

AN ABSTRACT OF THE THESIS OF

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Title: The Relationship of Personal and Social Resources  
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Clara Pratt, Ph.D. \_\_\_\_\_

Alzheimer's disease, a chronic and irreversible form of dementia, has been recognized as one of the most critical medical-social-economic problems facing our country. As Alzheimer's disease and other related dementias progress, the patient becomes increasingly dependent upon family and natural support systems to provide care. This dependency can place the caregiver in a role that is both difficult and demanding. The purpose of this study was to construct and assess a theoretical model which investigated the effects of patient functioning, personal and social resources on coping behaviors and adaptational outcomes (caregiver well-being) in caregivers of dementia patients.

The theoretical model was tested with data from caregivers of patients with dementia throughout a 14 state region primarily in the Southwestern and Northwestern United States. A total of 502 caregivers participated in this study and only those caregivers who were related to the dementia patient were selected for in this study. Data was obtained through self-report questionnaires mailed either directly to the homes of the family caregiver or sent to support group leaders who then mailed the questionnaire to the caregivers.

The theoretical model, which proposed latent variables, was assessed with the LISREL V computer program. Several other statistical analyses were also utilized, such as: one-way ANOVA's, Pearson product-moment correlations, factor analyses and multiple regression. Collectively the results from the LISREL analysis indicated a poor fit of the data to the proposed theoretical model. Subsequent analyses were conducted to further explore the validity of the proposed constructs and the structural relationships between them. Based on these results, it was found that several constructs were more integrated and conceptually complex than previously proposed. Internal control beliefs, problem-focused and reframing coping behaviors, and social support satisfaction were found to be predictors of positive adaptational outcomes in caregivers. Chance and Powerful Others control beliefs, avoidant/evasive and regressive coping behaviors were found to be predictors of negative adaptational outcomes.

These findings lent support for the development of intervention programs which assist caregivers in developing specific skills necessary for coping with the potential long-term role of careprovider. The findings also indicated the strong relations between social support and a caregiver's ability to adapt to the caregiving role.

The Relationship of Personal and Social Resources on  
Coping and Individual Well-Being in Caregivers  
of Dementia Patients

by

Scott D. Wright

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Associate Professor of Human Development and Family Studies  
in charge of major

Redacted for Privacy

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Head of Department of Human Development and Family Studies

Redacted for Privacy

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Dean of Graduate School

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# THE RELATIONSHIP OF PERSONAL AND SOCIAL RESOURCES ON COPING AND INDIVIDUAL WELL-BEING IN CAREGIVERS OF DEMENTIA PATIENTS

## INTRODUCTION

"The human tragedy of Alzheimer's is overwhelming for the individual suffering from it, those who surround the patient, as well as for society as a whole... As research tries to unravel the mystery of the disease, reflection and research are needed to better understand all its human dimensions both as it effects the person with the disease and those who surround him"

Msgr. Charles J. Fahey  
Third Age Center  
Fordham University, 1984

The absolute and proportional number of elderly people in the United States is increasing rapidly. This phenomena has been described as the "graying of America" and has far reaching implications for families, communities and the entire nation (Atchely, 1983). The older population is expected to increase by 30 percent over the next 20 years. However, it is the 85 plus age group that will exhibit the most dramatic growth. This group is expected to increase twofold by the year 2000 (Special Committee on Aging, U.S. Senate, 1982).

Along with the fact that greater numbers of people are surviving to old age there has been a parallel increase in the number of elderly persons with chronic illnesses that require long-term, expensive care (Burish & Bradley, 1983). Of those 65 and over in non-institutional settings, 85 percent report at least one chronic disease and 46 percent experience limitations in normal activities related to chronic health conditions (Mascciochi, 1984;). The rate of

death from chronic disease has increased during the past 80 years from 20 per 100 deaths to nearly 70 per 100 (Burish & Bradley, 1983). In fact, heart disease, stroke, cancer and Alzheimer's disease (a form of dementia), all of which are characterized by chronic conditions, now represent the major causes of death in the U.S. (Burish & Bradley, 1983; Katzman, 1980).

Alzheimer's disease, a chronic and irreversible form of dementia, is of particular interest in this study because of its marked presence in elderly populations. The incidence of Alzheimer's disease increases from 5 percent for persons in their sixties to 20 percent for those over 80 (Gwthyer and Matteson, 1982). Increasing numbers of older adults will be at risk due to the previously mentioned demographic transitions (Schneck, Reisberg, & Ferris, 1982). Alzheimer's disease is characterized by an insidious onset and is accompanied by a variety of cognitive and behavioral symptoms such as memory loss, confusion and in advanced stages, incoherent speech and incontinence. As Alzheimer's disease and other related dementias progress, the patient becomes increasingly dependent upon family and natural support systems to provide care (Zarit, Reever, & Bach-Peterson, 1980).

Approximately 80 percent of long-term health and social services are provided for the elderly and the chronically-ill by family members (Brody, 1985). But, families are not typically socialized to assume the role of

care-giver and are ill-equipped to manage the emotional and physical requirements of the role (Mascciochi, Thomas, & Moeller 1980). In the context of providing care for an Alzheimer's patient, the stressors are compounded by the fact that the disease is irreversible and current medical treatments for the disease have been found relatively ineffective.

The prospect of caregiving for a family member with an incurable disease that is relentless in it's symptomatology is eloquently stated by one caregiver in a recent study (Pratt, Schmall, Wright, & Cleland, 1985):

"I was not prepared for the totality of the takeover; the presence of a dementia person (Alzheimer's disease) in the home and careprovider's life permeates everything, without exception. The careprovider no longer has a life of her/his own; the careprovider no longer has an identity of her/his own; insofar as our self-hood is defined by what we do, the careprovider has no opportunity to be anything but a careprovider. The careprovider must forego any hopes for her/his own future, since hope is based on institutionalization or death of the Alzheimer's person...and this is inviting a massive guilt trip". (Daughter, aged 59)

Alzheimer's disease, has been recognized as one of the most critical medical-social-economic problems facing our country (Aronson & Lipokowitz, 1982). A national weekly news publication, Newsweek (Dec. 4, 1984), has labeled Alzheimer's disease as "the disease of the century". Yet with growing public awareness regarding the impact of Alzheimer's disease on our society, relatively few studies have investigated the equally important impact on the family system and primary caregiver.

What is also apparent from the review of the literature

is the notable lack of research that focuses on the cognitive and behavioral coping strategies caregivers utilize in managing the demanding role of caregiving for a dementia patient (Alzheimer's disease). Recent theoretical and empirical studies have emphasized the role of coping behavior in affecting adaptional outcomes in stressful situations (Lazarus & Folkman, 1984; McCubbin, Joy, Cauble, Comeau, Patterson, & Needle, 1980; Menaghan, 1980; Moos, 1984). Based on this premise, an inquiry into the coping responses utilized by caregivers and the resulting effects on individual well-being is deemed essential in order to better understand how caregivers adapt to the caregiving role. Research in this area has received additional support based on a recent report from the Department of Health and Human Service's Task Force on Alzheimer's Disease, 1984. The task force has recommended that research concentrate on a variety of areas, including:

identifying the most effective coping strategies and interventions used by caregivers; and identify the kinds of information, education, support, and treatment that best reinforce or increase coping abilities of families with Alzheimer's disease members.

Recent theoretical papers (Caplan, 1979; Halahan & Speack, 1980; Lazarus & Folkman, 1984; Mischel, 1981) and empirical studies (Duckitt, 1984; Sandler & Lakey, 1983; Sarason & Sarason, 1983) have recommended that in order to effectively assess the affect of mediating variables (e.g., coping behavior) on outcome measures, an ecological/interactionist approach is necessary.

Recent studies have primarily focused on either the

effects of personal resources (e.g., personality dispositions) on coping behavior (Flieshman, 1984; Kobasa & Pucetti, 1892; Pearlin & Schooler, 1978; Wheaton, 1983), the effects of environmental resources (e.g., social network and/or support) (Billings & Moos, 1981; Hirsch, 1980) on coping behavior, and the effects of coping strategies on caregiver burden (Pratt et al., 1985). No study to date has investigated how person-situation variables interact on coping behavior in a sample of caregivers of dementia patients.

Therefore, the purpose of the present study is to construct and test a causal model that integrates and assesses the effects of personal control and social resources on coping and subsequent well-being in caregivers of dementia patients. Coping responses are hypothesized to be influenced by both social resources and personal control characteristics, as well as patient functioning. Personal control is conceptualized as locus of control beliefs of the caregiver. Social resources represents both social network and support variables. Patient functioning is the objective and subjective evaluation of the dementia patient by the caregiver. Coping behavior is conceptualized as cognitive and behavioral efforts used by the careprovider to manage the caregiver role. Coping responses are then hypothesized to directly influence caregiver well-being. The interactional model is diagrammatically shown in Figure 1.

Based on this hypothetical causal model, four major areas



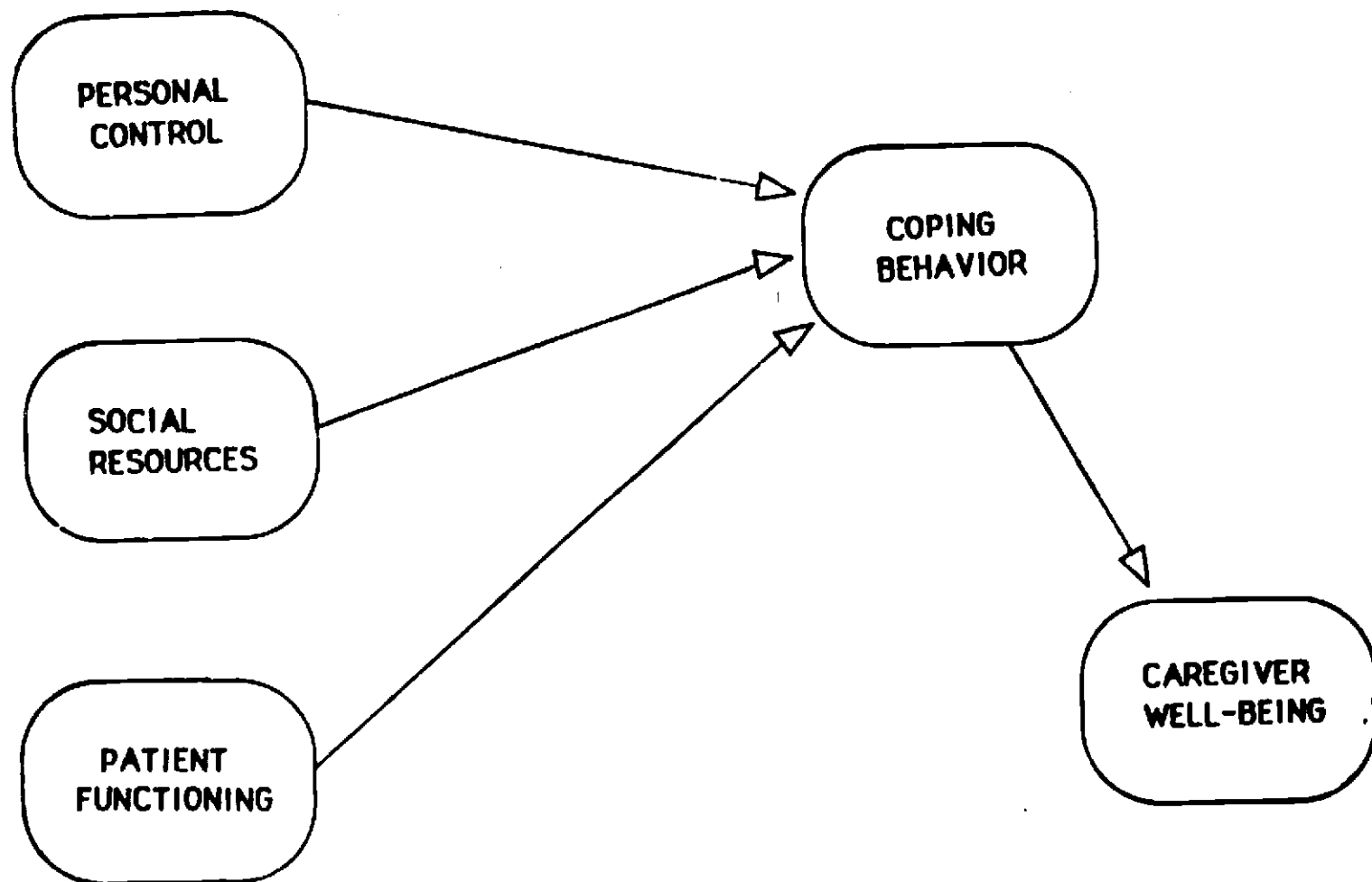


FIGURE 1      Theoretical Model for Predicting Coping  
Behavior and Caregiver Well-Being

of research are relevant to this study. The first area examines the symptomatology of Alzheimer's disease and the descriptive and empirical studies on the effects of Alzheimer's disease on the family and primary caregiver. The second area focuses on the construct of coping and highlights current conceptualizations of coping behavior and it's relation to adjustment in stressful situations. The third area involves a review of pertinent research which has investigated the role of personal resources (control beliefs) and social resources (network and support) on coping behavior. Finally, a review of theoretical and methodological issues regarding interactional frameworks that include stress and coping process will be examined.

## REVIEW OF THE LITERATURE

### Introduction

Recent gerontological research indicates that most intellectual and cognitive functioning remains relatively unchanged for the great majority of healthy older adults. Although some psychomotor and sensory-perceptual skills decline with increasing age, these decrements are associated with the normal aging process or senescence.

In contrast to those losses associated with senescence, are the severe deficits in memory, language and other related higher cognitive functions due to pathological brain syndromes, commonly categorized under the global term dementia. Defined more accurately, dementia refers to a group of closely related syndromes characterized by failing memory and loss of other intellectual functions due to chronic degenerative diseases of the brain (Adams & Victor, 1977). Dementia is the major psychiatric disorder of old age and it is estimated that about 15% of the population over age 65 suffer some degree (mild to severe) of dementia (Gershon & Herman, 1982; Schenck et al., 1982). About 3 to 4 million people in the U.S. are directly affected by dementia (Schenck et al., 1982).

It was once believed senile dementia was primarily the result of cerebral arteriosclerosis, but over 50 different causes for dementia are now recognized (Gershon & Herman,

1982). Alzheimer's disease, an irreversible form of dementia, accounts for 50 to 60% of the cases reported during adult life (Gershon & Herman, 1982). Because the incidence of Alzheimer's disease increases from 5% for persons in their sixties and 20% for those over eighty, (Gwyther & Matteson, 1983) increasing numbers of people are at risk due to the increase in the proportional numbers of older adults. Senile dementia of the Alzheimer's type as one of the most critical medical-social-economic problems facing our society (Aronson & Lipkowitz, 1982).

#### Alzheimer's Disease: Description and Symptomatology

Alzheimer's disease (named for the German neurologist, Alois Alzheimer, who described the disease as a specific clinical and pathological entity), is characterized by a variety of neurological abnormalities in the brain which manifest into serious deficits in memory and cognition. It is estimated that 1.5 to two million Americans are affected by Alzheimer's disease. It is now considered the fourth leading cause of death in the U.S. (Katzman, 1977).

The exact cause of the disease is the subject of great discussion in current medical circles. Although no one cause has been established, several hypotheses have been proposed which would account for the change and loss of neurons in the cortical and hippocampus regions of the brain (Wurtman, 1985). One hypothesis is that symptoms of Alzheimer's disease are due to the inability of neurons to produce adequate amounts of the

neurotransmitter, acetylcholine, in the brain. Other conceptual models propose that faulty genes, abnormal accumulation of proteins (amyloids) within the neurons, infectious agents, environmental toxins (e.g., aluminum), and a reduced flow of blood to the brain are responsible for the cognitive and behavioral deficits of the Alzheimer's patient (Wurtman, 1985).

Because the exact cause is still undetermined, effective treatment is still unavailable. Attempts to increase acetylcholine levels in the cortical and hippocampus region of the brain is the focus of many research projects across the country, but initial results of this treatment are still tentative and inconclusive (Wurtman, 1985). However, many researchers point out that there are treatments and intervention strategies which would reduce and control, to some degree, the behavioral problems, such as depression, paranoia, sleeplessness etc., of the Alzheimer's patient (Ware & Carper, 1982; Zarit & Zarit, 1982).

Alzheimer's disease is characterized by an insidious onset and is accompanied by a variety of cognitive and behavioral symptoms that typically manifest themselves over the span of five to ten years (Gwyther & Matteson, 1983). In the early stages of the disease memory loss, apathy and depression are common expressions of the disease. Loss of spontaniety, neglecting personal hygiene and the "loss of social graces" may be also apparent. As the disease progresses, the Alzheimer's patient becomes increasingly dependent on the care

and assistance of others, especially in eating, bathing and toileting. Often the patient becomes confused and disoriented and may engage in night wandering. Advanced stages are often marked by an inability to communicate or recognize family members and by urinary and fecal incontinence.

The burden of watching a dependent family member "who dies twice"--first the mind and then the body... can be physically and psychologically overwhelming. The caregiver faces the difficult and distressing task of witnessing the slow extinction of the personality, usually within an outwardly healthy body (Mace & Rabins, 1981). Despite the enormous responsibilities placed upon the family and the primary caregiver, the literature shows that families are responsive to the needs of older dependent family members. However, family caregivers are not immune from the potential stressors that can disrupt the normal functioning of the family system, particularly in the case of caring for mentally impaired elders.

#### The Role of the Family as Caregivers to Dependent Elders

One of the most persistent myths perpetuated in our society is the isolation and abandonment of older relatives when they become dependent because of physical or mental impairments. It is assumed that families are fragmented along generational lines, because of the demise of the heralded extended family (Nyedegger, 1983). Recent gerontological studies confirm that contrary to stereotypic views, families are the number one

caretakers for dependent elders (Brody, Poulshock, & Masciocchi, 1978; Brubaker, 1983; Shanas, 1980; Robinson & Thurner, 1980; Brody 1985). Particularly in the event of physical or mental impairments, most elderly can rely on relatives and offspring to provide substantial care and assistance (Brubaker, 1983; Cicirelli, 1981; Shanas, 1979). The presence of a family caregiver, particularly a spouse, is one of the major factors in preventing the institutionalization of a dependent older adult (Brody et al., 1978). In fact, 80% of the long-term health and social services to the elderly and chronically-ill are provided by family members (Brody, 1982; Special Committee on Aging, U.S. Senate 1982). The bleak picture of institutions as dumping grounds for the elderly is found to be unjustified. In reality, 5% of the 65 and over population reside in institutions (Brody, 1985). In contrast, the great majority of older adults maintain their own residences. Families facing the decision of institutionalization for a older family member is the "last resort" and usually after suffering personal, financial, social losses in the process (Brody et al., 1978). The final decision is not an easy one and it has been shown guilt feelings and burden remain even after the caregiver responsibility has been lifted from the shoulders of the family (Brody, 1982).

As the primary source of support for long-term care, families usually follow the "principle of substitution" in caregiving (Shanas, 1980; Johnson, 1982). This is providing

care in serial order rather than as a shared functioning unit. Typically, the responsibilities of caregiving fall primarily to the spouse or adult daughter. It is the middle-generation of women who provide the vast majority of personal care and instrumental services. This "sandwich generation" (where women provide care to both younger children and elderly parents) can be the most vulnerable to stress and burn-out. Furthermore, with the entrance of more women (traditionally the "kin-keepers") into the labor market and the increase of women heading single parent homes adds to a potential "collision course" between social roles and filial responsibility (Treas, 1982). Women's attitudes and values about family care of elderly adults have not eroded despite socioeconomic and demographic changes (Brody, Johnsen, Fulcomer, & Lang, 1983).

The role of the family as careproviders is further complicated by major demographic shifts occurring in older generations. An increase in chronic diseases, such as the irreversible dementias increases with a growing older population (Schneck et al., 1982). Although family careproviders are responsive and caring toward their elder dependents, families are not socialized to assume the role of caregiver and are often ill-equipped to manage the emotional and physical requirements of such a role (Mascciochi, Thomas, & Moeller, 1983). The effects of chronic illness on the family is succinctly stated by Bruhn (1977):

"Chronic illness especially disrupts the usual ways in which family members behave toward one another and then hampers



their ability to overcome the effects of this disruption. The effects of chronic illness on families are more often disintegrative than integrative; indeed, they change the attitudes and behavior of both sick and well family members of a family unit. Tasks and responsibilities must often be reassigned and this creates a period of disequilibrium. The duration and outcome of family disequilibrium is influenced by the clinical manifestations and management of the illness as well as how well the family adapts to the changes created by the illness" (p.1057).

Brody and Lang (1982) believe that this disequilibrium is detrimental to the family system and unless family caregiving efforts are supplemented and strengthened, emotional and physical problems may be perpetuated down through the generations. This can ultimately affect all family members and increase the social and economic costs to the community. The role of the family in the lives of dependent elders in the near future is also uncertain as the number of children per family decreases.

#### Providing Care to Impaired Relatives: Burden, Coping, and Intervention Strategies

The role of the family as careproviders to the impaired elderly as been amply documented (Shanas, 1980; Brubaker, 1983). It is only recently however, that researchers have begun to document the impact on caregivers of providing long-term care to older family members with chronic-illnesses. Early studies attempted to describe factors which effect the caregivers ability to provide care to mentally impaired relatives (Hoenig & Hamilton, 1966; Sainsbury & Grad de Alcorn, 1970). These studies found that behavioral problems

associated with the dementing illness contributed to familial burden in 80% of the families investigated. Sanford (1975) investigated specific factors which needed to be alleviated in the caregiving situation in order for the impaired elder to remain in the household of the careprovider. Problems such as sleep disturbances (due to nocturnal wanderings of the patient), incontinence, immobility of the patient were cited as major problems not well tolerated by family careproviders. Hirshfeld (1978) found that a family's ability to provide home care to a relative with senile dementia was dependent upon the level of tension resulting from the disease and the caregiving situation rather than from specific impairments of the patient or caregiver.

Sanford (1975) and Hirshfeld (1978) propose that intervention programs, both formal and informal, should be initiated in behalf of family caregivers in order maintain impaired relatives in the home environment. One of their proposals included a variety of services to enhance the coping abilities of caregivers to prevent premature institutionalization of the dementia patient. In a related study, Levine et al., (1983) initiated a skills training program for caregivers of dementia patients based on the hypothesis that tolerance of impairments in the dementia patient is related to the availability and quality of coping skills of the supporter. Preliminary results indicated that the skills training program was extremely useful to the caregivers and enabled the caregivers to cope more

effectively.

Zarit et al., (1980) found that levels of burden reported by caregivers to senile dementia patients were associated with the number of visits of relatives to caregiver's household. This indicates that the availability of natural support networks may reduce the strain upon the caregiver. Other studies have confirmed the benefits of social support groups where caregivers can "ventilate and validate" their emotional feelings in a supportive atmosphere. Membership in a support group has been found to strengthen the emotional well-being and morale of caregivers to Alzheimer's patients (Barnes, Raskind, Scott, & Murphy, 1981). In a similar study, Lazarus, Stafford, Cooper, Choler, & Dysken, (1981) found that discussion groups provided both educational and supportive functions to relatives of Alzheimer's patients. Therapeutic and educational benefits have also been derived from support groups for caregivers of senile dementia patients (Aronson, Levin, & Lipkowitz, 1984; Steuer & Clark, 1982).

However, unmet expectations of social support or negative input from important others, has been found to be the best predictor of depression in a sample of caregivers to Alzheimer's patients (Fiore, Becker, & Coppel, 1983). In fact, these unmet expectations accounted for 37% of the variance in depression even when upset relating to Alzheimer's patient had been statistically partialled out. The previous findings on social support indicate that, at least for caregivers of Alzheimer's patients, the availability and support of others

often helps to alleviate the stresses of caregiving. But for some caregivers the consequences of unmet expectations from the support others can be debilitating.

Other studies have related caregiver coping to factors other than social support. Pratt et al., (1985) investigated the relationship between coping strategies and sense of burden in caregivers to Alzheimer's patients. They found that two external coping strategies, spiritual support ( $r = -.25$ ) and extended family ( $r = -.16$ ) were significantly correlated with lower levels of burden. Three internal coping strategies, reframing ( $r = -.15$ ), confidence in problem solving ( $r = -.18$ ), and passivity ( $r = .26$ ) were also significantly correlated with burden scores. Internal coping strategies represent cognitive efforts to define the caregiving situation as either a challenge to overcome or as a situation that is beyond their control. This study supports that both external coping resources (social networks and support) and internal coping resources (cognitive/perceptual characteristics) are important mediators of sense of burden in caregivers.

Recently a proliferation of clinical and descriptive studies have emphasized intervention strategies that include both informal and formal service networks. For example, adult day care programs for Alzheimer's patients, which provide respite to caregivers, has been shown to reduce the stress of continuous caregiving and helps families to maintain the Alzheimer patient at home and delays institutionalization (Sands & Suzuki, 1983; Panella, Lilliston, Brush, & McDowell,

1984). Other studies have proposed management techniques that would enhance coping abilities in caregivers (Haley, 1983; Ware & Carper, 1982; Zarit & Zarit, 1983). Suggestions for counseling techniques with senile dementia patients (LaBarge, 1981), proposals for nursing intervention (Gwthyer & Matteson, 1983; Hayter, 1982), for physicians (Eisdofer & Cohen, 1981; Riefler & Wu, 1982), and mental health professionals (Teusink & Mahler, 1984) are representative papers which stress the importance of intervention programs for the entire family unit. Finally, it is important to add that several books have been published which are targeted to provide information to caregivers and the general public about Alzheimer's. The most notable books, *The 36-Hour Day* (Mace & Rabins, 1981), *Alzheimer's Disease: A Guide for Families* (Powell & Courtice, 1983), and *Alzheimer's Disease: A Guide for Families, Spouses, and Friends* (Reisberg, 1983) are examples of books that provide realistic descriptions of the responsibilities of the caregiver and more importantly present practical information on managing the Alzheimer's patient in a home environment.

In October 1984, the Department of Health and Human Services Task Force on Alzheimer's Disease presented their comprehensive report on the current status of research in the field and proposed suggestions for directions in future research. The Task Force concluded that while the family's key role in caring for the person with Alzheimer's is evident, the nature, dimensions, and impact of their role have yet to be determined. The Task Force emphasized that much of the

existing knowledge about the family as caregiver has been either on anecdotal information that has not been substantiated by empirical evidence or on extrapolations of findings from literature on the frail elderly, rather than on Alzheimer's disease patients. Although this may be true, the literature that does exist provides valuable information on the family caregiving role with a chronically-ill patient.

The following section represents a summary of major findings from a review of the literature regarding dementia:

- Alzheimer's disease, an irreversible form of dementia, causes a progressive decline in cognitive and intellectual functions of the patient.

- Because of the behavioral problems associated with the disease, the patient becomes increasingly dependent upon the family system for assistance and care in activities of daily living.

- As a major provider of care and assistance, the family has been substantiated as the number one caretaker of dependent older family members.

- Most dementia patients live in community settings and are typically cared for by women, daughters, daughters-in-law, or wives (who are aging themselves).

- Due to changing demographics and sex role orientation, the status of family caregiving will be seriously questioned as a viable source of support to dependent family members.

- The extremely debilitating and chronic nature of

Alzheimer's disease places a tremendous financial, social and psychological burden on family caregivers. The caregiver often faces the prospect of social isolation, lack of time for self, family, and friends, career disruptions, financial drain, and the unresolved heavy physical labor in caregiving. The average day in the life of the caregiver is best described as a "36-hour day" (Mace & Rabins, 1980) where the caregiver role seems neverending.

-Multi-dimensional intervention programs for Alzheimer's disease (and related disorders) patients and family caregivers have been initiated which include respite and day care services, social support groups, behavioral management techniques, intervention strategies for social workers, physicians and nurses and the health care delivery system.

-Through out the stages of Alzheimer's disease, the primary caregiver is faced with enormous responsibilities which without the support of other family members, friends and formal services, could lead to major psychological, social and physical problems.

-Not only have external coping resources, such as spiritual support and extended family, been shown to be associated with lower levels of burden, but internal coping strategies, which emphasize a cognitive/phenomenological interpretation of the caregiving situation, are also associated with the sense of burden in caregivers.

