the caregiver did have support persons, they were asked to identify them. The Social Support Questionnaire was included in data collection during times five and six only. The secondary analysis includes descriptive statistics on social support from time five only.

Secondary Data Analysis

Sample Description

Descriptive statistics were computed on the following DAT patient variables at time one and time four: total score on the DRS, total ADL score, and rating of physical health compared to others the same age. Behavioral problems are included for time four only. Descriptive statistics were computed on the following caregiver variables for time four: caregiver coping, caregiver depression, and caregiver burden. Because caregiver social support was collected during time five and time six only, and the response size for time six was quite small, descriptive statistics for caregiver social support were computed for time five only.

Choice of Measures to Represent Variables
for the Secondary Analysis

Several measures representing specific DAT patient characteristics were selected from the data available in the dataset. This section describes the procedures used to choose and/or develop measures to represent the following DAT patient variables: needs for assistance and supervision/vigilance, and rates of declines in cognitive function, functional health and physical health.

Identifying a measure to represent DAT patient "need for assistance". The variable DAT patient "need for assistance" was conceptualized as representing those patient characteristics requiring the caregiver to provide physical and functional assistance. Three measures were available in the time four dataset that could represent DAT patient "need for assistance:" the total score for the ADL's, the caregiver's report of the number of cognitive/self-care problems experienced by the DAT patient, and the caregiver's report of the number of motor/physical problems experienced by the DAT patient. The measure representing "need for assistance" was selected based on how normal the distribution appeared and the amount of shared variance among these measures. First, the distribution of each measure was assessed. Next, intercorrelations among these measures on time four data were computed. The total ADL score was normally distributed and shared the most variance with the other two measures and so was selected to represent DAT patient "need for assistance."

Identifying a measure to represent DAT patient "need for supervision/vigilance". The variable DAT patient "need for supervision/vigilance"

was conceptualized as representing those patient characteristics that are unpredictable or behaviorally abnormal and require the caregiver to constantly supervise the patient. Three measures in the time four dataset could represent this domain: the BSC subscales psychosis with aggression, sleep disorder, and disinhibition. A measure was selected based on the subscale distribution, the reliability estimate, and the amount of shared variance among the three subscales. An additional concern was that the measure representing "need for supervision/vigilance" not be highly correlated with "need for assistance," so that these two measures could, as much as possible, clearly represent different domains. Each subscale was first assessed in terms of the distribution and alpha reliability estimates. Intercorrelations among these three scales were then computed. One outlier case was identified and so these procedures were computed with and without the outlier case. Sleep disorder had the least normal distribution and shared little variance with the other two measures and so was not considered further. None of these scales had normal distributions probably because many of the items comprising these scales are rare events. However, disinhibition was the least skewed, while psychosis with aggression appeared to share the most variance with disinhibition.

Because the two subscales psychosis with aggression and disinhibition shared so much variance ($r = .59$; $p = .00$), a decision was made to create a new scale by combining the conceptually relevant items from the disinhibition subscale with the psychosis with aggression subscale, and then to assess the distribution, alpha reliability estimate, and the zero order item intercorrelations of this new scale, with and without the outlier. The following two items from the disinhibition subscale were combined with the psychosis with aggression

subscale to form a new behavioral problems subscale: "overactive/paces" and "looks angry/frustrated." Without the outlier case, this new subscale was less skewed than the disinhibition and psychosis with aggression subscales and had an alpha reliability estimate of .84. The alpha reliability estimate was unchanged, with or without the outlier included. Therefore, this new subscale was selected to represent DAT patient "need for supervision." The correlation between this new behavioral symptoms scale and the "need for assistance" measure, the total ADL score, was computed, with and without the outlier. With the outlier, the correlation was $-.37$ ($p = .007$); the correlation was $-.24$ ($p = .06$) without the outlier.

Creating the DAT patient rate of change variables. Rate of DAT patient decline in functional health, cognition, and physical health from time one through time four was represented by the slopes for each variable for each case. For those subjects with at least three observations for these variables, individual regression lines were fit as a function of the particular variable and time. The slope of the fitted line was assumed to be the observed change score. Functional health was represented by the total ADL score, and individual regression lines were fit as a function of the total ADL score and time. A negative slope indicates decline in functional health; the larger the negative slope, the more rapid the decline. Cognitive impairment was represented by the total score of the DRS, therefore individual regression lines were fit as a function of the total DRS score and time. Again, for this measure, a negative slope indicates cognitive decline, and the larger the negative slope, the more rapid the decline. Of the measures in the dataset that could represent the DAT patient's physical health, the family member's report of the DAT patient's

physical health status compared to other persons the same age was normally distributed and so was selected to represent this domain. Individual regression lines were fit as a function of this measure and time. For this variable, a positive slope indicates decline in health, and the larger the slope, the more rapid the change. The slope parameter can be treated similar to other parameters such as the mean or variance, in terms of statistical testing (Laird and Ware, 1982).

Relationships among Patient Characteristics, Caregiver Coping, and Consequences of Caregiving

Utilizing time four data only, relationships among patient and caregiver variables were evaluated first by examining plots to check for linear relationships and then by computing correlations between the five patient characteristics and caregiver coping and consequences of caregiving operationalized as depression and burden. The purpose of these correlations was to identify patterns of relationships supportive of the study hypotheses and consistent with the literature review and the model of caregiver stress and coping. Because a number of correlations were computed with small sample sizes, a conservative p value was used ($p < .01$) for statistical significance. P values of $< .05$ were considered only marginally significant. Plots and correlations were computed with and without the outlier so that the effects of an extreme pair of observations on the correlation coefficient could be evaluated. The DAT patient variables were "need for assistance" operationalized by the total ADL score, "need for supervision/vigilance" operationalized by the behavioral problems subscale developed to represent this variable, rate of cognitive decline operationalized by the slopes of the total DRS regressed on time for each subject, rate of functional

health decline operationalized by the slopes of the total ADL regressed on time for each subject, and rate of physical health decline operationalized by the slopes of the caregiver's report of the DAT patient's physical health regressed on time for each subject.

Changes Over Time in Caregiver Coping and Consequences of Caregiving

Data from caregivers who completed time four through time six were used to identify change over time in coping, depression, and burden. Time four through time six data were used because some of the caregiver variables were not available in earlier waves of data. In addition, it was hoped that data collected in follow-up interviews conducted by this investigator could be related to the more recent caregiver data available in the dataset. The small sample size restricted statistical testing, and so measures of central tendency were computed for those subjects with complete responses on the variables of interest for times four through six, in order to describe and illustrate change.

Qualitative Interviews with Caregivers

Purpose

The purpose of conducting follow-up interviews with caregivers was to collect in-depth, qualitative information relating to caregiver coping with the memory problems and disorientation of DAT. Although caregivers were asked about all of the coping responses listed on the coping instrument used in the original study, of particular interest were comments caregivers made relating to religious coping.

Sample

Subjects were approached through the principal investigator of the original study, Dr. Kiyak. First, a letter from Dr. Kiyak was sent to each caregiver, informing them that I would be calling to invite them to participate in the follow-up interview. A copy of this letter can be found in Appendix B. Next, each caregiver was called by this investigator, and invited to participate in the follow-up interview. Letters were sent to forty caregivers and of these, fourteen were available and consented to the follow-up interview. The demographic characteristics of this sample of caregivers are summarized in Table 6.2. Those caregivers who consented to the interview had a mean age of 66.5 years, were primarily the spouse of the DAT patient, had been in the caregiving role a mean of 6.7 years, and the median reported income category was \$20,000 to \$30,000 per year. All of the caregivers were white with the exception of one Chinese American caregiver. Of these fourteen caregivers, seven were providing care to DAT patients who had been placed out of the home, either into nursing homes, adult family homes, or the home of another relative. Table 6.3 summarizes the reasons caregivers declined the interview. Various reasons were given by those caregivers who did not want to participate in the interview. Excluding DAT patient death, the most common reason given by the caregiver was ill health, followed by being too busy with caregiving duties to be interviewed. In addition, the wording in the letter inviting caregivers to participate may have affected subject selection. For example, two subjects did not participate because they stated their relative did not have DAT. In addition, because the term coping was used in the letter, caregiver's who were psychologically oriented may have

Table 6.2

Demographic Characteristics of the Caregiver Sample ($n = 14$)

Age	\bar{x} (sd)	66.5	(6.3)
Gender	Men	1	(7%)
	Women	13	(93%)
Educational level	HS graduate	3	(21%)
	Some college	4	(29%)
	College graduate	5	(36%)
	Advanced degree	2	(14%)
Marital status	Married	12	(86%)
	Widowed	2	(14%)
Relationship to DAT patient	Spouse	10	(72%)
	Daughter	3	(21%)
	Daughter-in-law	1	(7%)
Years in caregiving role	\bar{x} (sd)	6.7	(2.2)
Income	< \$10,000	1	(7%)
	≥ \$10,000-\$20,000	3	(21%)
	≥ \$20,000-\$30,000	6	(42%)
	≥ \$30,000-\$40,000	2	(14%)
	≥ \$40,000-\$50,000	0	
	≥ \$50,000	2	(14%)
Religious affiliation	Baptist	1	(7%)
	Episcopal	3	(21)
	Jewish	1	(7%)
	Protestant	4	(29%)
	Presbyterian	1	(7%)
	Roman Catholic	2	(14%)
	Unitarian	1	(7%)
	Unity Church	1	(7%)

Table 6.3

Reasons for Not Participating in Follow-up Interviews

Unable to locate	1	(4%)
Caregiver did not return telephone calls	2	(7%)
Caregiver ill health	5	(19.5%)
Caregiver too busy with caregiving tasks	4	(15.5%)
Caregiver unable to take time off from paid employment	1	(4%)
Caregiver states that patient does not have DAT	2	(7%)
Caregiver "not interested"	2	(7%)
Caregiver deceased	3	(11.5%)
Patient deceased	6	(23%)
TOTAL	26	

selected themselves into the study. More general wording in the letter, e.g., an invitation to participate in an interview about how caring for your relative with dementia is affecting your life, may have resulted in a different pattern of subject participation. Therefore, the sample that consented to the interview were likely the healthiest and most psychologically oriented caregivers.

Interview Procedure

All of the interviews were conducted by this investigator and took place in the subjects' home with the exception of one interview, which took place in this investigator's office at the request of the subject. The subjects first read and signed a consent to participate in this study. A copy of the consent form can be found in Appendix B. The interviews lasted approximately one and one-half hours. All of the caregiver's responses were recorded by handwritten notes during and immediately after the interview.

Subjects were first asked about demographic information. Next, information specific to their particular caregiving situation was gathered, including length of time in the caregiving role, who else helps them with what types of assistance, and who the caregiver turns to for support. The caregiver was also asked about any health problems they were currently experiencing. If the DAT patient was no longer living with the caregiver, the caregiver was asked how the out-of-home placement affected their level of stress. The caregiver was next asked to describe the most stressful aspects of caring for the patient, and how they were coping with those particular problems. This was accomplished by going through the coping questionnaire, and gathering detailed information about each coping response the caregiver acknowledged using, including the

ways in which that particular way of coping helped or hindered the caregiver. Caregivers then chose their top six coping responses in terms of what they do the most and what they find most helpful. Caregivers were also asked to comment on the stability of their coping responses by thinking about other times during their lifetimes when they had coped similarly. Finally, caregivers were asked whether or not health care providers had talked with them about their own coping with DAT, and to describe what kinds of services and help caregivers need from health care providers. Appendix B includes an outline of the interview.

Human Subjects Review

This research was given a certificate of exemption and was reviewed at the departmental level. The exemption was granted because subject responses in the dataset were kept anonymous except when the subject gave written consent for their subject identification number to be revealed for the purpose of comparing responses on the coping questionnaire gathered during the follow-up interview to their responses in the dataset. The qualitative interview data gathered on follow-up and the data in the existing dataset did not include any sensitive information.

Chapter Seven

Results

This chapter will report the results of the study. First, results from the secondary analysis of the existing dataset will be reported. Included are descriptive statistics for the sample of DAT patients and caregiver coping, depression and burden, correlations representing relationships among patient and caregiver variables, and tables illustrating changes over time in caregiver coping, depression, burden and social support. Next, qualitative data collected from caregivers during the follow-up interviews will be reported. Included will be descriptions of particular caregiving situations, as well as caregiver coping responses. The sample sizes for the secondary analysis and the qualitative interview data are quite different. For the secondary analysis, response sizes for the variables of interest ranged from 25 to 37, while just 14 caregivers agreed to participate in the follow-up interviews.

Secondary Data Analysis

Descriptive Statistics

Table 7.1 summarizes the minimum and maximum scores possible, as well as the direction of interpretation for all of the study variables. The DAT patient sample at both time one and time four was moderately impaired on the measures of cognitive function, functional health and physical health. Table 7.2 summarizes the descriptive statistics for these DAT patient variables. At time one, the mean DRS score was 111.1 (*SD* 21.1), the mean ADL score was 32.6

Table 7.1
Summary of Study Variables

Variable	Range	Interpretation
<u>DAT Patient Variables:</u>		
ADL	0-40	lower score = more functional impairment
DRS	0-144	lower score = more cognitive impairment
Behavioral problems	0-56	higher score = more behavioral problems
Physical health	1-5	higher score = poorer health status
<u>Caregiver Variables:</u>		
Coping scales	0-1.00	higher score = more frequent coping
Depression (CES-D)	0-60	higher score = more depression
Cumulative burden	10-50	lower score = more burden
Objective burden	6-30	lower score = more burden
Subjective burden	4-20	lower score = more burden

Table 7.2

DAT Patient Variables: Time One and Time Four

		Time One	Time Four
Total ADL score (range 0-40)	\bar{x} (sd)	32.6 (5.3) $n = 57$	25.3 (8.5) $n = 47$
Total DRS score (range 0-144)	\bar{x} (sd)	111.0 (21.2) $n = 57$	103.1 (27.4) $n = 40$
Physical health (range 1-5)	\bar{x} (sd)	2.2 (1.2) $n = 54$	2.5 (1.2) $n = 46$
Behavioral problems (range 0-56)	\bar{x} (sd)		7.1 (9.7) $n = 41$

(*SD* 5.3), and the mean score caregivers gave for the DAT patients health compared to others the same age was 2.2 (*SD* 1.2), which indicates a health rating of "somewhat better" than others the same age. At time four, the remaining sample was slightly more impaired in terms of cognition with a mean DRS score of 103.1 (*SD* 27.4). However, these results are affected by the subject attrition, and eight of the ten subjects dropped from the study because of nursing home placement were likely more impaired than those DAT patients who continued in the study. The sample appeared more than moderately impaired in their functional health with a mean ADL score of 25.3 (*SD* 8.5). Caregivers gave similar physical health ratings at time one and four. In terms of behavioral problems, the mean score on the behavioral problems scale representing the DAT patient's need for supervision/vigilance was 7.1 (*SD* 9.7), indicating a low frequency of behavioral problems as this scale has a possible range of 0 to 56. The descriptive statistics for the slopes representing rates of decline from time one to time four in cognition, functioning and physical health are summarized in Table 7.3. These slopes represent moderate declines.