This summary of findings, together with the Task Force on Alzheimer's Disease recommendations for research pertaining to

family caregiving, will be used as a springboard for the direction and purpose of this study. It is evident that particular coping strategies are associated with lower levels of burden in caregivers to Alzheimer's patients. What is not known, are the factors or antecedents that either separately or in interaction, affect and influence the caregiver to utilize particular coping behaviors that ultimately affect caregiver well-being. It is hypothesized that personal resources (e.g., personal control beliefs) and situational resources (social network and support), and patient functioning characteristics have direct effects on coping behavior, which in turn affects the physical, psychological and social well-being of the caregiver. Before examining the literature associated with personal and social resources and their effects on coping and well-being, it is necessary to focus on the construct of coping and it's role as a mediator in the proposed hypothetical model of this study.



## COPING

### Introduction

The construct of coping is currently undergoing a dynamic transformation in measurement and conceptualization. The concept of coping has evolved rapidly to include not only intra-psychic dimensions but cognitive and behavioral responses as well (Billings & Moos, 1981). Coping theoretical orientations are diverse and extensive. In general, most researchers have defined "coping" as either behavioral or psychological responses in the context of adapting to stressful situations (Fleming, 1984).

The most prolific coping studies have originated from three main research centers. One main group is represented by Richard Lazarus and Susan Folkman and colleagues at University of California/Berkeley. Their book "Stress, Appraisal, and Coping" (1984) is an excellent treatise on the coping construct which elaborates on their earlier research project culminating in their classic article concerning an analysis of coping in middle aged men and women (Folkman & Lazarus, 1980). The second center generating theoretical models and empirical findings on coping has been the Social Ecology Laboratory under the auspices of Rudolf Moos and colleagues at Stanford University/Veterans Administration. They have published numerous research articles, but most relevant to coping are the articles by Billings and Moos

(1981), Cronkite and Moos, (1984), Mitchell et al., (1983), and Moos (1984). The third main center for research on coping is represented by Hamilton McCubbin and colleagues at the University of Minnesota. A decade review of family stress and coping authored by McCubbin, Joy, Cauble, Comeau, Patterson, and Needle, (1980) and a special issue of the Family Relations journal edited by McCubbin and Boss (1980) provides an extensive array of research focusing on both the normative and non-normative stressors that impact the the family system. A two volume effort edited by Figley and McCubbin (1983) investigates both intra-family and environmental stressors that impinge on the family system and represents the most recent studies regarding family coping behavior. The research conducted by Pearlin and Schooler (1978), Antonovsky (1979) and the recent empirical efforts of Menaghan (1984) are also considered key building blocks to the foundation of coping theory.

#### Definitions and Theoretical Models of Coping

Lazarus and Folkman (1984) have proposed that aside from their recent theoretical model there exists two distinct traditional approaches to the concept of coping. One approach has been heavily influenced by Darwinian thought which perceives coping as controlling environmental stressors by escaping or avoiding the aversive stimuli. A similar viewpoint is espoused by Tache and Selye (1978) who emphasize a phylogenetic perspective of stress and coping. Tache and

Selye (1978) believe biological reactions to environmental stressors continue to be mediated via the same non-specific coping mechanisms that humans have acquired through the evolutionary process. The other approach is the "psychoanalytic ego" psychology model which concentrates on the way people cope across a variety of situations by emphasizing coping styles or traits.

Lazarus and Folkman (1984) criticize both approaches for either neglecting the cognitive aspects of coping (by focusing on the unidimensional concept of drive or arousal instead) or disregarding coping as a dynamic ego process. In contrast, Lazarus and Folkman (1984) propose that coping is a shifting process influenced by a cognitive/phenomenological orientation. They stress that coping behavior is not to be regarded as a static style or trait, but rather a function of "countinuous appraisals and reappraisals of the shifting person-environment relationship" (p.142).

Expanding beyond the individual "microsystem", McCubbin (1979) has proposed that families adapt to stressors by initiating coping strategies "within the family as well as transactions with the community to decrease family vulnerability" (p.14). McCubbin (1979) has integrated coping behavior as a singular dimension in the ABCX model (originally formulated by Hill, 1949) which describes how families adapt to stressful events. In a similar mode, Reiss and Oliveri (1980) have adapted the concept of "paradigm" (Kuhn, 1970) to organize family coping efforts in a

theoretical framework according to how a family perceives the social context among them.

Although coping theory is beginning to expand, the definitions of coping are limited in operational diversity. Several attempts to operationalize coping do exist. Krohne (1978) views coping as a multi-stage process and includes any activities of an individual that control anxiety or arousal in the cognitive, physiological, or behavioral-motoric areas. Pearlin and Schooler (1978) refer to coping as any response to external life strains that serves to prevent, avoid, or control emotional distress. Using an ecological perspective, Holahan and Spearly (1980) have conceptualized coping as a function of an interactional relationship between person variables and environmental factors. Lazarus and Folkman (1984) define coping as the constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. In summary, it is apparent that coping is a multidimensional construct that is best understood as a function of both person and situational characteristics. Coping responses are engaged by the individual as an attempt to change or to adapt to the stressor's impact.

#### Dimensions of Coping

Many reseachers have conceptualized coping into a number of dimensions. Olson and McCubbin (1983) have proposed two

main categories of coping strategies families use over the life cycle: internal and external coping strategies. Reframing and passive appraisal are examples of internal strategies and represent attempts by the family to define the stressor as "a challenge to be overcome" (reframing) or "something that will take care of itself over time" (passivity). External coping strategies represent resources that families utilize outside the family boundary such as the church, extended family, friends, neighbors and formal networks such as community agencies and professional services.

Pearlin and Schooler (1978) have differentiated coping according to the nature of their functions: responses that change the situation; responses that control the meaning of the situation (e.g., selective ignoring); and responses which "function more for the management of stress for its vitiation" (p.7). Billing and Moos (1984) have classified coping responses into three general domains: appraisal-focused coping (which controls meaning); problem-focused coping (which changes the situation); and emotion-focused coping (which effect reactions).

Folkman and Lazarus (1980) suggest that coping efforts serve two main functions: the management or alteration of the person-environment relationship that is the source of stress (problem-focused coping) and the regulation of stressful emotions (emotion-focused coping). They also emphasize that the way a person appraises an encounter will strongly

influence the coping process and subsequent personal adjustment. Appraisal is further differentiated into two components: primary and secondary appraisal (Lazarus & Folkman, 1984). Primary appraisal is the initial judgement of the event that is determined to be either "irrelevant, benign-positive, or stressful" and stressful events can either be challenging (having positive potential) or threatening (having negative potential) (Lazarus & Folkman, 1984). Secondary appraisal consists of judgements that evaluates what coping resources are available in order to effectively deal with the demands placed upon the individual. The subjective appraisal dimension is influenced by the antecedent conditions within the person and in the situational context. This determines interactively the mediating appraisal process, which in turn affects in predictable ways the coping and emotional response (Lazarus & Folkman, 1984). The relationship between the interdependent antecedent conditions, appraisal, coping response and subsequent outcomes can be diagrammed as shown in Figure 2.

To summarize, Lazarus and Folkman (1984) present in a concise manner, their perspective on the coping process,

"the way a person copes is determined in part by his or her resources, which includes health and energy; existential beliefs, e.g. about God, or general beliefs about control; commitments which have a motivational property that can help sustain coping; problem solving skills; social skills; social support; and material resources" (p.179).

#### Coping and Adaptational Outcomes

In a research project conducted with over 2,000

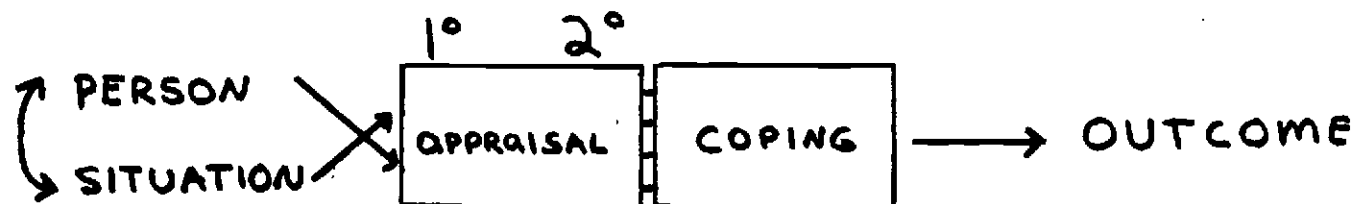


FIGURE 2

Situation-Person, Appraisal, Coping  
and Adaptational Outcome

individuals, Olson et al., (1983) reported that external resources (e.g., church, extended family, formal services) were used when the family does not have sufficient internal resources (psychological characteristics) to cope with stressful events. Furthermore, they suggest that in situations with low stress, social support may not be functional, but social support increases in importance as difficult stressors become more significant (Olson et al., 1983).

In situations where people have little direct control (e.g., finances and job), psychological characteristics of the individual may be more helpful in adjusting to stress. On the other hand, problems that may arise in close interpersonal relationships are seen as having greater potential for direct control, "it is the things that one does that makes the difference" (Pearlin & Schooler, 1978). Furthermore, a variety of resources and responses may be more suitable for dealing with stress than any one particular coping strategy (Pearlin & Schooler, 1978). Pearlin and Schooler (1978) also indicated that compared to women, men seem to have an advantage in controlling stress, but found no significant age differences in patterns of coping usage. Similar to Pearlin and Schooler (1978), Folkman and Lazarus (1980), and McCrae (1982) found no relationship between age and coping. Men were found to have used more problem-focused coping than women at work role situations. However, there were no gender differences in emotion-focused coping (Folkman & Lazarus, 1980).



Folkman & Lazarus (1980) found that subjects in their study showed more variability than consistency in their coping patterns and that both emotion-focused and problem-focused coping behaviors were utilized in the majority of episodes reported. However, the context of the episode differentially influenced the focus of coping behavior. In occupational settings, problem-focused coping seemed to predominate, whereas in health related stressful episodes there was an increased association with emotion-focused coping.

Several studies have examined coping and adaptation in the context of health-related situations. For example, Felton and Revenson (1984) examined whether the controllability of one's illness (e.g., cancer, rheumatoid arthritis, hypertension, diabetes) affects the impact of coping strategies utilized. It was found that coping strategies (information seeking and wish fulfilling fantasies) were not modified by illness controllability. But information seeking had a positive effect on adjustment whereas wish fulfilling has an opposite effect (Felton & Revenson, 1984). In another study, Ben-Sira (1984) indicated that dependence on environmental resources for coping with chronic illness had two main disadvantages. One is that support is not always available and secondly getting help may add to the overall burden, because of the "cost" of receiving support in an unequitable exchange (without the ability to reciprocate). In this study, it was shown that professional help, particularly from a physician, was the most sought for, but the least attainable.

Pratt et al., (1985) examined the relationship between coping strategies and subjective sense of burden in caregivers to Alzheimer's disease patients. In this study, three internal coping strategies and two external coping strategies were significantly related to subjective sense of burden. It was found that passivity (an internal coping strategy) characterized as an "avoidance response" (Olson et al., 1983) was associated with higher levels of burden. Although "passivity" carries a negative connotation of "giving up", in some situations direct control or problem-solving coping strategies may not be appropriate and may further add to the overall stress or burden experienced (Folkman, 1984). This perspective is similar to the situation where an external locus of control may be more adaptive in situations where the event is beyond the control of the individual (Wong & Sproule, 1984). The investment of energy in direct-problem solving coping activities where no actual changes are possible in the situation, may call for another coping strategy such as reframing or passivity (Olson et al., 1983) or emotion-focused coping (Folkman, 1984).

As an integral component of the overall framework for this study, coping is seen as influenced by antecedent factors (e. g., personal resources, social resources, and patient functioning) within the context of the caregiving role. Furthermore, coping responses are then hypothesized to directly affect subsequent caregiver well-being. Therefore, the next section of the literature review will examine

research that has investigated the role of personal resources (control characteristics) and social resources (network and support) on coping behavior and individual well-being.

## Personal and Social Resources that Influence Coping Behavior and Individual Well-Being

### Introduction

One of the most potentially productive areas in stress research and theory is that the conceptualization of "stress", whether measured in life change events (Dohrenwend & Dohrenwend, 1974; Holmes & Rahe, 1967) or in the measurement of daily hassles (Kanner, Coyne, Schaefer, & Lazarus, 1980), does not represent a uniform phenomenon for all individuals. Rather stress imposes a differential impact on people according to features of the social setting and upon characteristics of the individual (Fleishman, 1984; Wheaton, 1983).

A variety of factors and antecedents including environmental events (Holmes & Rahe, 1967), psychosocial processes (Folkman & Lazarus, 1980, Lazarus & Launier, 1978), physiological responses (Seyle, 1966; Tache & Seyle, 1978), social supports (Dean & Lin, 1976; Gore, 1973), and coping behaviors (Folkman & Lazarus, 1980; Pearlin & Schooler, 1980), are seen as contributing factors in the stress process (Fleming, Baum, & Singer, 1984). Yet, despite the awareness of these contributing factors, "the intricate linkages that join them have not yet been unraveled...as a consequence, little is known of the manner in which the various components of stress are interconnected to form a process" (Pearlin,

Lieberman, Menaghan, & Mullan, 1981; p. 387).

Many theoretical models and empirical designs have been utilized that emphasize an interactional/ecological approach which incorporates both person-situation variables in the research design to the study of coping with stressful events (Holahan, Holahan, & Belk, 1983; Lazarus & Folkman, 1984; Sarason & Sarason, 1981; Caplan, 1981). It is the intention of this paper to establish a similar model which includes variables measuring components of personal and situational constructs. This approach will help to unravel the complex process by which individuals cope and adjust to the role of caregiver to an Alzheimer's patient.

In order to provide a rationale for utilizing an interactional framework in this study, a review of relevant research relating to the effects of personal resources (personality and psychological characteristics) and contextual resources (social networks and social support) on the coping process and well-being and adaptation will be examined.

#### What are Personal Resources?

Pearlin & Schooler (1980) have proposed that coping responses (what people do behaviorally and cognitively to handle stressful events) are influenced by both social resources and psychological resources. Psychological resources, in their study, were defined as personality characteristics that people draw upon to help them withstand

threats posed by events and objects in the environment. Similarly, the term "personal resources" as used in this paper represents facets of personality that, by affecting such factors in coping situations as the range of responses considered and effort expended, may increase an individuals potential for dealing effectively with stress (Wheaton, 1983). These personal resources are conceptualized as precursors to actual coping behaviors within the context of a stressful event and may affect tendencies to use one type of coping strategy versus another (Wheaton, 1983).

Although personal resources are seen here to constitute a variety of personality dispositions and characteristics, many studies have concentrated on specific dimensions of "personal resources". For example, Kobasa (1979; 1981) has combined three personality dispositions- commitment, control and challenge- to represent a more general personality characteristic labeled as "hardiness". Wheaton (1983) hypothesized that characteristics such as fatalism and inflexibility, serving as measurable variables, would serve as moderating influences in a stressor event. Other variables that have represented personal resources in the literature are self-efficacy (Bandura, 1977, 1978; Holahan et al., 1983), self-esteem (Rosenberg, 1979), self-control skills (learned resourcefulness) (Rosenbaum, 1983), mastery, (Pearlin & Schooler, 1981), self-concept (Hobfoll & Walfisch, 1984), self-reliance (Funch & Marshall, 1984), and locus of control (Lefcourt, 1981; Rotter, 1966).

It is important to emphasize that personality dispositions are viewed as only one influence of actual coping behaviors utilized by individuals (Krohne, 1978). One of the arguments against the use of personality traits to predict behavior is that personality assessment scales presently available assume that one's interpersonal behavior has some consistency over time. This perspective may disregard environmental conditions which may also determine behavior (Lanyon & Goodstein, 1982). Perceptions of control over life events may be more of a function of characteristics of the event rather than personality characteristics in the people to whom events occur (Dohrenwend & Martin, 1979). Mischel (1968) has questioned the use of personality traits (as measured by assessment scales) to predict behavioral tendencies. However, Wheaton (1984) proposes that personality explanations for behaviors have been the target of unjustified criticisms. In this study, it is predicted that both personal and situational characteristics are reciprocal and influential in the effects on adjustment in stressful situations.

#### Personal Control Beliefs: A Personal Resource Influencing Individual Adaptation and Well-Being

Personality characteristics have been shown to greatly influence both physiological and psychological adjustment in stressful situations. One classic example regarding the link between personality characteristics and physiological outcome

is the relationship between "Type A" behavior and coronary disease (Matthews & Glass, 1981). Type A behavior is defined as the outcome of a set of predispositions interacting with specific types of stressful situations. Matthews and Glass (1981) indicate:

"Type A's have a distinctive type of coping with uncontrollable stressors. When confronted by an uncontrollable event, they exert greater efforts than their Type B counterparts to assert control. As their efforts meet with repeated failure, Type A's blame themselves for not being able to succeed and eventually give up responding" (p.181).

In the case of physiological response to stressful situations, Type A individuals seem to emit particular coping responses which over a period of time may be detrimental to physical health.

The relationship between personality characteristics and psychological adjustment has been the target of numerous research endeavors, particularly centering on the construct locus of control. The utility of this construct is indicated by the fact that Rotter's monograph (1966) on locus of control has been cited over 2,500 times and continues today to be a dynamic and useful construct (Lefcourt, 1981). The locus of control orientation refers to the extent that individuals believe that events in their lives are under their own control (internal locus of control) or are determined by forces outside themselves such as luck, fate, or chance (external locus of control) (Rotter, 1966).

Lefcourt (1976; 1982) and Strickland (1973) have reviewed



studies which included locus of control and conclude control orientation is influential for individuals adjusting to stressful situations. Those with an external orientation seem to be more susceptible to maladjustment in stressful periods than those with an internal control orientation. Recent studies however, have indicated that the issue is more complex and in fact externals may cope better in certain stressful situations (Burish, Carey, Wallston, Stein, Jamison, & Lyles, 1984; Reid, 1984; Wong & Sproule, 1984). For example, like the Type A individual who strives for control, even in uncontrollable situations, the individual with an internal locus of control belief may attempt to maintain control even though such control is not possible. This tendency to exert control can have negative or adverse physiological consequences (Blankstein, 1984).

In general, however, it is the internals who seem to fare better in a variety of stressful situations. Kobasa et al., (1982) proposes that hardiness (of which control is one dimension) may not only influence coping processes but may also exercise a buffering effect on stressful events. Results from their study supported the hypothesis that hardiness functions to decrease the effects of stressful life events. Correlations between negative life events and anxiety were greater for externals than internals in one recent study (Sandler & Lakey, 1982).

In another related study, Krause and Stryker (1984) explored how locus of control beliefs mediated the impact of

stress on well-being. It was hypothesized that locus of control could be measured not only by the traditional internal vs. external orientation, but also by the degree of control (moderate vs. extreme). Their findings indicate that men with a moderate internal locus of control coped more effectively with stress than those whose locus of control beliefs were categorized as extreme internal, extreme external or moderately external. They interpreted these findings to suggest that externals (both degrees) were less likely to initiate constructive efforts to deal with the stressful event because any self-initiated actions would not be expected to cause any influence on the chain of events. As for the extreme internals, it was proposed that effective coping actions were not undertaken because of overwhelming guilt feelings resulting from the beliefs that one's own actions are responsible for the occurrence of the initial event. Brewin and Shapiro (1984) suggest that locus of control for positive outcomes should be regarded as distinct from locus of control for negative outcomes.

Thus, the construct locus of control as conceptualized by Rotter (1966) may be limited by its unidimensional structure and ironically, for being too general in scope. Even Rotter (1975) has voiced concern over the misuse of the scale and has claimed that the locus of control scale:

"was developed as a broad gauge instrument-- not as an instrument to allow for very high prediction on some specific situation, such as achievement or political behavior, but rather to allow for a low degree of prediction of behavior across a wide range

of potential situations (p.105).

The limitations and misconceptions of the Internal-External Locus of Control Scale are also documented by Lowery (1981) who suggests that utilization of multi-dimensional scales, such as Levenson's IPC scale (1974) may be more productive in assessing control beliefs. Wong and Sproule (1984) point out that:

"the individual is neither an almighty controller nor a powerless controllee. Nevertheless, the unidimensional conflict view of control... continues to dominate psychological thinking... so pervasive is this unidimensional view that its limitations are rarely noted and its adaptiveness is seldom questioned" (p.324).

Another concern over the use of locus of control is the applicability of the construct in general versus situation specific events in research designs. Folkman and Lazarus (1984) caution against the use of general control beliefs as predictors of behavior in specific situations. They believe that the appraisal of control can change depending on the contingencies of the situation. In other words, a person may feel in control of one situation but not another. Folkman and Lazarus (1984) have indicated that recent modifications to the original Internal-External Locus of Control Scale have resulted in more instruments which measure situational control expectancies and thus improves the predictive power of the construct.

Lefcourt (1981; 1984) has edited three volumes which contain contributions from authors who have created scales

with more specific applications; examples include the IPC scale (Levenson, 1974), Health Locus of Control Scale (Wallston et al., 1976), Sphere-Specific Scales (Paulus & Christie, 1981), and Locus of Control Among Alcoholics (Worell & Tumilty, 1981), and the Multidimensional-Multiattributitional Causality Scales (Lefcourt, 1981). These scales represent attempts to take into account the contextual variability that influences the coping efforts of individuals in stressful situations. For example, Reid, Haas and Hawlings (1977) used a locus of control instrument that was specifically designed to take into account the environmental characteristics surrounding an elderly population in order to assess control beliefs.

In summary, a review of the literature regarding personality characteristics, particularly personal control beliefs, has revealed that traditional perspectives on control in stressful situations have been challenged by recent developments in theory and methodology (Folkman, 1984). However, the construct locus of control or personal control beliefs, continues to flourish with research activity (Lefcourt, 1981). Furthermore, the incorporation of the construct into interactional designs has been proven to be a productive strategy in investigating how people adjust to stressful situations. The current perspective on the role of personal control as a personal resource, is accurately stated by Lazarus and Folkman (1984):

"It is clear that beliefs about control, whether shaped more by person factors or situational

contingencies, play a major role in determining the degree to which a person feels threatened or challenged in a stressful encounter...the important point is that whether general or specific, illusory or realistic, one's belief in one's ability to control an event influences how that event is appraised and, through appraisal subsequent coping activity" (p.77).

## Personal Resources and Social Network Utilization and Support

The relationship between personal resources and social support have only recently received empirical testing. One of the major indicators of personal resources that has been investigated in relation to social support is locus of control. One study, examined the relationship between social support and hardy personality (of which "control" is one dimension) and noted that dimensions of hardiness were significantly correlated with social support (Canellan & Blaney, 1984). This suggested that social support and hardiness are interrelated and actually may represent two sides (interpersonal and intrapersonal) of the same coin (coping resources) for the individual (Canellan & Blaney, 1984). Lefcourt, Martin & Saleh (1984) found that those persons with an internal locus of control belief derive greater benefits from social support than those who have a more external orientation. Furthermore, they concluded that it is the individuals who seem to be generally less sociable or more autonomous that benefit most from the presence of social support. In a similar study by Sandler and Lakey (1982), it was found that although subjects with external locus of

control beliefs received a greater quantity of support, it is the internals who qualitatively receive the stress buffering effect from social support.

Using an interactional approach to investigate psychological well-being, Duckitt (1984) found that extraversion (identified as a personality trait) showed significant interaction with social support on the prediction of distress. Unsupported extraverts reported higher levels of psychological distress than non-extraverts, while supported extraverts tended to report reduced stress. Self-reliance has also been found to act as a modifier between both social support and stress particularly with respect to negative affect (feelings of boredom and depression) in a sample of women with breast cancer. (Funch & Marshall, 1984).

In general, it seems that personal resources, specifically locus of control beliefs, do influence the potential buffering effects of social support. Internals seem to obtain and use information more effectively from networks than did externals. For those individuals with an external locus of control, the mere availability of support networks does not seem to affect stress adaptation (Sandler & Lakey, 1982). This raises the question as to whether social support is responsible for the buffering effects or is it the characteristics of the person which attract or negate the potential buffering effects offered by support groups (Sarason and Sarason, 1982). Tolsdorf (1976) indicates that, at least for psychiatric patients, the potential effects of

social support are usually discounted by the patient. Personality characteristics, such as a defensive attitude, may actually discourage others from giving help and encourages the gradual withdrawal of the network and diminished support for the patient (Gottlieb, 1983). This dynamic exchange between person and environment is perhaps best described by Lerner (1984):

"If a person's characteristics match the demands of a particular setting, adaptive outcomes in that setting will accrue. Those people whose characteristics match most of their contexts' should receive supportive or positive feedback and should show evidence of the most adaptative behavioral development. In turn...mismatched people, whose characteristics are incongruent with one or more contexts, should experience maladaptive developmental outcomes" (p.152).

Social support has been shown to be both a distress (Fiore et al., 1983) and a buffer against stress (Barnes et al., 1980; Lazarus et al., 1981) in caregivers to Alzheimer's patients. This relationship between the caregivers personal resources (control beliefs) and social resources is an area demanding additional research.

#### Personal Resources and Coping Behavior

Personality dispositions can influence coping processes and may exercise a buffering effect on stressful events (Kobasa et al., 1982). Other investigators consider that cognitive appraisal and coping responses are determined primarily by specifics of the threatening or challenging event (Folkman & Lazarus, 1980; 1984). These contrasting

views illustrate the difference in theoretical models which differentiate coping as a function of personality traits and coping as a function of situational factors (Fleishman, 1984). Folkman and Lazarus (1980) maintain that trait measures are poor predictors of coping processes. They argue that trait measures are based on the assumption that people are behaviorally consistent across a variety of situations. They view coping as a shifting process dependent on the status of the situation as it changes. For this reason they are reluctant to connect static measures of personality characteristics to the dynamics of coping behavior. Wheaton (1983) suggests that the ultimate role of personality is an indirect one, in the sense that personality is likely to affect the outcome of coping via its consequences for certain broad tendencies in coping behavior. In contrast, Lazarus and Folkman (1984) discourage the conceptualization of coping as a style or trait based on dispositions and instead champion the perspective that coping is the function of cognitive appraisal which is more related to situation-specific factors. But they also recognize that dispositions may influence appraisal.

Although the cognitive/transactional model of Lazarus and Folkman (1984) heavily influences the theoretical model of this paper, it is important to note studies that have documented personality characteristics as directly affecting coping behavior. Rosenbaum and Palmon (1984) found that individual differences in learned resourcefulness



(self-control skills) influenced the coping levels in less severe cases of epilepsy. Those who rated higher in resourcefulness were significantly less depressed, anxious, and coped better with their disability than low resource subjects. In another study, self-esteem influenced both coping response and subsequent depression in the stress-illness relationship (Conkrite & Moos, 1984).

Personality attributes (locus of control beliefs) were also found to be predictive of coping behavior in children facing minor elective surgery (LaMontagne, 1984). In this study, it was found that active copers had a more internal locus of control than children rated as avoidant or a combination of avoidant-active modes. Schoeneman and Reznikoff (1983) examined personality variables (locus of control orientation) that might enhance a spouses' ability to cope with the unique stress of living with a spouses chronic illness namely, chronic kidney failure and the accompanying hemodialysis treatment. The results from this study indicated that external oriented spouses (faced with the long term stress of living with chronic-illness) are less likely to adapt as well as more internally oriented women. Schoeneman and Reznikoff (1983) further suggested that if external-oriented women were identified and trained through therapeutic intervention to become more internal, this may facilitate adjustment in a long-term situation.

However, not all studies have substantiated the direct effect of personality beliefs on coping behavior. For

example, Sandler and Lakey (1982) found that locus of control beliefs were not related to perceptions of control over negative life events. At least for this study, differences in coping behavior were not associated with differences in dispositional characteristics.

Other studies indicate that coping behavior may be more a result of both person and situation characteristics (Fleishman, 1984; Wheaton, 1983). Wheaton (1983) found that increasing personal resources reduced the effects of environmental stressors, but stress-moderating effects of personal resources may depend on the stress encountered. Similarly, Fleishman (1984) found modest relationships between personality traits and coping behaviors particularly emotion-focused behaviors. However, Fleishman (1984) concluded that situational factors appears to be more influential than personality characteristics in shaping the coping process. Fleishman (1984) indicates that coping appears to be a product of both personal and situational influences. These findings reinforce Lefcourt's (1982) perspective on the role of locus of control on coping behavior:

"It is obvious... that locus of control does play some role in affecting the ways in which people cope with their experiences. However, that role is complex, interacting with as it does with other variables such as time of life stress, social support and no doubt other variables as well." (p.110).