Caregiver variables for time four data are summarized in Table 7.4. Mean scores for acceptance coping ($\bar{x} = .76$; *SD* .27) and religious coping ($\bar{x} = .58$; *SD* .46) were higher than mean scores for emotion-focused coping ($\bar{x} = .40$; *SD* .32) and problem-focused coping ($\bar{x} = .39$; *SD* .35). The range possible for all of the coping scores was 0 to 1.00 with a higher score indicating more use of that coping response. These caregivers were moderately depressed with a mean CES-D score of 33.4 (*SD* 8.7), out of 60 possible. The mean score for cumulative burden, or cumulative effects from caregiving on the caregiver's life, was 26.4 (*SD* 9.5), out of 50 possible. For this scale, a lower score indicates

Table 7.3

Slopes Representing DAT Patient Rate of Decline Variables (Time 1-Time 4)

	\bar{x}	<i>sd</i>	
Total ADL score	-2.72	2.50	<i>n</i> = 54
Total DRS score	-6.15	10.28	<i>n</i> = 52
Physical health	1.33	.39	<i>n</i> = 43

Table 7.4
Caregiver Variables at Time Four

Variable	\bar{x}	<i>sd</i>	
Coping (range 0-1.00)			
Emotion-focused coping	.40	.32	<i>n</i> = 37
Problem-focused coping	.39	.35	<i>n</i> = 37
Acceptance coping	.76	.27	<i>n</i> = 37
Religious coping	.58	.46	<i>n</i> = 37
Depression			
(range 0-60)	33.4	8.7	<i>n</i> = 29
Cumulative burden			
(range 10-56)	26.4	9.5	<i>n</i> = 33
Objective burden			
(range 6-30)	13.6	6.7	<i>n</i> = 36
Subjective burden			
(range 4-20)	13.0	4.4	<i>n</i> = 33

more burden. Thus, these caregivers were reporting a moderate amount of burden from caregiving. When objective burden and subjective burden were assessed, these caregivers reported a moderate amount of subjective burden, with a mean score of 13 (*SD* 4.4), out of 20 possible, and high objective burden with a mean score of 13.6 (*SD* 6.7), out of 30 possible.

Caregiver social support at time 5 is summarized in Table 7.5. Data from time five was used because this measure was available at time five and time six only, and time five had a larger response size. In response to the question "Do you have someone who distracts you?" ten caregivers (38.5%) had multiple family members and friends who distracted them, but six (23%) reported no one available to provide this support. Similarly, nine caregivers (37.5%) stated they had no one who helped them relax, while seven (29.2%) had multiple family members and friends who gave this support. All of the caregivers had someone who accepted them. However, the most frequently reported categories were spouses (six caregivers or 20%), and of these, all except one was the DAT patient, suggesting that DAT patients continue to be a source of support for their spouses. Multiple family members and friends (six caregivers or 20%) and multiple family members (eight caregivers or 32%) were also reported as sources of acceptance. In terms of having someone available to care for the caregiver, 12 caregivers (44.4%) reported that this support was given by multiple family members and six caregivers (22.2%) reported that friends in addition to multiple family members provided them with this support. Only one caregiver had no one to "care for" them. In response to "do you have someone who helps you feel better?", seven caregivers had no one (33.3%), while the rest of the caregivers reported that a variety of persons helped them

Table 7.5

Caregiver Social Support: Time 5

Do you have someone who	Distracts you (n = 24)	Helps you relax (n = 24)	Accepts you (n = 25)	Cares for you (n = 27)	Helps you feel better (n = 21)	Consoles you (n = 25)
No one	6 (23%)	9 (37.5%)		1 (3.7%)	7 (33.3%)	6 (24%)
Spouse			5 (20%)	1 (3.7%)	1 (4.7%)	1 (4%)
Daughter/ stepdaughter			1 (4%)	1 (3.7%)	2 (9.5%)	1 (4%)
Son/stepson	1 (3.8%)		1 (4%)	3 (11.1%)		2 (8%)
Sibling	1 (3.8%)	1 (4.2%)				
Friend, neighbor	1 (3.8%)	2 (8.3%)	4 (16%)	2 (7.4%)	3 (11.3%)	2 (8%)
Multiple family/friends	10 (38.5%)	7 (29.2%)	5 (20%)	6 (22.2%)	3 (14.3%)	5 (20%)
Multiple family	4 (15.4%)	3 (12.5%)	8 (32%)	12 (44.4%)	3 (14.3%)	6 (24%)
Multiple friends	3 (11.5%)	2 (8.3%)	1 (4%)	1 (3.7%)	2 (9.5%)	2 (8%)

feel better. Caregivers also reported whether or not they had someone who consoled them. Six (24%) said no one consoled them. Six caregivers (24%) had multiple family members who consoled them and five caregivers (20%) reported having multiple family members and friends who provided them with this support. The caregivers reporting that they had no one providing support to them were often the same caregivers in each of the different support categories.

Correlations among Patient Characteristics, Caregiver Coping, and Consequences of Caregiving

The intercorrelations of all of the study variables with the outlier included are summarized in Figure 7.1. When these correlations were computed without the outlier, the results were different for only one of the correlations: the association between the ADL score and the behavioral problems score became $r = -.25$ ($p = .06$). Therefore, results of the analysis including all cases are reported. First, the correlations between the DAT patient and caregiver variables will be reported as they relate to the study hypotheses. Then the relationships between ways of coping and caregiver depression and burden will be reported. Because a total of 40 correlations were computed on variables with sample sizes ranging from 25 to 37 making the risk of significance due to chance alone high, a more conservative p value of $< .01$ was required for an association to be considered statistically significant. The correlations with p values $< .05$ are considered marginally significant and only suggestive of relationships. Figure 7.1 indicates which correlations had p values of $< .05$, $< .01$, and $< .001$.

	Behavioral problems	Slope for DRS	Slope for ADL's	Slope for health	Emotion-focused coping	Problem-focused coping	Acceptance coping	Religious coping	Cumulative burden	Objective burden	Subjective burden	Depression (CES-D)
Total ADL score	-.38** n = 41	.54*** n = 46	.76*** n = 47	.07 n = 39	-.11 n = 36	-.39** n = 37	.18 n = 37	.03 n = 37	.57*** n = 33	.47** n = 36	.55*** n = 33	-.26 n = 29
Behavioral problems		-.07 n = 40	-.13 n = 41	-.08 n = 33	.38* n = 33	.56*** n = 33	.26 n = 33	-.00 n = 30	-.56*** n = 30	-.34* n = 33	-.61*** n = 30	.40* n = 26
Slope for DRS			.37** n = 52	.11 n = 42	-.02 n = 36	-.33* n = 36	.21 n = 36	.01 n = 36	.27 n = 32	.23 n = 35	.20 n = 32	-.15 n = 28
Slope for ADL				.06 n = 43	-.31* n = 37	-.34* n = 37	.15 n = 37	-.04 n = 37	.43** n = 33	.33* n = 36	.48** n = 33	-.34* n = 29
Slope for health					.09 n = 31	-.17 n = 31	-.19 n = 31	-.19 n = 31	.06 n = 28	.15 n = 30	-.05 n = 28	.08 n = 25
Emotion-focused coping						.15 n = 37	-.15 n = 37	.43** n = 37	-.40* n = 31	-.11 n = 34	-.59*** n = 31	.44** n = 28
Problem-focused coping							.23 n = 37	-.11 n = 37	-.43** n = 31	-.30* n = 34	-.52*** n = 31	.20 n = 28
Acceptance coping								-.18 n = 37	.36* n = 31	.26 n = 34	.25 n = 31	-.21 n = 28
Religious coping									-.24 n = 31	-.20 n = 34	-.33* n = 31	.04 n = 28
Cumulative burden										.92*** n = 33	.80*** n = 33	-.54** n = 26
Objective burden											.50** n = 33	-.43* n = 27
Subjective burden												-.53** n = 26

*p < .05 (marginal significance)
 **p < .01
 ***p < .001

Figure 7.1 Intercorrelations of All Variables

Hypothesis 1: It was hypothesized that rapid rates of decline in DAT patient's cognitive, functional and physical health would be positively correlated with caregiver depression, burden, and emotion-focused coping.

There was very little support for hypothesis 1. Greater DAT patient cognitive decline from time one to time four was only marginally significantly associated with the presence of problem-solving coping in the caregiver ($r = -.33; p < .05$), suggesting that rapid rate of cognitive change in the DAT patient results in more caregiver problem-focused coping. Results only weakly suggested that greater DAT patient functional decline from time one to time four was associated with more caregiver depression ($r = -.34; p < .05$), emotion-focused coping ($r = -.31; p < .05$), and problem-focused coping ($r = -.33; p < .05$). Those caregivers coping with the least amount of DAT patient functional change reported the least amount of cumulative burden ($r = .43; p < .01$), such that these caregivers reported the fewest effects on their lives from caregiving. This same relationship held for subjective burden ($r = .49; p < .01$), while the correlation between change in functional health and objective burden was only marginally significant ($r = .33; p < .05$). Change over time in DAT patient physical health was not associated with any of the caregiver variables.

Hypothesis 2: It was hypothesized that DAT patient need for supervision/vigilance would be positively correlated with caregiver depression, burden and emotion-focused coping.

Results supported hypothesis 2. Although only approaching significance, the behavioral problems score, which represents the DAT patient's need for supervision/vigilance, was associated with emotion-focused coping ($r = .38; p < .014$), such that those caregivers coping with more behavioral problems

reported more emotion-focused coping. DAT patient behavioral problems was strongly correlated with problem-focused coping ($r = .56; p < .001$). DAT patient behavioral problems was associated with cumulative burden ($r = -.57; p < .001$) such that caregivers of DAT patients with more behavioral problems (need for supervision/vigilance) were experiencing more burden. Further, subjective burden was associated with behavioral problems ($r = -.61; p < .01$) whereas objective burden was only weakly related ($r = -.34; p < .05$). A relationship between the DAT patient's need for supervision and caregiver depression was suggested ($r = .40; p < .05$), such that as behavioral problems increased, so did caregiver depression.

Hypothesis 3: It was hypothesized that DAT patient's need for assistance would be positively correlated with problem-focused coping and caregiver depression and burden.

There was partial support for hypothesis 3. The total ADL score, which represents the DAT patient's need for assistance, was associated with problem-focused coping ($r = -.39; p < .01$) such that those caregivers coping with DAT patients needing more assistance reported more problem-focused coping. The total ADL score was also associated with cumulative burden ($r = .57; p < .001$), objective burden ($r = .47; p < .01$), and subjective burden ($r = .55; p < .001$) such that caregivers caring for DAT patients with low needs for assistance reported the fewest effects on their lives from caregiving. DAT patient need for assistance was not related to caregiver depression.

Relationships among caregiver coping, depression and burden. In terms of the relationship between the coping subscales and caregiver depression and burden, patterns consistent with the coping literature emerged. Emotion-

focused coping was associated with caregiver depression ($r = .44; p < .01$) such that caregivers with more depression also reported more emotion-focused coping. Emotion-focused coping was also related to more subjective burden ($r = -.59; p < .001$), but was only weakly associated with increases in cumulative burden ($r = -.40; p < .05$) and not related to objective burden. Problem-focused coping was associated with more subjective burden ($r = -.52; p < .001$) and more cumulative burden ($r = -.43; p < .01$), but only marginally associated with more objective burden ($r = -.30; p < .05$). This indicates that those caregivers reporting more problem-focused coping were experiencing more effects on their lives from caregiving, primarily in the subjective dimension of burden. However, contrary to what would be expected based on the literature review, problem-focused coping was not associated with depression. The associations between acceptance coping and religious coping and caregiver burden were only marginally significant and only provide weak support for relationships. Acceptance coping was associated with cumulative burden ($r = .36; p < .05$) such that those caregivers reporting the fewest effects on their life from caregiving reported more coping through acceptance. Religious coping was weakly related to subjective burden ($r = -.33; p < .05$) such that those caregivers reporting more effects from caregiving in the subjective domain also reported more religious coping. Acceptance and religious coping were not associated with depression.

Changes over Time in Caregiver Coping,
Depression, and Burden

Very few subjects gave complete data for times four through six, therefore no statistical tests for change over time were conducted. Instead, measures of central tendency for times four through six for those subjects who completed all data collection were computed. However, because the sample sizes are small, these estimates may be unstable and the median values for these variables provide the best descriptive information. Descriptive statistics for caregiver variables for times four through six are summarized in Table 7.6.

For the caregivers with complete data for acceptance coping and religious coping ($n = 11$), no change occurred as the median score was 1.00 for time four through time six. These caregivers consistently reported frequent use of religious and acceptance coping. These caregivers reported moderate emotion-focused coping. Very little change occurred for emotion-focused coping ($n = 11$), with a slight increase in the median score from time five (.25) to time six (.50), indicating a slight increase in emotion-focused coping. There was no change in the median score for problem-focused coping ($n = 9$) from time four (0.00) to time five (0.00), but the median score increased markedly from time five to time six (1.00), indicating an increase in problem-focused coping. In terms of cumulative burden ($n = 11$), the median score demonstrated a slight decrease from time five (31) to time six (26), indicating a slight increase in cumulative effects from caregiving. The median score for depression ($n = 9$) showed no change from time four (30) to time six (30).

Table 7.6

Caregiver Variables: Change Over Time

Variable	Time 4	Time 5	Time 6
Coping (range 0-1.00)			
Emotion-focused coping			
\bar{x} (sd)	.386 (.342)	.273 (.236)	.432 (.318)
Median	.250	.250	.500
$n = 11$			
Problem-focused coping			
\bar{x} (sd)	.277 (.292)	.333 (.353)	.694 (.370)
Median	0.00	0.00	1.00
$n = 9$			
Acceptance coping			
\bar{x} (sd)	.818 (.229)	.939 (.135)	.939 (.135)
Median	1.00	1.00	1.00
$n = 11$			
Religious coping			
\bar{x} (sd)	.636 (.504)	.606 (.490)	.666 (.472)
Median	1.00	1.00	1.00
$n = 11$			
Cumulative burden (range 10-50)			
\bar{x} (sd)	30 (9.6)	31.82 (9.78)	30 (10.28)
Median	30	31	26
$n = 11$			
Depression (range 0-60)			
\bar{x} (sd)	31 (7.04)	30 (4.2)	30.78 (6.80)
Median	30	29	30
$n = 9$			

Summary

Those DAT patients with more needs for assistance tended to have caregivers who were problem-focused copers experiencing more total effects from caregiving (cumulative burden), particularly in the subjective dimension of burden. Those DAT patients with more needs for supervision/vigilance tended to have caregivers using both emotion-focused and problem-focused coping responses and experiencing more reported effects from caregiving (cumulative burden), particularly the subjective dimension of burden. Those caregivers coping with the least amount of DAT patient functional change reported the fewest effects on their life from caregiving (cumulative burden). In terms of the relationships among the coping subscales and caregiver depression and burden, emotion-focused coping tended to increase with caregiver depression and subjective burden. Caregivers using more problem-focused coping tended to report more cumulative burden, particularly subjective burden. Neither acceptance or religious coping were significantly correlated with caregiver depression or burden. Few changes in the ways of coping, caregiver depression, and cumulative burden were reported from time 4 to time 6.

Follow-up Interviews with Caregivers

This section reports the qualitative information gathered from caregivers during the follow-up interviews. The sample size for the qualitative data is very small as only fourteen caregivers agreed to participate in the follow-up interviews. First, examples of caregiving situations representative of this sample will be described in order to set the context for the analysis. Next, caregiver characteristics will be reported, including caregivers' perceptions of how their

stress changed when the DAT patient was placed out of the home. This will be followed by the caregiver's descriptions of what is most stressful about current caregiving and how they are coping. During the interviews, caregivers were asked about each of the coping responses on the 26 item coping questionnaire developed by Kiyak (1988), and this instrument formed the basis of the data collection for caregiver coping responses. The caregivers' perceptions relating to the effects of coping responses will be reviewed, as well as the caregivers' perceptions of the stability of their coping responses. Caregivers' recollections of whether health care providers discussed caregiver coping with them will be reported. Finally, these caregivers' opinions of the kind of help DAT caregivers need from professionals will be reviewed.

Caregiving Situations

The most common caregiving situation involved a wife caring for her husband. Table 7.7 summarizes descriptive information about the caregivers and their caregiving situations. Three caregiving situations will be described in more detail in order to set the context for the results of the qualitative analysis. Caregiver A is a 72 year old woman who lives with and cares for her husband, who was diagnosed with DAT nine years ago. Caregiver A sees herself as having been in the caregiving role for 11 years, however, because her husband began having symptoms such as memory loss, and mood and personality changes two years before he was diagnosed with DAT. Caregiver A reports that this two year period of time prior to diagnosis was extremely difficult, because she knew something was wrong, and felt that her physician did not take her concerns seriously; she also believes that knowing the diagnosis

Table 7.7

Descriptions of Caregivers and Their Situations

Age	Sex	Relation to DAT pt	Yrs of caregiving	Health	Who helps?	With what?	Pt resides
73	M	Spouse	8	"OK"; recent prostate surgery	Paid chore worker	Chores	at home
72	F	Spouse	9	"Ok" - heart disease, recent shoulder surgery	Paid help Son	Heavy chores Emotional support	at home
54	F	Daughter	5	"Good"	Husband, 2 sons	Chores, respite, emotional support	at home
56	F	Daughter	6.5	"Good"; high blood pressure	Friend	Monthly respite	at home
67	F	Spouse	10	"Good"	Daughter, daughter-in-law	Respite	at home
71	F	Spouse	5	"Good"; high blood pressure, peptic ulcers	Paid help	Heavy chores	at home
73	F	Spouse	3	"Ok"	3 children	Emotional support	at home
60	F	Daughter-in-law	7	"Good"	No one		n.h.
65	F	Spouse	7	"Ok"; peptic ulcers, depression	Friends	Emotional support	n.h.
53	F	Daughter	5	"Good"	Husband	Emotional support	n.h.
78	F	Spouse	9	"Poor"; stroke in 1987	Friends	Emotional support	w/oth family
70	F	Spouse	7	"Good"	No one		n.h.
75	F	Spouse	4	"Ok"	Son	Emotional support	n.h.
64	F	Spouse	6	"Ok"	Friends	Emotional support	n.h.

sooner would have reduced her stress. Caregiver A and her husband have three children. One son recently moved back in with them because of job changes. Caregiver A sees this as positive for her in the sense that her son provides her with emotional support and companionship, while at the same time having him home is negative for her in that at times, she feels she has more housework to do. Caregiver A's caregiving responsibilities involve managing all of the family legal and financial decisions, as well as all of the housework and upkeep on their home. Her husband can still do all of his own personal hygiene, but needs directions and instructions from her. Over the past six months, she has begun to worry about leaving him alone in the house, which has caused her to curtail her own activities such as painting classes and playing bridge. He has become more withdrawn interpersonally, and so it has become more difficult for them to do activities together as a couple. Other than her son at home, who helps her with caregiving by providing emotional support, the only other help she receives is a paid helper two times per month who does the heavy cleaning. Although Caregiver A considers her health to be "ok," she reports fatigue and arthritis pain currently, and in the past two years has had a heart attack, episodes of angina, and surgery on her shoulder. The most stressful aspects of caregiving for Caregiver A is the unpredictability of her husband's behavior. "Each day it can change . . . one day he's asking questions repeatedly and the next day he's very inconsiderate . . . it's the little things that are stressful . . . he's very independent and has been all his life--now he's withdrawn so he's much less sociable and this is upsetting . . . it's hard to see him go downhill . . . it's very sad."

Caregiver B is a 75 year old woman who cares for her husband, who was placed into a nursing home one and 1/2 years ago. Caregiver B's husband was diagnosed with DAT 4 years ago, but she reports that he had been having symptoms such as memory loss and personality changes for about a year prior to the diagnosis. The nursing home placement occurred after he fell and broke his hip; he was in a wheelchair and Caregiver B could not provide the physical care necessary. Caregiver B reports that adjustment to the nursing home placement has been "terrible" for her. For the first time in her life, she is living alone and she hates it. She reports that she is afraid at night and the evenings spent alone are very long. Caregiver B goes to see her husband every day. He requires total care. Every day she feeds, shaves and toilets him. She reports that he recognizes her, but does not recognize others. Caregiver B and her husband have one son, who lives 90 miles away, and visits once a month, providing her with emotional support. She does not receive any other assistance with caregiving. She feels her health is good, but she worries about what would happen to her husband if she became ill. The most stressful aspect of her current caregiving is the daily drive to the nursing home. The best nursing home she could find for her husband is 22 miles round trip on heavily traveled roads and she finds this drive very stressful. Caregiver B feels much better seeing her husband daily and helping to care for him because then "I know how he is doing." She worries about what will happen when she is no longer able to make this drive.

Caregiver C is a 56 year old widow who lives with and cares for her mother, and has done so for the past 6 1/2 years. Caregiver C's mother requires total care, with the exception that she can feed herself as long as

Caregiver C is supervising her; she is no longer mobile and is completely non-verbal. Caregiver C has one brother who lives about 15 miles away, but he doesn't participate in providing care for their mother. Caregiver C has three children who live in the area, who also do not help with caregiving as "they are busy and work." She reports that one daughter helps her with caregiving "rarely," by staying with the patient so Caregiver C can get out by herself. Caregiver C reports that she has a "terrific" network of friends who provide her with emotional support, and one friend who stays with her mother once a month, so that she can have some time away from caregiving. She receives no other assistance with caregiving. Caregiver C reports that there are two aspects of her current caregiving responsibilities that she finds very stressful: 1) the physical care is getting to be difficult for her, especially getting her mother in and out of the bath, and 2) being "tied down" by caregiving responsibilities which confines her to the home.

Caregiver Characteristics

Studies intended to identify variables associated with nursing home placement of DAT patients have found that it is caregiver characteristics, such as distress, burden and relationship to the patient, and not particular DAT patient symptoms, that tend to predict nursing home placement. These studies report that closeness to the patient tends to be negatively associated with nursing home placement, and if the caregiver were the adult child of the DAT patient, risk of nursing home placement increased (Colerick and George, 1986; Hirschfeld, 1983; Lund, Pett and Caserta, 1985; Steinberg, 1985). Variables

such as caregiver social support or health have not emerged as important predictors.

The qualitative data relevant to caregiver characteristics are reported here in terms caregivers providing home care versus out-of-home care in order to describe patterns that emerge in relation to where the caregiving occurs. In contrast to reports in the literature, the relationship of the caregiver to the DAT patient, or closeness to the DAT patient did not seem to be related to where the care was being provided. For those caregivers providing care out of the home, 5 were spouses, 1 was a daughter, and 1 was a daughter-in-law. For caregivers providing care in the home, 2 were daughters and 5 were spouses.

For the seven caregivers still living with the DAT patient, four described their health as "good," while three described their health as "ok." Five of these caregivers had someone providing at least one type of assistance: two reported chore workers helping, two had someone available to give them respite, and one reported having emotional support provided to them. Two caregivers reported multiple helpers helping with two caregiving tasks: emotional support and chores. Caregivers identified their helpers as paid chore workers, family members and friends. In response to the question "Who can you turn to when you need help for yourself?", three caregivers stated "no one," one caregiver responded "God," one caregiver stated "my friends and God," one caregiver said "my children," and one caregiver responded "my children and my friends."

Three of the seven caregivers whose relative had been placed out of the home reported their health as "good," three described their health as "ok," and one stated they had "poor" health. Four of these caregivers reported receiving

emotional support for caregiving from family and friends, but there were no other reports of caregiving assistance. Three of the seven caregivers felt no one helped with their caregiving. In response to the questions "who can you turn to when you need help for yourself?", two caregivers stated "no one," three caregivers responded "friends," one caregiver stated "God," and one caregiver stated "my husband." The caregiver who reported turning to her husband for help was providing care for her mother.

In summary, health was reported as slightly better for those caregivers still providing care in the home compared to their out of home caregiving counterparts. It also appeared that those caregivers providing care in the home were receiving slightly more help with caregiving tasks compared to the out of home caregivers. In terms of relationship to the DAT patient, closeness to the DAT patient did not seem to emerge as a pattern in relation to placement out of the home.

Caregiver Perceptions of the Effects of Out of Home Placement on Caregiver Stress

Caregivers gave a variety of reasons for the decision to place the patient out of the home for care. Two caregivers specifically stated that they themselves were too depressed to continue caregiving. One caregiver reported that she became physically ill due to caregiving, indicating that she had a stroke, due, in part she felt, to stress from caregiving. Another caregiver indicated that she could not provide the 24 hour supervision because of her own work and family demands. Two patients were placed because of wandering and agitation, and one of these patients became assaultive. Finally,

one patient was placed because his needs for physical care were too great for the caregiver to provide. The DAT patients had been out of the home for the following time periods prior to the interview: two for 3 years, two for 2 years, and one each for 8 months, 14 months and 3 1/2 years.

Only one caregiver felt that stress definitely improved after the patient was placed into a nursing home and in this situation, the caregiver was the patient's daughter and had been stressed by caring for her mother while managing her own home responsibilities. Most caregivers reported either the same amount of stress from caregiving or an increase in stress after the patient was placed out of the home. One caregiver who felt she was near suicide at the time of the nursing home placement felt that her depression definitely improved after placement, but that her level of stress remained the same because "now I run interference between (the patient) and the nursing home staff." Another caregiver who was being treated for depression at the time of placement reported that the first several months after placement were "terrible," with grief, depression, and physical illness. It has now been nearly two years since placement and that caregiver feels that only now is she beginning to recover from the depression. Similarly, another caregiver felt that stress from the physical demands of caregiving decreased and her own physical health improved after the patient was placed, but she experienced terrible grief and sadness at this loss, and her stress has been complicated by on-going conflicts about her husband's care with his two daughters, with whom he now lives.

Another caregiver reported increased stress after placement because of anger she felt at not having any control over the care her husband now receives and depression and grief because of the loss of his companionship. Along

these same lines, another caregiver reported an increase in stress after placement, due to the loss of her husband's companionship and the stress of living alone for the first time in her life. Finally, another caregiver reported a similar experience in that after her husband was placed into a nursing home, she experienced more stress and depression for the first 1 1/2 years after the placement, including stress due to supervising the care provided for her husband in the nursing home. Although at the time of the interview the patient had been in the nursing home for 3 1/2 years, this caregiver indicated that it had only been in the last six months that she felt that she could be less vigilant about supervising his care at the nursing home.

Caregivers' Reports of What They Find

Most Stressful about Caregiving

Even though most caregivers reported their stress level to be about the same after the DAT patient was placed out of the home, the particular aspects of caregiving found to be stressful were different for home caregivers compared to out of home caregivers. For those caregivers providing care in the home, caregiving tasks related directly to supervising the DAT patient tended to be reported as the most stressful aspects of caregiving. For those seven caregivers providing home care, three stated they were stressed by having to constantly watch or supervise the DAT patient because of fears the patient would wander or because of unpredictable patient behaviors such as unsafe smoking or alcohol consumption. Two caregivers reported that they had to keep their emotions under tight control because the DAT patient would get agitated or upset if there was stress in the home, and they found this to be

especially difficult. Those caregivers providing care in the home also reported feeling stressed by the following problems: handling all the legal and financial decisions, lack of sleep because the patient is often up during the night, inconsiderate patient behaviors, watching the patient "go downhill," the patient losing and misplacing things, and the patient never leaving the caregiver alone.

Those caregivers providing care out of the home reported more stress associated with caregiving tasks related to managing the DAT patient's care rather than direct provisions of care. For example, having to advocate for the patient and supervise the care provided by nursing home staff was reported by two caregivers as especially difficult. Other aspects of caregiving reported to be stressful for caregivers providing care out of the home included conflicts with other family members over type of care needed and the cost of that care, daily drives back and forth from the nursing home, and times when the patient did not recognize close relatives. Although relationship to the DAT patient seemed unrelated to nursing home placement in this sample, the configuration of the caregiver's family relationships may affect what the caregiver perceives as stressful. For two of these spousal caregivers, their marriage to the DAT patient was their second (for both spouses). One of these marriages had been fairly recent, but the other had been very long term. Even so, these two caregivers reported stress associated with conflicts or lack of support from the DAT patient's adult children. Finally, similar to caregivers providing home care, two caregivers reported making all the legal and financial decisions to be particularly stressful.

Caregiver Coping

The 26-item coping questionnaire developed by Kiyak (1988) formed the basis for the data collection for caregiver coping. In response to the question "how are you coping with the memory problems and disorientation of DAT," these caregivers reported using many of the responses on the 26 item coping questionnaire, and appeared to be coping in diverse ways. Caregivers were also asked about any ways they were coping that were not included on the questionnaire and two caregivers reported the additional coping response of seeking support from family members. Caregivers found that not all of their coping responses resulted in decreased stress, and some of their coping actually made them feel worse. Consistent with the quantitative analyses, this seemed especially so for emotion-focused coping, although three caregivers felt that problem-focused coping also increased their level of stress. This section will report caregivers' comments relating to the following ways of coping: emotion-focused coping, problem-focused coping, acceptance coping, religious coping, coping through denial or wishful thinking, coping through self-talk, and coping by attending a support group. Because only one caregiver was male and the majority of the DAT patients were male, the gender language in this section is not neutral. Results are reported with the assumption that caregivers are women and DAT patients are men. There did not appear to be differences in caregiver coping responses for caregivers providing care in the home compared to those providing care out of the home. Caregivers' perceptions of which ways of coping they used most frequently, the stability of these coping responses, and whether or not health care providers discussed their coping will be reported.

Emotion-focused coping. The following five items on the coping questionnaire were emotion-focused coping responses: got upset, got angry about the situation, got bitter about the situation, got resentful about the situation, and brooded or worried about it. The majority of the caregivers reported using some emotion-focused coping. Getting angry or getting upset were the most frequently reported emotion-focused coping responses (6 caregivers), followed by resentment (5 caregivers), bitterness (3 caregivers), and brooding/worrying (2 caregivers). Three caregivers did not report using any emotion-focused coping. Of the eleven caregivers reporting emotion-focused coping, five felt that experiencing and expressing their feelings helped them to feel better, while seven caregivers felt emotion-focused coping made them feel more upset and stressed, which typically called into play additional coping responses.

One caregiver stated that the coping with feelings of resentment caused her to "feel terrible, much worse, so then I tell myself how things could be worse and try to accept things the way they are," thereby coping with resentment by self-talk. Another caregiver stated "I feel bitter about the diagnosis; it's not fair, he was too young to have this happen . . . but when I feel bitter, I feel more upset so then I try to keep active and stay busy as much as I can," thereby coping with feelings by trying to do things to help herself feel better. Another caregiver reported coping by getting upset and angry: "When I feel upset I can't sleep, I feel restless and then I get angry and feel worse . . . nothing really helps so I just try to see it through, and I wish I could not be involved emotionally . . . just put it out of my head." This caregiver coped with her feelings by wishing she could change the way she felt.

Another caregiver coped by feeling angry, bitter and resentful: "I feel very guilty when I get angry and then I feel much worse . . . I try not to think about it and then I also thank God for the good things, like my health, and tell myself things could be much worse for me." This caregiver's coping through anger, resentment and feeling bitter called into play coping through self-talk, religion, and denial. Another caregiver reported coping by getting angry: "I get really angry, especially when he won't leave me alone, but I try not to express it, because then he'll get upset, too . . . trying not to show my feelings causes me more stress, so I just try to accept things, no matter what his behavior is" (coping by trying to accept the situation). Another caregiver coped by getting upset, which affected her by making her feel guilty "then I cry a lot and a good cry releases the tension for me, but doesn't really help me feel less stressed."