Perhaps the most pertinent research on personal resources in relation to coping and stressful situations is a study conducted by Parkes (1984). Based on the premise that

internals and externals (locus of control) differ in coping behavior, Parkes (1984) investigated how locus of control, cognitive appraisal and coping behavior interact in mediating stressful episodes. Results from this study indicated significant interactions between locus of control and appraisal for each of the coping subscales (General coping; Direct Coping; and Suppression). The interaction effects showed that the patterns of coping reported by internals were potentially more adaptive in relation to types of appraisals than those of externals. Parkes (1984) proposes that internals will be more likely to use strategies focused on altering the stressful situation, whereas externals will be more likely to adapt palliative coping strategies. The addition of an appraisal assessment in this study is intriguing because it enhances the theoretical model that Lazarus and Folkman (1984) have proposed. The role of cognitive appraisal is important because the individual's perceptions and judgements may influence the significance of a specific stressful situation and may also influence the perception of available resources needed to remedy the situation. The relationship between locus of control and coping would be mediated by subjective perceptions of situational characteristics (Parkes, 1984). Internals and externals may respond differently to situations appraised as amenable to change.

Internals appear to modify their coping responses in relation to their appraisal of the stressful situation, whereas externals exhibit little alteration which encourages maladaptive adjustment to the situation. Thus the role of locus of control as a mediator between stressor and outcome is primarily due to the different ways in which internals and externals adapt their coping in relation to their appraisal of the stressor event. In this case, internals will modify their coping abilities according to the way they appraise the situation as amenable to change. For example, if some control over a stressful situation is possible then direct coping (problem solving) may be more effective. Whereas, suppression or selective ignoring may be a more appropriate response to situations that cannot be controlled (Parkes, 1984). These findings are similar to studies by Wong and Sproule (1984) and Cronkite and Moos (1984) who have found that coping strategies may differ according to how controllable the situation is. Wong and Sproule (1984) suggest that when a problem is appraised as uncontrollable by self, but controllable by powerful others, then the appropriate coping strategy is external control. For the severely handicapped or chronically ill external control can be more important than internal control in coping with various problems (Burish et al., 1984).

In summary, it is apparent that both personal and situational beliefs about control do influence coping behavior. Some studies indicate that the relationship between

personal resources and coping behavior is direct (Scheoneman et al., 1983), while others believe that cognitive appraisal (which is influenced by control beliefs) serves to mediate the relationship between generalized locus of control beliefs and coping behavior (Parkes, 1983; Lazarus & Folkman, 1984).

A review of the literature indicates that locus of control (and other personality characteristics) not only affect coping behavior and individual well-being, but influence the perception of social resources as well. If this is the case for caregivers to Alzheimer's patients, then intervention programs can focus on developing the skills necessary to cope with the long-term role of caregiving. Wheaton (1983) elaborates on the potential goal of intervention:

"Stressors often occur beyond the control of friends, family and co-workers, where the therapists cannot work easily to reduce the environmental stressors, however they can work with the more immediate facets of personality and cognitive orientations which influences coping and thus may be effective in reducing the effects of environmental stress" (p.222).

In relation to this study, the investigation of how personal resources of the caregiver affect coping behavior and subsequent adjustment, is an important component in the overall design of the theoretical model. Gaining more information on the relationship between psycho-social resources, coping and adjustment in caregivers may enhance potential intervention programs for caregivers of Alzheimer's patients.

## The Role of Social Resources on Coping Behavior and Individual Well-Being

### Introduction

Although the social environment can be a source of stress, the social systems that envelope the individual may also serve as resources that help individuals mediate the impact of stressor events (Dohrenwend & Dohrenwend, 1974; Schaefer et al, 1981). In this section of the literature review elements of social resources will be examined in order to analyze how situational factors influence coping behavior and adaptation in the face of stressful events.

The concept of social resources is a global term that implies both quantitative and qualitative dimensions (Bruhn & Philips, 1983). Although quantitative resources in the form of social networks (the number of relatives, friends, neighbors and co-workers) may be present, the potential benefits derived from these networks may not be qualitatively effective. The "support" in social support may objectively seem to exist, yet the individual may perceive the network to be hindering instead of facilitating coping and adaptation (Jung, 1984). This distinction seems relatively straightforward, however the issues are complex. Empirically, the concept of social resources has provided abundant research opportunities and numerous findings. Yet with the proliferation of studies utilizing variables such as social support, a number of shortcomings in the theoretical and methodological designs of

past studies exists (Thoits, 1983). Several excellent reviews and articles address the limitations inherent with the construct of social support, but also provide positive suggestions for future research directions (Bruhn & Philips, 1983; Gottlieb, 1983; Jung, 1984; Schaefer et al., 1981; and Thoits, 1982).

One of the most glaring problems identified is that there is little consensus on how to define and measure social support. A common agreement that indices of situational variables be included in stress research exists, but the common thread which would provide a unified conceptualization of social support is lacking. Furthermore, methodological clarity is weak which burdens the supposed benefits that have been attributed to social support. Previous studies may have inadvertently confounded the buffering effects of social support with life events that directly affect the support used by individuals, as in the case of divorce, widowhood, and marriage (Dohrenwend et al., 1984; Thoits, 1982). Gottlieb (1983) is also concerned with methodological issues and indicates:

"the process whereby social support accomplishes its preventative health functions has not been adequately documented; is it indirectly linked to health outcomes via its amelorative influences on the way people appraise and cope with life stressors or does it exert an independent and direct effect on health?" (p. 20).

These and other concerns are certainly valid, but perhaps to be expected for an area of inquiry that is relatively new. Accompanying the critiques are suggestions for future research

directions. Wallston et al., (1983) have provided several recommendations including: (1) the need for differentiating among the specific components of social support; (2) making use of extant theory to relate social support causality to other variables; (3) matching measurement procedures to theoretical conceptualizations of support; (4) and to include individual as well as situational factors that might influence psychological processes related to support. With these critiques and suggestions in mind, several dimensions of social support will be reviewed. First, a review of the definitions and components of social support will be presented. Second, current measurement scales of social support are examined. Third, studies which have investigated social support as a moderator of stress and as an influence on coping behavior are reviewed. Finally, the role of social support within an interactional model is examined.

#### Definitions and Components of Social Support

Recent critical reviews of social support studies have proposed that future research consider social support as a multidimensional construct (Wallston et al., 1983; Schaefer et al., 1981; Jung, 1984; Bruhn & Philips, 1984). Most studies in the past have typically measured and interpreted social support as a global unidirectional construct (Fiore et al., 1983). Unfortunately, clear definitions of the construct are not always presented in studies and findings are discussed without any reference to the source of the support (Gottlieb,



1983).

From these early studies the "buffering hypothesis" emerged which emphasized that at high levels of life change, social support protects the person from the deleterious effects of stressful life events, but at low levels of life change, social support is unrelated to level of psychological distress (Wilcox, 1981). More recent studies have investigated the buffering hypothesis and have found supporting evidence for the hypothesis (Wilcox, 1981; Dean & Lin, 1977; LaRocco, House, & French, 1980; Gottlieb, 1983). However, as Thoits (1982) has recently indicated, the construct of social support is still without major conceptual refinement. A proposed conceptualization by Gottlieb (1983) is perhaps the most concise definition to date; he states:

"Social support consists of verbal/ or non-verbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial emotional or behavioral effects on the recipient" (p.28).

This definition helps to distinguish social support from related concepts such as social networks or natural helping networks. Typically, the quantitative aspects of social resources are referred to as the individual's social network; whereas a more qualitative dimension implies perceived support or satisfaction from the network (a subjective appraisal). Schaefer et al., (1981) contend that it is important to distinguish the two because perceived support and social networks have different effects on health, morale, and psychological functioning.

Recent measurement techniques have begun to assess the dimensions of social support both qualitatively and quantitatively (Bruhn & Philips, 1983; Sarason, Levine, Basham, & Sarason, 1983; Norbeck, Lindsey, & Carrieri, 1983). Another facet of social support are the types of social support obtained from social support interactions (Caplan, 1979). Dean and Lin (1977) have differentiated support into two broad categories: instrumental and expressive. In a similar fashion, Schaefer et al., (1979) have proposed three support functions: (1) emotional support (intimacy; attachment and the ability to confide in another person); (2) tangible support is representative of providing direct aid and services in the form of money and goods; and (3) informational support is giving information and advice that may help a person solve a problem. They emphasize that by distinguishing among types of support will enable research designs to analyze the independent effects of different kinds of social support on health and psychological functioning.

### Social Support and Individual Well-Being

Several review articles regarding social support have found that social support is associated with psychophysiological adaptation and adjustment in stressful situations (DiMatteo & Hayes, 1981; Dunkel-Schetter & Wortman, 1981; Gottlieb, 1983; Wallston et al., 1983). One study that focused on the family, found a strong relation between a family's response to stress and the aid received from an informal network of relatives,

friends, neighbors, and acquaintances (Unger & Powell, 1980). Families in this study, seem to prefer informal sources of aid (relatives, friends, clergy members, etc.) instead of formal service agencies (mental health centers, hospitals, etc.). Unger and Powell (1980) suggest that networks may help to bridge the connection between families who are in need and the formal services that exist in the community. Randall and Evanswick (1982) suggest that informal social systems, particularly the relatives, are important in determining an older person's use of health and social services.

Schaefer et al., (1981) in an investigation of patterns of stress events, coping, and adaptation in middle-aged persons, found that different dimensions of social support (tangible, emotional, and information) had a differential impact on outcomes measures (morale, health status, depression). Tangible and emotional support had separate, but equal effects in reducing depression. However, informational support was not a factor in either depression or negative morale. Overall, it was shown that the perceived social support variables, were strongly associated with symptomatology and morale rather than the social network.

Blazer (1982) in a study of 331 persons 65 years of age and older included three parameters of social support; (1) roles and available attachments, (2) frequency of social interactions and (3) perceived social support. This study found that when confounding variables (e.g., age, sex, race, health status) were controlled for, perceived social support was the

parameter with the highest prediction value of mortality status. Blazer (1982) suggests that perceived support may be of particular value in later life because of greater environmental influences on disease onset and increase in perceived vulnerability which accompanies the aging process.

Similarly, Mancini (1980) found that the qualitative aspects of friendship in the elderly are more important than the quantity of personal contact in the measuring morale in older adults. However, Wan (1982) found that the role of social networks in the lives of the elderly to be preventative in nature, mainly by reducing the amount of change experienced by older adults. Based on these and other studies it seems that social support is much more than numbers of persons in a network or number of contacts with an individual. Support is also related to the individual's perception of how helpful the network is and how satisfactory the "help" is. Thus it seems that both assessments are necessary in order to evaluate the effects of social support as a modifier of stress.

Results about the conclusiveness of the benefits of social support should be regarded cautiously because of methodological limitations in research designs and the lack of a substantial theoretical base (Jung, 1984; Thoits, 1982). Dunkel-Schetter and Wortman (1981) also suggest that because most studies are correlational, "it is not clear whether support facilitates coping or whether one's coping or prognosis determines the amount of support available" (p.351).

This point illustrates the complex and reciprocal

interactions that may occur between person and context. Although person-environment dynamics have been addressed theoretically (Riegel, 1980; Lerner, 1984; Bronfenbrenner, 1980; Lazarus & Folkman 1984), little if any empirical verification has been attempted to discover the nuances between person and contextual variables in relation to adjustment to stress (Gottlieb, 1983; Wallston et al., 1982). Mitchell and Moos (1984) have indicated that stress may have "detrimental effects on the supportivness of one's social ties" (p.446). In other words, deficient social networks are associated with greater levels of stress because depressed individuals are likely to experience both (Mitchell and Moos, 1984).

Another illustration of the nexus between person and environment interaction is a study by Sarason and Sarason (1982) which proposes that individual differences in social support may be influenced by personality characteristics of the person seeking help. In other words, some individuals have the social skills or personality dispositions that facilitate the potential benefits offered through social networks. Crandall (1982) has conceptualized the willingness to cooperate and share experiences with others as "social interest". Crandall (1982) proposes that social interest is negatively related to ego defenses and therefore should help to facilitate effective coping with life tasks.

In addition to the possible interdependence between personality and social support are the recent reviews which

propose social networks are not always able nor willing to be helpful to members in need during times of stress. It is entirely possible that social "support" may in fact be harmful or have negative psychological consequences for the recipient (DiMatteo & Hays, 1981; Gottlieb, 1983). Gottlieb (1983) has cautioned researchers to refrain from supporting a "romantic view of social support". Similarly, Jung has noted that "social support is popular in part because it embodies values we want to foster...we find it reassuring that when distress occurs, the rallying efforts of friends and families will be a source of improvement" (p.144). But, as Jung (1984) suggests, if a person receives little or no support from the network, that knowledge alone could be highly depressing for people because it seems to disconfirm the cultural norm of social support. For example, Fiore et al., (1983) found that unmet expectations of support or negative input from others was the best predictor of stress in a chronically-stressed population. In another example, Dunkel-Schetter and Wortman (1983) suggest that the elderly may not receive the high-quality support that is often times needed because "like other victimized populations, the elderly may generate negative affect because they threaten our assumptions about the world, shatter out illusions of invulnerability and engender strong feelings of helplessness" (p.363). Similarly, Gottlieb (1983) cites examples of where both social support networks and persons in need of support may discourage each others attempts to cope with the stressful event. Coping strategies such as denial and

depression may serve well the person under stress, but may obstruct network member's coping ability. This can possibly lead to the gradual withdrawal of the network and diminished support for the patient (Gottlieb, 1983).

### Social Resources and Coping Behavior

Gottlieb (1983) has emphasized that questions about the influence of social environment on the cognitive and affective dimensions of coping demand attention. The direct effects of social resources (social support) on coping behavior has not been vigorously empirically tested. Many research findings have indicated that social support does have buffering effects on life stress and personal functioning. It is generally assumed that social support exerts a positive influence on individual coping most of the time (Jung, 1984). Ward (1985) has recently proposed a conceptual model which emphasizes the indirect effects of social support on well-being through coping responses with stressful life events.

DiMatteo and Hayes (1981) in reviewing the literature, suggest that social support may be associated with recovery and coping with severe illness and injury but the relation between the two is based on correlational designs which cloud the causal relationships between the various components of stress models. Jung (1984) emphasizes that there are methodological problems in analyzing the relationship between social support and coping. He makes the point that particular coping behaviors may occur in self-sufficient individuals

because of their personal resources, even when they happen to have high social resources. Undoubtedly, interactive effects exist between person and situational variables, but the question becomes what resources are most influential and should they be considered separately or jointly? Perhaps as DiMatteo and Hays (1981) have suggested there is a need for the use of other research designs, theoretical models and statistical tools (e.g., path analysis) in order to increase the explanatory power of the various components of personal and social resources on coping and adjustment.

In summary, the role of social support has been proposed as an integral component in integrative studies focusing on stress and coping. Although social support has been found to act as a modifier of stressful events, there is concern that findings in past studies may have been confounded with stressful life events and based on unclear conceptualizations as to what social support means. Recently, social support has been differentiated from a unified global term to a more multidimensional construct that includes both quantitative and qualitative elements. Thus support derived from networks may be a function of characteristics of both person and contextual variables. Finally, the presence of support networks may inhibit coping efforts by the individual and can actually add to the stress that is already present. Because social support groups and family networks have been shown to play an important role in the lives of caregivers to dementia patients, the investigation of both the quantitative and



qualitative dimensions of social support and the personality variables that might influence the perception of support becomes an integral component of this research project.

## Integrated Conceptual Frameworks:Theoretical Models and Methodological Considerations

### Theoretical Models

A review of the literature has revealed that numerous research studies have investigated separately the role of personal and social resources, appraisal, coping responses and their effects on subsequent functioning. However, as Cronkite and Moos (1984) point out, "in spite of the abundance of research focusing on each aspect of the stress process, we have limited knowledge about the linkages among those components and their relative importance for subsequent adaption" (p.372). Therefore, a review of integrated models will be presented in this section.

An early attempt at producing interactive theoretical models to describe stress and adaptation is represented by the congruence model of person-environment fit (Kahana, 1975). For example, French, Rodgers, and Cobb (1974) suggested "adjustment" to be conceptualized as the goodness-of-fit between characteristics of the person and of the individuals context. Kahana, Liang, and Felton (1980) used the congruence model of person-environment fit to predict morale in older adults.

Caplan (1979) has further modified the person-environment congruence model by integrating social support and coping resources within the overall framework. In this conceptual framework, Caplan (1979) discusses in detail the hypothesized

paths between the panels of variables. The model is largely untested but is substantiated on previous theory and empirical studies that have incorporated both person-situation variables. Caplan (1979) has also proposed that empirical testings of his model may reveal possible intervention strategies to enhance social support, coping and environmental mastery.

Elwell and Maltbie-Crannell (1981) utilized an integrative model to describe the interrelationships between coping resources (personal characteristics, personal resources, availability of social support) and the impact of role loss on the lives of the elderly. It was hypothesized that the coping resources would exert independent direct effects on life satisfaction scores (Figure 3). The relationships between the variables were analyzed by path analytic techniques. It was concluded that role loss has direct and indirect effects on coping resources and life satisfaction, especially for men.

The most integrative theoretical designs that include person-contextual variables have been advanced by Rudolf Moos and colleagues of the Social Ecology Laboratory at Stanford University/ Veterans Administration (Moos, 1984). In one study, Finney Moss, Cronkite, and Gamble (1983) utilized a conceptual framework to determine the effects of several predictor variables (e.g., spouse ethnic status, education, partner impairment, family social environment, stressors, spouse functioning and spouse coping responses) on the functioning of spouses of alcoholic patients. In order to

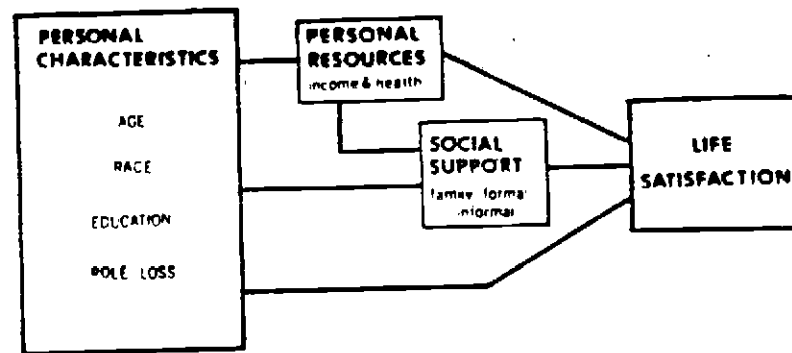


FIGURE 3

Integrative Model: Coping Resources and  
Adapatational Outcome

analyze the complex interrelationships between person and environmental variables. The theoretical model was assessed through path analytic techniques. Similarly, Cronkite and Moos (1984) have developed an integrative model to assess the stress process among marital dyads (Figure 4).

According to their model, an individual's exposure to stress may be influenced by predisposing factors such as social status and prior functioning. Stress was hypothesized to influence later functioning both directly and indirectly via moderating factors. Cronkite and Moos (1984) utilized multiple regression techniques to analyze the relationships between the independent and dependent variables.

Other studies that have integrated both person and situational variables into conceptual models are represented by Andrews et al., (1978), McFarlane et al., (1983), Pearlin et al., (1981), Wheaton (1983), Billings and Moos, (1980), and Kogasa and Pucetti (1983). The inclusion of cognitive/phenomenological variables has added another dimension to stress models by emphasizing the subjective appraisal for person-situation interactions; representative examples include Sarason and Sarason (1981), Lazarus and Folkman (1984), and Parkes (1984).

By integrating both person-contextual variables as interactive predictors (which include subjective appraisal components), which in turn affects coping response, an overarching ecological perspective of coping and life-functioning is achieved (Holahan & Spearly, 1980). The

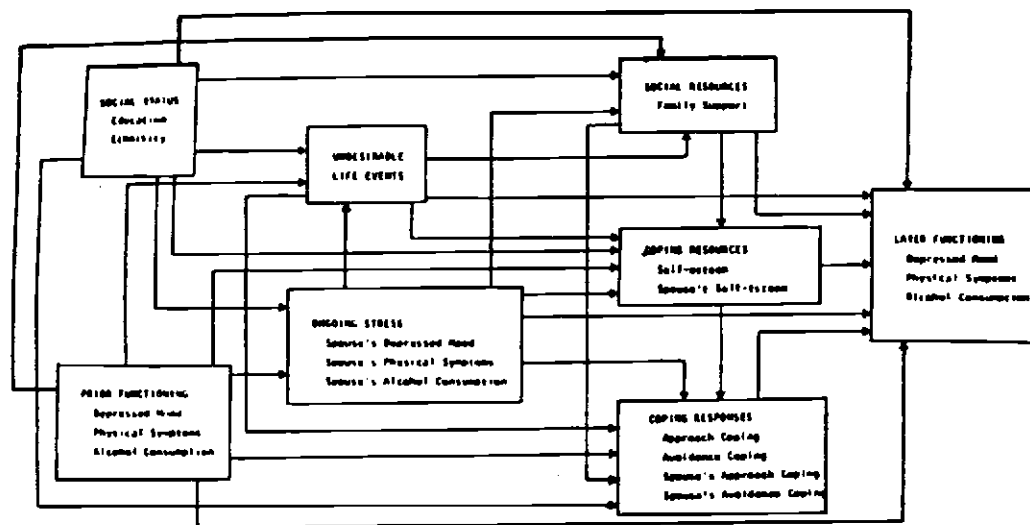


FIGURE 4

Integrative Model Predicting Stress

integrative proposal in this study follows closely the ecological model proposed by Holahan and Spearly (1980) which emphasizes four tenets about the coping process:

1. The coping process involves simultaneous influences across multiple levels of the environment.
2. The coping process includes a cognitive component, reflecting the individual's perceptions, evaluations and inferences about the environment.
3. The coping process is the product of an interactional relationship between characteristics of the individual and of the environmental situation.
4. The coping process is characterized by reciprocal influences between it's environmental, cognitive and behavioral components.

By relying on these assumptions, the outcome measures in the present study (life satisfaction, burden, and physical health status) convey a relativistic notion, specific to a particular temporal perspective. Furthermore, "adjustment" is conceptualized as a relative balance or imbalance between the components of the system, and not a function of the individual alone (Holahan & Spearly, 1980).

### Methodological Issues

Complex integrative conceptual models are designed to theoretically address the presumed interrelationships among person-situational variables, moderating variables (e.g., in the present, coping response), and outcome measures (e.g., burden, life satisfaction, and health status).

Aside from the advancement of theoretical clarity, there are practical issues at stake as well, such as "influencing

decisions about who might or might not benefit from preventative mental health services to increase their social resources or personal coping skills" (Finney et al., 1984; p.85). Thus, it is obvious that any interpretations and conclusions regarding the predicted effects of variables  $X_{1..n}$  on variables  $Y_{1..n}$  need to be assessed with statistical techniques that would capture the indirect and direct effects among the variables considered.

Kim and Kohout (1975) have indicated that the use of multiple regression in conjunction with causal modeling (and theory) can provide analysis and interpretation of linear relationships which are typical of the conceptual frameworks previously mentioned. Multiple regression is used to evaluate the conceptual model by determining the magnitude of direct and indirect effects that each variable has on other variables which are presumed to follow in an a priori causal ordering of cause and effect linkages (Kim & Kohout, 1975). For example, in Figure 5 the path linkage ( $P_{23}$ ) between variables  $X^3$  and  $X^2$  is estimated from the regression of  $X^3$  on  $X^2$ , whereas  $P_{13}$  and  $P_{12}$  is estimated from regression of  $X^3$  on  $X^2$  and  $X^1$ .

Values of path linkages are usually expressed as either standardized (path coefficients) or unstandardized (path regressions) coefficients (Wright, 1960). Path coefficients indicate the proportion of change in the dependent variable for which an independent variable is responsible, while simultaneously taking into account and controlling for all other variables (Elwell et al., 1981; Quinn, 1982). Arrows in



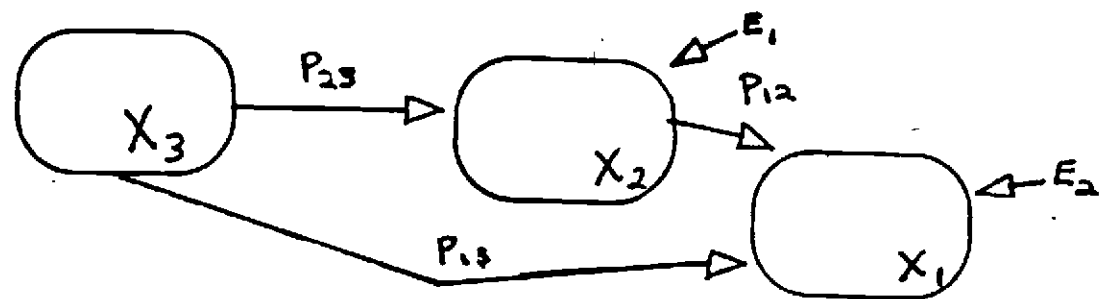


FIGURE 5  
Path Model

the path model (Figure 6) represent presumed causal linkages or paths of causal influences.

Although path analysis has the capacity to test causal models the use of this method is predicted on a set of very restrictive assumptions (Pedhazur, 1982). Path analysis assumes: (1) variables are measured without error, (2) the causal flow is unidirectional (e.g., recursive models) (Blalock, 1968; Pedhazur, 1982).

The first assumption assumes the use of "errorless" measurements, which is a condition that is rarely met in the social and behavioral sciences (Blalock, 1968; Pedhazur, 1982). Multiple regression techniques (in conjunction with path analysis) are particularly sensitive to measurement errors. For example, the estimation of regression coefficients and the estimation of  $R^2$  can fluctuate in an upward and/or downward bias due to errors of measurement in both the independent and dependent variables (Blalock, 1968; Pedhazur, 1982). Path analysis also assumes a unidirectional causation, thus ruling out any reciprocal causation among variables (Kenny, 1978). Based on the theoretical orientation of this study, many reciprocal interactions are assumed to exist between person-situation variables (exogenous).

Finally, path analysis typically utilizes a single indicator to represent a more complex construct. It is unrealistic to expect that one indicator can validly and reliably tap into an unobservable latent variable (e.g., attitudes, anxiety, stress. Rather the use of multitude

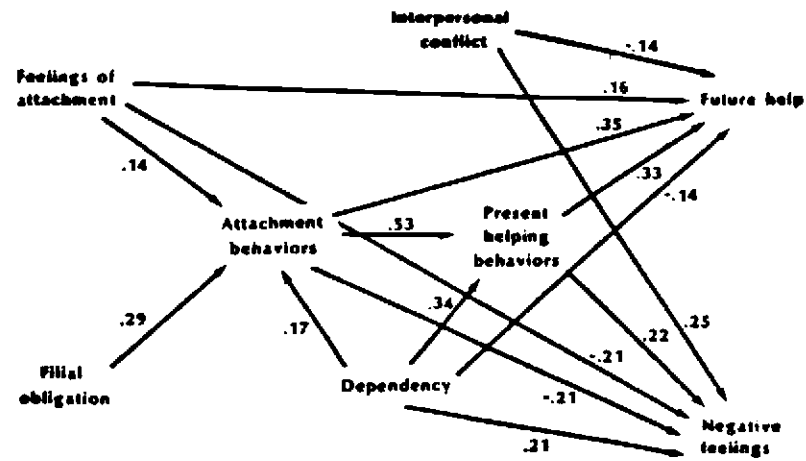


FIGURE 6

Path Model and Path Coefficients

indicators is potentially more effective for causal models.

Structural equation models, particularly the analytic technique of linear structural relations or LISREL (Joreskog & Sorbom, 1977), have proven to be extremely powerful and versatile in estimating a variety of causal models (Bentler, 1980). The computer program LISREL has the capacity to analyze causal models with multiple indicators of latent variables, reciprocal causations, measurement errors, correlated errors and correlated residuals (Pedhazur, 1982). Latent variable causal models usually employ multiple indicators of each construct to separate "error-free" (unobserved) variables from error present in each of the measured (observed) variables. The causal effects are then assessed among these latent variables or "factors" within the structural relations model (Aneshenel et al., 1984). One of the primary advantages of using the LISREL program is that it can analyze both factor models (or measurement model) and the structural relations model simultaneously (Aneshenel et al., 1984). In other words, it combines the similar analysis of confirmatory factor analysis and path analysis together in one computer program.

Yet with the advantages in analyzing non-experimental data with LISREL, this analytic technique is not sufficient to determine causality, but rather tests the plausability of theoretical models.

In summary, the use of the path analysis is subsumed within the more versatile LISREL technique for the theoretical model proposed in this study. It is important to state that it is

the theoretical model that generates the presumed hypothetical factors and causal paths, instead of coefficients and correlations producing a posteriori conceptual models (tail wagging the dog approach) (Pedhazur, 1982). The relationship between theory and research is a dynamic process. In the context of the present study, the following passage crystallizes that process:

"the analysis of data is designed to shed light on the question of whether or not the causal model is consistent with the data. If the model is inconsistent with the data, doubt is cast about the theory that generated it... consistency of the model with the data ... does not constitute proof of a theory... it only lends support to it" (Pedhazur, 1982, p.579).