One caregiver coped by getting upset, angry, bitter and resentful, and felt coping in this way lessened her stress. "I am a very emotional person . . . I always have been. Expressing my feelings makes me feel better because I feel like I can move through it and even though sometimes I feel a little guilty about my feelings, expressing them almost always makes me feel better." Another caregiver who coped by getting angry and resentful felt that these coping responses helped by lessening her stress. "Feeling these feelings makes me feel better because I can identify what I'm upset about, and then act on it . . . I also get rid of the feelings by talking it out or writing in my journal." A similar experience was reported for a caregiver coping by getting upset and resentful "this definitely makes me feel better . . . letting out my feelings lets me get on with things . . . I don't stew . . . if I didn't get upset I'd feel worse." Similarly, one caregiver who coped by getting upset stated "getting upset helps me feel better

because I can get rid of the feelings . . . anyone would get upset over this . . . it's not good to hold your feelings in." This same caregiver also reported coping by brooding/worry "I worry about finances . . . but at least when I worry, I can usually figure out a plan to solve the problem." Along the same lines, coping with getting upset and angry was experienced by this caregiver in a positive way by "getting upset and angry is like an outlet for me, like a release . . . I feel less stress after I get upset." This caregiver also coped by brooding and worry, but felt "brooding doesn't really help . . . it doesn't make me feel worse, but I don't think it really helps me feel any better." These last two subjects report responses that suggest different effects from anger and upset, compared to brooding and worry.

Those caregivers using emotion-focused coping and judging their coping to be effective insofar as it decreased their stress seemed to value emotional expression itself. They viewed their feelings as a normal and natural response to their level of stress from caregiving. However, some caregivers who valued expressing anger or upset also acknowledged negative effects or no effect when coping through brooding or worrying. Age appeared unrelated to the caregiver's perception that emotion-focused coping responses were positive: their ages ranged from 53 to 73 years. How then do these qualitative data relate to the quantitative findings, which indicate emotion-focused coping to be significantly related to increases in caregiver depression and subjective burden? Those caregivers who perceived their emotion-focused coping to be positive also had time six scores on the CES-D indicating moderate to severe depression, and time six scores on the burden measure indicating moderate to high levels of burden. Those caregivers using emotion-focused coping, but

judging this coping to be ineffective by increasing their stress, tended to try not to express their feelings. Their emotion-focused coping tended to produce increased stress, which called into play additional coping by acceptance, denial, religion, trying to keep busy or self-talk. These caregivers had depression and burden scores in the time six dataset indicating mostly moderate depression and moderate burden. It may be that those caregivers who perceive emotion-focused coping as helpful are more emotional in general, and it is this "emotionality" that accounts for the relationship between emotion-focused coping and depression and burden.

Problem-focused coping. The following items on the coping questionnaire comprised problem-focused coping responses: felt inspired to solve the problem, came up with a creative solution to the problem, came up with a couple of different solutions to the problem, changed something about yourself in an attempt to solve the problem, did something totally new to solve the problem, and read books/newspaper or magazine articles to learn how to deal with the problem. Problem-focused coping was reported by all but one caregiver. Thirteen caregivers reported coping by reading books/newspaper or magazine articles, ten caregivers reported coping by coming up with a couple of different solutions, nine caregivers reported feeling inspired to solve the problem, seven caregivers reported coming up with creative solutions, and two caregivers reported doing something totally new to solve the problem. The majority of the caregivers reported that their stress was decreased through problem-focused coping, but three caregivers gave examples of problem-focused coping making them feel worse, and three caregivers felt their problem-focused coping had no effect on their level of stress.

Those caregivers who reported increased stress through problem-focused coping gave the following examples: "It seemed like even though I kept trying different ways to get him to stay in one room, he kept following me around the house--nothing I tried helped and this made me more angry and upset." Another caregiver stated "the more I tried to come up with different ideas to keep him from misplacing things, the worse I felt because nothing worked--I got more frustrated and felt like my spirit was crushed." Another caregiver coped by reading a book about DAT and stated "it scared the hell out of me . . . I wanted to put my head in the sand . . . knowing what would come later on made me more worried and upset." The caregivers who reported that problem-focused coping didn't seem to help but also didn't hurt offered the following comments: "I came up with lots of ideas about how to help with reminders about the time and date, but nothing really worked, so it didn't really help, but at least I tried, that helped me to accept things." "At the beginning, I read everything I could get my hands on about DAT, and it helped at first, but now it makes me feel sad, because there really isn't any new information out there." "Getting information helped me get ideas about how to deal with the problems and that helped, but thinking about the future and what I can expect makes me worry more."

Most caregivers believed their problem-focused coping decreased their level of stress. Several caregivers made comments about how their problem-focused coping promoted feelings of control, success and acceptance, and decreased feelings of helplessness, guilt, and self-blame. "When I get all the information I can, then I feel like I can make good choices, and then I feel a lot less helpless." "I read all the current research, and this gives me ideas about

what needs to be done and then I don't feel so hopeless . . . I can also analyze why he is behaving the way he is . . . I feel a lot more in control." "I've always been a problem-solver, and coming up with different approaches can be kind of fun sometimes." "When I know I've tried all the different solutions I can think of, than I feel better because it's easier to accept the way things are." "Learning about the illness made me feel better because then I didn't feel so guilty, and I can remind myself how sick he is, and how he can't help how he is." These last two comments illustrate how a problem-focused approach, even if solutions fail, seemed to help caregivers accept their situation.

Acceptance coping. The following three items on the coping questionnaire represent acceptance coping responses: accepted the situation, refused to let it get to you, and made the best of it. Acceptance coping was reported by all but two caregivers, and caregivers reported that acceptance coping tended to decrease the stress they felt. None of the caregivers reported that acceptance coping made them feel worse. Twelve caregivers reported coping by making the best of the situation and accepting the situation, while seven caregivers reported coping by refusing to let it get to them. Many of the comments made by caregivers, throughout the interview, suggested that acceptance was more of a desired outcome, rather than a means of coping to decrease stress.

Several caregivers reported that coping through acceptance helped in terms of keeping them from getting upset. "I try to live by the rule that if you can't change something, then just try to forget about it and go on . . . there's nothing else you can do . . . when I saw that I couldn't keep the house up on my own, I just accepted it and sold it, that kept me from getting upset." "It takes a

lot less energy to accept things the way they are—I don't have any choice, so I have to accept it, and then I can move on and do the things I have to do."

"What else can I do? Accepting the situation keeps me from getting angry and bitter." "Not accepting things would make me feel a lot worse . . . besides, I don't have any choice . . . I have to go on, and I have to take care of myself and keep active." "I think acceptance keeps me from moaning and groaning about my situation." "I remind myself to accept things the way they are because things could be a lot worse."

Caregivers also reported coping by "making the best of the situation" and "refusing to let it get to me" by including the DAT patient as much as possible and by keeping active and busy themselves. "I try to keep really busy, and keep to a regular daily schedule as much as I can and include him as much as I can." "I make the best of it by trying to take care of myself—keeping my hair done, dressing nicely, and keeping the house nice." "I try to make the best of it by trying to ignore the situation by keeping busy and this helps keep my mind off of it." "I refuse to let it get to me by distracting myself—I keep very busy and keep active no matter how I feel." "I try to accept reality and I try to keep it to myself, and not talk about it with anyone, so I guess I won't let it get to me by trying not to talk about it." Keeping busy, distracting oneself, and caring for one's own needs were ways that caregivers tried to accept their situation and make the best of it. Acceptance of one's situation appeared to be a desired outcome of other types of coping. For example, coping with problem solving was perceived by many caregivers as helping them with acceptance because of feeling they had done all they could.

Religious coping. The following five items on the coping questionnaire represent religious coping responses: this experience renewed your faith in God or religion, this experience gave you new faith, turned to religion/prayer, sought help from religion or God, and sought spiritual strength. Thirteen of the fourteen caregivers reported using religious coping, and all of these reported that religious coping helped them to feel less stress. Twelve caregivers reported coping through prayer, nine caregivers reported coping through religion or God, eight caregivers reported seeking spiritual strength, seven caregivers reported a renewal of faith, and four caregivers reported developing new faith.

Caregivers offered the following comments related to coping through prayer: "I am always having a conversation with God, but I do pray more when I feel upset and I find this very comforting." Another caregiver who also felt prayer was like a conversation with God felt prayer gave hope. "I trust in prayer because I know when I ask for help, it will be there for me." "I pray every day, I ask for guidance, but I also give thanks. "Prayer releases me and gives me a sense of calmness." "I pray for patience, and then I feel better." "I pray every day and this helps me feel more positive about myself." "I pray and then I feel a connection to God, and I don't feel so alone." "Talking to God every day makes me feel less alone." "Even though sometimes I feel that God has abandoned me, I meditate and then I feel less alone." These comments indicate that prayer provides a sense of calmness and hope, as well as a feeling of support from the relationship with God. Although most caregivers using prayer as a coping response tended to report increased prayer in response to stress, three caregivers reported that they had always had a private prayer or meditation

ritual, and that their prayer was unaffected by the amount of stress they experienced.

The following comments illustrate caregiver coping through faith, turning to religion, or seeking spiritual strength: "I asked the prayer group from the church to pray for us, and it helps me to know that they are also praying." "My faith has a calming effect on me . . . I see caregiving as an act of love for God." "I am working out my own theology, my own personal spiritual philosophy, and this helps me to accept this situation." "My faith gives me strength . . . I feel better when I realize how much I rely on God. Sometimes I think of Bible verses that help me see how what I am doing is both a duty and a privilege. I do a lot of religious reading, too, and this helps me carry on." "It gives me a feeling of security knowing the Lord will take care of us." "I believe I am here to live this experience, and this gives me a meaning behind what is happening and always helps me to feel better." "It helps me to see that I am serving God by doing this (caregiving)." These observations imply that coping through religion and spiritual strength provides a sense of meaning for these caregivers.

Only two caregivers spontaneously offered that attending formal church activities or meeting with their minister were ways they sought help from religion or God. "I've gotten much more involved in the church . . . the warmth and support of the people there has really helped and this has also made my faith stronger." "I see my minister regularly, and then I feel more support." Church attendance in this sample of caregivers varied a great deal, and did not seem related to the use of prayer or informal religious activities. Four caregivers attend church services weekly, one caregiver attends twice monthly, two caregivers reported "occasional" church attendance, two caregivers reported

attending services two times in the past year, and five caregivers had not attended church at all in the previous two years. Since only one caregiver in this sample did not report using any religious coping, it is difficult to comment on how age may influence religious coping. However, that one caregiver was the youngest caregiver (53 years of age) in this sample.

Coping through self-talk. One of the items on the coping questionnaire related to self-talk: told yourself things to cope with the problem. Nine caregivers reported coping in this manner, and similar to religious coping, and acceptance coping, all of the caregivers felt that coping through self-talk lessened their stress. Caregivers tended to remind themselves of the positives in their situation, or remind themselves to accept the illness. For example, one caregiver stated "I tell myself things could be a lot worse." Another caregiver reported "I remind myself of all the positives--at least we can still do things together and I still have my health." Another caregiver stated "sometimes I just tell myself to calm down, and this seems to help." Additional comments were "I remind myself how much better I am doing with coping." "I tell myself 'this won't go on forever.'" "I remind myself that he can't help the way he is, and that makes me feel better."

Coping through denial or wishful thinking. Five items on the coping questionnaire related to coping through denial or wishful thinking: wish you could change the way you felt, refused to believe it had happened, hoped a miracle would happen, just waited for the problem to work itself out, and wished that the problem would solve itself. Five caregivers reported coping by waiting for the problem to work itself out, and two of these felt that this was the same for them as accepting the situation. One caregiver reported waiting for the problem

to work itself out was a successful way to deal with temper outbursts. Another caregiver stated "waiting for the problem to work itself out, that's like ignoring it, I do that sometimes and it helps, I just tell myself 'don't think about this today'." Two caregivers felt that waiting for the problem to work itself out was "waiting for death . . . it will be a blessing when he dies." Four caregivers reported wishing they could change the way they felt. Three caregivers had this reaction to feeling angry, while one caregiver wished "I wasn't so emotionally involved." Four caregivers reported "wishing the problem would solve itself," and all of these caregivers stated that they knew this was not realistic, yet still found themselves with this thought. None of the caregivers coping with denial or wishful thinking felt that coping in this manner had any negative consequences for them, but only two caregivers thought these coping responses were helpful in reducing their stress.

Coping through participation in a support group. Only one caregiver was currently attending a support group for caregivers, and this individual stated "the first one or two times I went I didn't like it at all, but after I got to know a few of the people, I got a lot of support and information, it's been very helpful and I still attend." Seven caregivers had attended groups in the past. Of these seven caregivers, five found the groups helpful, while two caregivers felt more upset after attending: "I went just once and didn't go back because hearing about everyone else's problems made me feel worse." "I went to meetings for about six months but I finally quit because I found them too depressing." The five caregivers that found the support groups helpful had the following comments: "I stayed in the same group for four or five years and the support was wonderful--I'd like to find another support group." "Going to the group was a

good place to let off steam and that always helped me feel better." "The information other people had really gave me good ideas." "Going to the group made me feel less isolated." "I only went to two groups, but I got information about DAT and that helped me." Although just two of the six caregivers who had a positive response to a support group were caregivers who reported that emotion-focused coping decreased their stress, the two caregivers who had a negative response to a support group were both caregivers who perceived emotional expression as negative for them by making them feel worse. Six caregivers had never attended any support groups and of these, three caregivers stated the reason for not going was not wanting to hear others' sad stories. Other reasons for not attending support groups were not having anyone to stay with the DAT patient, inconvenient meeting time and location, and already having enough information and support.

Six most frequently reported coping responses. Caregivers were asked to identify their six most frequently used coping responses in coping with the memory problems and disorientation of DAT. Table 7.8 lists those coping responses caregivers reported as their six most frequent responses. Four of the top six coping responses were religious coping items. Accepting the situation was reported in the top six by 11 (78.5%) caregivers, seeking help from religion or God was in the top six for 8 (57.1%) caregivers, seeking spiritual strength was in the top six for 7 (50%) caregivers, prayer and reading books/newspaper or magazine articles to learn how to deal with the problem were in the top six for 6 (42.8) caregivers, and renewing faith , refusing to let it get to you, making the best of it, telling yourself things to cope with the problem,

Table 7.8

Most Frequently Reported Coping Responses

Accepted the situation	11 (78.5%)
Sought help from religion/God	8 (57.1%)
Sought spiritual strength	7 (50.0%)
Turned to religion/prayer	6 (42.8%)
Read books/newspaper or magazine articles to learn how to cope	6 (42.8%)
Renewed your faith in God	5 (35.7%)
Refused to let it get to you	5 (35.7%)
Made the best of it	5 (35.7%)
Told yourself things to cope	5 (35.7%)
Gave yourself encouragement, support, things to feel better	5 (35.7%)
Changed something about yourself	4 (28.5%)
Came up with a creative solution	3 (21.4%)
Came up with a couple of different solutions	3 (21.4%)
Got upset	2 (14.2%)
Got angry	2 (14.2%)
Got support from family	2 (14.2%)
Got bitter	1 (7.1%)
Got resentful	1 (7.1%)
Brooded, worried about it	1 (7.1%)
Felt inspired to solve the problem	1 (7.1%)
Just waited for the problem to work itself out	1 (7.1%)

and giving yourself encouragement, support, or things to feel better about the situation were in the top six for 5 (35.7%) caregivers.

Six caregivers included at least one emotion-focused coping response in their six most frequently used coping responses. Again, age appeared unrelated to the frequency of emotion-focused coping as these six caregivers age ranged from 54 to 73 years. These six caregivers were coping with diverse caregiving situations, but were coping with similar DAT patient behaviors. Five caregivers were providing care for a DAT patient with the following unpredictable and difficult to manage behaviors: unsafe smoking, wandering, alcohol consumption, agitation with verbal threats, temper outbursts, defecating/urinating in inappropriate places, and poor judgement with denial of memory problems. Three caregivers were providing care after their relative had been placed out of the home. Finally, one caregiver was providing care for a DAT patient who required nearly total care and could not respond appropriately to interactions with other people. Although the majority of these caregivers (10) included religious coping items in their top six coping responses, four caregivers did not. This is too few to assess an age cohort influence, but two of these four caregivers were the two youngest in this sample (age 53 and 54 years), while the other two caregivers were older (age 67 and 75 years).