#### A Restatement of Purpose

The purpose of the present study is to construct and test a causal model that integrates and assesses the effects of personal and social resources on coping and subsequent well-being in caregivers to dementia patients. It is hypothesized that personal and social characteristics (subjective and objective) and patient status will directly influence the coping responses utilized by the caregiver. It is hoped that the proposed causal model and its empirical assessment will shed light on caregiver coping and adjustment and help to facilitate effective intervention programs.

## THE METHOD

### Overview

The purpose of this research was to construct a latent variable causal model based on pertinent coping theories discussed in the previously presented in the review of the literature. The hypothetical causal model was designed to predict caregiver well-being by utilizing an ecological framework that integrates both person-situation and subjective appraisal variables.

The causal model was tested with data gathered from caregivers of patients with dementia (Alzheimer's disease and related disorders) throughout a 14 state region, primarily in the Southwestern and Northwestern United States. A total of 502 caregivers participated in this study and only those caregivers who were relatives of the dementia patients were selected in this study.

The causal model consisted of two portions which were estimated simultaneously. The measurement model (first portion) specifies the relationships between the measured (observed) variables and the latent (unobserved) variables. The proposed latent variables utilized in the causal model can be differentiated into five clusters: personal resources, social resources, patient functioning, coping behavior, and caregiver well-being. The measured variables were selected as representative indicators of the latent variables based on

empirical and theoretical studies (see Appendix B).

The structural relations model (second portion) specifies the pattern of causal influences among the latent variables. The paths of influences between the exogenous and endogenous variables were specified according to coping and stress models that have been theoretically postulated and/or empirically tested (see Appendix B).

A variety of statistical techniques for comparative analysis were also utilized through the Statistical Package for the Social Sciences (SPSS) such as: descriptive statistics (frequencies, percentages, and means), one-way ANOVA's, Pearson product-moment correlations, reliability analyses and factor analyses.

## Participants

The original number of respondents in the present study consisted of 502 individual caregivers, but preliminary analyses had revealed that 44 caregivers responded in retrospect because the dementia patient was deceased. Therefore, only those caregivers who provided care to dementia patients who were living (at the time of the survey) would be included in this research study. The final sample was also restricted to only those caregivers who were related to the Alzheimer's patient either by direct kinship (consanguine) or related through marriage (e.g., in-laws), because this study focused on how family members adapt to the careproviding role. Those who provided care either professionally or

para-professionally were not included in this study. Using these selection criteria, the sample was reduced to 458 caregivers. All subsequent analyses were based on this sample of 458 caregivers.

Although Alzheimer's disease is the most common form of dementing illness (accounting for 50 to 60% of reported cases in adult life), some participants in this study were caregivers to family members who had other forms of dementia (e.g., multi-infarct, Parkinson disease, Pick disease). Therefore, the sample included caregivers who provided care to relatives with a dementing illness. Comparative analyses (one way ANOVA's) were performed to determine if significant differences in selected demographic and measured variables were present among the caregivers of patients with different forms of dementia. Comparative analyses (one way ANOVA'S) were also utilized to test for significant mean differences between caregivers whose impaired relative resided in the community versus those caregiver's whose dementia patients who were insititutionalized.

### Caregiver Profile

The ages of the caregivers in this study ranged from age 24 to age 89, with the average age of the caregiver at 61.2 years (SD= 13.65). Of the total sample of 458, 73.8% were females (n = 338) and 26.2% were males (n = 120). The great majority of participants were White/Caucasian (94.1%, n = 431). Native Americans were the second largest racial category of



participants (2.6%). The remainder (3%) were either Hispanic or Black.

Eighty-three percent ( $n = 380$ ) of the caregivers were high school graduates and 18% ( $n = 86$ ) had college degrees. The average household income level for the sample was between \$20,000 and \$29,000. The majority of caregivers (83%,  $n = 379$ ) had household income levels of \$39,000 or less.

Eighty-six percent ( $n = 385$ ) of the caregivers were married, while 6.3% ( $n = 18$ ) were widowed. Most (41.2%,  $n = 183$ ) of the caregivers were retired, 25.9% ( $n = 115$ ) of the caregivers responded as "full-time homemaker" and another 20.7% ( $n = 92$ ) reported they were employed full time.

Over half of the caregivers were affiliated with the Protestant faith (58.5%,  $n = 258$ ), 17% ( $n = 75$ ) were Catholic, 10.7% ( $n = 47$ ) were members of the Church of Jesus Christ/ Latter Day Saints (Mormons), which reflects the sampling of caregivers in the state of Utah.

The spouse of the dementia patient was most frequently the primary caregiver (56%,  $n = 257$ ). The daughters of the dementia patient were the second most frequent caregiver (27.5%,  $n = 121$ ); sons were third most frequent caregiver (4.2%,  $n = 21$ ); sisters fourth most frequent caregivers (3%,  $n = 15$ ); and daughters-in-law were fifth most frequent caregivers (2.6%,  $n = 12$ ). Sons-in-law, grandsons, and granddaughters were the least frequent careproviders, with each accounting for less than 1% of the total number of caregivers. These and previous research findings (Brody, 1985),

have indicated that the role of caregiver in the United States is largely a female phenomenon. The woman is indeed the "kin-keeper" for American families. Although male spouses in this study did provide care for their impaired wives (35.8%), the great majority of spouse caregivers were female (64.2%). Furthermore, when an impaired elderly parent needs aid and assistance and spouse is not available, it is the adult daughter who typically assumes the responsibility.

Most caregivers reported that they had a close or very close relationship with their impaired family member (79.3%, n = 361). Only 1.8% said that they had a distant relationship with their impaired family member.

In response to the question, "what percentage of the health care costs of your impaired family member are paid by you?", 37.4% (n = 164)) paid 100% of the health care costs, 37.7% (n = 165)) paid no health care costs. When asked, "what percentage of the caregiving responsibilities do you provide for the impaired person ?", 36% (n = 155) of the caregivers reported that they provided 100% of the caregiving responsibilities. The remaining respondents provided varying degrees of caregiving responsibilities, with the majority (71.1%, n = 309) providing 50% or more of the responsibilities. Forty-six percent (n = 188) of the caregivers needed 20 hours a day or more (in a 24 hour period) in preparing for the responsibilities in the careproviding role. Thirty-five percent (n = 145) of the caregivers used 21 to 25 hours in each day in their role. However, about 34% (n =

140) of the caregivers used 5 hours or less each day in their caregiving responsibilities.

The median length of time for providing care to the dementia patient was 36 months or about 3 years. The mean was not reported because several respondents had indicated unusually high estimates of the length of time for caregiving which biased the mean score and therefore represented an inaccurate representation of the average score.

Over half of the dementia patients (52.1%,  $n = 234$ ) lived in the same household with the primary caregiver, while 34.3%,  $n = 154$ ) were residing in nursing homes or adult residential care facilities. About 12% ( $n = 54$ ) were living in a home separate from the primary caregiver. Based on the results from this study most of the dementia patients resided in the community (64%) versus residing in an institutionalized setting.

Thirty-three percent ( $n = 112$ ) of the caregivers caring for a dementia patient in the community believed that the family member with dementia would be living in a nursing home in one year from the time of the survey. A similar proportion of caregivers (34.5%,  $n = 116$ ) thought that the dementia patient who was residing in the community would not be in a nursing home in one year.

In response to the question, "at the present time, how would you rate your desire to have this person placed in a nursing home?", (62.7%,  $n = 213$ ) of the caregivers caring for a dementia patient in the community said they had no desire to

place the family member in an institution at the time of the survey. About 18% (n = 65) of the caregivers (caring for a dementia patient in the community) said they had a high desire to place the dementia patient in a nursing home.

The caregivers identified the sources of financial support for the dementia patient and 50% (n = 225) said that the patient received Medicare payments, 50% (n = 225) relied on personal savings, 83% (n = 376) relied on Social Security payments, 39.6% (n = 178) relied on retirement pensions, 16.4% (n = 74) relied on family support, and 11% (n = 53) relied on Medicaid payments. It was evident many dementia patients and their caregivers depended primarily on Social Security, Medicare, and personal savings in order to maintain the well-being of the impaired family member.

Most of the caregivers (68.8%, n = 306) in this study were members of a support group, many of which were sponsored local chapters of the National Alzheimer's Disease and Related Disorders Association. Ninety percent (n = 301) of the caregivers reported that their support group had either been very helpful or helpful in providing knowledge and information. A smaller percentage (9%, n = 30) reported that the group was not very helpful in providing knowledge and information. Seventy-seven percent (n = 240) of the caregivers indicated that their support group had either been very helpful or helpful in providing emotional support. Some caregivers reported that the group was not very helpful (18.8%, n = 59) or not helpful at all (4.5%, n = 14) in

providing emotional support. Fifty-eight percent ( $n = 193$ ) of the caregivers indicated that the support group met their expectations most of the time. Thirty percent ( $n = 101$ ) reported that the support group met their expectations some of the time and 9% ( $n = 30$ ) reported that their group met their expectations very little of the time.

Finally, an attempt was made to identify those sites which could be designated either "urban" or "rural" cities in which the caregiver resided. This analysis was based on the rationale that potential differences in demographic variables and the availability or lack of social resources needed by the caregiver could be influenced by residing in urban versus rural sites. As defined by the Census Bureau (U.S. Department of Commerce, 1980), an urban center has 2,500 or more inhabitants, whereas a rural center has less than 2,500 inhabitants. Based on this criteria it was found that all of the sites (where questionnaires were distributed) were designated as urban centers.

#### Dementia Patient Profile

Theoretically, this research study was based upon an ecological model and it was therefore important to assess the interrelationships between the caregivers and their social environment. Because the dementia patient was an integral component of the caregiver's environment, it was important to describe the characteristics of the dementia patient in the context of the caregiving situation.

The average age of the dementia patient in this study was 74 years, with an age range of 49 to 99 years. There was a greater proportion of female (53.5%,  $n = 243$ ) than male (46.5%,  $n = 211$ ) dementia patients. Both males and females are equally affected by Alzheimer's disease and Multi-infarct dementia, however, the noted sex difference in this study may be attributed to the fact that women outlive men by seven to twelve years (Powell and Courtice, 1983). Thus, the greater percentage of women in this study with reported dementia may reflect the increased longevity of women.

Over 90% ( $n = 424$ ) of the dementia patients were White/Caucasian which follows the similar ethnicity pattern found in the caregiver sample. The educational level for the dementia patient sample was slightly lower than that of the caregiver sample. For example, 82.8% ( $n = 294$ ) of the dementia sample had completed a high school education and 9.4% ( $n = 42$ ) had college degrees as compared to the caregiver sample.

The religious preference of the dementia patient was also very similar to the caregiver sample. For example, the majority (60.1%,  $n = 271$ ) of the dementia sample were Protestant, 16.9%, ( $n = 76$ ) were Catholic, 11.1% ( $n = 50$ ) were members of the Church of Jesus Christ/ Latter day Saints (Mormons).

Caregivers were asked to evaluate in their own subjective opinion whether the course of the impairment had been gradual or rapid. Eighty-four percent ( $n = 379$ ) said the course of impairment was gradual and 15.4% ( $n = 69$ ) said it was rapid.

The evaluation of the course of impairment by the caregiver validated the incidence and typical symptomatology of Alzheimer's disease which has an insidious onset and a slow, progressive prognosis. In this study, 73.7% (n = 308) of the dementia patients were diagnosed as having Alzheimer's disease (although it is more correct to indicate "probable" Alzheimer's disease), while another 7.7% (n = 32) received no formal diagnosis or the exact dementia entity was not known. Therefore, the majority of the dementia patients were Alzheimer's disease patients, however, 18.7% (n = 78) were diagnosed with other forms of dementia (e.g., Multi-infarct, Parkinson's disease). It should be noted that many caregivers indicated that their impaired family member had a combination of dementias (e.g., Alzheimer's disease and Multi-infarct). Most dementia patients had diagnostic tests performed such as the CAT SCAN (73%, n = 311) and the EEG (65%, n = 265).

## Procedure

Data collected for this study was obtained through self-report questionnaires (see Appendix D) mailed either directly to the homes of the family caregivers or sent in bulk to the support group leader, who then mailed the questionnaires to the caregivers in their respective support groups.

Although the collection of data through the use of self-report techniques has inherent problems (e.g., problem of memory; desire of subjects to present themselves in a positive

light), given the theoretical structure of the proposed causal model, data collection via self-report methods were needed for the desired information in this study. Lazarus and Folkman (1984) indicate that researchers cannot afford to abandon the information of what people tell about their feelings and how they construe what is happening to them. They suggest "subjective reports allow us to learn more about stress and emotion, and about coping and it's adaptational outcomes, than any other single source, despite the difficulties in validation" (Lazarus and Folkman, 1984; p.322). Furthermore, Todd, Zarit and Zarit (1985) have proposed, based on their longitudinal study, that the caregiver role is largely a subjective experience where the caregiver's reaction to specific problems may be more important in caregiver adjustment than the problem itself. For these reasons, the survey method was utilized to capture the caregivers subjective experience in thier role as family careprovider.

During the intial phase of the research project support group leaders were identified through Alzheimer's Disease and Related Disorders Association support group directories in the U.S. Department of Health and Human Services (hereafter abbreviated as DHHS) regions VI and VIII and in a support group directory for the state of Oregon and southern Washington (see Appendix E). The DHHS Region VIII consists of six states: Utah, Colorado, Wyoming, North Dakota, South Dakota, and Montana, with headquarters in Salt Lake City, Utah. The DHHS Region VI consists of five states: Texas,



Louisiana, Arkansas, Oklahoma, and New Mexico, with headquarters in Dallas, Texas. A support group in northern California (Alturas) also decided to participate in this study (see Appendix E).

Support group leaders throughout the fourteen state region were contacted by letter (see Appendix F) which explained the research study and its objectives. The letter addressed the need for obtaining mailing lists for reaching caregivers and it also emphasized the confidentiality of any lists utilized for this study. If a response to the initial inquiry was not received after a three week period a follow-up letter (see Appendix G) was sent as a reminder.

As of August 6, 1985 (end of the time frame for this study), 38 different support groups (see Appendix H) responded either to the initial or reminder inquiry regarding mailing lists of caregivers in local support groups. In Oregon and Washington 12 groups out of 36 responded to the inquiry (out of the 36 groups, 3 had disbanded). In DHHS Region VIII 15 groups out of 20 responded and in DHHS region VI 10 groups out of 45 responded. One support group in California (Alturas) also participated. The support group leaders in DHHS region VI were contacted at a late point in the research project and it is possible that with an earlier contact, a higher response rate might have occurred within this region.

Although the original intent was to obtain mailing lists so that questionnaires could be sent directly to the homes of the caregivers, some group leaders expressed concern (through

written letters) for their professional responsibility in maintaining the confidentiality of their support group members (see Appendix I). In fact, for some groups (and this policy is now being accepted by a larger number of groups), it was an established rule not to release the names and addresses to outside interests. Evidently, too many commercial entities were utilizing mailing lists for promoting their products, much to the disdain of the caregivers. However, by cooperating with the support group leaders, they helped to distribute the questionnaires in their respective sites.

The required number of questionnaires, cover letters, return envelopes (with postage) and envelopes for mailing out were all boxed up and sent to the support group leader, who with the help of volunteers, mailed out the questionnaires from their residence. This method allowed questionnaires to be distributed, but maintained the group members' anonymity and preserved the sanctity of mutual confidentiality between group leader and group member. The group leader was asked to maintain a "master list" of names and addresses with the corresponding identification numbers (placed on the questionnaire beforehand) so that a reminder post card could be sent to those who had not responded after a period of time (see Appendix J). The group leader was sent a list of identification numbers representing those who had responded to the questionnaire. As of August 6, 1985, 7 support group leaders (out of 36) had requested this method of questionnaire distribution.

In order to meet the post office criteria for bulk mailing of the questionnaires, the distribution of the questionnaires were centered around four major mailings or "waves". Mailing lists sent by the support group leaders were obtained in a staggered process, therefore, it was necessary to wait until over 200 caregivers (minimum number accepted for bulk rate) were identified through the mailing lists before questionnaires could be sent out.

In the first wave 318 questionnaires were mailed to 10 different support groups. In the second wave 312 questionnaires were mailed to 7 different support groups. In the third wave 359 questionnaires were mailed to 9 different support groups. Finally, in the fourth wave (which did not meet bulk criteria) 107 questionnaires were mailed out to 5 different support groups. A total of 230 questionnaires were boxed and mailed to 7 different support groups. Thus, a total of 1326 questionnaires were mailed during June and July of 1985 (see Appendix K for mailing dates).

Each individual mailing consisted of a business size envelope (9 X 12) which included the questionnaire, a cover letter (see Appendix C), and a return envelope (with postage). Each support group throughout the 14 state region was assigned a site number (a three digit code) and each caregiver on the mailing list was assigned an identification number (a three digit code) which was marked on the questionnaire along with the site number (see Appendix D)

As of August 6, 1985, 16 questionnaires were returned

undeliverable due to insufficient address or no forwarding address. Forty-two questionnaires were returned incompletd (in the return envelope) usually because the respondent either was not a family caregiver (some mailing lists included people who had professional intrests in Alzheimer's disease (e.g., Registered Nurse) or because the respondent refused to participate in the study. Some respondents offered no explanation for the uncompleted returned questionnaire, while others simply stated they could not participate for "personal" reasons.

The overall response rate was calculated at 40%, although questionnaires were still being received as of October 1, 1985. The support group in Salt Lake City, Utah, had the largest number of respondents (78) which accounted for 15.5% of the total number of participants. San Antonio, Texas, had the second largest response number (54) which accounted for 10.8% of the total number of participants. Medford, Oregon, had the third largest number of respondents (49) which accounted for 9.8% of the total number of participants.

If support group leaders volunteered to include their own cover letter, which expressed their personal support and encouragement, response rates tended to be higher. For example, the Colorado Springs, Colorado ADRDA support group leader was sent 45 questionnaires (along with the cover letters of this research project) and by August 6, 1985, forty-four questionnaires were returned completed which represnets a 98% response rate.

Reminder post cards (see Appendix L) were sent approximately 4 weeks after each mailing wave. Four weeks were allotted because this allowed the necessary time for mail delivery, completion of the questionnaire and the return mail delivery. By maintaining a list of identification numbers (matched with names and addresses) for questionnaires returned, a second list was tabulated for caregivers who had not responded after four weeks of time. Those caregivers who had not responded received a reminder post card.

The effectiveness of the reminder post card was based on two indicators. First, a period of seven days was allowed to elapse for mail delivery and questionnaire completion, before any returned questionnaire (from each respective wave) was attributed to the reminder post card. For example, if a first wave reminder was sent on July 5, any questionnaires received after July 13, were attributed to the reminder post card. Secondly, it was observed that the great majority of questionnaires were being returned during a two week period immediately following the initial mailing wave date. Therefore, the returned response could be described as a positively-skewed distribution phenomena. When reminder post cards were being sent out, most of the response activity for the corresponding questionnaire mailing wave had dramatically tailed off. After a seven day period the response activity for that mailing wave had increased again. In fact, some returned questionnaires had also included the reminder post card as well.

Twenty-six questionnaires were received and attributed to the first wave reminder post card. Twelve additional questionnaires were received and attributed to the second wave reminder post card. Because the third wave reminder was sent on July 30 and the closing date for this research study was August 6, questionnaires returned due to the reminder post card could not be accounted for at that time.

In summary, the response rate was enhanced with the reminder post cards, but the overwhelming majority of questionnaires obtained in this study were returned without the reminder post card. As of August 6, the sample size had reached 502, which represented a sufficient number of respondents ( $n = 458$ ) for data analysis purposes.

## Measurement of Variables

In this section, operational definitions of latent variables are given. These operationalizations state which observed variables were hypothesized to load on (e.g., to indicate) the latent variables. In addition, the specific measurements of the observed indicators are presented.

The causal model proposed in this study consisted of three latent exogenous variables. Each latent exogenous variable consisted of objective and subjective assessments. The subjective component was related to the role of subjective appraisal (perceptions and judgements) about the specific nature of the caregiver role.

Personal control, one of the latent exogenous variables, was conceptualized as psychological dispositions or facets of personality individuals draw upon to help manage stressor events. Four measured variables were hypothesized to produce significant loadings on the latent variable (factor) personal resources (Appendix B). These were: belief in internal control, belief in powerful others, belief in chance, and situational appraisal/control. Generalized locus of control (Internal, Powerful Others, and Chance) was measured by a 24-item Likert type scale developed by Levenson (1978). Internal consistency (Kuder-Richardson reliability) has been established at .64 for the Internal scale (I scale); .77 for the Powerful Others scale (P scale); and .78 for the Chance scale (C scale) (Levenson, 1974). Split-half reliabilities (Spearman-Brown) are reported at .62, .66 and .64 for the I,P

and C scales. The validity has been demonstrated through convergent and discriminant methods (Levenson, 1981). Situational appraisal/control was measured by an 3-item Likert type scale adapted from measurements by Parkes (1984) and Stone & Neale (1984).

Levenson (1981) stressed that it is empirically possible for a respondent to score high or low on all three scales, although the occurrence of such a profile has been rare. Levenson (1981) further adds that a low score on a scale, for example the I scale, does not indicate that the person believes in chance, but rather the person does not perceive themselves as determining outcomes. Although both the Powerful Others and Chance scales represent "external" dimensions of control, a potential for control exists for the Powerful Others dimension, whereas the Chance scale assesses those who believe the world to be unordered and unpredictable.

Social resources, the second latent exogenous variable, was conceptualized as comprising of quantitative and qualitative dimensions. The quantitative dimension relates to a more objective indicator of an individual's social network, specifically the number of available others to whom one can turn to in times of need. The qualitative dimension is concerned with a more subjective appraisal of the network, specifically the degree of satisfaction with the available support. The measured variables for the latent variable, social resources, were based on previous theoretical (Bruhn and Philips, 1983; Sarason et al., 1983) and empirical studies



(Tardy, 1985; Vaux and Harrison, 1985; Dimond and Lund, 1983) which have addressed the quantitative and qualitative dimensions of support. Therefore, there were two indicators (observed variables) hypothesized to produce significant loadings on the latent variable, social resources (Appendix B).

The quantitative dimension of social resources was assessed by items (Appendix D) which asked the caregiver: "How many people (friends and relatives) are available to you for support in your caregiving responsibilities?"; "Are there any community services available to you for help in your caregiving responsibilities?... If so, what are they?"; "Are you now a member of a support group for caregivers of patients with Alzheimer's disease and related disorders?". The qualitative dimension of social resources was measured by items (Appendix D) which asked: "How satisfied are you with the support you receive from relatives and friends?"; "How easy is it for you to contact these people?"; "As a group, how often do they help you?"; "How helpful has the support group been to you in providing knowledge/information?"; and in "emotional support?", (the qualitative questions are answered on a Likert type scale).

The third latent exogenous variable, patient functioning, was conceptualized as the caregiver's perception and evaluation of the mental and physical status of the Alzheimer's patient. There were two indicators of the latent variable "patient functioning", and again corresponding to the

objective and subjective dimensions of the latent variable (Appendix B). The objective dimension was measured by a 20-item Functional Dementia Scale (Moore et al., 1983). A Cronbach alpha coefficient on the FDS scale has been reported to be .90 and a test-retest stability range from .77 to .88. The subjective dimension was operationalized as the caregiver's appraisal of the patient's emotional and physical status. The subjective indicator was measured by two items previously utilized in a study of caregivers to Alzheimer's patients (Pratt et al., 1985), which specifically assesses the caregiver's perception of the patient's overall cognitive and physical functioning level.

Two latent endogenous variables were utilized in the causal model. One latent endogenous variable, coping behavior, was conceptualized as the behavioral and emotional responses engaged by an individual in order to adapt to a stressor event. Four indicators were hypothesized to significantly load on the latent variable, coping behavior (see Appendix B) and were measured by four factors from the Jalowiec Coping Scale (Jalowiec et al., 1984). The Jalowiec Coping Scale is a multidimensional scale that has been factor analyzed into four distinct coping methods: (1) problem-oriented, (2) avoidant-evasive, (3) pessimistic, (4) dependency-oriented. A coefficient alpha (Cronbach) of .86 was reported for this scale indicating overall homogeneity for the scale. The stability of the scale was indicated by significant reliability coefficients of .79 for total coping scores.

Caregiver well-being (an endogenous variable) was conceptualized in terms of the physical and psychological functioning of the caregiver within the context of providing care to a dependent relative with a dementing illness. Three indicators were hypothesized to produce significant loadings: subjective health status, life satisfaction and burden (see Appendix B). Subjective health status was measured by 3 items taken from an earlier study of caregivers to Alzheimer's patients which assesses the caregivers health status in relation to caregiving responsibilities (Pratt et al., 1985).

Life satisfaction was measured by a 13-item scale using the trichotomous scoring system proposed by Wood, Wylie, & Sheafor (1969). Test reliability for this scale, known as the Life Satisfaction Index-Z, was reported at .79. A correlation of .57 (significant at the .01 level) was obtained between the LSI-Z and the Life Satisfaction Index-A (Neugarten, Havighurst, & Tobin, 1961), indicating strong validity for the shorter version (LSI-Z).

Burden was measured by a 22-item Burden Scale developed by Zarit et al., (1980). The questions in the Burden Scale were selected based on clinical experience with caregivers and prior studies (e.g., Lowenthal et al., 1967). The questions cover the areas most frequently mentioned by caregivers as problems, including caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the impaired person (Zarit et al., 1980).

## Analysis of Data

The proposed theoretical relationships in both the measurement and structural relations model will be analyzed using the LISREL procedure (Joreskog & Sorbom, 1978). The LISREL V computer program fits and tests various models for linear structural relationships among quantitative variables. The variables in the system of structural equations may be observed measurements or unobserved factors (or latent variables). The LISREL model assumes that there is a causal structure among a set of latent variables or hypothetical factors which are designated as independent variables (exogenous) or dependent variables (endogenous).

It was previously noted that LISREL estimates all parameters simultaneously, however the LISREL program can be conceptualized as comprising of two major subdivisions. The first subdivision is the measurement model which relates observed variables (indicators) to the unobserved factors. The assessment of the measurement model by the LISREL procedure corresponds to the similar technique of confirmatory factor analysis. The indicators the of endogenous factors are denoted by  $y$ 's and the indicators the of exogenous factors by  $x$ 's. The endogenous factors are represented by eta vectors ( $\eta$ ) and exogenous factors as xi vectors ( $\xi$ ).

The second subdivision, the structural relations model, refers to relations among exogenous and endogenous latent variables (factors). The assessment of the structural relations model in the LISREL procedure roughly corresponds to

the technique of path analysis. However, in comparison to path analysis, the LISREL procedure provides a more versatile analysis by taking into account measurement errors in the indicators of the latent variables, reciprocal causations, and correlated residuals (Long, 1983). In essence, LISREL has the ability to assess hypothetical path models and factor models simultaneously.

Using a covariance matrix among the observed indicators of the latent variables, LISREL arrives at estimates of elements in the eight matrices listed below by the method of maximum likelihood.

- (1)  $\Lambda_y$  (lambda) is the matrix of coefficients, or loadings, relating indicators of endogenous variables to latent endogenous variables ( $\eta$ ).
- (2)  $\Lambda_x$  (lambda) is the matrix of coefficients, or loadings, relating indicators of exogenous variables to latent exogenous variables ( $\xi$ ).
- (3)  $B$  (beta) is the matrix of coefficients of the effects of latent endogenous variables on latent endogenous variables.
- (4)  $\Gamma$  (gamma) is the matrix of coefficients of the effects of latent exogenous variables on latent endogenous variables.
- (5)  $\Phi$  (phi) is a variance-covariance matrix of the latent exogenous variables ( $\xi$ ).
- (6)  $\Psi$  (psi) is a variance-covariance matrix of the residuals ( $\zeta$ ).
- (7)  $\theta_e$  (theta) is a variance-covariance matrix of errors of measurements of y's.
- (8)  $\theta_\delta$  (theta) is a variance-covariance matrix of errors of measurements of x's.

(see Appendix B).

Two equations describe the measurement model:

$$x = \Lambda_x \xi + \delta,$$

$$y = \Lambda_y \eta + \epsilon,$$

The structural equation model is described as:

$$B\eta = \Gamma\xi + \zeta.$$

The LISREL program accepts raw data, a covariance matrix or a correlation matrix as input. A correlation matrix was used as input in this study.

LISREL outputs several pieces of information which allows the assessment of the causal model. The measurement model can be assessed through an inspection of the significant loadings of measures on constructs; a chi-square statistic for overall goodness-of-fit; and residual values. Because the chi-square statistic is directly related to the size of the sample, it is recommended that a chi-square comparison with degrees of freedom be used as a indication of the goodness of fit ( $\chi^2/df$ ).

The structural model can be assessed by inspection of the structural maximum likelihood coefficients that interrelate endogenous variables (betas) and the structural maximum likelihood coefficients that relate exogenous variables to endogenous variables (gammas) (Long, 1983).

In addition to the LISREL procedure, information on the distribution, variability, and central tendencies of variables were analysed via the Statistical Package of the Social Sciences (SPSS). Select variables were also analyzed by utilizing one-way ANOVAs and Pearson product-moment correlations. The scales that were utilized to indicate latent variables were analyzed by factor analysis and reliability techniques to verify theoretical constructs and to assess internal consistency for the scales.

## RESULTS

### Overview of Statistical Analysis

The analysis of the data was organized at two major levels. First, preliminary analyses were performed to describe and examine each measured variable. Second, the theoretical model, as outlined in earlier chapters, was analysed with the Linear Structural Relations (LISREL V) computer program.

In the preliminary analysis, each measured variable identified in the theoretical model was analyzed by utilizing descriptive statistics (frequencies, percentages, means), measures of association (Pearson product-moment correlations), and analyses of variance (one-way ANOVAs and a posteriori contrasts). For selected measured variables, factor-analytic techniques and reliability tests were used to confirm underlying patterns of relationships of variables and internal consistency within the scale being tested. These analyses were performed for three purposes, specifically: to provide descriptive information for each variable; to identify possible demographic factors (associated with the caregiver and dementia patient) that could affect the caregiver's response to the items in the questionnaire; and to prepare the data for use in the LISREL computer program. In this chapter, each measured variable will be discussed in the order in which

they occur within the theoretical model (e.g., exogenous variables then endogenous variables).

The second major level of analysis focused on the theoretical causal model in which both the measurement model and the structural relations model were analysed by utilizing the Linear Structural Relations (LISREL V) computer program (Joreskog and Sorbom, 1978). This analysis provided an assessment of the theoretical model which proposed a structural ordering of relationships between the measured variables and the latent variables and a pattern of causal influence among the latent variables.

## Descriptive Statistics and Analysis of the Measured Variables

### Personal Control

Personal control, a latent exogenous variable, was conceptualized as psychological traits or dispositions of personality which individuals draw upon to help manage stressor events. Four measured variables were hypothesized to produce significant loadings on the latent variable of personal control. Three of the measured variables (Internal Control, Powerful Others, and Chance) were measured by a 24-item Likert type scale modified from Levenson's scale (1981) which represented an assessment of generalized control beliefs. The generalized locus of control scale was constructed to tap beliefs about the operation of the three dimensions of control: beliefs in personal control (Internal



Scale), powerful others (Powerful Others Scale), and chance or fate (Chance Scale) (Levenson, 1981).

Because the scales used in this study were modified from Levenson's (1981) original scales, the scales for Internal Control (I scale), Powerful Others (P scale) and Chance (C scale) were tested for internal consistency. For this sample ( $n = 458$ ), the Cronbach's alpha coefficient was .54 for the I scale, .70 for the P scale, and .72 for the chance scale. These reliabilities compare favorably with those obtained by Levenson (1974).

The modified version of the I, P, and C scale had a possible scoring range of 8 to 24, with a low score indicating a tendency of the caregiver not to believe in that locus of control and a high score reflecting high expectations of control by the source designated (Levenson, 1981). The mean score for the caregivers on the I scale (Internal Control) was 20.9 ( $SD = 2.6$ ). The P scale (Powerful Others) measures one external dimension of control with items assessing beliefs in powerful others as controlling factors in one's life. The C scale (Chance) measures the other external dimension of control with items assessing beliefs in unpredictable and chaotic events. The mean score for caregivers on the P scale (Powerful Others) was 12.4 ( $SD = 3.4$ ) and the mean score for the sample on the Chance scale was 12.7 ( $SD = 3.5$ ).

Male caregivers reported a significantly higher internal control orientation ( $X = 21.6$ ) than did female caregivers ( $X = 20.7$ ) ( $F = 10.8$ ,  $p < .01$ ) (Table 1). Men also reported higher

TABLE 1

## Analysis of Variance by Sex on Powerful Others Control Beliefs

Source	df	SS	MS	F ratio
Between groups	1	115.29	115.29	10.10 ***
Within groups	428	4882.24	11.40	
Total	429	4997.54		

\*\*\*  $p < .001$

powerful others control orientation ( $X = 13.2$ ) than women ( $X = 12.1$ ), ( $F = 10.1$ ,  $p < .01$ ) (Table 2). There were no significant differences in chance mean scores by caregiver sex.

Comparing caregivers whose dementia patient was institutionalized to caregivers whose patient was living in the community, there were no significant differences in internal or powerful others mean scores. However, mean chance scores were higher for caregivers with the dementia patient residing in an institution ( $X = 13.2$ ) than when the patient was residing in the community ( $X = 12.5$ ) ( $F = 3.8$ ,  $p < .05$ ) (Table 3). For both caregiver groups, these mean scores indicate moderate levels of belief in the Powerful Others and Chance control orientation.

There were no significant differences in the control orientation scores based on the diagnosis of the dementia patient (e.g., Alzheimer's Disease versus other forms of dementia). There were also no significant differences in caregivers' mean control orientation scores by their religious preference groups or for caregivers in support groups compared to those caregivers who were not in support groups.

Utilizing a zero-order correlation matrix (Pearson product-moment correlations), several substantive associations between the control orientations and other variables were observed (Appendix M). For example, there was a moderate positive correlation between the internal control orientation and life satisfaction ( $r = .27$ ,  $p < .001$ ). However, life satisfaction was negatively associated with both powerful

TABLE 2

Analysis of Variance by Patient Residence on Chance Control Beliefs

Source	df	SS	MS	F ratio
Between groups	1	72.17	72.17	10.79 ***
Within groups	432	2889.80	6.68	
Total	433	2961.98		

\*\*\* p < .001

TABLE 3

Analysis of Variance by Patient Residence on Chance Control Beliefs

Source	df	SS	MS	F ratio
Between groups	1	48.22	48.22	3.83 *
Within groups	426	5364.23	12.59	
Total	427	5412.46		

\*  $p < .05$

others ( $r = -.32$ ,  $p < .001$ ) and chance ( $r = -.40$ ,  $p < .001$ ) control orientations. These external control orientations were also associated with certain coping behaviors. For example, avoidant/evasive coping strategies were significantly correlated with both powerful others ( $r = .29$ ,  $p < .001$ ) and chance ( $r = .36$ ,  $p < .001$ ) control orientations. Beliefs in the chance control orientation was also inversely associated ( $r = -.15$ ,  $p < .001$ ) with a caregiver's ease of contact with members in their social network.

Situational control was measured by a 3-item Likert type scale adapted from measurements by Parkes (1984) and Stone and Neale (1984). These three items focused on the how caregiver perceived their control beliefs in the context of the careproviding situation (Appendix D). Fifty-seven percent ( $n = 249$ ) of caregivers reported that they had very little control over their lives now that they were caregivers. Thirty-two percent ( $n = 131$ ) disagreed with this belief and 12.4% ( $n = 54$ ) were uncertain. Although 30.5% ( $n = 132$ ) of the caregivers disagreed that the role of caregiver was a very satisfying and fulfilling responsibility, 47.8% ( $n = 207$ ) of the caregivers agreed that the role was satisfying and fulfilling, while 21.7% ( $n = 94$ ) were uncertain. Only 19.9% ( $n = 87$ ) of the caregivers thought that the caregiving role was the most stressful situation that has happened in their lives. The great majority (68.9%,  $n = 301$ ) responded that the caregiving role was not the most stressful situation in their lives.

A reliability analysis for the situational control measure

indicated that the three items did not have internal consistency (Cronbach's  $\alpha = -.35$ ). An examination of the zero-order correlation matrix revealed that one item (e.g., "The caregiver role is a very satisfying and fulfilling responsibility") had inverse relationships with the two other items in the situational control scale (Appendix M). With this one item omitted from the second reliability analysis, a Cronbach  $\alpha$  of .40 was obtained for the two item scale indicating a fairly internally consistent measure. Although descriptive information for the omitted item was included in this section, all subsequent analyses would not include this item within the construct of situational control.

#### Patient Functioning

Patient functioning, a latent exogenous variable, was conceptualized as the caregivers evaluation and perception of the mental and physical health status of the dementia patient. Two indicators of patient functioning formed the objective and subjective dimensions of the latent variable.

The objective dimension was measured by the Functional Dementia Scale (Moore et al., 1983). The reliability coefficient (Cronbach's  $\alpha$ ) for this scale was reported at .90 and a reliability coefficient obtained for this sample on the scale was .89 (Cronbach's  $\alpha$ ). The Functional Dementia Scale (Appendix D) distinguished varying degrees of severity of functional limitation in the dementia patient. Each item employed a four-point rating scale for rating the frequency of

functional impairment, ranging from "none or little of the time" (1) to "most or all of the time" (4). Because all items were positive in a symptomatic direction, a high score indicated more severe problems with the dementia patient. The possible range of scores were 20 (mild impairments) to 80 (severe impairments) for this scale. The mean score on the Functional Dementia Scale for was 50.2 (SD = 12.1) which indicated that the average dementia patient in this study suffered moderate functional limitations, although the standard deviation score of 12.1 emphasized the range from mild to severe cases found in this sample.

There were no significant differences in the mean levels of functional impairment for male and female dementia patients. Furthermore, based on one way analysis of variance there were no significant differences between the mean levels of functional impairment in Alzheimer's disease patients and in patients with other forms of dementia (e.g., Multi-infarct dementia, Parkinson's disease). There was a significant difference ( $F = 58.2$ ,  $p < .01$ ) in the level of functional impairment between dementia patients who resided in the community ( $X = 46.9$ ) and patients who resided in a nursing home or adult residential care facility (Table 4). The mean level of patient functional impairment did not significantly differ according to whether or not the caregiver was or was not a member of a support group.

Several functional impairments of the dementia patient reported by the caregivers in this sample were indicative of



TABLE 4

Analysis of Variance by Patient Residence on the Level of  
Functional Impairment for the Dementia Patient

Source	df	SS	MS	F ratio
Between groups	1	7373.00	7372.00	58.228 ***
Within groups	366	46337.96	126.60	
Total	367	53709.96		

\*\*\*  $p < .001$

the early and middle stages of Alzheimer's disease previously described in the review of the literature. These indicators supported the finding that the dementia patient in this study had moderate limitations in activities of daily living. For example, 72% (n = 318) of the caregivers reported that the dementia patient had difficulty in completing simple tasks on their own (e.g., dressing, bathing); 78% (n = 328) reported that the dementia patient would lose things for the most or good part of the time; 58% (n = 240) reported that the dementia patient had to be watched constantly for fear of self-injury due to falling, leaving the stove on, etc.; 75% (n = 325) said that the impaired family member was confused and did not know where he/she is; 93% (n = 403) reported that the patient had trouble remembering; 81% (n = 356) said that the impaired family member spent most or a good part of the time either sitting or in apparently purposeless activity.

Indicators of more advanced functional limitations associated with Alzheimer's disease and other dementias were also reported by some caregivers. For example, 32.4% (n = 140) said that their impaired family member could not control bowel functions, 36% (n = 156) reported that the dementia patient could not control bladder functions, and 36.2% (n = 158) reported that the dementia patient wandered at night or needed to be restrained to prevent wandering.

Out of the twenty behaviors assessed by the Functional Dementia Scale, the four behaviors which were reported to be the most difficult for the caregivers were: 1) sudden changes

of mood (16.6%); 2) trouble remembering (11.9%); 3) difficulty in completing tasks on own (12%); 4) lack of control of bowel function (10%).

There was a significant negative correlation ( $r = -.21$ ,  $p < .001$ ) between the functional level of impairment in the dementia patient and the self-reported health status of the caregiver (Appendix M). A significant positive correlation ( $r = .30$ ,  $p < .001$ ) existed between the level of patient impairment and the extent to which caregivers believed that their own health status had changed from the start of caregiving role to the present (Appendix M).

The inclusion of the subjective dimension in the evaluation of the dementia patient was used to balance the more objective Functional Dementia scale (Moore et al., 1981). The caregiver's own personal evaluation of the dementia patient helped to contribute to more contextual accuracy, the patients current physical and mental health status. In other words, it was feasible that a high score on the Functional Dementia Scale would have objectively indicated severe impairments, yet it is possible that the severe impairments for one caregiver may not be so severe for another caregiver. The opposite could also be true, it was possible that a mild level of impairment could be appraised by one caregiver as severe and by another caregiver as moderate.

Two questions were utilized to represent the subjective evaluation of the dementia patient by the caregiver. Specifically, caregivers assessed the patients emotional and

physical health status on scales of 1 (poor) to 4 (excellent) (Appendix D). These items were analyzed for reliability and a Cronbach's alpha of .57 was obtained for this sample which indicated that the items showed a moderate to strong degree of internal consistency.

Forty-percent of the caregivers ( $n = 177$ ) evaluated their impaired family member's emotional health status as poor; 33.9% ( $n = 150$ ) said that the emotional status was fair. Twenty-two percent ( $n = 100$ ) rated the patients emotional health status as good, while only 3.4% ( $n = 15$ ) rated the emotional health as excellent. Nineteen-percent ( $n = 85$ ) of the caregivers rated the patient's physical health as poor; 29.5% ( $n = 132$ ) evaluated the physical status as fair. Thirty-five percent ( $n = 161$ ) rated the patient's status as good and 15.6% ( $n = 70$ ) said that the patient's status was excellent.

A significant inverse relationship ( $r = -.21$ ,  $p < .001$ ) was observed between levels of burden and the assessment of the patient's emotional health status (Appendix M). A significant inverse relationship ( $r = -.22$ ,  $p < .001$ ) was also found between the utilization of avoidant/evasive coping strategies and the assessment of the patient's emotional health status (Appendix M).

The caregivers assessment of both the patient's emotional and physical health status were both inversely related ( $r = -.42$ ,  $p < .001$  and  $r = -.23$ ,  $p < .001$ ) to the objective assessment of the patient via scores obtained through the

Functional Dementia Scale (Moore et al., 1981) (Appendix M). That is, higher levels of functional limitations were significantly related to poorer subjective assessments of patient well-being.

### Social Resources

Social resources, a latent exogenous variable, was conceptualized as comprising both quantitative and qualitative dimensions. The quantitative dimension relates was an objective indicator of the size of the caregivers' social network, specifically, the number of available others to whom the caregiver could turn to in times of need. The qualitative dimension related to the more subjective evaluation of the network in terms of satisfaction and degree of availability (Appendix D).

The quantitative dimension was assessed by the open-ended item which asked the caregiver: "How many people (friends and relatives) are available to you for support in your caregiving responsibilities?" The average number of people listed as part of the caregiver's support network was about 6 ( $X = 5.7$ ,  $S.D. = 8.5$ ). Based on frequency distributions for this item, 5.7% ( $n = 24$ ) of the caregivers listed no one as part of their social network; 9.1% ( $n = 38$ ); 18.7% ( $n = 78$ ) listed two people; 15.1% ( $n = 63$ ) listed 3 people; 8.4% ( $n = 35$ ); listed 4 people; 11.5% ( $n = 48$ ) listed five people; 7.2% ( $n = 30$ ) listed 6 people; and 8.9% ( $n = 37$ ) listed 10 people as part of their social network. The reported frequency for a network

greater than 11 was less than 2%.

There were no significant differences in the mean number of people available to the caregivers by the dementia patient residence (in the community or in a nursing home). There were also no significant differences between male and female caregivers in the number of people available for assistance.

The qualitative dimension of social resources was assessed by three items: "How satisfied are you with the support you receive from relatives and friends?", "How easy is it for you to contact these people?", and "As a group, how often do they help you?". The reliability coefficient obtained for these three items (representing the qualitative dimension) was .71 (Cronbach's alpha) which indicated a strong internal consistency among the items.

Forty-seven percent of the caregivers ( $n = 196$ ) reported that it was fairly easy to contact people in their social network, while 30.7% ( $n = 126$ ) said it was very easy to contact these people. A small percentage (7.7%,  $n = 31$ ) said it was very difficult or fairly difficult to contact people in their support network, while 14.1% ( $n = 58$ ) said it was neither difficult nor easy to contact these people.

Thirty-four percent of the caregivers ( $n = 139$ ) reported that, as a group, their social network were sometimes helpful, 28.6% ( $n = 116$ ) said that as a group they were quite often helpful. Fifteen percent of the caregivers ( $n = 61$ ) said that their social network was not very helpful, 12.6% ( $n = 51$ ) reported that the group was very often helpful and 9.6% ( $n =$

39) said that, as a group, their social network was never helpful.

Forty-percent of the caregivers ( $n = 161$ ) reported that they were quite satisfied with the support received by their social network, 26% ( $n = 105$ ) said they were very satisfied with the support received. Twenty-two percent of the caregivers ( $n = 88$ ) said they were somewhat satisfied with the support received, while 8.2% ( $n = 33$ ) said they were a little satisfied and 4.2% ( $n = 17$ ) said that they were not at all satisfied with the support received from the people in their social network.

There were significant correlations (although substantially weak) between the quantitative dimension of and the qualitative dimension of social resources. For example, social network size was positively associated with both degree of help ( $r = .13$ ,  $p < .01$ ) and support satisfaction ( $r = .15$ ,  $p < .001$ ). Significant positive correlations (again substantially weak associations) were also found between social network size and life satisfaction ( $r = .14$ ,  $p < .01$ ); and between social network size and the caregivers' self-reported physical health status ( $r = .11$ ,  $p < .01$ ) (Appendix M).

There were no significant differences between male and female caregivers on the reported ease of contact, the degree of helpfulness, and satisfaction with support from people in their social network. There were no significant differences in degree of helpfulness (e.g., how often does the social network help?) from the people in the network by dementia patient

residence (residing in the community or in a nursing home). However, compared to caregivers to community dwelling patients, caregivers to insitutionalized patients reported greater ease in contacting people in the support network ( $F = 5.7$ ,  $p < .01$ ) (Table 5).

Level of burden in caregivers was inversely related to all three items of the qualitative dimension of social resources, e.g., ease of contact ( $r = -.31$ ,  $p < .001$ ), degree of helpfulness ( $r = -.25$ ,  $p < .001$ ), and degree of satisfaction ( $r = -.25$ ,  $p < .001$ ) (Appendix M). There were positive correlations between life satisfaction and both ease of contact ( $r = .19$ ,  $p < .001$ ) and degree of satisfaction with the support network ( $r = .21$ ,  $p < .001$ ) (Appendix M). There was a positive correlation ( $r = .16$ ,  $p < .001$ ) between ease of contact with the social network and the caregiver's present physical health status. Finally, there was a positive correlation ( $r = .25$ ,  $p < .001$ ) between degree of satisfaction with support received from the social network and the degree of satisfaction derived from being a caregiver to an impaired family member (Appendix M).



TABLE 5

Analysis of Variance by Patient Residence on the Ease  
of Contact with Social Network

Source	df	SS	MS	F ratio
Between groups	1	4.91	4.91	5.75 **
Within groups	403	344.06	.85	
Total	404	348.97		

\*\*  $p < .01$

## Coping Behavior

Coping behavior, a latent endogenous variable, was conceptualized as the behavioral and emotional responses used by the caregiver in adapting to the careprovider role. The instrument utilized in this study, The Jalowiec Coping Scale (Jalowiec et al., 1984), assessed four distinct coping patterns tentatively labeled: 1) problem-oriented, 2) avoidant/evasive, 3) pessimistic, and 4) dependency-oriented.

Although the Jaloweic Coping Scale has received rigorous psychometric analysis, Jaloweic et al., (1984) indicated that further testing would help to determine the soundness and replicability of the structure of coping. In the current sample, a reliability coefficient of .76 (Cronbach's alpha) was obtained for the entire scale which compares favorably with the coefficient (.86) obtained by Jalowiec et al., (1984).

Factor analysis procedures were utilized to determine if the four-factor solution, as proposed by Jaloweic et al., (1984), provided the best conceptual pattern of coping behavior in the current sample. In order to replicate the findings of Jalowiec et al., (1984), all attempts were made to follow factor analysis procedures reported in their study. For example, several factor solutions were run to determine the best multidimensional characteristics of coping behavior for this caregiver sample; Varimax rotation was utilized to provide the clustering of variables; and similar significance criterion tests were also utilized (e.g., a minimum .30 factor loading).

A four-factor solution, similar but not identical to the Jaloweic solution, provided the best conceptual pattern of coping behavior for this sample. The items that significantly loaded on Factor 1 in the study by Jaloweic et al., (1984), had for the most part, significantly loaded on Factor 1 in a factor analysis for this study (Table 6). Representative items included: try out different ways to solve the problem, set specific goals to solve problem, use past experience to handle problem, find out more about situation, and maintain control over the situation. Collectively, the items loading on this factor were described as problem-solving or problem-oriented coping mechanisms.

The other three factors that emerged as a result of the factor analysis in this study were somewhat different than described by Jaloweic et al., (1984). Specifically, some items which had loaded on the factors reported by Jallowiec et al., (1984) loaded on different factors for this study (Table 6). The items that significantly loaded on Factor 2 could best be described as avoidant/evasive coping mechanisms. Two items (worry and get nervous) which had significantly loaded on Factor 3 in the Jaloweic et al., (1984) study loaded significantly on Factor 2 in this study. Other items which represented Factor 2 (avoidant/evasive) in this study were: get prepared to expect the worst, resign yourself to the situation because the situation looks hopeless, resign yourself...because it is you fate, and cry; get depressed.

Factor 3, which was described as pessimistic in the

Table 6  
Factor Loadings for Coping Behaviors After Varimax Rotation,  
4-Factor Solution, Total Population (n = 458)

Names for Behaviors	Factor 1: Problem-oriented	Factor 2: Avoidant/ evasive	Factor 3: Reframing	Factor 4 Regressive
Ways/Handle situation	.68	.05	-.02	-.20
Learn more of situation	.65	.04	-.09	-.06
Try out different ways	.62	.02	.00	-.01
Set specific goals	.58	-.09	.14	.07
Use past experiences	.56	-.03	.09	-.08
Break problem down	.55	-.01	.01	-.00
Try to find meaning	.48	-.01	.21	-.01
Try to maintain control	.47	.11	-.15	-.14
View prob. objectively	.46	-.11	-.02	-.24
Active/change situation	.36	-.17	.13	.28
Talk problem over	.35	.00	.13	.14
Seek comfort/family	.34	-.00	-.01	.09
Problem resolve itself	-.32	.25	.20	.09
Physical activity	.31	.03	.20	.06
Hope for better things	.30	.12	.07	.11
Get nervous	.08	.67	-.05	.34
Worry	.06	.65	-.14	.29
Resign/hopeless	-.10	.58	.09	-.14
Do nothing	-.03	.51	-.04	.35
Resign/fate	-.09	.49	.24	-.16
Pessimism	.04	.40	.01	-.02
Just do something	.02	.37	.28	.14
Everything will be o.k.	.14	-.22	.57	-.16
Sleep/better in morning	.23	.10	.50	.09
Withdraw/situation	-.08	.05	.46	.25
Problem/out of mind	-.05	.20	.43	.10
Laugh it off	.20	-.23	.39	-.05
Daydream/fantasize	-.02	.19	.38	.23
Settle for next best	.13	.03	.35	-.07
Someone else/problem	-.22	.02	.30	.16
Put tensions on others	-.02	.07	.10	.45
Blame someone else	-.05	.09	.20	.42
Get mad; swear; curse	-.08	.30	-.06	.42
Eat; smoke; chew gum	.11	.16	.04	.40
Accept situation	.12	.16	.09	-.38
Drink alcohol	-.01	.01	.05	.30
Meditation; yoga	.11	.01	.24	.04
Take drugs	.02	.01	.01	.23
% of variance	38.7	31.7	17.8	11.7
Eigenvalues	4.1	3.3	1.9	1.2

Jaloweic et al., (1984) study, could best be described as a type of "reframing" coping strategy in this study. Reframing described cognitive efforts to see the caregiving situation in another frame of reference. Representative items included: laugh it off/figuring it could be worse, daydream/fantasize, go to sleep/figuring things will be better in the morning, try to put problem out of mind, and don't worry about everything will probably work out (Table 6).

Factor 4, which was described as dependency oriented in the Jaloweic et al., (1984) study, could best be described as a form of "regressive" coping in this study. Regressive coping described strategies which were the probably least productive way of handling stress over the long term. Representative items included: eat, smoke, chew gum, get mad/swear/curse, blame someone else for your problems, and take your tensions out on someone or something else (Table 6). The two items, seeking help or comfort from others and discussing problem with others, had loaded on Factor 4 (dependency-oriented) in the Jallowiec et al., (1984) study, but loaded on Factor 1 (problem-oriented) in this study. One item in particular, take drugs, did not load significantly on any factor. This finding is not suprising as Jaloweic et al., (1984) encountered the same result.

Cronbach's alpha was computed for the four factors to assess internal consistency for each factor and alpha coefficients of .78, .73, .64, .60 were obtained for each scale respectively. For each factor, the alpha would not improve to

any substantial degree if some items were deleted, because most items were sufficiently correlated. These alpha's compare favorably to the coefficients found in the Jaloweic et al., (1984) study (.86, .73, .75, and .55), although the Jaloweic did delete potentially less homogeneous items which increased the alpha coefficients for some factors.

Several coping strategies were used often or almost always by a great majority of caregivers, while other coping strategies were rarely or never used by the caregivers. For example, 64% (n = 278) of caregivers used the coping behavior, hope things will get better, often or almost always as a way adapting to the caregiving situation. Ninety-five percent of the caregivers (n = 414) tried to maintain control over the situation most of the time; 93% (n = 408) found out more about the situation so they could handle it better; 94% (n = 409) thought through different ways to handle the situation; 81% (n = 349) drew upon past experiences to help handle the situation; and 83% (n = 358) tried looking at the problem more objectively most of the time.

In contrast, 97% (n = 419) said that they rarely or never used drugs as a coping strategy. Ninety-two percent (n = 393) reported that they rarely blame others for their problems; 76% (n = 323) rarely used meditation/yoga/biofeedback; 89% (n = 380) rarely or never let someone else solve the problem; 90% (n = 386) rarely or never drank alcoholic beverages as a coping mechanism; 82% (n = 347) rarely or never withdrew from the situation; and 77% (n = 329) said they rarely or never got

mad or cursed as a coping strategy.

Although 35% of the caregivers ( $n = 151$ ) reported that they rarely or never got nervous, 57% ( $n = 247$ ) said they got nervous most or all of the time. Similarly, 30.5% ( $n = 110$ ) of the caregivers said that they rarely worried however, 65% ( $n = 279$ ) reported that they worried most of the time.

Female caregivers had a significantly higher mean score ( $X = 49.9$ ) for problem-oriented coping efforts than male caregivers ( $X = 48$ ) ( $F = 6.2$ ,  $p < .01$ ) (Table 7). Female caregivers also had a significantly higher mean score ( $X = 12.5$ ) for regressive coping strategies than male caregivers ( $X = 11.5$ ) ( $F = 5.8$ ,  $p < .01$ ) (Table 8). There were no significant differences between male and female caregivers in the mean scores for reframing and avoidant/evasive coping behavior.

There were significant differences in the mean score for avoidant/evasive coping efforts for caregivers whose impaired family member resided in the community ( $X = 25.1$ ) versus those patients who resided in a nursing home ( $X = 26.6$ ) ( $F = 5.3$ ,  $p < .05$ ) (Table 9). There were also significant differences in the mean score for regressive coping behaviors for caregivers whose impaired family member resided in the community ( $X = 12$ ) versus those patients who resided in a nursing home ( $X = 12.8$ ) ( $F = 4.2$ ,  $p < .05$ ) (see Table 10). There were no significant differences by patient residence in the mean scores for reframing and problem-oriented coping behaviors.