Stability of coping responses. Caregivers were also asked to look at their top six coping responses and to comment on whether they have used these coping styles during other times of high stress and at other times in their lives. Eleven of the fourteen caregivers felt their coping responses had been stable and consistent for other stressful events during their lives. For those three caregivers who did not feel their coping responses were stable and consistent,

one caregiver felt that her coping had evolved over time, another reported that nothing she had ever coped with in the past came close to the catastrophic nature of coping with DAT, and the other caregiver felt that it had only been recently that she had learned to cope by expressing her feelings.

Although the qualitative interview focused on coping responses in the here and now, four caregivers spontaneously commented on coping responses they had used earlier in the course of their relative's illness. For example, one caregiver responded with emotion-focused coping initially "I brooded quite a bit, especially in the very beginning." Similarly, another caregiver stated "at first I tried not to let it get to me by trying to keep up with all of my usual activities, but then I became very resentful, and had to try to just accept things." Two caregivers reported coping by seeking information. "I read a lot at first, and that helped me to plan for the future and know what to expect." One caregiver coped with wishful thinking "at first I hoped for a miracle, but not anymore." These comments give some support to the idea that emotion-focused coping and passive coping such as wishful thinking are evoked in the early stages of adaptation to a chronic illness. However, two caregivers also coped with the initial diagnosis by active coping through obtaining written information about the disease.

Four caregivers had complete responses to the coping questionnaire available in the dataset for time 6. The time 6 data were collected approximately two years prior to the follow-up interview. These four caregivers' qualitative responses in relation to their most frequently used coping responses tended to be consistent with their time 6 coping subscale scores. For example, one subject who reported coping primarily with acceptance and problem-focused

coping had time 6 scores of 1.00 for acceptance and .75 for problem-focused coping. Another subject who reported coping mostly with emotion-focused coping and acceptance had scores of 1.00 for emotion-focused coping and .67 for acceptance. Therefore, those caregivers with complete coping responses for time 6 in the dataset seemed to reflect the stability of their coping over time.

Do health care providers talk to caregivers about coping? Only half of these caregivers reported that health care providers had ever talked with them about their own coping with DAT. When asked about who had talked with them about their own coping, one caregiver reported that a psychiatrist had discussed this with her. The other six caregivers stated that all of the health care providers involved expressed concern for them and asked them how they were coping. No particular health care discipline was identified by these caregivers.

What Types of Services

Do Caregivers Say They Need?

Caregivers gave diverse answers to the open-ended question "based on your own caregiving experiences, what do caregivers need the most from professionals?" Table 7.9 summarizes these responses. The most frequent response was respite, sitters or day care, with six caregivers giving this response. However, many caregivers indicated the need for more psychosocial support. For example, five caregivers indicated that they needed caring and support and two caregivers requested help in coping with their feelings. Two caregivers felt that professionals should give permission for caregivers to get angry and encourage them to get their feelings out. Comments included "the

Table 7.9

What Caregivers Need Most from Professionals

Respite/sitters/day care	6 (24.0%)
Psychosocial interventions	
Caring and support	5 (20.0%)
Validation/praise	1 (4.0%)
Respect for individuality	1 (4.0%)
Help caregiver express anger/get feelings out	2 (8.0%)
Help caregiver cope with feelings	2 (8.0%)
Discuss religion/philosophy of life	2 (8.0%)
Don't make simple suggestions to difficult problems without understanding caregiver's problems	1 (4.0%)
Care planning	
Encourage early respite and nursing home placement	1 (4.0%)
Help with future planning	1 (4.0%)
More discussions about patient condition	1 (4.0%)
Health care professionals need more training and education about DAT and caregivers' experiences	2 (8.0%)

individuality of the caregivers has to be respected." "Someone needs to praise and validate the caregiver for what they are doing." Yet another caregiver stated "don't try to make simplistic and unrealistic suggestions about how to solve problems, without understanding what we go through." Two caregivers felt that professionals needed to help caregivers with accepting the illness, in part by talking to caregivers about their philosophy of living and discussing their religious beliefs with them.

Caregivers also indicated they need help with planning for the future. One caregiver specifically stated help to plan for the future was needed, and a second caregiver stated that caregivers should be encouraged to seek respite and nursing home care early, so that their love for the patient could be preserved. Another caregiver commented that families need more follow-up information and discussion about the patient's condition. Finally, two caregivers commented that professionals, particularly family practice physicians and general practitioners, need more training and education about DAT and the caregiving experience.

Summary

The most common caregiving situation involved a wife providing care for her husband. These caregivers had been providing care over a long period of time, with an average of 6.7 years in the caregiving role. Half of these caregivers were providing care after the DAT patient had been placed out of the home. These caregivers perceived their stress to either increase or stay the same after placement of the DAT patient out of the home. It appeared that those caregivers still providing care in the home perceived their physical health

as slightly better and reported more help with caregiving tasks compared to their out of home caregiving counterparts. In terms of the specific aspects of caregiving found to be stressful, handling all legal and financial decisions was reported as difficult for both in home and out of home caregivers. The out of home caregivers reported stress associated with managing the provision of care for the DAT patient, whereas the in home caregivers reported stress associated with day to day caregiving tasks such as supervising the DAT patient.

A primary theme emerging from the qualitative data is that these caregivers are coping in diverse ways, utilizing multiple coping responses, and perceive their coping styles to be stable over time and across other difficult life experiences. However, they also indicated that coping with the memory and disorientation of DAT and the total caregiving experience is unique, and requires that professional helpers carefully assess each caregiver's individual experience before providing suggestions for their support. Their comments also illustrate the interactive nature of coping responses, that is, the effects from the use of one coping response can call into play additional responses. For example, coping by becoming angry produced more stress for some caregivers, and this tended to call into play additional coping, through acceptance for instance, in response to their increased stress. Comments suggest that caregiver's perceive acceptance to be more of an outcome, than a way of coping to minimize stress. Emotion-focused coping was not consistently perceived by these caregivers as increasing stress. It appears that those caregivers who value emotional expression tend to perceive emotion-focused coping as decreasing their stress. Problem-focused coping was perceived by these

caregivers as helpful in that it promoted feelings of control, rather than because solutions were effective. Those caregivers who perceived their problem-focused responses as increasing their stress saw this as a result of solution failure, to which they responded with emotion-focused coping responses.

Religious coping and coping through acceptance emerged as commonly used coping responses that were perceived as decreasing the caregivers stress. The use of religious coping behaviors appeared to be unrelated to formal church activities or church membership. Caregivers perceived their religious coping to be helpful through providing a sense of meaning and order to their experience, and a sense of support derived through their relationship to a deity. Acceptance was viewed as a necessity by these caregivers: something that must occur and a key to maintaining their mental health. Some caregivers found themselves coping through denial or wishful thinking, but felt coping in this way was neither helpful or detrimental. Coping through self-talk, however, was another frequently used coping response which caregivers perceived as helpful.

Coping by attending a support group for caregivers was a strategy used by half of these caregivers, and of these, the majority judged the groups to be helpful. However, those that dropped out of the group did so because they felt hearing others' "sad stories" made them feel more depressed. These same caregivers judged emotion-focused coping as detrimental since it increased their stress. Yet many of these caregivers want health care providers to talk with them about their coping, and perceived themselves as in need of other kinds of psychosocial interventions, such as empathy, respect, and caring. Only half of these caregivers reported that health care workers discussed their

coping with them. Again, the need to individually assess each caregiver's experience and needs for support arises as an important theme. These caregivers want support, but the manner in which it is provided may differentially affect them. For example, support given in a group situation may not be the best approach for all caregivers. Similarly, promoting problem-focused coping may not be helpful for all caregivers, and for those caregivers who value emotional expression, encouraging emotion-focused coping responses could be of value.

Chapter Eight

Discussion

Introduction

This chapter will discuss the results of the study. First, patterns in the results that support the study hypotheses will be discussed. The results will then be reviewed in relation to the literature review, including caregiver coping, religious coping, and coping and adaptation in general. Next, the limitations of the study will be reviewed. Implications of the results for social welfare policy and practice will be discussed. This discussion will encompass suggestions for provisions of support services to caregivers. The chapter will conclude with suggestions for further study based upon the results of this research.

Discussion of Results

Study Hypotheses: Specific DAT Patient

Characteristics and Caregiver Outcomes

Although this study was primarily descriptive, where possible, attempts were made to detect relationships supportive of the study hypotheses. An alpha of $p < .01$ was required for significance. Associations with p -values of $< .05$ were considered to be marginally significant. Although the hypotheses imply that specific DAT patient behaviors produce particular types of coping and negative consequences of caregiving such as depression and burden, correlations can only identify associations, and cannot be considered as tests that can support a temporal order to these relationships.

The hypotheses are based upon the coping and adaptation conceptual framework of the study, the person-environment interactive model of coping. This model predicts that the situational characteristics of the caregiving context and the caregiver's appraisal of the stressful caregiving events will be the primary determinants of caregiver coping responses. Therefore, caregivers coping with DAT patient problems that are not amenable to problem-focused coping will likely cope with emotion-focused responses. Additional rationale for the study hypotheses comes from the caregiver coping literature, since emotion-focused coping responses have been associated with deficits in caregiver well-being.

h₁ Rapid rates of decline in DAT patient's cognitive, functional and physical health will be positively correlated with caregiver depression, burden, and emotion-focused coping.

This hypothesis was only partly supported by the results. Rapid rates of DAT patient physical decline were not significantly correlated with any of the caregiver variables. This is in part due to the presence of very little change over time in DAT patient physical health. Rapid rates of cognitive decline were only marginally significantly associated with the presence of problem-focused coping in the caregiver, and were not associated with the other caregiver variables. This finding was unexpected. Rapid cognitive decline was thought not to be amenable to coping intended to change or control symptoms, thereby evoking coping intended to manage feelings aroused by the decline. This finding may be explained, however, by results from the qualitative analyses since those caregivers who used problem-focused coping tended to perceive their coping

as providing themselves with a perception of control over the patient symptoms, rather than actual control of the symptoms. Alternatively, it may be that it is the here and now effect of cognitive dysfunction, rather than the rate of cognitive decline, that influences caregiver coping, depression and burden. Although not part of the original study, this hypothesis was tested by correlating the total score on the DRS at time four with caregiver coping, depression and burden at time four. Interestingly, cognitive dysfunction was significantly related to acceptance coping ($r = .45; p < .01$) such that those caregivers coping with DAT patients with the least amount of cognitive impairment were using more acceptance coping. Cognitive dysfunction was also significantly related to cumulative burden ($r = .50; p < .01$) and subjective burden ($r = .46; p < .01$), such that those caregivers coping with DAT patients with less cognitive dysfunction experienced less cumulative and subjective burden. These findings suggest that it is what the caregiver experiences in the present, and not rate of change over time, that influences caregiver coping and burden.

The relationship between greater DAT patient functional decline over time and caregiver burden demonstrated some support for hypothesis 1: greater functional health decline was correlated with more burden, especially in the subjective dimension, but not related to emotion-focused coping or caregiver depression. Again, it would appear that it is the current ADL functioning, rather than how it may have changed over time that exerts an influence on caregiver coping and depression. The relationship between DAT patient need for assistance (the total ADL score) and caregiver coping, depression and burden is discussed in the section describing support for hypothesis 3.

h₂ DAT patient need for supervision/vigilance will be positively correlated with caregiver depression, burden and emotion-focused coping.

This hypothesis was partially supported by the results. DAT patient need for supervision/vigilance was only marginally significantly associated with increases in emotion-focused coping and caregiver depression, suggesting that those caregivers caring for a DAT patient with many behavioral problems experience more emotion-focused coping and depression. DAT patient need for supervision/vigilance was associated with problem-focused coping. This result is surprising, since it would be expected that behavioral problems would not be amenable to problem-focused coping such as attempts to change or control them. Again, the explanation for this result may lie in the qualitative data as caregivers appear to experience a perception of control via problem-focused coping. Those caregivers coping with DAT patients with more needs for supervision/vigilance also reported cumulative burden. When the objective and subjective dimensions of burden were assessed separately, only subjective burden was significantly associated with DAT patient need for supervision/vigilance. Overall, these results are only somewhat consistent with the notion that behavioral problems are unpredictable and more likely to call into play emotion-focused coping responses and caregiver burden, but not depression.

h₃ DAT patient's need for assistance will be positively correlated with problem-focused coping and caregiver depression and burden.

As expected, those caregivers caring for DAT patients with more needs for assistance also reported more problem-focused coping. This is consistent with

the idea that coping with patients who require functional assistance evokes coping intended to change or manage the problem situation directly. Interestingly, DAT patient need for assistance was strongly associated with cumulative burden ($r = .57; p < .001$), more so in the subjective dimension ($r = .55; p < .001$), than the objective dimension ($r = .47; p < .01$). This is somewhat surprising since providing functional assistance has been linked to caregiver burden in objective aspects such as time to oneself, time for recreation, and time for socializing. Generally, those caregivers caring for DAT patients with low needs for assistance reported the fewest effects on their lives from caregiving. Again, these results suggest that it is the here and now effects of the current functional disability, rather than the effects from change over time in functional disability, that strongly influences caregiver coping, depression and burden.

Caregiver Coping with DAT and the Caregiving Experience

Results are consistent with the caregiver coping literature in many ways, providing additional evidence to support the existing knowledge base, but from a sample of caregivers who are not already engaged in the process of "help-seeking" through their attendance in support groups. However, this sample of caregivers could be conceptualized as "actively coping" by nature of their participation in research studies on DAT, since many of these caregivers were referred to the original study after completing previous studies on DAT. Consistent with the literature on the negative effects from caregiving, those caregivers with their loved one placed outside of the home were still

experiencing stress from caregiving. In particular, caregivers reported feeling stress due to managing and supervising the care of the DAT patient. Bowers (1988), in a study of family caregiving in nursing home settings, found family caregiving responsibilities in nursing homes to be much more complex and extensive than what would be indicated by visible tasks. Bower's (1987) results indicated that family members attributed responsibility for the performance of most caregiving tasks to the nursing home staff, but held themselves responsible for monitoring and evaluating the effectiveness and quality of both technical and nontechnical caregiving tasks. Bowers (1987; 1988) hypothesizes that family caregiving is a complex process involving more invisible processes, such as those that are protective and preservative in function, rather than observable caregiving tasks like hands-on instrumental care. Results from this study support Bower's (1987; 1988) hypothesis.

Consistent with the literature on caregiver coping with DAT, emotion-focused coping was correlated with more caregiver depression and subjective burden. These findings are consistent with the results reported by Coppel et al. (1985), Wright et al. (1987) and Myers and Pruchno (1987). Emotion-focused coping was not associated with objective burden, which demonstrates the importance of assessing dimensions of burden separately. However, the qualitative results suggest that emotion-focused coping may be experienced as producing more stress primarily for those caregivers who do not value emotional expression and perceive their emotions as "bad" in some way. This finding may have relevance for support group attendance: those caregivers who value emotional expression may have the most positive effects from support groups. Even so, qualitative data pertaining to perceived helpfulness of

emotion-focused coping for some caregivers showed little relevance to the presence of caregiver depression in the time six dataset. It was suggested that those caregivers using more emotion-focused coping, while perceiving this as helpful, may experience significant amounts of depression and burden, and that this may be related to "emotionality."