There were no significant differences in the mean scores in any of the coping behaviors for caregivers of Alzheimer's

TABLE 7

## Analysis of Variance by Sex of Problem-Oriented Coping Behaviors

Source	df	SS	MS	F ratio
Between groups	1	292.01	292.01	6.24 **
Within groups	418	19541.71	46.75	
Total	419	19833.73		

\*\*  $p < .01$



TABLE 8

## Analysis of Variance by Sex on Regressive Coping Behaviors

Source	df	SS	MS	F ratio
Between groups	1	82.29	82.29	5.87 **
Within groups	419	5867.17	14.00	
Total	420	5949.46		

\*\*  $p < .01$

TABLE 9

Analysis of Variance by Patient Residence  
on Avoidant/Evasive Coping Behaviors

Source	df	SS	MS	F ratio
Between groups	1	197.52	197.52	5.35 *
Within groups	411	15148.48	36.85	
Total	412	15346.01		

\*  $p < .05$

TABLE 10

Analysis of Variance by Patient Residence on Regressive Coping Behaviors

Source	df	SS	MS	F ratio
Between groups	1	60.16	60.16	4.26 *
Within groups	413	5819.94	14.09	
Total	414	5880.19		

\*  $p < .05$

patients versus caregivers of patients with other types of dementia.

There was a significant difference in the mean score of regressive coping behaviors for caregivers who were members of a support group ( $X = 12.6$ ) versus caregivers who were not members of a support group ( $X = 11.4$ ) ( $F = 8.5$ ,  $p < .01$ ) (see Table 11). There were no significant differences in the mean scores for reframing, problem-oriented, and avoidant/evasive coping behaviors for caregivers in support groups compared to those caregivers who are not members of support groups.

An examination of the zero-order correlation matrix (Pearson product-moment) revealed that problem-oriented coping behaviors were not significantly correlated with the majority of the relevant measured variables in the theoretical model, except for life satisfaction ( $r = .20$ ,  $p < .001$ ) (Appendix M). In contrast, the avoidant/evasive coping behaviors were very gregarious, statistically speaking. For example, avoidant/evasive coping strategies were positively associated with several other variables, including: powerful others control beliefs ( $r = .30$ ,  $p < .001$ ); chance control beliefs ( $r = .37$ ,  $p < .001$ ); appraisal that the caregiving situation was a stressful event ( $r = .35$ ,  $p < .001$ ); levels of functional impairment in the dementia patient ( $r = .27$ ,  $p < .001$ ); and with caregiver burden ( $r = .47$ ,  $p < .001$ ). Avoidant/evasive coping strategies were negatively associated with life satisfaction scores ( $r = -.43$ ,  $p < .001$ ); caregivers' current physical health status ( $r = .31$ ,  $p < .001$ ); and with

TABLE 11

Analysis of Variance by Support Group Membership  
on Regressive Coping Behaviors

Source	df	SS	MS	F ratio
Between groups	1	116.50	116.50	8.5 ***
Within groups	411	5599.77	13.62	
Total	412	5716.28		

\*\*\*  $p < .001$

satisfaction in the caregiving role ( $r = -.25$ ,  $p < .001$ ) (Appendix M).

Reframing coping efforts were positively associated with the degree of satisfaction in the caregiving role ( $r = .16$ ,  $p < .001$ ) (Appendix M).

### Caregiver Well-Being

Caregiver well-being, a latent endogenous variable, was conceptualized as the physical and psychological functioning of the caregiver within the context of providing care to a dependent relative with a dementing illness. Caregiver well-being was operationalized with measures of subjective evaluation of health status, caregiver burden, and life satisfaction.

### Subjective health status

Subjective health status was measured by 3 items taken from an earlier study involving caregivers of Alzheimer's patients (Pratt et al., 1985). The initial reliability analysis for three items indicated that there was a lack of homogeneity for the scale (Cronbach's  $\alpha = -.14$ ). An examination of the inter-correlations among the three items revealed that the item, "if health status has changed do you feel your caregiving has affected that change?", was negatively correlated with the other two items. If this item was deleted from the scale, the reliability coefficient (Cronbach's  $\alpha$ ) increased to .73 which indicated a stronger internal

consistency for the scale. Based on the final reliability analysis and because the item in question had over 70 missing cases, it was decided to drop the item from all subsequent analyses, except for the descriptive information in the next paragraph.

The majority of the caregivers (87.6%,  $n = 376$ ) rated their physical health as good to excellent before the start of the caregiving role. Rating their health at the present time, 60.5% of the caregivers ( $n = 267$ ) described their health status as good to excellent and 30% ( $n = 136$ ) of the caregivers rated their health as fair. Asked if their health status had changed due to the caregiving role, 33.8% ( $n = 132$ ) of the caregivers said it had changed a great deal, 41.7% ( $n = 163$ ) said it changed a little, and 24.6% ( $n = 96$ ) said it had changed not at all.

There were no significant differences by patient diagnosis (Alzheimer's Disease or some other form of dementia) at the start of the caregiving situation or the present time for caregivers self-evaluation of physical health status. Similarly, there were no significant differences by patient residence (community or nursing home) for caregivers physical health status at the start of caregiving or at the present time. There was also no significant differences in the initial or current physical health status of male compared to female caregivers.

The caregiver's current physical health status was negatively associated with both of the external control

orientations (powerful others,  $r = -.16$ ,  $p < .001$ ) and chance, ( $r = -.18$ ,  $p < .001$ ), and with the caregivers satisfaction in the caregiving role ( $r = -.25$ ,  $p < .001$ ) (Appendix M). The caregiver's current health status was also negatively associated with the functional impairment level of the dementia patient ( $r = -.21$ ,  $p < .001$ ). The caregiver's current health status was positively associated with the dementia patient's physical ( $r = .23$ ,  $p < .001$ ) and emotional health status ( $r = .21$ ,  $p < .001$ ) (Appendix M).

### Caregiver burden

Caregiver burden was measured by the 22-item Burden Scale developed by Zarit et al., (1980). A Cronbach's alpha of .89 was obtained for the scale for this sample. The mean burden score for this sample was 41 (SD = 15.5).

Examination of individual items in the burden scale revealed several diverse sources of concern for caregivers. For example, the majority of the caregivers (66.4%,  $n = 287$ ) reported that they were quite frequently or nearly always afraid of what the future held for their impaired family member; 78% ( $n = 329$ ) said that they quite frequently or almost nearly felt that their impaired family member was dependent upon them; and 51.7% ( $n = 219$ ) said that felt quite frequently or almost always that their social life had suffered because of the caregiving situation.

Fifty-eight percent of the caregivers ( $n = 253$ ) reported that they never or rarely feel embarrassed over the dementia



patient's behavior, 43% (n = 187) said that their health has never or rarely suffered because of their involvement with the impaired family member, and 62.1% (n = 257) reported that they never or rarely felt uncomfortable having friends over (with the dementia patient in the same residence). When responding to the question regarding how burdened the caregivers felt overall, 9.2% of the caregivers (n = 37) said that they never felt burdened by caring for their impaired family member, 18.5% (n = 74) said they felt rarely burdened, 30.7% (n = 123) said they felt sometimes burdened; 23.7% (n = 95) reported they felt frequently burdened, and 18% (n = 72) said they felt nearly always burdened with the providing care for their impaired family member.

The mean levels of caregiver burden did not significantly differ by patient residence (residing in the community or in a nursing home). The mean caregiver burden levels did not significantly differ by patient diagnosis (Alzheimer's disease or some other form of dementia). There was no significant difference in the mean levels of burden for male caregivers compared to female caregivers. There were also no significant differences for mean burden levels by religious orientations of the caregiver.

The mean level of burden for members in support groups was significantly higher ( $X = 42.3$ ) than the mean level of burden for caregivers not in support groups ( $X = 37.8$ ) ( $F = 6.2$ ,  $p < .01$ ) (Table 12). There were significant differences between caregivers who provided varied amounts (hours per day) of care

TABLE 12

Analysis of Variance by Support Group Membership  
on Caregiving Burden Levels

Source	df	SS	MS	F ratio
Between groups	1	1495.80	1495.80	6.25 **
Within groups	354	84662.09	239.158	
Total	355	5716.28		

\*\* p < .01

for the dementia patient. Post hoc analysis (LSD,  $p < .01$ ) revealed that as hours per day of caregiving responsibilities increased, the mean level of reported burden increased concomitantly (Table 13). There were also significant differences in mean levels of burden depending on the relationship of the caregiver to the dementia patient. Post hoc analysis (LSD,  $p < .01$ ) revealed that spouses, as caregivers, had significantly higher mean burden scores than daughters, sons, daughter-in-laws and any other category of relationship (Table 14).

Levels of burden were positively associated with avoidant/evasive coping ( $r = .47$ ,  $p < .001$ ), regressive coping ( $r = .37$ ,  $p < .001$ ), the degree of control in the caregiver's life ( $r = .37$ ,  $p < .001$ ), and with the level of functional impairment in the dementia patient ( $r = .27$ ,  $p < .001$ ) (Appendix M). Levels of burden were negatively associated with caregiver role satisfaction ( $r = -.34$ ,  $p < .001$ ), with the current physical health status of the dementia patient ( $r = -.21$ ,  $p < .001$ ), with the caregiver's ease of contact with their social network ( $r = -.31$ ,  $p < .001$ ), the degree of help from the social network ( $r = -.25$ ,  $p < .001$ ), with the degree of social support satisfaction ( $r = -.25$ ,  $p < .001$ ), and with the caregiver's current physical health status ( $r = .56$ ,  $p < .001$ ) (Appendix M).

### Life Satisfaction

Life satisfaction was measured by the Life Satisfaction

TABLE 13

Means of Caregiver Burden by Hours (per day) of Caregiving

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Mean Caregiver Burden Levels	
Hours per day	
Less than two	31.73
2 to 5	39.00
6 to 10	41.92
11 to 15	43.38
16 to 20	44.40
21 to 24	44.53

TABLE 14

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**Means of Caregiver Burden by Relationship to the Dementia Patient**

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**Mean Caregiver Burden Levels**

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**Relationship**

Granddaughter	12.00
Sister	23.50
Son	25.00
Daughter-in-law	38.33
Daughter	39.23
Spouse	43.69
Brother-in-law	45.00
Grandson	45.00

Index-Z (LSI-Z) developed by Wood, Wylie, & Sheafor (1969). A reliability coefficient of .81 (Cronbach's alpha) was obtained for the scale using the sample of the present study. The mean score for the LSI-Z scale for this sample was 18 (SD = 5.9).

Forty-eight percent of the caregivers (n = 212) disagreed with the statement "these are the best years of my life", while 32% (n = 144) agreed with this statement. Thirty-five percent of the caregivers (n = 157) thought that things had not gotten better as they grew older, while 47% (n = 209) thought that things had gotten better with age. Sixty-six percent of the caregivers (n = 294) said that this was not the drearest time of their life, while 20.4% (n = 91) thought that it was the drearest time of their lives. Eighty-three percent of the caregivers (n = 372) were fairly satisfied with their life retrospectively, while only 9.9% (n = 44) reported that they were not satisfied as they look back on their life. Although 20% of the caregivers (n = 92) thought that the "lot of the average man" was getting worse, 58% (n = 258) thought that things were getting better for the average man.

There were no significant differences in the mean level of life satisfaction for male caregivers compared to female caregivers. There were no significant differences in the mean level of life satisfaction of caregivers by patient residence (community versus residing in a nursing home facility). There were no significant differences in the mean level of life satisfaction score for caregivers by patient diagnosis (Alzheimer's disease or some other form of dementia). There

were no significant differences in the mean level of life satisfaction for caregivers in different religious orientations. Finally, there were no significant differences in the mean level of life satisfaction for caregivers who were members of a support group compared to those who were not members of a support group.

There was a positive association between life satisfaction and internal control orientations ( $r = .27$ ,  $p < .001$ ) (Appendix M). There were negative associations between life satisfaction and powerful others ( $r = -.32$ ,  $p < .001$ ); life satisfaction and chance control orientations ( $r = -.40$ ,  $p < .001$ ) (Appendix M). There were also negative associations between life satisfaction and the degree of control in the caregiver's life now that the person was careproviding for an impaired family member ( $r = -.41$ ,  $p < .001$ ), the appraisal of the caregiving role as a stressful event ( $r = -.22$ ,  $p < .001$ ), and levels of caregiver burden ( $r = -.25$ ,  $p < .001$ ).

After obtaining these results, the second major level of analysis which involved testing the the theoretical model through the utilization of the Linear Structural Relations (LISEL V) computer program was performed.

## Analysis of the Theoretical Model with LISREL V and Subsequent Analyses

### Introduction

There was an initial concern that the demographic subgroups of the sample of caregivers would respond differently to the measured variables. For example, responses could vary by caregiver sex or by patient diagnosis (Alzheimer's disease versus other forms of dementia). Using one way ANOVA's to examine the relevant measured variables, it was determined that the sample could be treated as homogeneous because there were no significant differences between subgroups associated with select demographic variables. There were also relatively few significant differences between subgroups for the measured variables used in the theoretical model.

The first step in preparing the data for the LISREL analysis was to produce a zero-order correlation matrix which included all of the measured variables previously described in the theoretical model (Appendix B). The preliminary run using the Pearson correlation procedure (via the Statistical Package for the Social Sciences) produced a correlation matrix of coefficients that were based on a different number of cases. Because the input for the LISREL analysis in this study used a correlation matrix, a second correlation matrix was produced utilizing a listwise deletion of missing data. This procedure created coefficients that were all derived from the same cases. Listwise deletion has the effect of reducing the number of



cases upon which the coefficients are computed because a case would be omitted from all calculations if the case contains any missing values. Therefore, the input data for the LISREL analysis consisted of a correlation matrix based on 436 cases, instead of the previously described sample of 458. Twenty-two cases were omitted from the LISREL analysis because these caregivers were identified as not completing one or more of the pertinent scales which were crucial to the estimation of theoretical model. There was negligible change in the coefficients in the correlation matrix based on the sample of 436 caregivers compared to the correlation coefficients based on the sample of 458 caregivers.

Before discussing the LISREL analysis for the theoretical model, it is important to discuss the implications of model identification and the evaluation of the fit of the model to the data. As shown in Figure 7, certain indicators were hypothesized to load on specified latent variables and paths of causal influence among the exogenous latent and endogenous latent variables are hypothesized to exist in a specified causal order. When only one solution is possible for the linear equations, as specified in the hypothetical model, then a model is said to be identified. For example, in Figure 7 it was hypothesized that the measured variables of social support and social network size would uniquely load on the latent variable "social resources" and not on the latent variable "personal control". In a similar mode, measured variables which were hypothesized to load on latent exogenous variables

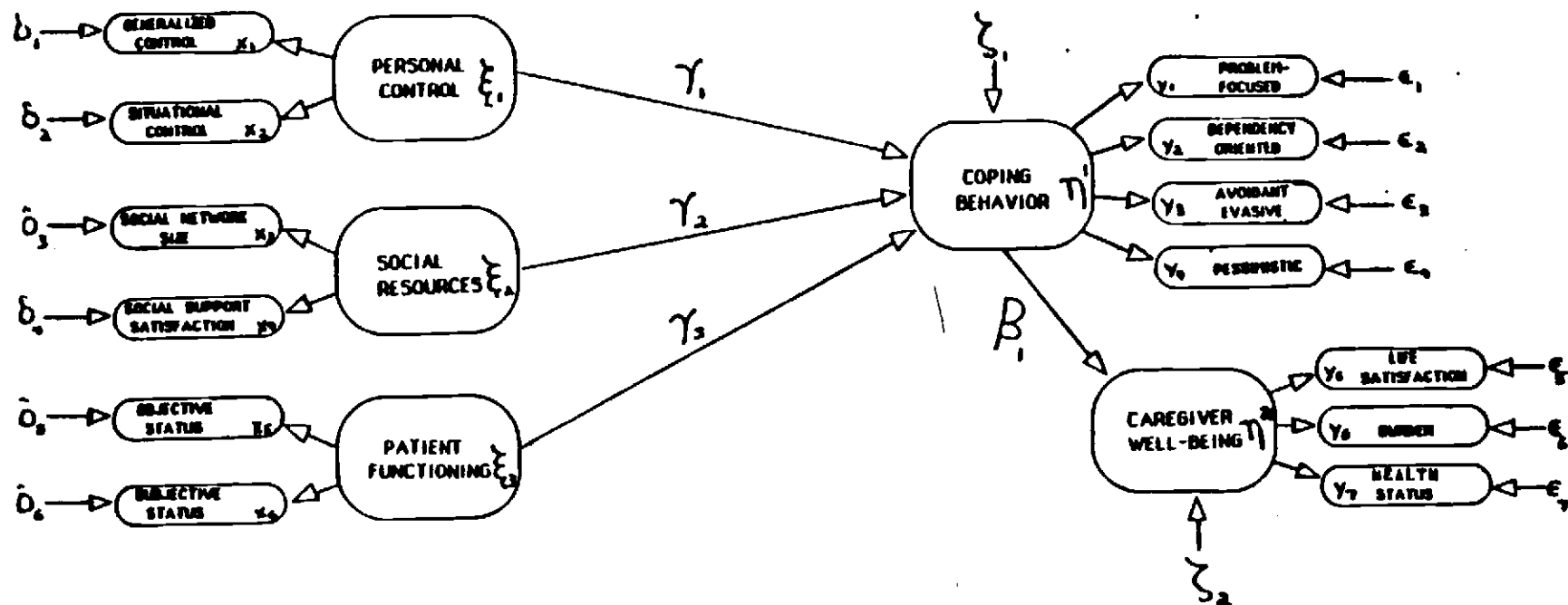


FIGURE 7 Lisrel Model for Predicting Coping Behavior and Caregiver Well-Being

were not expected to load on latent endogenous variables. Because LISREL employs confirmatory factor analysis it is assumed that the measured variables will only load on the latent variables that the researcher specifies "a priori". In contrast, an exploratory factor analysis would allow all measured variables to produce a factor loading on all of the latent variables, and therefore, the hypothetical model would be exactly identified.

The output from the LISREL V computer program produces several indices of evaluation, which assessed collectively, allow an assessment of the theoretical model. Selected indices include: the chi-square test of overall fit, the goodness of fit index, the adjusted goodness of fit index, the root mean square residual for the model, and a Q-plot of normalized residuals.

The chi-square provides a test of the proposed model against the general alternative that the measured variables are simply correlated to an arbitrary extent (Bentler, 1980). However, the chi-square statistic is sensitive to large sample sizes. As a consequence, in large samples almost any model with positive degrees of freedom would be likely to be rejected as providing a statistically unacceptable fit (Long, 1983). Furthermore, the chi-square test is a valid test statistic only if all of the observed variables have a multi-variate normal distribution and the analysis is based on the sample covariance matrix (Joreskog and Sorbom, 1981). Because these two assumptions are rarely fulfilled in

practice, Joreskog and Sorbom (1981) suggest that the chi-square test statistic be used as a goodness (or badness) of fit measure with the degrees of freedom serving as a standard by which to judge whether the chi-square statistic is large or small. Therefore, large chi-square values relative to the number of degrees of freedom indicate poor fit while small chi-square values indicate a better fit.

The goodness of fit index is a coefficient that indicates the amount of variability in an input matrix that can be explained by the model. The adjusted goodness of fit index is the same coefficient after having been adjusted for the degrees of freedom in a model. The larger the coefficient (Range = 0 to 1) the better the fit of the model.

The root mean square residual is the measure of the average of the residual variances and covariances. When the input is a correlation matrix, the residual can be interpreted in terms of percentage of variance/covariance not explained by the model.

The Q-plot of the normalized residuals provides a visual evaluation of the fit of the model. The residuals are plotted on a plane bisected by a plotted slope equal to 1. When the slope of the plotted residuals is greater than 1, the fit is good. However, when the slope of the plotted residuals approaches or drops below 1, the fit of the model is poorer.

Collectively, the indices for assessing theoretical model suggested that the fit of the proposed model to the input data was poor and that the model could be substantially modified (Table 15) The proposed model produced a chi-square value of 907.7 with 91 degrees of freedom. A comparison of the chi-square to the degrees of freedom revealed a ratio of about 10 to 1. This ratio was interpreted as representing a poor fit.

The goodness of fit index was reported at .746. This indicates that about 75% of the variability in the input correlation matrix is accounted for by the proposed model. The adjusted goodness of fit index was .665. As a point of comparison, a goodness of fit index of about .90 and higher would have indicated a relatively good fit between the data and the model. The root mean square residual was .162 which indicated a large average residual variance. An inspection of the Q-plot (see Figure 8) revealed that the slope of the plot was less than one, further supporting the overall assessment that the model is a poor fit of the data.

The results of the LISREL analysis for the measurement model and the structural relations model are presented in Figure 9. The output from the LISREL analysis revealed that several parameters in the theoretical model were statistically significant. For example, in Figure 9, Powerful Others and Chance (measured variables) produced significant loadings on

TABLE 15

## Goodness of Fit Indices

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Chi-square	907.7
degrees of freedom	91
Goodness of Fit Index	.746
Root Mean Square Residual	.162
Slope of Q-plot	< 1

LISREL TEST

Q-Plot of Normalized Residuals

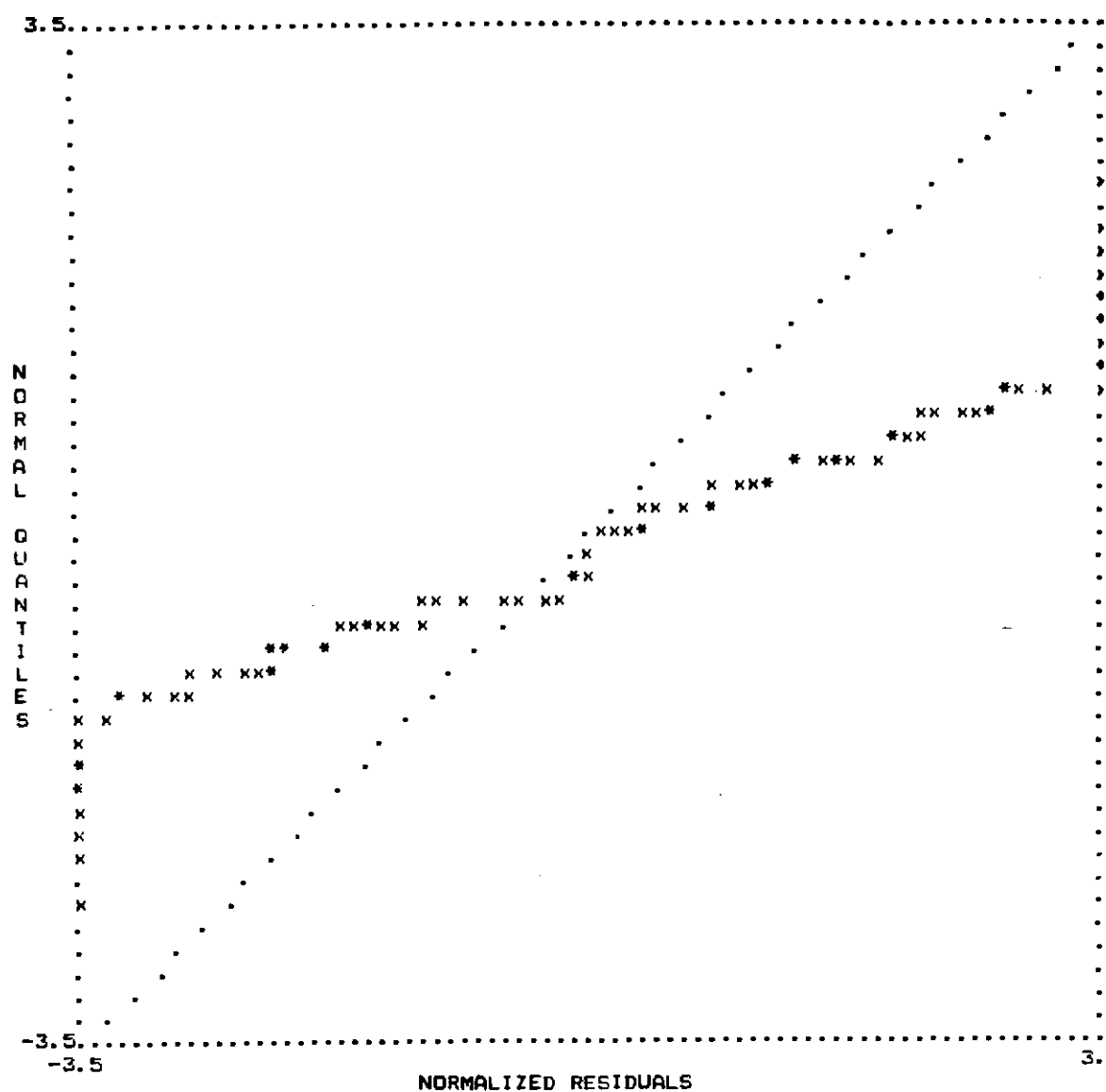


FIGURE 8

Q-Plot of Normalized Residuals

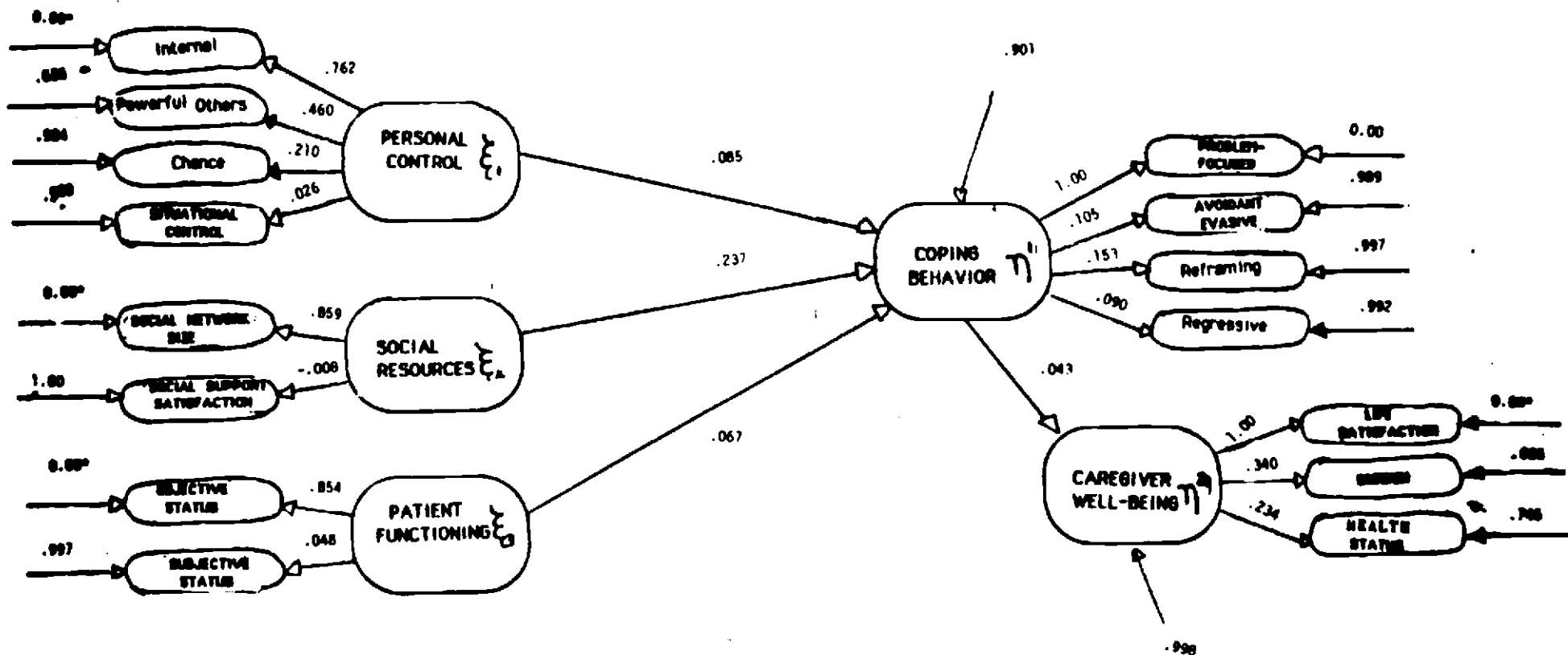


FIGURE 9 Lisrel Analysis for Theoretical Model Predicting Coping Behavior and Caregiver Well-Being



the hypothesized factor of personal resources. Also, in the structural relations model, the gamma matrix (relating exogenous variables to endogenous variables) indicated a statistically significant effect of social resources on coping behavior ( $\text{Gamma} = .237$ ,  $t = 5.1$ ). However, when examining the factor loadings and structural coefficients compared to the residual terms for each parameter it was evident that the entire model needed to be modified before attempting any further analysis of the results for estimating coping behavior and caregiver well-being from the proposed model.

LISREL V produced modification indices which provided information on how the model should be modified to fit the data better. For each parameter which was fixed (assigned given values) in the model there was a modification index equal to the expected decrease in the chi-square value if this single parameter alone would be free (not constrained to be equal to any other parameter). However, Joreskog and Sorbom (1981) have warned that the model cannot be modified strictly on a statistical basis; rather, there should be a substantive theory that can be used to decide how the model should be changed. In other words, parameters should not be freed without a theoretical justification. Although the modification index provided information for identifying parameters to be freed for the model in this study, the theoretical rationale for doing so could not be supported without drastically changing the structural foundation of the hypothetical model. Therefore, instead of going on "significance searches"

(Hennessy, 1985) by overanalyzing the data set hoping to chance upon a significant "good-fitting model", a more theoretically based approach was attempted.

The first step taken in reconstructing the theoretical model was to assess the measurement model of the LISREL analysis. The measurement model specified the relationships between the measured variables and the latent variables. Based on an examination of the LISREL output, it was determined that several measured variables did not produce significant loadings on the hypothetical factors as proposed "a priori" in the theoretical model. As a result, an exploratory factor analysis was performed with all of the indicators in the model analyzed in order to identify potential constructs that were different than originally proposed.

The number of solutions was restricted to five which corresponded to the original number of latent variables proposed in the model. A Varimax-rotated factor matrix indicated that two of the three proposed latent exogenous variables (Patient Functioning and Social Resources) were reproduced with strong to moderate factor loadings in each factor (Table 16). However, in the Personal Resource factor "internal control beliefs" did not load with the other "control" variables, but instead loaded with several coping behaviors (problem-oriented and reframing) and one of the variables originally proposed to indicate caregiver well-being (Life satisfaction) (Table 16). Furthermore, caregiver burden, also originally proposed to indicate caregiver well-being had

TABLE 16

Factor Loadings for Measured Variables used in LISREL Analysis  
After Varimax Rotation, 5-Factor Solution, Total Population (n = 436)

Names for Variables	Factor 1: Perceived Control	Factor 2: Maladaptation	Factor 3: Patient Functioning	Factor 4: Bondadaptation	Factor 5: Social Resources
Chance	.80	.10	.08	-.09	-.08
Powerful Others	.70	.09	-.00	-.00	-.12
Situational Control	.41	.01	.09	-.00	.03
Avoidant/Evasive	.29	.70	.25	-.07	-.11
Regressive	.00	.68	.00	-.04	-.09
Caregiver Burden	.04	.48	.22	.06	-.39
Objective Status	.06	.06	.61	.06	-.12
Subjective Status	-.06	-.07	-.59	.01	.06
Reframing	.16	.18	.05	.49	.05
Problem-Oriented	-.01	-.02	.10	.49	.04
Life Satisfaction	-.35	-.31	-.19	.49	.15
Internal control	-.08	-.08	-.08	.33	.02
SupportSatisfaction	-.00	-.22	.08	.05	.53
Network Size	-.05	.00	-.09	.08	.31
% of variance	47.9	18.2	15.5	12.6	5.8
Eigenvalues	2.7	1.0	.87	.71	.32

loaded with two of the coping behaviors (avoidant/evasive and regressive coping) (Table 16).

The next step was to conceptualize these factors within the theoretical orientation of this study. It was first recognized that the three latent exogenous variables (e.g., Personal Control, Patient Functioning, and Social Resources) had maintained a relative degree of construct stability. With the exception of the measured variable, internal control beliefs, all of the measured variables had loaded where the model had originally hypothesized.

However, the two latent endogenous variables, originally conceptualized as Coping Behavior and Caregiver-Well Being, were dramatically modified. Based on past theoretical and empirical studies, it was originally proposed that coping and outcome measures served as distinct constructs. However, in this sample the measures of coping behaviors and measures of caregiver well-being had loaded together. Conceptually, the newly constructed latent endogenous variables were described as caregiver Bonadaptation and Maladaptation. Caregiver Bonadaptation and Maladaptation corresponds to McCubbins and Patterson's (1983) theoretical outcome constructs in the ABCX Model of Family Stress (Hill, 1949).

Conceptually, Personal Control was changed to Perceived Control; this modification reflected the change of loading patterns for the measured variable, internal control, from the construct of Personal Control. Because it appeared that the latent exogenous variables had remained relatively stable

based on the exploratory factor analysis, multiple regression analyses were performed utilizing the newly constructed latent endogenous variables as dependent variables.

Multiple regression analyses were utilized because the new latent variables (Maladaptation and Bonadaptation) were treated as two separate endogenous variables (or separate dependent variables), without any causal modeling implied. Therefore, instead of testing for more complex structural relationships between several endogenous variables (via LISREL V) only one dependent variable (Maladaptation or Bonadaptation) was analyzed at a given time, using a forced regression technique for all regression analyses. The forced regression entered all the variables into the regression equation in a single step. In this approach, the proportion of variance accounted for by all the independent variables was identified by the  $R^2$  value. In each table, both standardized and unstandardized coefficients were presented.

Table 17 presents the results from the regression analysis of Bonadaptation on Perceived Control, Patient Functioning, and Social Resources. Two of the three exogenous variables, Perceived Control and Social Resources, were found to be significant predictors of Bonadaptation. An examination of the unstandardized coefficients indicated an inverse relationship between Perceived Control and Bonadaptation and a positive relationship between Social Resources and Bonadaptation. However, the  $R^2$  indicated that only about 4% of the variance in Bonadaptation could be explained by the three latent

TABLE 17

Regression of Bonadaption on Perceived Control,  
Patient Functioning, Social Resources

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Perceived Control	-.3613 *	-.1781	.0962	3.75	1
Patient Functioning	.0343	.0290	.0543	.632	3
Social Resources	.1363 *	.0945	.0681	2.00	2

R<sup>2</sup> .043  
 Standard Error  
 of the Estimate 12.72  
 Standard Deviation 12.96  
 of Bonadaption  
 df 432

\* p < .05

exogenous variables.

Table 18 presents the results from the regression analysis of Maladaptation on Perceived Control, Patient Functioning, and Social Resources. All of the exogenous variables were found to be significant predictors of Maladaptation. An examination of the unstandardized coefficients indicated that both Perceived control and Patient Functioning had positive relationships with Maladaptation, while Social Resources had a positive relationship with Maladaptation. The  $R^2$  indicated that about 12% of the variance in Maladaptation could be explained by the three latent exogenous variables.

The final step in the analysis was to perform separate multiple regression analyses utilizing caregiver burden, life satisfaction, problem-oriented, reframing, regressive and avoidant/evasive coping strategies as criterion variables. The predictor variables included internal, powerful others and chance control beliefs, situational control, the objective and subjective evaluations of the dementia patient, social network size, and support satisfaction.

The first set of regression analyses utilized the four coping behaviors (problem-oriented, avoidant/evasive, regressive and refaming) as criterion variables. Table 19 presents the results of the regression of problem-oriented coping on the predictor variables. Two variables were significant at the .05 level. Internal control belief was a positive predictor of problem-oriented coping efforts, while chance control belief was a negative predictor of

TABLE 18

Regression of Maladaption on Perceived Control,  
Patient Functioning, Social Resources

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Perceived Control	.6043 *	.1939	.1419	4.25	1
Patient Functioning	.3513 *	.1937	.0802	4.37	3
Social Resources	-.3712 *	.0945	.0681	2.00	2
R <sup>2</sup>	.118				
Standard Error of the Estimate	18.76				
Standard Deviation of Maladaption	19.92				
df	432				
* p < .05					



TABLE 19

Regression of Problem-Oriented Coping on Internal, Powerful Others,  
and Chance Control Beliefs, Social Support, Social Network Size, and  
Objective and Subjective Evaluation of the Dementia Patient

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Internal Control	.3553 *	.1354	.1255	2.83	1
Powerful Others	.0814	.0408	.1195	.861	6
Chance	-.2333 *	-.1216	.1186	1.96	3
Situational Control	.3110	.0503	.3119	.996	2
Objective Evaluation	.0522	.0908	.0298	1.75	7
Subjective Evaluation	-.0945	-.0212	.2289	.412	5
Social Support	.2274	.0796	.1372	1.65	4
Network Size	-.0281	-.0346	.0390	.720	8
R <sup>2</sup>	.045				
Standard Error of the Estimate	6.68				
Standard Deviation of Problem-Oriented	6.77				
df	427				

\* p &lt; .05

problem-oriented coping behaviors. About 0.4% of the total variance in problem-oriented coping behaviors was accounted for by the predictor variables.

Table 20 presents the results of the regression of avoidant/evasive coping on the predictor variables. Five predictor variables were significant at the .05 level. Chance, powerful others control beliefs, and level of functional impairments in the dementia patient were positive predictors of avoidant/evasive coping strategies. Social support satisfaction and the subjective evaluation of the dementia patient were negative predictors of avoidant/evasive coping efforts. About 22% of the variance in avoidant/evasive coping efforts was accounted for by the predictor variables.

Table 21 presents the results of the regression of reframing coping strategies on the predictor variables. One variable was significant at the .05 level. Internal control belief was a positive predictor of reframing coping behaviors. About 0.4% of the total variance in reframing coping was accounted for by the predictor variables.

Table 22 presents the results of the regression of regressive coping behaviors on the predictor variables. One variable was significant at the .05 level. Social support satisfaction was a negative predictor of regressive coping strategies. About 0.6% of the total variance in regressive coping efforts was accounted for by the predictor variables.

The second set of regression analyses utilized the two major outcome measures, caregiver burden and life

TABLE 20

Regression of Avoidant/Evasive Coping on Internal, Powerful Others,  
and Chance Control Beliefs, Social Support, Social Network Size, and  
Objective and Subjective Evaluation of the Dementia Patient

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Internal Control	-.1170	-.0507	.0998	1.17	6
Powerful Others	.1961 *	.1119	.0950	2.06	5
Chance	.4299 *	.2547	.0943	4.55	3
Situational Control	-.1095	-.0201	.2481	.433	7
Objective Evaluation	.7071 *	.1398	.0237	3.42	1
Subjective Evaluation	-.4806 *	.1233	.1820	2.63	2
Social Support	-.3742 *	-.1492	.1091	3.42	4
Network Size	-.0128	-.0180	.0310	.414	8
R <sup>2</sup>	.217				
Standard Error of the Estimate	5.31				
Standard Deviation of Avoidant/Evasive	5.95				
df	427				
* p < .05					

TABLE 21

Regression of Reframing Coping on Internal, Powerful Others, and  
Chance Control Beliefs, Social Support, Social Network Size, and  
Objective and Subjective Evaluation of the Dementia Patient

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Internal Control	.2432 *	.1298	.0897	2.71	1
Powerful Others	.0740	.0519	.0854	.866	3
Chance	.0585	.0427	.0847	.689	4
Situational Control	.4220	.0956	.2229	1.89	2
Objective Evaluation	.0162	.0395	.0213	.760	7
Subjective Evaluation	-.1265	-.0399	.1636	.773	6
Social Support	-.0183	-.0089	.0980	.187	8
Network Size	-.0236	-.0407	.0279	.845	5
R <sup>2</sup>	.042				
Standard Error of the Estimate	4.77				
Standard Deviation of Reframing	4.8				
df	427				

\*  $p < .05$

TABLE 22

Regression of Regressive Coping on Internal, Powerful Others, and  
Chance Control Beliefs, Social Support, Social Network Size, and  
Objective and Subjective Evaluation of the Dementia Patient

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Internal Control	-.0977	-.0682	.0678	1.44	2
Powerful Others	.0408	.0374	.0646	.632	6
Chance	.0613	.0585	.0641	.956	3
Situational Control	-.1343	-.0398	.1686	.796	5
Objective Evaluation	.0055	.0177	.0161	.344	8
Subjective Evaluation	-.1387	-.0572	.1237	1.21	4
Social Support	-.3256 *	-.2087	.0741	4.39	1
Network Size	.0151	.0341	.0211	.716	7
R <sup>2</sup>	.065				
Standard Error of the Estimate	3.61				
Standard Deviation of Regressive	3.70				
df	427				
* p < .05					

satisfaction, as criterion variables. Table 23 presents the results of the regression of burden on the predictor variables. Three predictor variables were significant at the .05 level. Powerful others control beliefs and the level of functional impairment in the dementia patient were positive predictors of caregiver burden. About 18% of the variance in caregiver burden was accounted for by the predictor variables.

Table 24 presents the results of the regression of life satisfaction on the predictor variables. Six predictor variables were significant at the .05 level. Internal control beliefs, social support satisfaction, and the subjective evaluation of the dementia patient were positive predictors of life satisfaction. Powerful others, chance, and situational control beliefs were negative predictors of life satisfaction. About 27% of the variance in life satisfaction was accounted for by the predictor variables.

The final set of regression analyses again utilized caregiver burden and life satisfaction as criterion variables, but used the four coping behaviors as predictor variables. Table 25 presents the results of the regression of caregiver burden on the four predictor variable. Two variables were significant at the .05 level. Both regressive and avoidant/evasive coping behaviors were positive predictors of caregiver burden. About 24% of the variance in burden was accounted for by the four predictor variables.

Table 26 presents the results of the regression of life satisfaction on the four predictor variables. Three variables

TABLE 23

Regression of Burden on Internal, Powerful Others, and Chance  
Control Beliefs, Social Support, Social Network Size, and  
Objective and Subjective Evaluation of the Dementia Patient

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Internal Control	.0450	.0078	.2557	.176	7
Powerful Others	.5621 *	.1282	.2435	2.30	3
Chance	-.1041	-.0247	.6355	.431	6
Situational Control	-.0024	-.0001	.0608	.000	8
Objective Evaluation	.2670 *	.2112	.2795	4.38	2
Subjective Evaluation	-.5101	-.0523	.4664	1.09	5
Social Support	-1.973 *	-.3146	.2795	7.05	1
Network Size	-.0945	-.0523	.0795	1.18	4
R <sup>2</sup>	.178				
Standard Error of the Estimate	13.61				
Standard Deviation of Burden	14.8				
df	427				
* p < .05					

TABLE 24

Regression of Life Satisfaction on Internal, Powerful Others,  
and Chance Control Beliefs, Social Support, Social Network Size,  
and Objective and Subjective Evaluation of the Dementia Patient

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Internal Control	.5077 *	.2244	.0947	5.35	2
Powerful Others	-.1823 *	-.1059	.0902	2.01	6
Chance	-.3937 *	-.2380	.0895	4.39	1
Situational Control	-.5703 *	-.1070	.2355	2.42	5
Objective Evaluation	.0033	.0067	.0225	.148	8
Subjective Evaluation	.4720 *	.1233	.1728	2.73	4
Social Support	.3200 *	.1300	.1036	3.08	3
Network Size	.0428	.0612	.0294	1.45	7
<hr/>					
R <sup>2</sup>	.267				
Standard Error of the Estimate	5.04				
Standard Deviation of Life Satisfaction	5.8				
df	427				
* p < .05					



TABLE 25

## Regression of Burden on Coping Behaviors

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Regressive	.7139 *	.1775	.1933	3.69	2
Problem-Oriented	.1395	.0635	.0962	1.44	3
Avoidant/ Evasive	.9668 *	.3866	.1213	7.96	1
Reframing	-.0184	-.0059	.1363	.134	4
<hr/>					
R <sup>2</sup>	.248				
Standard Error of the Estimate	12.96				
Standard Deviation Burden	14.88				
df	431				
* p < .05					

TABLE 26

## Regression of Life Satisfaction on Coping Behaviors

Predictor Variables	Unstandardized Coefficient	Standardized Coefficient	Standard Error of B	t statistic	Beta rank
Regressive	-.1122	-.0711	.0756	1.48	4
Problem-Oriented	.1218 *	.1413	.0376	3.23	3
Avoidant/Evasive	-.4135 *	-.4213	.0475	8.70	1
Reframing	.1758 *	.1456	.0533	3.29	2
R <sup>2</sup>	.251				
Standard Error of the Estimate	5.07				
Standard Deviation Life Satisfaction	5.84				
df	431				
* p < .05					

were significant at the .05 level. Both problem-oriented and reframing coping strategies were positive predictors of life satisfaction; however, avoidant/evasive coping was a negative predictor of life satisfaction. About 25% of the variance in life satisfaction was accounted for by the four predictor variables.

## DISCUSSION

### Discussion of Results for the Measured Variables

The purpose of this section of the study was to briefly discuss the preliminary findings for each of the measured variables in the theoretical model (see Appendix B). The information obtained from the preliminary analyses would set the stage for analyzing the entire theoretical model via the LISREL computer analysis.

#### Personal Control

#### Internal Control, Powerful Others, Chance and Situational Control

The range of possible scores for the Internal Control Scale (Levenson et al., 1980) was 8 to 24. The sample mean of 20.9 (SD = 2.6) indicated that overall, this sample of caregivers had strongly believed that they were in control over the events in their lives. Despite the relentless nature of Alzheimer's disease and its impact on the caregiver, most of the caregivers felt they had a high amount of control in their personal lives (77% scored 20 or higher on the Internal Control Scale). The mean scores for the two types of external control orientations indicated a low to moderate belief that

either powerful others or chance were controlling factors in the caregiver's life.

Levenson (1981) reported that scores on the Internal scale have been consistently higher than those on the Powerful Others or Chance scales. Levenson (1981) proposed that for most Western societies belief in personal control is a cultural perception and that a certain degree of personal means-end connection is basic to survival and coping in this world. Therefore, despite the seemingly objective hardships that caregivers endure, this study indicated that caregivers still maintained a sense of personal control in the face of a situation that at times appears "hopeless".

Although male caregivers reported a significantly stronger internal control orientation than female caregivers, this did not appear to benefit male caregivers over female caregivers in terms of the two major outcome measures in this study: caregiver burden and life satisfaction. For both males and females, both external control orientations (powerful others and chance) were negatively associated with life satisfaction. These findings are consistent with past research findings that persons with internal control beliefs handled stress more effectively than those with external control beliefs and thus enhanced psycho-physiological well-being (Kobasa et al., 1982; Kruase & Stryker, 1984; Sandler & Lakey, 1982).

The findings revealed that caregivers with impaired family members in a nursing home had higher chance scores than those with impaired family members residing in the community. This

finding suggests that when a dementia patient resided in an institutionalized setting, family caregivers are more apt to believe that events are controlled by unordered and unpredictable forces. This belief is better understood when placed within the context of the caregivers decision to institutionalize a spouse or family member with a dementing illness. Tobin and Kulys (1981) have reported that family members suffer great guilt when institutional care becomes necessary. Perhaps the belief that events (including institutionalization) were uncontrollable and unpredictable was a way for caregivers to adapt to the difficult decision of institutionalization of their spouse or relative.

Both powerful others and chance control beliefs were associated with a greater utilization of avoidant/evasive coping behaviors. Caregivers with stronger external control beliefs may engage in coping behaviors which focus on resigning to the situation because either the situation looked hopeless or because it was fate. Persons with external control orientations are reinforced by events that are determined by forces beyond one's control (e.g., fate, chance or powerful others) (Levenson 1981). This suggests that when caregivers believe that life events are controlled by forces outside their control (either by powerful others or random chaotic situations) they chose coping strategies that reflect a resignation of individual effort in order to solve the problem. This resignation is exemplified by the coping strategy of "letting the problem take care of itself".

Based on previous research, it was expected that caregivers with internal control orientations would derive more qualitative benefits from their social network. For example, Lefcourt et al., (1984) and Sandler and Lakey (1982) found that persons with an internal locus of control derive greater benefits (qualitatively) from social support resources. Although those with external control beliefs received a greater quantity of support, they received less of the potential benefits from the support network. Yet, in this present study the correlations between internal control beliefs and social support variables were substantially weak and non-significant. This indicated that beliefs in internal control did not facilitate greater benefits in social support for caregivers in this study. In contrast, it was revealed that those caregivers with a stronger chance control orientation had a more difficult time contacting members in their social network.

Most caregivers expressed concern over the loss of control in their lives due to their role responsibilities. Yet, this perception was not associated with a diminished feeling of satisfaction derived from performing their role as caregiver. Neither had loss of control in the caregiver's life led to the perception that caregiving was, relatively speaking, a particular stressful situation in their lives.

Overall, when caregivers reported that they felt in control (Internal control beliefs) over general life events, this feeling did not seem to substantially influence any other

measurable variables in this study. In contrast, when caregivers reported a lack of control over events in their lives (due to Powerful Others and/or Chance), several important indicators of "maladaptation" (McCubbin & Patterson, 1983) were evident in coping behaviors, social support, and life satisfaction. These findings seem to support Levenson's (1981) contention that internal beliefs are "culturally expected" beliefs in our society, yet internal control beliefs were benign in relation to other variables in this study. External control beliefs for caregivers in this study were much more substantially related to the coping and adaptational outcome.

## Patient Functioning

### Objective and Subjective Evaluation of the Patient

A significant difference in levels of impairment was found for dementia patients residing in the community compared to those residing in nursing home facilities. Patients with severe functional limitations were more often institutionalized than those with mild to moderate impairments. However, it should be noted that the nursing home alternative is typically a "last resort" decision and only after the besieged caregiver has exhausted all other possible resources to keep the family member in the community (Brody, 1985; Tobin & Kulys, 1981).



It was anticipated that as the dementia patient's level of functioning increasingly deteriorated there would be a greater need to be associated with a support group for emotional support and for more information on the prognosis of Alzheimer's disease (and/or related disorders). It was found that the level of impairment in the dementia patient did not significantly differ according to whether or not the caregiver was in a support group or not. This suggested that the support group membership was not associated with the level of functional impairment in the dementia patient.

A significant negative correlation was found between the level of impairment in the dementia patient and the self-reported physical health status of the caregiver. Specifically, increased levels of patient impairment were associated with a poorer self-rated health status for the caregiver. Furthermore, a positive correlation existed between level of patient impairment and degree of physical health status change for the caregiver. Collectively, these findings suggest how caregiving for a dementia patient, especially with the Alzheimer's disease patient, can greatly influence the physical health status of the careprovider.

The inclusion of the subjective dimension in the evaluation of the dementia patient was used to balance the more objective Functional Dementia scale (Moore et al., 1981). The caregiver's own personal evaluation of the dementia patient helped to contribute to more contextual accuracy, the patients current physical and mental health status. In other words, it

was feasible that a high score on the Functional Dementia Scale would have objectively indicated severe impairments, yet it is possible that the same objectively severe impairments for one caregiver may not be perceived as so severe for another caregiver. The opposite could also be true, that is, it was possible that a mild level of impairment could be appraised by one caregiver as severe and by another caregiver as moderate or mild. It was found that the subjective appraisal of the dementia patient by the caregiver appeared to contradict to the more objective evaluation of the patient by the Functional Dementia Scale (Moore et al., 1981). For example, the majority of patients were categorized as moderate to severely impaired based on the mean score on the objective Functional Dementia Scale. However, most caregivers subjectively rated the patient's physical health status as good to excellent; although most caregivers rated the dementia patient's emotional status as either fair or poor. Thus, objectively, the average dementia patient being cared for in this study suffered from moderate to severe levels of functional impairment. Nevertheless, most of the caregivers evaluated the dementia patient with at higher levels of physical and emotional health status than the more objective scale seemed to indicate. This discrepancy was further supported by the negative correlation between the subjective and objective items for evaluating the dementia patient. In conclusion, these findings supported the theoretical need for two indicators (subjective and objective) in order to accurately

assess the level of impairment in the dementia patient.

## Social Resources

### Social Network Size and Social Support

Although the associations (Pearson correlations) between social network size and other variables were substantially weak in strength, this information still offered interesting results. For example, the positive correlations between social network size, caregiver life satisfaction and self-reported physical health status suggested that a larger support network facilitated a better psycho-physiological well-being. Two caveats are in order for this interpretation. First, larger size of network alone does not equal more or better "support", it is important to consider what the network does to influence well-being. Secondly, a caregiver could potentially be enmeshed in a social network with 100 people, yet personality characteristics (e.g., external control orientations) of the caregiver which are not conducive to receiving the benefits of the network could effectively negate any support tendered, regardless of network size. With these conditions in mind, the results indicated that a larger network was beneficial to caregivers.

Correlations among the items in the qualitative dimension of social resources revealed stronger associations. For example, when caregivers reported higher levels of satisfaction with

their social network, there were lower levels of reported burden for caregivers. In contrast, with higher levels of satisfaction from the support network, caregivers reported higher levels of life satisfaction. Collectively, these findings supported the "buffering hypothesis" (Wilcox, 1981) of social support. That is, it appeared that social resources protect the person from the deleterious effects of stressful life events and enhance individual well-being, a finding also reported in other investigations (Dean & Lin, 1977; Gottlieb, 1983).

## Coping Behavior

### Multi-dimensional Coping Strategies

The construct of coping is undergoing a dynamic transformation in measurement and conceptualization. To label past and current coping theoretical orientations as diverse and extensive would be an understatement. Based on the analysis of the coping scale used in this study, it was evident that the construct of coping is still in need of conceptual refinement and empirical investigation. However, the current study did indicate that distinct coping strategies can be measured and that these coping behaviors were related in a logical way to the outcome measures of caregiver burden and life satisfaction.

A factor analysis of the Jaloweic Coping Scale (Jaloweic et

al., 1984) with this sample of caregivers revealed that a four-factor solution was the best conceptual pattern explaining coping mechanisms for this sample. Collectively, the items in the first factor indicated a coping pattern best described as problem-solving or problem-oriented where the caregiver copes by confronting the problem directly. The items that loaded on this factor were very similar to those in Jalowiec et al., (1984). This indicated relative stability in those items representing the problem-focused domain of coping.

However, it was obvious that the other three factors in this study, were describing different coping mechanisms than those described by Jaloweic et al., (1984). Some items that loaded on Factors 2 (Avoidant/Evasive Coping), 3 (Reframing Coping), and 4 (Regressive Coping) were similar to those in the original scale, but some items had loaded differently. One explanation for this occurrence is that the "problem-oriented domain" (Factor 1) had emerged as a more stable factor for both studies. As Jaloweic et al., (1984) suggested, the "affective domain", which is reflected in Factors 2, 3, and 4, would be a much more complex coping pattern to conceptually deliniate.

This conceptual complexity initially lead Jaloweic et al., (1984) to criticize the dichotomous differentiation of coping (Lazurus & Folkman, 1980) as inadequate enough to explain the affective domain of coping. Jaloweic et al., (1984) instead proposed that the items which did not load onto the two-factor

solution (representing the problem versus affective coping dichotomy) may represent other conceptual patterns of coping. It was possible that the predominant mixing of items in Factors 2, 3, and 4 (labeled as avoidant/evasive, reframing, and regressive coping, respectively) and to a lesser degree in Factor 1 (problem-oriented), reflected the theoretical and empirical soundness of the problem-oriented coping pattern across a variety of situations. But it also reflects the more malleable coping pattern of the affective domain which may deviate according to the contextual characteristics of the person-environment dialectic.

With this interpretation in mind, several findings regarding the relationships of coping mechanisms deserve attention. First, caregivers were more likely to utilize avoidant/evasive and regressive coping efforts when their impaired family member or spouse resided in a nursing home facility. This finding tied in nicely with the previous discussion on the prevalence of external control beliefs when the dementia patient was institutionalized. Because both avoidant/evasive and regressive coping behaviors were positively correlated with external control orientations (Powerful Others and Chance), a reasonable explanation for the occurrence of the positive associations was the possible influence of external control beliefs on specific coping behaviors, specifically, avoidant/evasive and regressive behaviors. Furthermore, avoidant/evasive coping behaviors were positively associated with higher levels of caregiver burden

and negatively associated with higher levels of life satisfaction. Collectively, these findings emphasized how external control beliefs influenced avoidant/evasive coping efforts and that these coping efforts were associated with negative outcomes for the caregiver when faced with institutionalizing their family member with dementia.

The relative lack of substantial associations between problem-oriented coping behaviors and other pertinent variables in the theoretical model was suprising. Problem-oriented coping was positively associated with life satisfaction suggesting that problem-oriented coping may be adaptive for caregiving well-being. However, the adaptive consequences of problem-oriented coping should not be looked upon as the "answer" to caregiver well-being. It is also possible that in some situations direct control or problem-directed coping may not be appropriate. For example, in a situation where the control of the event is beyond the caregiver, reframing or a more "passive" form of coping (avoidant/evasive) may be more appropriate. In the context of situations without control, problem-oriented behaviors may actually lead to more overall stress and burden (Folkman, 1984).

## Caregiver Well-Being

### Physical Health, Caregiver Burden, and Life Satisfaction

External control orientations were negatively related to the self-reported physical health status of the caregiver. This finding again emphasized the influence of personal resources on an individual's psychological and physiological processes.