Escape/avoidance coping as described in the literature review is similar to what is reported in the qualitative analysis to be coping through denial or wishful thinking. Pratt et al. (1985; 1987), Wright et al. (1987), and Stephens et al. (1988) report escape/avoidance coping to be associated with negative caregiver outcomes, yet the qualitative data do not support this relationship. Caregivers reported no effects, positive or negative, on their level of stress because of coping through denial or wishful thinking. Similarly, passive coping responses have been linked to negative caregiver outcomes (Pratt et al., 1985; 1987). Coping through denial and wishful thinking may be considered similar to passive coping responses and the qualitative analysis is not consistent with Pratt et al. (1985; 1987), since caregivers reported no reductions in their stress because of coping through denial or wishful thinking.

Problem-focused coping has been reported to be associated with caregiver well-being and fewer depressive symptoms in the caregiver (Coppel et al., 1985; Wright et al, 1987; Myers & Pruchno, 1987). Results from the statistical analysis partially support these findings. Caregivers reporting more problem-focused coping also reported more cumulative burden, in both the objective and subjective dimensions, however, depression was unrelated to problem-focused coping. The qualitative analysis does tend to be consistent with the other studies reviewed since most caregivers perceived their problem-

focused coping to be helpful in reducing stress. Of interest are the caregivers' comments relating to how problem-focused coping reduced stress by promoting the caregiver's perception of control. This perception is similar to the concept of self-efficacy, which is also reported to be associated with increases in caregiver morale and decreases in caregiver depression (Zeiss et al., 1987; Lovett and Gallagher, 1988).

Acceptance coping has been reported to be associated with lower levels of caregiver burden (Meyers and Pruchno, 1987). Support for this finding was weak in the current study, since the relationship between acceptance coping and burden was marginally significant. However, the qualitative results support caregivers' perceptions of the positive effects from coping through acceptance since this was a frequently used coping strategy. In fact, all the caregivers using acceptance coping judged it to be effective in reducing their stress. Further, caregiver comments suggested that acceptance was a desired outcome, rather than simply a style of coping. Consistent with Coppel et al. (1985) Pratt et al. (1985; 1987), and Wright et al. (1987), the qualitative analysis suggests that coping through self-talk (cognitive coping; cognitive reframing) is a very useful technique for reducing caregiver stress.

Very little is reported in the literature on the ways in which caregiver coping, caregiver depression, and caregiver burden change over the course of DAT. Those caregivers who completed the last three waves of data collection demonstrated little change in these variables over that 18 month period of time. It may be that 18 months is too short a time period for assessing change. It is also possible that subject attrition (through death, nursing home placement, or incorrect diagnosis) produced a unique sample with no change. However, the

qualitative results suggest that caregivers perceive their most frequently used coping responses to be strategies they have employed at other times in their lives to cope with other difficult life situations, which supports the theory that coping styles are stable to some degree. In addition, three caregivers gave comments that suggest emotion-focused coping and passive coping such as wishful thinking occur early in the process of adaptation to chronic illness. Although poor caregiver health has been reported to be an important variable influencing caregiver coping and negative outcomes associated with caregiving (Pratt et al., 1985; 1987; Fletcher et al., 1986; Kosberg et al., 1990), the caregivers in this sample judged their health to be average or good. Therefore, the relationship between caregiver health and caregiver coping, depression and burden could not be described. Similar to what is reported in the literature (Pratt et al., 1987; Coppel et al., 1985), there did not appear to be differences in coping for caregivers providing home care compared to out of home caregivers. However, as was elaborated in the discussion of the study hypotheses, particular DAT patient characteristics did appear to influence differentially caregiver coping, depression and burden.

The qualitative and quantitative results provide limited support for selected components of the model of caregiver stress and coping discussed in Chapter Four and summarized in Figure 4.1, specifically the relationships among the DAT patient characteristics of rates of decline, needs for assistance, and needs for supervision/vigilance, and the interactions between caregiver coping and alterations in caregiver mood states. Testing this model cannot be considered part of this study, since to do so would be a multivariate problem requiring a much larger sample. In addition, addressing the temporal order or causal

relationships among the variables cannot be established without a longitudinal study or non-caregiving controls. Even so, specific DAT patient characteristics did appear to be related to different types of coping responses. The qualitative analysis suggests that caregiver values toward and meaning of the caregiving experience influence caregiver coping. For example, one caregiver felt providing care to her mother in the home set an important example for her children, teaching them lessons about life. Another caregiver believed caregiving represented spiritual service. The qualitative analyses also illustrated how coping responses interact with alterations in mood states, which call into play additional coping responses. A good example of this interaction is emotion-focused coping leading to increased stress, which in turn calls into play coping through self-talk.

A revised model of caregiver stress and coping is suggested by the results of this study. This model is illustrated in Figure 8.1. In relation to the DAT patient characteristics, only cognitive function, need for assistance, need for supervision/vigilance, and co-morbid health conditions are retained. There were no data strongly supportive of an effect from patterns of decline or patient residence. The variables specified under caregiver characteristics and coping resources were not modified since this study did not address these variables. Under caregiver coping, coping through self-talk has been added, and acceptance deleted. Acceptance has been moved to a separate category, entitled positive caregiver outcomes, to illustrate the hypothesis that acceptance is an outcome rather than a coping response. There are likely interactional effects among coping, negative caregiver

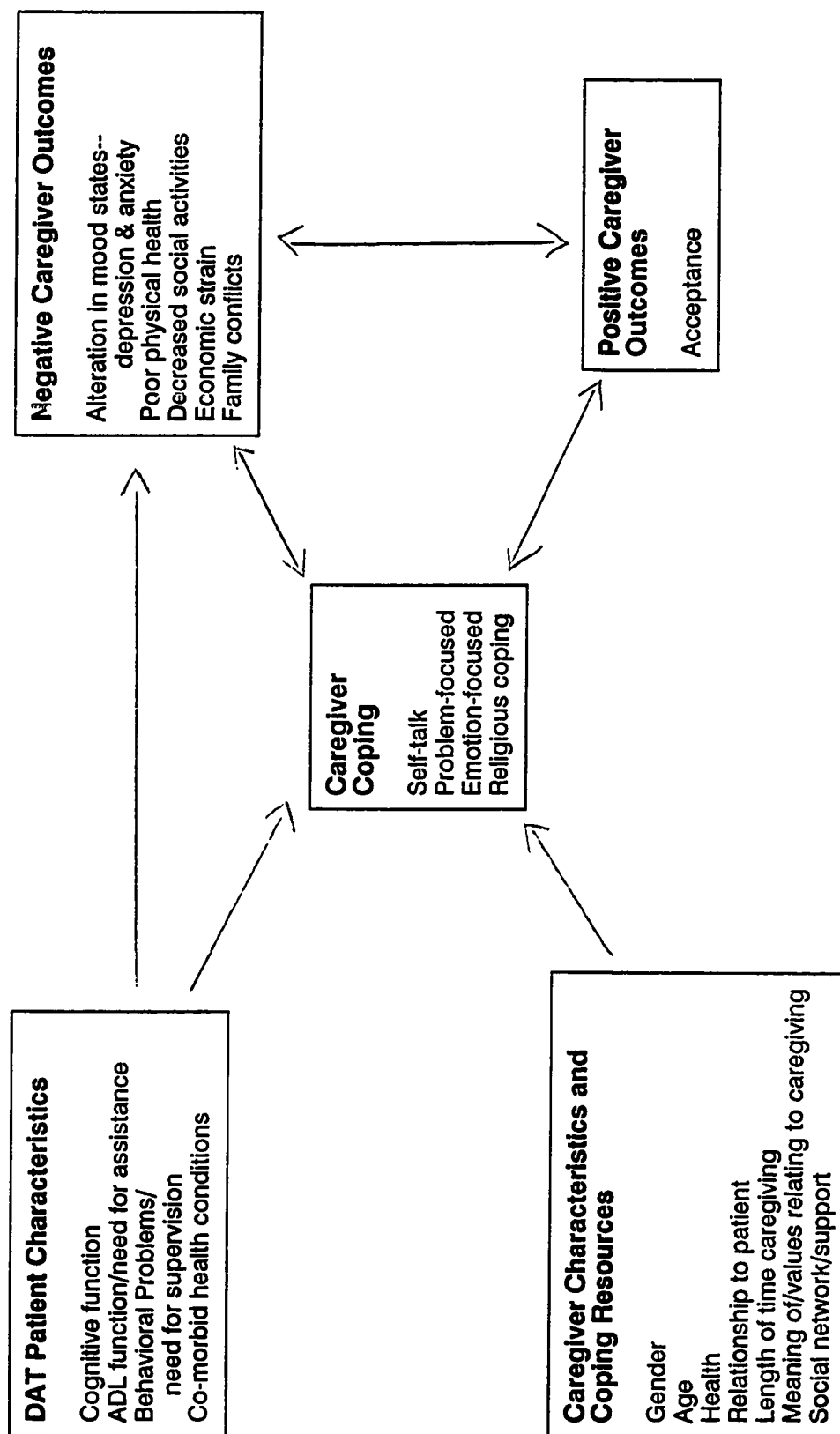


Figure 8.1 Revised Model of Caregiver Stress and Coping

outcomes, and positive caregiver outcomes, and direct effects between DAT patient characteristics and negative caregiver outcomes. Further research studies are needed to refine and clarify this model.

Finally, caregivers' request for respite care is very consistent with the literature relating to the negative effects from caregiving. Haley, Brown, and Levine (1987) report respite to be the service requested most by DAT caregivers. Caserta, Lund, Wright, and Redburn (1987) report that 71.3% of caregivers providing care to community dwelling elderly persons need some type of respite, daycare, or in-home care relief. However, only 2.3% of these caregivers wanted mental health counseling (Caserta et al., 1987). The finding in this study that caregivers who participated in the follow-up interviews wanted psychosocial interventions from health care providers may not generalize to other samples of caregivers.

Religious Coping

Religious coping was weakly correlated with subjective burden, suggesting that those caregivers reporting religious coping were also experiencing greater subjective effects from caregiving. However, there were no significant correlations among religious coping and the caregiver variables. This may have been due in part to the limited variability in the religious coping score. The qualitative analysis suggests that religious coping behaviors are frequently used coping responses, and those caregivers using religious coping perceive their coping to be effective in reducing stress. Consistent with Manfredi and Picket (1987), Bearon and Koenig (1990), and Koenig, Kvale and Ferrel (1988), prayer was a frequently reported coping response. What was

less clear, however, was whether prayer increased as a result of stress or was a stable and consistent behavioral pattern. Most caregivers indicated that they prayed daily, or engaged in on-going conversations with God, especially when they felt upset. However, three caregivers spontaneously indicated they had always prayed, and this was unrelated to the amount of stress they experienced.

There are two main hypotheses relating to how religious coping influences well-being: 1) by functioning to provide social support through formal church activities and 2) by providing a sense of meaning and purpose, and thereby a perception of control in a stressful situation (Tellis-Nayak, 1982; Hunsberger, 1985). Support for both hypotheses are found in the qualitative results. Several caregivers spontaneously commented that faith provided a sense of meaning for their experience. However, similar to Pollner (1989), the provision of social support through religious activities included social support provided through a relationship with a deity more so than organized church activities with other people. Only two caregivers described support received from other church members and visits with their minister as part of their religious coping repertoire.

Several investigators have emphasized the multi-dimensional nature of religiosity and religious coping, and the importance of measuring these variables with more than single item questions relating to church membership or church attendance (Stock et al., 1985; Koenig, Kvale, & Ferrel, 1988). The qualitative analysis supports this viewpoint, as those caregivers using religious coping were not consistently or regularly attending church services. Instead, they were much more engaged in informal religious activities such as prayer, conversations with God, reading religious materials, and listening to and

watching religious TV or radio programs. Historically, mental health professionals have avoided discussing religiosity with their clients (Kroll & Sheehan, 1989). However, it may be useful for health care professionals to discuss religious coping and religiosity with caregivers. Two caregivers spontaneously suggested this when asked what they felt caregivers need from professionals.

Coping and Adaptation

Results of this study, particularly the qualitative results, are consistent with the conceptual framework for the study, the person-environment interaction model of coping. This model conceptualizes coping as a process of adaptation. Coping is defined as both action oriented and intra-psychic efforts to manage internal and environmental demands. It is fluid, dynamic, and functions to mediate the effects of stress. Coping is determined by the particular exigencies encompassed in the stressful situation, the cognitive appraisal made by the individual, any previous experience the person has had with the stressful event, whether or not the stressful event has been anticipated, and the presence or absence of a support system to call upon. Results suggested that it was the here and now experience of the DAT patient's symptoms, rather than change over time, that most influenced coping responses. Individual attributes such as physical health status, and intra-psychic qualities such as values, aspirations, self-confidence and previous coping responses, will interact to influence coping responses. The qualitative analysis supports the fluid, dynamic and interactive nature of coping responses, as well as the mediating role of coping.

The results from this study are also consistent with the broader literature relating to coping and adaptation. For example, this sample of older adults, primarily women, was coping in diverse ways. This finding supports the growth and adult development model of how coping may be different for older individuals (Vaillant, 1977), and does not support the regression hypothesis (Pfeiffer, 1977). Vaillant (1977) proposed a model that predicted more adaptive coping as an individual grows older, while Pfeiffer's (1977) model predicted regressed and maladaptive coping responses in older individuals, with a restriction in the diversity of coping. The literature relating to gender differences in coping provides conflicting results. Some investigators report that women use more passive and emotion-focused coping responses (Billings & Moos, 1981; 1984; Pearlin & Schooler, 1978), while other investigators find no gender differences (Folkman & Lazarus, 1980). The female caregivers in this study were not primarily using emotion-focused or passive coping responses. Although acceptance coping and religious coping behaviors were the most frequently reported coping responses, and other investigators have conceptualized both of these styles as passive coping responses, in this sample, the caregivers described very active behaviors as attempts to "make the best of things." Religious coping also involved active behaviors such as prayer. Therefore, acceptance coping and religious coping in this sample were "passive," only in the sense that they were not directed toward actively changing the specific problem situation (the DAT patient's memory problems and disorientation). Because these caregivers were not experiencing variations in their perceived physical health, health as a coping resource could not be described. Although the focus of the study was caregiver coping with current

problems, some caregivers gave spontaneous comments relating to how they responded to the initial diagnosis of DAT. Therefore, some support for the theory that the process of adaptation to chronic illness initially evokes emotion-focused or passive coping responses was provided by the qualitative analysis.

Limitations of the Study

Results from this study must be interpreted in view of several limitations. First, the limitations of the quantitative analysis will be discussed, followed by a discussion of the limitations of the qualitative analysis. A major limitation of this study is that it is a secondary analysis of data from a study already completed. In using data that were collected for a purpose different from this study, errors in interpretation are more likely to occur. This is because instruments that were valid for the original study may be used in analyses for which they were not designed. In addition, the process of defining the research purpose is restricted by which variables are available in the existing dataset, and the response sizes to those variables. The response sizes for the variables in the secondary analyses were quite small, ranging from 25 to 37 for the correlational analysis. The small sample size creates several problems in interpreting the results of this study. First, statistical power to detect unidirectional moderate effects is quite low (.44 to .57), which may lead to type II errors (Cohen, 1977). Therefore, nonsignificant results are ambiguous. Also, correlation coefficients based on a relatively small number of observations can be quite misleading. With small samples, a single pair of values may contribute excessively to the value of the correlation coefficient, and an excessively high negative or positive correlation coefficient may be the result of an extreme pair of observations, and

not reflect the population correlation coefficient (Edwards, 1984). This could lead to type I error.

Type I error may also occur because of the number of correlations that were computed. When multiple statistical tests are conducted, especially with small samples, it is possible that results may be significant due to chance alone. The remedy for this is adjusting the alpha level to take into account the number of statistical tests (Brown & Hollander, 1977). While reducing type I error, this procedure increases the possibility of type II error. To adjust an alpha of $p = .05$ when 40 correlations are computed, the alpha must be reset at $p = .001$. Since type II error was already a significant limitation to the study, the alpha level was adjusted to $p < .01$, rather than $p < .001$. Making type I errors in the study of coping has fewer implications, in terms of the effects that coping interventions might have on caregivers, than type II errors, which might restrict the use of interventions with the potential for reducing caregiver depression or burden through enhancing coping responses.

The sample size also influences the reliability and validity of the study instruments. Part of the purpose of the study that generated the data was development and refinement of instruments measuring behavioral problems, coping responses, and activities of daily living. Factor analytic techniques were used to identify subscales for both the behavioral problems scale and the coping response scale; because the sample size was small, these factor solutions may be unstable and may not generalize to other samples. Estimates of internal consistency and test-retest reliability estimates may also be unstable due to the small sample size. Further, the results of analyses including the

coping subscale scores must be interpreted in view of low estimates of internal consistency.

For applied disciplines such as social welfare and gerontology, external validity is a very important consideration. Yet, according to Campbell & Stanley (1966), generalization is never fully justified logically and almost always turns out to involve extrapolation into domains not represented by the sample at hand, assuming that the rules or relevant laws are known (Campbell & Stanley, 1966). The external validity in terms of generalizing the results of both the quantitative and qualitative analyses is quite limited in this study, by the characteristics of the sample, the sample selection, and attrition. For the original study, DAT patients were selected based on moderate impairment from their illness. This was important because these patients were to be followed over time to describe adaptation to and changes as a result of DAT. However, this selection process also produced a sample without a great deal of variation in symptoms. There was only one minority caregiving dyad in the sample. The homogeneity of the sample in terms of race and cognitive impairment limits the extent to which these results can be generalized and likely influenced the results of the statistical analysis.

Attrition in the sample may also have influenced the results of this study and the extent to which results can be generalized. Those DAT patient subjects that developed more severe symptoms were placed into nursing homes and many of these subjects dropped out of the study. Thus, there was a loss of more severely impaired DAT patients from the study. These subject's caregivers may have been coping differently from the rest of the sample, and experiencing more severe levels of depression and burden. By time six, some

subjects were lost to follow-up because of the end point of the grant. However, subject availability for interviews could have played a part. It is possible that some of these subjects were not restricted in their travel and recreation and were lost to follow-up because of their own travel plans. This would have had the effect of excluding higher functioning caregiving dyads. In addition, attrition may have produced a unique, homogeneous sample, which produced results that suggest there is no change in caregiver coping, depression or burden over an 18 month time period, when, in fact, there is change.

In terms of those caregivers consenting to the follow-up interviews, caregivers self-selected based on their willingness to discuss coping and admit to a diagnosis of DAT. Caregivers who were in denial about the diagnosis of DAT likely selected out of the interview. Similar to the caregivers who exclude themselves from support groups, those caregivers who expect that discussion of their coping responses would make them feel worse may have excluded themselves from this study. Because some caregivers refused to participate in the interview due to ill health or lack of time due to caregiving responsibilities, generalizability was further restricted, and the study results were also affected. Those caregivers who did not participate due to ill health may have been coping very differently compared to caregivers with good health. Further, caregivers overwhelmed with caregiving tasks may also have reported very different coping experiences. In order to assess how those caregivers who consented to the follow-up interviews compared to those that did not, *t*-tests were computed on all of the major variables at time four. There was only one significant result: those caregivers who consented to the interview were reporting significantly more emotion-focused coping responses compared to the caregivers who

refused the follow-up interviews ($t = 4.00$; $p < .001$). This finding suggests that caregivers experiencing more emotion-focused coping self-selected into the group consenting to the follow-up interview.

The results from the qualitative analysis are limited by the small sample of caregivers who consented to the follow-up interview. There may also be measurement error in recording the interview, because notes were taken during and immediately after the interview, rather than being tape recorded and transcribed verbatim. Bias in the recording and interpretation of the data may also have occurred, since this investigator conducted the interviews and analyzed the data. Less bias would have occurred had the interviews been tape recorded and transcribed, and analyzed by an investigator different from the interviewer. However, tape recording the interview could also result in caregiver's being more reluctant to discuss their feelings, censoring their experiences.

Implications for Social Welfare

Policy and Practice

As long as the emphasis in social welfare policy relating to long term care is placed upon families providing care, policies must be directed towards supporting family caregivers and decreasing their stress. This means that long term health care policy should include funding and reimbursement for support and educational programs for caregivers, respite programs, and individual and family counseling around issues related to coping with the caregiving experience. However, reducing caregiver stress must be viewed as a socially just goal solely in relation to preserving and enhancing that individual's mental

and physical health, and not simply to avoid costly nursing home care for DAT patients. Results from this study support the importance of strengthening the coping responses of DAT caregivers as a means of reducing stress. These caregivers would like health care professionals to talk with them about how they are coping, including assistance with emotional expression, help with acceptance of their situation, and discussions of religion and philosophy of life. On the other hand, results suggest that not all caregivers will respond positively to discussions of coping that occur in a support group context. Further, although teaching or promoting problem-focused coping has been a focus in current support and education groups for caregivers, these results suggest that some caregivers respond negatively to problem-focused attempts at coping, while there are other caregivers who benefit from emotion-focused coping. And those caregivers who do benefit from problem-focused coping report that they do so because of a perception of control over their situation, rather than successful problem solutions.

Results from the study suggest several avenues for providing support for caregivers. Respite programs should be available to caregivers and should provide respite both in and out of the home. Caregivers need to have "sitters," so that they can leave the home for recreation and errands. Caregivers also appear to need time to be home alone, without the DAT patient present. Two caregivers discussed the stress they felt in "never being alone" and having the DAT patient constantly follow them around the house, no matter what they were doing. Programs intended to provide emotional support and education should be kept separate, rather than combined. Support groups should provide emotional support, while classes can provide information and education about

DAT and caregiving. Separating these functions may maximize caregiver participation. Caregivers who value their own emotional expression may be more likely to participate in a support group, while other caregivers may prefer an educational format and perceive themselves as needing information, rather than emotional support. Even so, some caregivers will select themselves out of a group context, and so these same services should be offered in different formats, such as brief term individual or family counseling. Telephone consultation services could also provide individual emotional support and education. Further, in counseling caregivers about coping, strengthening the coping responses the caregiver perceives as helpful needs to be the focus, rather than promoting problem-focused coping over emotion-focused coping. Coping strategies that maximize the perception or expectation of control may be most helpful for caregivers, and this could include a wide variety of coping responses, from a problem-focused approach like getting information to religious coping that provides meaning to one's experience.

The results also imply needs for changes in the behavior of health care providers. Only half of the caregivers who consented to the follow-up interviews recalled health care providers initiating discussions with them about how they were coping with their loved one's DAT. This may serve to increase the caregiver's sense of isolation in their caregiving experience. The qualitative analysis suggests that caregivers want health care providers to initiate discussions with them about their coping, help them manage their emotions (particularly anger and guilt), and talk with them about their religious beliefs and philosophy of living. It appears that religious coping activities are frequent and highly valued by these caregivers. However, Kroll and Sheehan (1989) suggest

that health care providers are reluctant to discuss religion with their patients. This reluctance, if it exists, needs to be further studied and understood, because professionals may be overlooking an area of with potential benefit to caregivers. Health care providers working with DAT patients need to begin providing psychosocial interventions to caregivers, or minimally, making referrals for caregivers to obtain these services elsewhere. Health care providers, especially family practice and general practice physicians, need to become more knowledgeable about DAT and the family caregiver's experience and more comfortable discussing such topics as caregiver coping and religious beliefs. Medical school curriculum may need to change in order to meet this need.

Suggestions for Future Research

Studies that address caregiver adaptation to DAT could shed light on the process of adaptation to chronic disease. Comments made by caregivers in this study suggest that initial coping with the diagnosis of DAT involves emotion-focused responses and coping through denial or wishful thinking. It is not known how initial coping responses influence adjustment, or negative caregiver outcomes, later on in the course of the illness. And caregiving for a relative with DAT can be a very long term process. It may be that interventions at different stages of adaptation have the potential for minimizing negative caregiver outcomes and enhancing caregiver coping. For example, initially, caregivers may need emotional support in the form of encouragement for and permission to express their feelings. Caregivers may also need to have their denial supported initially, with a slow introduction of information about DAT. Studies

that address these issues provide information from which interventions could be planned and tested.

A related area of study has to do with determining what encompasses normal, maladaptive, or pathological responses to caregiving. Studies that are designed to gather detail about the responses of caregivers over the course of this long illness could provide detailed information that would help determine what is "normal." This area of study is important for two reasons. First, coping and adaptation under conditions of chronic stress have not been studied nearly as thoroughly as coping during acute stress or normative life strains. The study of caregiving for DAT could serve as a paradigm for the study of exposure to chronic stress. Second, understanding what is normal, maladaptive, or pathological in terms of caregiver responses will have direct implications for caregiver support programs. Caregivers who are experiencing "normal" responses may not need formal interventions, whereas those caregivers responding in maladaptive or pathological ways may require formal intervention, including psychiatric or mental health care. It seems prudent to try to determine which caregivers are in need of what level of support, so that programs can be targeted to the right caregiver.

Studies need to be conducted to determine whether health care providers discuss coping with family caregivers, and if not, to define the reasons why this does not occur and to suggest remedies. The suggestion in the literature that health care providers resist discussing religion with their patients needs to be further documented and, if present, studies that help clarify the reasons for this reluctance should be conducted. Are there value biases against discussing coping, particularly religious coping, or, are health care providers simply not

trained to provide this kind of support? It may be that health care providers are discussing coping more often now compared to when this sample was diagnosed with DAT.

Further study of how caregiver values influence the perceived effectiveness of coping responses, and whether these values predict response to provision of support services are suggested. This suggestion is derived from the finding that caregivers who had a negative response to support groups were caregivers who experienced emotion-focused coping as producing more stress. Although it may be premature to propose an experiment based on the results of this study, a study evaluating how the different components of a caregiver support program (separating the components of support and education) affect caregivers with different "predominant" coping styles (emotion-focused versus problem-focused) could shed light on the issue of how to target support/education group services to caregivers. Finally, further study of how caregiver stress and the caregiving experience are influenced when the caregiver/care-receiver dyad is a second marriage for one or both partners is suggested. The spousal caregivers in this study who were in second marriages appeared to be experiencing caregiving stresses complicated by their family configuration.

Finally, the sample in this study was quite heterogeneous in terms of level of DAT patient impairment and race/ethnicity of the caregiving dyads. The experiences of racial, ethnic and sexual minority caregiving dyads and families need to be studied. Just as "normal" responses to caregiving experiences are not known, cultural variations in caregiving responses have not been thoroughly studied. Therefore, the needs of minority caregivers may be overlooked when

social policies relating to caregiver intervention programs are formulated and carried out. Generally, research in this area needs to be conducted with much larger samples of caregivers. Studies with very large sample sizes would have the statistical power to test complex models of caregiver stress and coping, through path analysis or structural equation modeling. Studies with large samples might also detect the effects of different levels of caregiving and caregiver relationship to the care receiver upon coping and negative caregiver outcomes. In addition, there is a need for qualitative studies of the caregiving experience, which have the potential for suggesting new outcome variables, such as acceptance. Further qualitative study may also help clarify the complex processes involved in caregiving.

Summary

This study described the relationships among DAT patient characteristics (needs for assistance and supervision; rates of decline in cognition, physical and functional health), caregiver coping, and caregiver depression and burden. Existing data were used for a secondary analysis. Qualitative data regarding caregiver coping with DAT, particularly religious coping, were gathered from those caregivers who participated in the study that generated the original dataset and were available to be re-interviewed. Results from both the quantitative secondary analysis and the qualitative analysis must be interpreted in view of the small, homogeneous sample.

Results of the secondary analysis suggest that caring for DAT patients in need of assistance is associated with problem-focused coping and cumulative burden, especially in the subjective dimension. Providing care to DAT patients

in need of supervision was associated with problem-focused and emotion-focused coping, cumulative burden and subjective burden. Rapid functional health decline was associated with with cumulative burden and subjective burden. Emotion-focused coping was linked with depression and subjective burden. Caregiver coping, depression, and burden showed little change over an 18 month time period.

A primary theme emerging from the qualitative analysis is the uniqueness of the caregiving experience for these individual caregivers. The importance of understanding the meaning of the caregiving experience to the individual caregiver, and of investigating what that caregiver perceives as both stressful and helpful, prior to suggesting solutions or recommending "helpful" ways the caregiver can cope, cannot be over emphasized. These caregivers were coping in diverse ways, utilizing multiple coping responses, and perceived their coping styles to be stable over time and across other difficult life experiences. Predominant coping styles appeared to be religious and acceptance coping; caregivers reported these ways of coping to be very helpful in reducing stress. Caregivers' comments suggested that acceptance was perceived as a desirable outcome, rather than as a coping response. Caregivers perceived their religious coping to be helpful through providing meaning to their experience and by the support derived from their relationship to a deity. Emotion-focused coping was perceived by some caregivers as decreasing their stress. Not all caregivers felt problem-focused coping was of help, but rather, in instances where solutions failed, problem-focused coping served to increase the caregiver's frustration and hopelessness.

Several avenues of providing support for caregivers are suggested. Separating the support and education components of caregiver support programs might better meet caregiver's needs, since they may perceive their needs to be for emotional support or for education and information, but not necessarily both. Further, the caregiver's predominant coping style may influence whether support group participation is pursued. Those caregiver's who value emotional expression may be more likely to request support group services. However, not all caregivers will join groups. Psychosocial services (supportive individual and family psychotherapy and educational or information services) should be available in formats besides groups or classes. These caregivers want respite services, as well as psychosocial interventions. Health care providers could provide additional support to caregivers by initiating discussions of caregiver coping, including religious activities.

Future research in this area needs to clarify the long term process of adaptation to chronic disease, and the components of normal, maladaptive, and pathological responses to the long term stress of caregiving. Studies are needed that can describe the extent to which health care providers discuss coping strategies, especially religious coping, with caregivers, and the barriers to such discussions. Studies which include racial, ethnic, and sexual minorities need to be conducted. Finally, studies describing the caregiving experience for caregiving dyads that are second marriages for one or both partners are needed, since spouses who are "second" partners may experience different stressors which might require different interventions.

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APPENDIX A

INSTRUMENTS

DEMOGRAPHICS

1. When were you born? Month____ Day____ Year____
2. What was the last grade you completed in school? ____
If college grad or higher, specify number of years of college ____;
degree obtained ____

3. What type of work have you done during most of your life?

(If unclear, ask for job title, type and size of organization)

When did you retire? 19____

Or are you still working? (full-time____ or part-time____)

4. FOR MARRIED RESPONDENTS:

What type of work has your husband/wife done during most of his/her life?

(If unclear, ask for job title, type and size of organization)

When did he/she retire? 19____

Or is he/she still working? (full-time____ or part-time____)

5. Think about all your total annual family income from Social Security, retirement pension, current employment, dividends and rental income. Which of the following categories best describes your family's *average* income for the past few years? (Show subject a card on which he/can point to correct category.)

- a. less than \$10,000
- b. \$10,000-\$20,000
- c. \$20,000-\$30,000
- d. \$30,000-\$40,000
- e. \$40,000-\$50,000
- f. more than \$50,000

PHYSICAL HEALTH STATUS

1. How many days has Mr./Mrs. _____ spent in a hospital in the past 6 months?
_____ days
2. How many times has he/she seen a physician for reasons of illness or disability in the past 6 months? _____ times
3. How many days has he/she stayed at home, in bed, or under the care of a physician for illness during the past 6 months? _____ days
4. In comparison to other men/women of his/her age, how would you generally rate his/her health during the past 6 months?
 - a. much better than others his/her age
 - b. somewhat better than others
 - c. about average, OK
 - d. not as good as others
 - e. much worse than others
5. In comparison to 6 months ago, how would you rate his/her health these days?
 - a. much better these days
 - b. somewhat better
 - c. about the same
 - d. not as good as 6-7 months ago
 - e. much worse than 6-7 months ago

ACTIVITIES OF DAILY LIVING

		(2) w/o help	(1) w/some help	(0) not able	(-) no answer
1.	Can you use the telephone...	___	___	___	___
2.	Can you use the television (and radio)...	___	___	___	___
3.	Can you get to places out of walking distance...	___	___	___	___
4.	Can you go shopping for groceries or clothes (assuming available transportation)...	___	___	___	___
5.	Can you prepare your own meals...	___	___	___	___
6.	Can you do your housework...	___	___	___	___
7.	Can you take your own medicine...	___	___	___	___
8.	Can you handle your own money...	___	___	___	___
9.	Can you eat...	___	___	___	___
10.	Can you dress and undress yourself...	___	___	___	___
11.	Can you take care of your own appearance, for example combing your hair and (for men) shaving...	___	___	___	___
12.	Can you walk...	___	___	___	___
	12a. How far can you walk by yourself with a walker or a cane? ___ blocks or miles				
13.	Can you climb and descend stairs...	___	___	___	___
	13a. How many stairs can you walk up without any help even if you have to stop for a minute to catch your breath? ___ (#stairs)				
14.	Can you climb and descend ramps...	___	___	___	___
15.	Can you get in and out of bed and a chair...	___	___	___	___
16.	Can you reach objects under beds and chairs...	___	___	___	___

- | | | | | | |
|------|---|-------------|-------------|---------------|--------------|
| 17. | Can you reach objects on high closet and cabinet shelves... | _____ | _____ | _____ | _____ |
| 18. | Can you take a bath or shower... | _____ | _____ | _____ | _____ |
| 19. | Can you use the toilet (water closet)... | _____ | _____ | _____ | _____ |
| | | (2) | (1) | (0) | (-) |
| | | no | yes | cathe-
ter | no
answer |
| 20. | Do you ever have trouble getting to the bathroom on time?... | _____ | _____ | _____ | _____ |
| | | (2) | (1) | | (-) |
| | | 1-2
week | 3+/
week | | no
answer |
| 20a. | How often do you wet or soil yourself (either day or night)?... | _____ | _____ | | _____ |

BEHAVIORAL SYMPTOMS

	never	seldom (once or twice)	some- times (1-2 times/wk)	often (once/ day)	always (several times/dy)
Sleep Disorder					
Trouble falling asleep	_____	_____	_____	_____	_____
Awakens early	_____	_____	_____	_____	_____
Diurnal variation	_____	_____	_____	_____	_____
Wakes family	_____	_____	_____	_____	_____
Disinhibition					
Excessive appetite	_____	_____	_____	_____	_____
Craves sweets	_____	_____	_____	_____	_____
Drinks more alcohol	_____	_____	_____	_____	_____
Mute, won't talk	_____	_____	_____	_____	_____
Does embarrassing things	_____	_____	_____	_____	_____
Overactive; paces	_____	_____	_____	_____	_____
Looks angry, frustrated	_____	_____	_____	_____	_____
Psychosis/Aggression					
Hears imaginary voices	_____	_____	_____	_____	_____
Feels watched/talked about	_____	_____	_____	_____	_____
Suspicious, accusing	_____	_____	_____	_____	_____
Believes in conspiracy	_____	_____	_____	_____	_____
Hides valuables	_____	_____	_____	_____	_____
Grandiose, unrealistic about self	_____	_____	_____	_____	_____
Attempts to injure others	_____	_____	_____	_____	_____
Destroys things	_____	_____	_____	_____	_____
Threatens to hurt others	_____	_____	_____	_____	_____
Verbal aggression	_____	_____	_____	_____	_____
Potentially dangerous behavior	_____	_____	_____	_____	_____
Unpredictable behavior	_____	_____	_____	_____	_____

BEHAVIORAL SYMPTOMS SCALE
REPRESENTING DAT PATIENT NEED FOR SUPERVISION
(COMBINED DISINHIBITION/PSYCHOSIS/AGGRESSION)

OVERACTIVE, PACES

LOOKS ANGRY, FRUSTRATED

HEARS IMAGINARY VOICES

FEELS WATCHED, TALKED ABOUT

SUSPICIOUS, ACCUSING

BELIEVES THERE IS A CONSPIRACY AGAINST HIM/HER

HIDES VALUABLES

GRANDIOSE, UNREALISTIC ABOUT SELF

ATTEMPTS TO INJURE OTHERS

DESTROYS THINGS

THREATS TO HURT OTHERS

VERBAL AGGRESSION

POTENTIALLY DANGEROUS BEHAVIOR

UNPREDICTABLE BEHAVIOR

COPING RESPONSES

- E 1. Got upset
- A 2. Accepted the situation
- 3. This experience renewed your faith in God or religion
- 4. This experience gave you new faith
- A 5. Refused to let it get to you
- A 6. Made the best of it
- E 7. Got angry about the situation
- E 8. Got bitter about the situation
- E 9. Got resentful about the situation
- 10. Wished you could change the way you felt
- 11. Refused to believe it had happened
- R 12. Turned to religion/prayer
- R 13. Sought help from religion or God
- R 14. Sought spiritual strength
- 15. Brooded, worried about it
- P 16. Felt inspired to solve the problem
- P 17. Came up with a creative solution to the problem
- P 18. Came up with a couple of different solutions to the problem
- 19. Told yourself things to cope with the problem
- 20. Gave yourself encouragement, support, things to feel better about the situation
- 21. Changed something about yourself in an attempt to solve the problem
- P 22. Did something totally new to solve the problem.
- 23. Read books/newspaper or magazine articles to learn how to deal with the problem.
- 24. Hoped a miracle would happen.
- 25. Just waited for the problem to work itself out.
- 26. Wished that the problem would solve itself.

Please tell me about any other ways you have coped with DAT that I have not asked about.

- P = Problem-focused coping subscale
- E = Emotion-focused coping subscale
- A = Acceptance coping subscale
- R = Religious coping subscale

CES-D		Less than one day	1-2 days	3-4 days	5-7 days
1.	I was bothered by things that usually don't bother me.	_____	_____	_____	_____
2.	I felt that everything I did was an effort.	_____	_____	_____	_____
3.	I felt I was just as good as other people.	_____	_____	_____	_____
4.	I had trouble keeping my mind on what I was doing.	_____	_____	_____	_____
5.	I felt sad.	_____	_____	_____	_____
6.	I felt fearful.	_____	_____	_____	_____
7.	I felt lonely.	_____	_____	_____	_____
9.	My sleep was restless.	_____	_____	_____	_____
10.	I talked less than usual.	_____	_____	_____	_____
11.	I enjoyed life.	_____	_____	_____	_____
12.	I felt that I could not shake off the blues even with the help of my family or friend.	_____	_____	_____	_____
13.	I thought my life had been a failure.	_____	_____	_____	_____
14.	I was happy.	_____	_____	_____	_____
15.	I could not get "going."	_____	_____	_____	_____
16.	I felt hopeful about the future.	_____	_____	_____	_____
17.	People were unfriendly.	_____	_____	_____	_____
18.	I did not feel like eating; my appetite was poor.	_____	_____	_____	_____
19.	I felt depressed.	_____	_____	_____	_____
20.	I felt that people disliked me.	_____	_____	_____	_____

EFFECT ON PARTICIPANT'S LIFE

Now I'd like to know whether assisting and having other contact with your (RELATIVE) has affected your life. As I read through this list, I would like you to use these response categories:

- 1 Very much
- 2 Somewhat
- 3 So-so
- 4 Not much
- 5 Not at all

Time you have to yourself	1	2	3	4	5
Stress in your relationship with your (relative)	1	2	3	4	5
Personal privacy	1	2	3	4	5
Attempts by your (relative) to manipulate you	1	2	3	4	5
Time you have to spend in recreational activities	1	2	3	4	5
Vacation activities and trips you take	1	2	3	4	5
Nervousness and depression you have concerning your relationship with your (relative)	1	2	3	4	5
Time you have to do your own work and daily chores	1	2	3	4	5
Demands made by your (relative) that are over and above what s/he needs	1	2	3	4	5
Time you have for friends and other relatives	1	2	3	4	5

SOCIAL SUPPORT QUESTIONNAIRE

1. Is there someone whom you can really count on to distract you from your worries when you feel under stress? Yes/No
If yes, who is this person? _____
2. Is there someone whom you can really count on to help you feel more relaxed when you are under pressure or tense? Yes/No
If yes, who? _____
3. Is there someone who accepts you totally, including both your worst and your best points? Yes/No
If yes, who? _____
4. Is there someone whom you can really count on to care about you, regardless of what is happening to you? Yes/No
If yes, who? _____
5. Is there someone whom you can really count on to help you feel better when you are feeling down-in-the-dumps? Yes/No
If yes, who? _____
6. Is there someone whom you can count on to console you when you are very upset?
If yes, who? _____

APPENDIX B

INTERVIEW PROCEDURE

LETTER TO SUBJECTS

October 9, 1989

Dear _____:

I am writing to invite you to participate in an extension of our study on adaptation to aging and Alzheimer's disease. These follow-ups will be conducted by Ms. Nina Ramsey, a graduate student in Social Welfare here at the University of Washington. She is helping us analyze data from our study and would like to conduct follow-up interviews with interested participants. The purpose of the interview is to gather more detailed information about how family members are coping with the changes brought about by Alzheimer's disease, including which types of coping are used most often and which types of coping seem to help the most. The emphasis is on how you are coping; the interview will not involve the person with Alzheimer's disease. The interview will last from one to one and one-half hours and will be conducted by Nina Ramsey in your home. Since many family support programs for caregivers of persons with Alzheimer's disease focus on improving coping, it is hoped that information from this follow-up study will help develop better family support programs.

Nina will be contacting you by telephone in the next two to three weeks to ask for your consent to participate in this study and to answer any questions you may have. Thank you for your past participation in our research project, and your willingness to contribute your knowledge and experience in this important area.

Sincerely,

H. Asuman Kiyak, Ph.D.
Professor

University of Washington**Consent Form**

**Nina Ramsey, Ph.C., Social Work, 543-5640, or 522-5243
Nancy Hooyman, Ph.D., Chair, Supervisory Committee
Dean, School of Social Work, 545-1662**

Investigator's Statement**Purpose and Benefits**

I am asking you to participate in a study of how older persons caring for a relative with Alzheimer's disease cope with the disorientation and memory changes associated with this disease. Through a better understanding of how family members cope and which types of coping are most helpful, programs intended to provide family members with support may be improved.

Procedures

I will ask you to tell me about the different ways you may have coped with caring for your relative with Alzheimer's disease. I will ask you to give me examples of situations that illustrate particular types of coping, and I will ask which ways of coping have been most helpful to you. I will also ask that you consent to have your responses from the previous study identified for the purposes of comparing your present coping with your previous responses.

Risks, Stress, or Discomfort

The interview will last one to one and one-half hours. There may be some discomfort associated with the interview due to the length of time the interview will take and the nature of some of the questions about coping.

Other Information

All information collected will be kept confidential and will be available to no one outside of myself and my academic supervisory committee. You are free to withdraw from the study at any time without penalty.

Signature of Investigator**Date**

Participant's Statement

The study described above has been explained to me, and I voluntarily agree to participate in this activity. I have had an opportunity to ask questions. I understand that future questions I may have about the research or about subject's rights will be answered by Nina Ramsey.

Signature of Participant

Date

I agree to allow my responses in the dataset from "Adaptation to Aging and Alzheimer's Disease" to be identified, for the purpose of comparing current coping with previous coping.

Signature of Participant

Date

OVERVIEW OF INTERVIEW PROCEDURE

Subjects were asked open-ended questions pertaining to demographics, caregiver characteristics, caregiving situation, coping responses, and what they feel caregivers need the most from professionals.

The coping questionnaire (see Appendix A) was the basis for the coping responses. For each response the caregiver acknowledged using, he/she was asked open-ended questions designed to elicit information about the stability and effectiveness of that response. For example, "In what ways did this way of coping help? Tell me about any ways of coping like this made you feel worse."

DEMOGRAPHICS/CAREGIVER CHARACTERISTICS

1. Age _____
 month day year
2. Education
Highest grade completed in school _____
If college grad or higher, # of years of college _____
Degree obtained _____
3. Employment
What type of work have you done during most of your life?

What year did you retire? _____, or still working F/T __, P/T __
4. Marital status _____
5. Relationship to patient _____
6. How would you describe your race or ethnicity?

7. Income
Think about all your total family income from Social Security, retirement pension, current employment, dividends, and rental income. Which of the following categories best describes your family's average income over the past two years:

a) < \$10,000	d) \$30,000 - \$40,000
b) \$10,000 - \$20,000	e) \$40,000 - \$50,000
c) \$20,000 - \$30,000	f) > \$50,000
8. Tell me about your physical health.
9. What is your religious affiliation?
10. How often do you attend church services?

CAREGIVING SITUATION

1. Length of time in caregiving role: _____ years
2. Does anyone else help with caregiving?
Who?
How often?
3. Type of help? Financial
 Emotional support
 Chore
 Transportation
 Respite
4. Have you attended any support groups for caregivers? How did the group affect you?
5. Who can be counted on when you need help yourself?
6. What are you finding to be most stressful about caregiving?

OUT OF HOME PLACEMENT

1. What type of facility? AFH _____ SNF _____ CCF _____
2. How long in facility? _____ yrs _____ mos
3. Describe current caregiving responsibilities
(frequency of contacts, types of help given to patient)
4. What went into the decision to place the DAT patient?
5. Describe what, if anything, changed in terms of how you felt after the patient was placed into the nursing home.

COPING RESPONSES

Caregivers were asked about each coping response in the 26-item coping scale (see Appendix A).

For each affirmative response, caregivers were asked the following:

Please give an example of a situation with (DAT pt) in which you coped in this way.

Tell me about any other situations like this that come to mind.

How did this way of coping affect you?

In what ways did this style of coping help you?

Tell me about any ways coping like this made you feel worse.

FREQUENCY OF COPING RESPONSES

Please list the six most frequently used coping responses:

Coping response #

- 1.
- 2.
- 3.
- 4.
- 5.
- 6.

Thinking about these six coping responses as a "style," what are some of the other times in your life when you may have coped in this way (births, deaths, life transitions)?

Did any professionals you have come in contact with in seeking care for (DAT pt) talk with you about how you were coping?

Yes _____ No _____

If yes, who?

Finally, what are your thoughts about the type of help or support you would like from professionals?

CURRICULUM VITAE

NINA S. RAMSEY

Academic and Professional Education

Ph.D. in Social Welfare
School of Social Work, University of Washington (1990)

M.N. in Psychosocial Nursing
University of Washington, Seattle (1980)

Master's Thesis:

Learned Helplessness Associated with
Caring for the Elderly Depressed Person

B.S. in Nursing
University of Washington, Seattle (1975)

Current Professional Employment

Private Practice
Adult and Geriatric Mental Health Services, Seattle, Washington
(June 1983-present)

Professional Activities

Clinical Instructor
Department of Psychosocial Nursing
University of Washington

Psychosocial Nursing Consultant
Department of Community Health Care Systems
Family Nurse Practitioner Program
University of Washington

Professional Memberships

American Nurses' Association
Washington State Nurses' Association
Gerontological Society of America