The mean score for the burden scale ( $X = 41$ ,  $SD = 15.5$ ) was very similar to the mean score ( $X = 40$ ,  $SD = 17.9$ ) found in another study of caregivers of Alzheimer's patients by Pratt et al., (1985). But the mean score for this sample represented a much higher mean burden score than reported by Zarit et al., (1980) ( $X = 31$ ,  $SD = 13.3$ ) in their study. The higher mean scores for this study and in Pratt et al., (1985) compared to Zarit et al., (1980) could reflect the differences in sampling procedures and characteristics of the caregivers. For example, most of the caregivers that responded to questionnaires in this study and in Pratt et al., (1985) were members of support groups, whereas in Zarit et al., (1980) the sample was primarily based on caregivers in clinical settings.

The finding that caregivers as members of support groups had significantly higher burden scores than caregivers not in support groups seems at first contradictory. After all, the implied objective of support groups was to alleviate burden, not to increase it. One possible explanation was that the functional level of the dementia patient was more impaired for caregivers in support groups. However, no significant differences were found in the functional levels of dementia patients for caregivers in support groups compared to those



and not in support groups. Perhaps caregivers who were most burdened to begin with sought the support that caregiver groups had to offer. Thus, the significantly higher burden scores of those in support groups versus those not in support groups may reflect the tendency for support groups to attract those who are in most need of support. Although the research design of this study can not conclusively validate this interpretation, further investigation in support group-caregiver dynamics warrants continued research.

It was also found that levels of burden were positively associated with avoidant/evasive and regressive coping behaviors. These coping behaviors may seem as counterproductive methods of adapting to the caregiving situation on the basis of associated higher levels of reported burden. However, it is important to emphasize that in cases where the caregiver may not have control over the event (e.g., institutionalization), these coping behaviors may have more short-term advantages for the caregiver, then trying to use problem-oriented coping efforts (Folkman, 1984). What is at stake for the well-being of the caregiver is whether or not the continuation of avoidant/evasive coping efforts are beneficial over a longer period of time compared to the use of other "passive" coping efforts as reframing (e.g., seeing the role of caregiver in a different perspective). These issues may be resolved by conducting longitudinal studies which focus on coping behavior over time.

Although problem-oriented coping behaviors were not

significantly associated with lower levels of burden, problem-oriented coping behaviors were significantly associated with higher levels of life satisfaction. Similarly, stronger internal control orientations were also associated with greater levels of life satisfaction. Thus, caregivers had a greater sense of life satisfaction when they believed that they had control over events in their lives and coped by utilizing problem-directed coping efforts. However, as previously indicated, a combination of internal control orientations and problem-oriented coping behaviors was not substantially associated with lower levels of caregiver burden. Therefore, it would appear that burden and life satisfaction, while associated, are in fact different dimensions of well-being and should be distinguished as such in future studies.

### Summary of Preliminary Results

This sample was restricted to only those caregivers who were related to a dementia patient either by direct kinship (consanguine) or related through marriage (affinal kin). The original number of respondents consisted of 502 individual caregivers, but preliminary analyses had revealed that 44 caregivers had responded in retrospect because the dementia patient was deceased.

The average caregiver in this sample was 61 years of age,

female, White/Caucasian, and Protestant; and most caregivers were married and were high school graduates. The most frequent caregiver in this study was the spouse of the dementia patient, with the adult daughter as the second most frequent caregiver.

The average age of the dementia patient was 74 years, slightly more than half of the dementia patients were female. The great majority of the dementia patients (about 75%) were diagnosed as having Alzheimer's disease, although other forms of dementia (Multi-infarct, Parkinson's disease) were also reported. Most of the dementia patients resided in a community setting (in same household with caregiver or in separate household) rather than in a nursing home facility. The dementia patient, on average, was moderately to severely impaired with cognitive and behavioral deficits. Most caregivers rated the dementia patient's emotional health as either poor or fair, while most caregivers rated the dementia patient's physical health as fair or good.

Most caregivers reported a strong belief in internal control orientations. Internal control beliefs were associated with a greater sense of life satisfaction, but had little substantive association with lower levels of reported caregiver burden. In contrast, the external control orientations had a negative association with life satisfaction and were strongly associated with the utilization of avoidant/evasive coping behaviors.

Although most caregivers reported a strong sense of

internal control for life in general, they also reported that there was little control in their lives because of the specific role of caregiving. Furthermore, despite the lack of situational control, there was little direct expression of role dissatisfaction among the caregivers and the caregiving role was not perceived as the most stressful event, that had occurred in their lives.

Most caregivers reported that they had at least several people in their social network and most caregivers found it easy to contact these people. Most caregivers reported their social network to be helpful and were satisfied with the support they were receiving from their networks.

Qualitatively, social resources had a positive influence on life satisfaction and seemed to buffer against the sense of burden in caregivers.

Four different coping patterns were proposed in this study: problem-oriented, avoidant/evasive, reframing, and regressive coping. Problem-oriented coping behaviors influenced greater feelings of life satisfaction, but had no substantial impact on lower levels of burden. In contrast, avoidant/evasive coping efforts were associated with higher levels of reported burden, and negatively correlated with life satisfaction. Reframing coping efforts were positively associated with the feelings of satisfaction in the caregiving role and with a greater feeling of life satisfaction in general. Regressive coping behaviors were associated with greater difficulty in contacting people in the social network and the perception of

less help offered from this network, and with caregiver dissatisfaction with the support received from the social network. Regressive coping behaviors were also associated with greater feelings of burden and more dissatisfaction with life in general.

Caregiver well-being was assessed by their physical health status, burden levels, and life satisfaction. Most caregivers rated their physical health as either good or excellent during their tenure as caregivers, but also reported that their health status had been negatively changed from good to fair because of the caregiving situation. The mean level of caregiver burden indicated that, overall, this sample was highly burdened with the caregiving situation. The spouses to the dementia patient reported significantly higher burden levels compared to other related family member caregivers (e.g., daughter, son). Higher levels of burden were negatively correlated with general life satisfaction for the caregivers in this sample.

Although families (consanguine and affinal) continue to be a viable support system for elder family members who are impaired or disabled (Brody, 1985), it was found in this study that the caregiving responsibilities are typically the primary responsibility of women caregivers. This finding validates earlier research studies which have found similar familial caregiving patterns (Brody, 1985; Masciocchi et al., 1984).

Social networks and the potential support offered and received by the caregiver influenced the caregiver's sense of

well-being in a positive way. However, caregiver burden was still prevalent as indicated by the mean score for this sample. Thus, while the availability of resources (both in personal control and in social support) may have buffered or diluted the negative consequences of burden, yet the feelings of burden remained.

## Discussion of Results for the LISREL Analysis and Subsequent Statistical Analyses

### The LISREL Analysis of the Theoretical Model

Collectively, the results from the LISREL analysis indicated a poor fit of the data to the proposed model that attempted to explain coping behavior and well-being in caregivers of dementia patients. Although several factors could have accounted for the poor fit, the most identifiable problem was in the specification of the measurement model. As indicated earlier in the study, LISREL has the ability to separate latent variables from errors in measurement. However, this ability is predicated on the accurate choice of the measured variables. Thus, even if the theoretical rationale for developing a model is sound, "care must be taken to provide adequate indicators of each construct" (Bentler, 1980; p. 425). Bentler (1980) further elaborates:

"Since the Latent Variables are in practice abstractions that presumably underlie Measured Variables, a poor choice of Measured Variables will create doubt as to whether a theory's constructs are in fact embedded in the model. Choosing the right number of indicators for each Latent Variable is something of an art: in principle, the more the better; in practice, too many indicators make it difficult if not impossible to fit a model to data" (p. 425)

In relation to the model proposed in this study, it was reasonable to suspect that the method of measurement (whether in the choice of indicators or in the proposed loadings of those indicators) was not sufficient enough to tap into the

unique dimensions of the proposed constructs (latent variables). Although some factor loadings and structural relations were statistically significant in the LISREL analysis, the inspection of the residual terms for each parameter indicated that there was a substantial proportion of the variance in each parameter due to measurement error. The proposed latent variables were not sufficiently "indicated" by the specified measured variables. Furthermore, the specified structural relations among the latent variables were questionable, due the weak coefficients found between the latent exogenous and latent endogenous variables and between the latent endogenous variables. However, if the proposed latent variables were poorly specified, then it would follow that the proposed structural relations were also affected. A subsequent exploratory factor analysis was performed to conceptualize latent variables a posteriori, because several measured variables failed to produce significant loadings on the proposed latent constructs.

The original intention of this study was to conceptualize the construct of coping as a distinct phenomenon which could serve as a mediating construct between predictor variables and outcome measures within the theoretical model. However, based on the exploratory factor analysis it appeared, at least for this sample, that the construct of coping was more a combination of resources, perceptions, behavioral efforts and adaptations than an autonomous construct of cognitive and behavioral mechanisms. In other words, the coping process was



found to be much diverse in complexity than initially proposed. This conclusion is supported by other studies, for example, McCubbin and Patterson (1983) have recognized this complexity by noting that "coping appears to be a multifaceted process" and that the relationship between stressor and adaptational outcome be conceptualized and measured as a complex phenomenon that includes pertinent events, perception, resources, and coping efforts. McCubbin and Patterson (1983) further indicate that the adaptational outcome be conceptualized on a continuum with a positive pole or "bonadaptation" and a negative pole or "maladaptation". The conceptualization of coping and adaptation within this perspective was then adopted to represent the factors that were manifest in the exploratory factor analysis. For example, the measured variables of internal control, problem-focused and reframing coping, and life satisfaction loaded together under one factor which was conceptualized as the adaptational outcome of bonadaptation. These variables represented the more positive end of the adaptational continuum for caregivers. In contrast, caregiver burden, avoidant/evasive and regressive coping loaded under another factor which was conceptualized as the more neagative (in terms of consequences for the caregiver) end of the adaptational continuum. Thus, the results from the exploratory factor analysis supported the conceptualization of coping as an integrative construct where coping, perception, and adaptational outcomes were interconnected. This was conceptually different than what was originally proposed in

the theoretical model.

The two constructs, bonadaption and maladaption, were utilized as latent criterion variables in separate multiple regression analyses based on the previously discussed theoretical rationale. The regression results indicated that perceived control (measured by external control belief indicators) was predictive of less bonadaption, while social resources was predictive of more bonadaption. Patient functioning was not a significant predictor of bonadaption. The results were consistent with previous studies which have shown how those individuals with external control beliefs were more susceptible to negative adaptational outcomes than those with more internal control beliefs (Kobasa et al., 1982; Krause & Stryker, 1984). Other studies have reported that social support can facilitate positive adaptations in stressful events (Dean & Lin, 1977; Gottlieb, 1983; Wilcox, 1981). Although two of the three predictors were statistically significant, the proportion of variance accounted for by the three predictors was disappointingly low. This result could be again indicative of the poor indicators utilized to represent the proposed latent variables.

Utilizing maladaption as a criterion variable, the regression analysis revealed that external control beliefs and increased impairments in the dementia patient were predictive of more maladaption for caregivers, whereas the availability and satisfaction of social support was predictive of less maladaption. Again the results were consistent with past

empirical studies which have found similar directional influences on adaptational outcomes. All of the predictors were significant predictors of maladaptation, yet the low amount of variance accounted for by the three variables still had suggested that the measured variables had not adequately "tapped" into the proposed constructs designed after the initial LISREL analysis of the theoretical model.

Therefore, the next step was to utilize regression analyses to assess the individual measured variables as predictor and criterion variables. This step was taken in accord with the theoretical orientation of this study, which emphasized the effects of person-situation variables on coping behavior and caregiver well-being.

When examining the regression results for the coping behaviors as criterion variables several findings were relevant to the theoretical premise of this study. First, internal control belief was found to be a significant predictor of problem-oriented coping which is again consistent with previous research findings (Parkes, 1984). However, it was also found that person-situational variables had a more integrative impact on the caregiver's utilization of avoidant/evasive coping behaviors than any other coping behavior. For example, when the caregiver believed that chance or powerful others were controlling forces in their lives or when the dementia patient was more functionally impaired, the caregiver was more inclined to use coping behaviors which evaded or avoided solving the problem which confronted them.

In contrast, higher levels of perceived satisfaction with the support network was associated with lower utilization of avoidant/evasive coping efforts.

In other regression analyses, internal control beliefs were found to be significant predictors of problem-oriented and reframing coping strategies, while chance and powerful others control beliefs were predictive of avoidant/evasive coping strategies. These findings support the position that person resource characteristics (such as control beliefs) do influence coping behaviors (Fleishman, 1984; Wheaton, 1983), although the person-situation variables were more predictive of avoidant/evasive coping strategies than of problem-oriented, reframing, and regressive coping strategies.

The prevailing influence of social support as a situational predictor variable was also evident in the regression analyses. For example, the perceived satisfaction and availability of the support from the caregiver's network appeared to buffer against the use of avoidant/evasive and regressive coping behaviors. Finally, the level of functional impairment for the dementia patient was associated with coping behaviors in the caregiver. When the patient was more functionally impaired there was an increased tendency for the caregiver to use avoidant/evasive coping strategies. This implied that caregivers were more likely to use coping behaviors which evaded or avoided the problem (e.g., resignation, withdraw from situation) when the dementia patient was more functionally impaired.

With caregiver burden as the criterion variable, social support was a significant predictor of less burden in caregivers. This finding validates earlier studies which have shown that social support benefits caregivers of dementia patients (Barnes, et al., 1981; Lazurus, et al., 1981; Morycz, 1985; Zarit et al., 1980). In contrast, more functional impairments in the dementia patient and beliefs in powerful others as controlling events were significant predictors of greater levels of burden in caregivers.

With life satisfaction as the criterion variable, internal control orientations were found to be predictive of greater life satisfaction for caregivers. The benefits of social support were again evident with support satisfaction also predicting greater levels of life satisfaction. In contrast, those caregivers who believed that events were controlled by powerful others and/or chance events experienced lower levels of life satisfaction. In summary, external control orientations and increased levels of functional impairments in the dementia patient were contributors to negative adaptational outcomes (as measured by caregiver burden) in caregivers. Internal control orientations and social support satisfaction were contributors to positive adaptational outcomes (as measured by life satisfaction) in caregivers.

In the final set of regression analyses, the four coping behaviors were utilized as predictor variables of both life satisfaction and caregiver burden. When caregivers utilized problem-oriented and reframing coping strategies there was an

associated lower level of burden and greater levels of reported life satisfaction. In contrast, when caregivers utilized avoidant/evasive and regressive coping strategies there were higher levels of burden and lower levels of life satisfaction. The association between avoidant/evasive coping behaviors and caregiver burden has also been found in an previous study by Pratt et al., (1985). In that study, "passivity", a type of avoidant/evasive coping strategy, significantly associated with higher levels of burden.

These findings suggest that when caregivers cope by trying to solve the problem or to redefine the caregiving experience in a way that makes it more manageable and understandable, this leads to a more positive adaptational outcome. But when caregivers avoided and denied the problems within the caregiving situation or use coping efforts that were regressive (e.g., get mad, swear, curse; eat, smoke, chew gum) more negative adaptational outcomes were evident.

In summary, both personal (control beliefs) and situational (social resources) characteristics were found to be influential on the way caregivers cope with the caregiving role. These results are consistent with the concise perspective that Lazarus and Folkman (1984) have proposed:

"the way a person copes is determined in part by his or her resources, which includes health and energy; existential beliefs, e.g., about God, or general beliefs about control; commitments which have a motivational property that can help sustain coping; problem-solving skills; social skills; social support; and material resources (p.179).

Futhermore, specific coping behaviors were associated with

different adaptational outcomes in the caregivers. Several researchers have suggested that avoidant/evasive and external control beliefs may be more suitable for people when the stressor event is appraised as uncontrollable (Parkes, 1984; Wong & Sproule, 1984). When the caregiver cares for a dementia patient, particularly a patient with Alzheimer's disease, the situation often appears uncontrollable and hopeless (Mace & Rabins, 1981; Powell & Courtice, 1983), yet in this study it was indicated that avoidant/evasive and external control beliefs were associated with negative adaptational outcomes. Therefore, in the context of caregiving for a dementia patient, problem-oriented and reframing coping efforts may prove to be more advantageous in adaptational outcome, regardless of the perceived controllability of the situation.

## IMPLICATIONS AND CONCLUSIONS

This study developed and tested a theoretical model assessing the effects of person and situational variables on caregivers' coping behaviors and well-being. The measured variables utilized in this study were hypothesized to represent latent variables which were related within a structural relations model based on past theoretical and empirical studies. Personal and situational characteristics of the caregiver and characteristics of the dementia patient were hypothesized as influencing the coping responses utilized by caregivers. Coping behaviors were also hypothesized to affect adaptational outcomes for caregivers.

The proposed theoretical model, which included both a measurement and structural relations model, was not supported by the data obtained from caregivers in this study. The results from the LISREL analysis indicated that several latent variables were not specified according to the proposed measurement model. This assessment suggested that the measured variables chosen to indicate the latent variables were not representative of the proposed constructs. Nevertheless, important findings were derived from the assessment of the theoretical model which have important implications for future theoretical and empirical studies. Results from the



preliminary analyses (one-way ANOVAs) and from the analyses conducted after the assessment of the theoretical model (factor analysis and multiple regression) also have important implications for both researchers and professionals involved in intervention programs.

In this section, the limitations of the present study will be presented, then the implications and conclusions for the study will be discussed. This discussion will focus on three areas. First, the findings from the assessment of the theoretical model and subsequent factor analysis will be discussed in relation to previous theoretical and empirical studies. Second, the findings from the preliminary analyses and multiple regression analyses will be discussed in relation to practical applications for professionals involved in intervention programs. Third, suggestions for future research will be presented.

### Limitations

A major limitation of this study was the sampling procedure utilized which relied on mailing lists of caregivers who were support group members. Because there was no randomization in the sampling design, the data generated from the data was from a nonprobability sample. Therefore, the sampling design has implications for the generalizability of results. About 80 % of the caregivers in the sample were members of a support group which implies that the findings in this study should be primarily restricted to caregivers who are support group

members. These findings may not apply to all caregivers of dementia patients.

Because not all caregivers contacted through mailing lists responded to the questionnaire, it is valid to ask what characteristics were prevalent in those caregivers who did respond compared to those caregivers who did not. It is possible that the caregivers who did respond to the questionnaire, as opposed to those who did not, possessed characteristics or traits that could possibly have influenced their responses to the items in the questionnaires. The findings in this study could reflect personality or contextual characteristics of the caregivers which have not been accounted for by the research design. This limitation falls under the general rubric of ex post facto research (Kerlinger, 1973).

Regardless of the theoretical rationale or statistical sophistication utilized, there is the question of accuracy in the interpretation of data when the present design had little or no control over extraneous independent variables. Although several variables were found to be significant predictors of the criterion variables, it was possible that extraneous variables (or variables not accounted for by the model) could have also explained for the variance in the criterion variables.

Another limitation in the present study was the use of self-report data. Lazarus and Folkman (1984) have proposed that the use of self-report data is essential if research is

to capture the essence of stress, emotion, and coping and its adaptational outcomes. Nevertheless, self-report data had inherent faults that need to be addressed in relation to the present study. The caregivers were asked to respond to a variety of questions regarding their caregiving role and their responses were dependent upon their ability to recall events and emotions. The responses generated by the caregiver could have been potentially inaccurate due to problems in memory and therefore may not have reflected the "true" representation of events or reactions which actually did occur. Another potential problem inherent within self-report data is the question of social desirability (the desire to present oneself in a positive light) in response to otherwise sensitive issues in the caregiving role. It was possible that many responses to items in the questionnaire were answered in "retrospective falsification" (Lazurus & Folkman, 1984). There could have been the tendency for caregivers to respond to the questions in a way that was socially acceptable (e.g., "My relationship with my impaired relative is very close, because we are 'family'") rather than express actual feelings or emotions that are contrary to what people would expect. This is particularly likely in the assessment of Internal Control beliefs which Levenson (1981) describes as highly desirable in our society. Therefore, the possibility of biased responses exists and findings in this study should be interpreted within this context, although there is no reason to believe such bias exists in the study to any greater extent than any other

utilizing similar methodology.

A final limitation of this study was both theoretically and methodologically related. This study was cross-sectional in design and therefore assessed the person-situation influence as a static phenomenon (Lazurus & Folkman, 1984). This approach essentially presents a snap-shot of coping and adaptational outcomes in caregivers of dementia patients. To accurately assess coping and adaptational outcomes, caregiver coping behavior should be examined over time within longitudinal designs. Such longitudinal designs allow the transactional process of coping and adaptation to be captured and understood.

#### Implications of the Findings for the Assessment of the Theoretical Model

The original theoretical design proposed fifteen measured variables to be indicators of five latent variables. As previously mentioned, the LISREL analysis revealed that the measurement model (which specifies which measured variables are hypothesized to indicate or load onto the proposed latent variable) was poorly specified. That is, the chosen measured variables had not adequately represented the proposed constructs that were identified in the model. In relation to the measurement model portion of the LISREL analysis for the theoretical model, it was evident that many indicators (measured variables) had not shared sufficient covariation with each other in order to represent the proposed latent

variables.

Therefore, in this study the resulting poor fit of the data to the proposed theoretical model was centered around the issue of isomorphism, "does the theoretical model perform the same way (empirical) reality performs" (Miller, Rollins, & Thomas, 1982; p.860). Miller, Rollins, and Thomas (1982) further elaborate: "Whenever problems of fit are raised, researchers in essence are questioning the validity of the operationalization of theoretical constructs and relationships between constructs".

In order to further assess the validity of the operationalization of the theoretical constructs a subsequent factor analysis was performed to identify which factors (constructs) were existent within the chosen measured variables. Three latent exogenous variables had maintained a relative degree of construct stability with only one measured variable, internal control belief, loading under another factor. However, the two proposed latent endogenous variables had changed substantially in conceptualization after the factor analysis. This suggested for the present sample, the construct of coping and caregiver well-being were not conceptually distinct as had been originally proposed. As stated in the review of the literature, the construct of coping is currently undergoing a dynamic transformation in measurement and conceptualization. In general, previous research studies have conceptualized coping as either behavioral or psychological responses in the context of

adapting to stressful situations (Fleming et al., 1984).

Recently, Lazarus and Folkman (1984) have crystallized their theoretical orientation of coping to include coping as a function of "continuous appraisals and reappraisals of the shifting person-environment relationship" (p.412).

Collectively, these studies have conceptualized coping as a function of both person and situational characteristics (Billings & Moos, 1981; Caplan, 1979; Fleishman, 1984; Lazarus & Folkman, 1984; Parkes, 1984; Wheaton, 1983).

Based on these studies, the conceptualization of coping was designed to be influenced by both person-situation variables and served as a mediating construct between the construct of caregiver well-being and the influences of the person-situation constructs. However, the results from the factor analysis suggested that coping and adaptational outcome (caregiver well-being) were conceptually interconnected. Furthermore, coping behaviors and adaptational outcomes were interconnected in such a way as to indicate that some coping behaviors were associated with negative adaptational outcomes (maladaptation) or associated with positive adaptational outcomes (bonadaptation) (McCubbin & Patterson, 1983).

Lazarus and Folkman (1984) have suggested that the mixing of conceptual systems is not appropriate in investigating the relationship between coping and outcome and researchers should manage to keep the study of process and outcome independent. However, their concern was targeted primarily with the traditional animal and ego psychological models which have

confounded coping with outcome. Lazarus and Folkman (1984) had criticized those models for describing coping per se as indications of person's ability to successfully adapt (efficacy) while those who did not "cope" were considered ineffective or inadequate. The message that Lazarus and Folkman (1984) have underscored is that no one coping strategy should be considered inherently better than the other in predetermined criteria. The efficacy of coping should be determined only within specific contexts and over periods of time. In relation to the present study, it appears that in the context of caregiving for dementia patients the theoretical constructs of coping and adaptational outcome were not conceptually distinct. For example, the measured variables of reframing, problem-oriented, life satisfaction, and internal control orientations were conceptualized as the positive end of the adaptational continuum (Bonadaptation) and caregiver burden, avoidant/evasive coping, and regressive coping as the negative end of the adaptational continuum (Maladaptation). These conceptualizations were not predetermined, rather they were proposed within the context of the caregiving role and after the data collection process. The implications of these findings suggest that theoretical models which incorporate latent variables within the design should consider how coping and adaptational outcome are to be conceptually defined and measured, and how they are to be structurally related in the context of the caregiving role. For example, the role of reciprocal action among latent variables is one area that

should be discussed in terms of conceptually distinct constructs.

Although the theoretical model (Figure 1) was ecological in the sense that person-situation variables were included within the design, the design was depicted in a unidirectional flow of input variables as antecedents of output variables. Based on the conceptualization of coping and adaptational outcome as being interconnected, this also suggests the reciprocal nature of the constructs in the context of the caregiving role. Holahan and Spearly (1980) have proposed the coping process to be characterized as the reciprocal influences between its environmental, cognitive, and behavioral components. In their ecological model of coping, each component in the coping process may operate as an independent, mediating, or dependent variable (Holahan & Spearly, 1980). The application of Holahan and Spearly's (1980) ecological model of coping to the present study would incorporate personality (control beliefs), social resource, patient functioning, coping and well-being variables as reciprocally interactional as diagrammed in Figure 10. This design proposes that the relationships are more interconnected and notion of reciprocity is paramount instead of treating the constructs as unique and hierarchically distinct. The proposed model (Figure 10) and the findings of this study suggest that coping and adaptational outcome and person-situation variables in the context of caregiving should be considered as ecologically integrated.



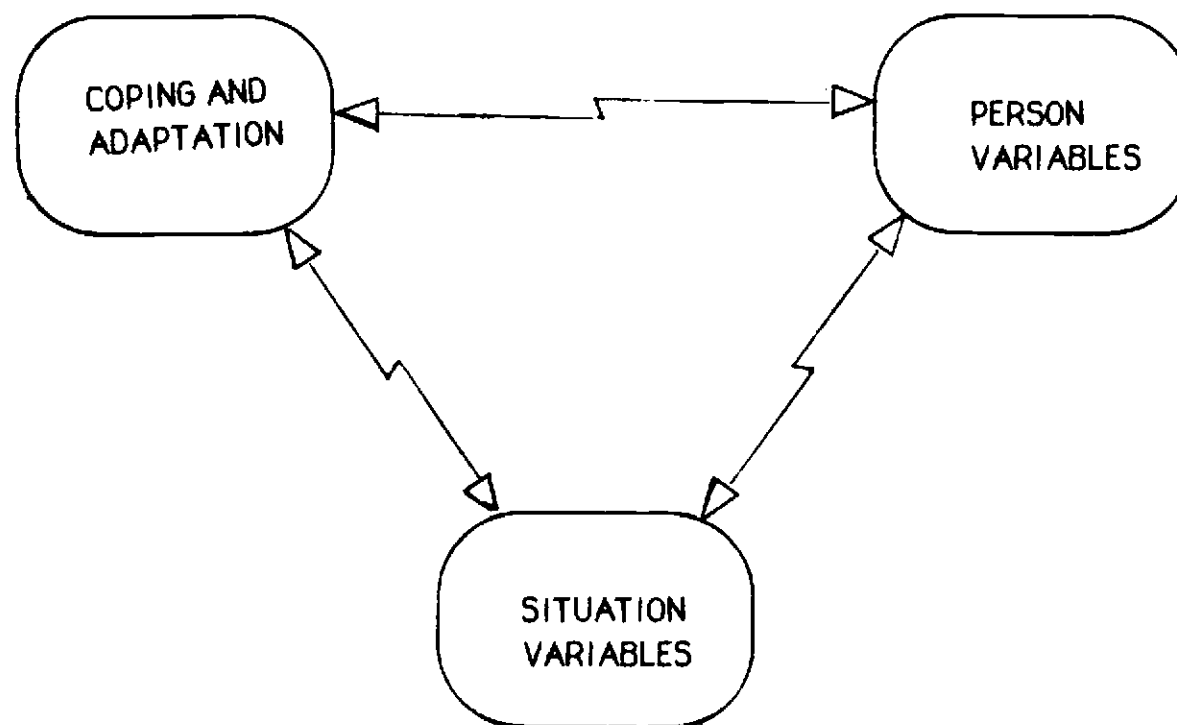


FIGURE 10 Ecological Model for Investigating Reciprocal Interactions Among Person-Situation and Coping/Adaptation Variables

## Practical Applications

Findings of this study are important to practioners who work with family caregivers to dementia patients. First, it was found that when the dementia patient was residing in an institution, caregivers were more likely to believe that events are externally controlled by unordered and unpredictable forces. This belief could be rationalized within the context of the complex and difficult decision-making process of institutionalization. However, chance control beliefs were associated with avoidant/evasive coping behaviors. When the dementia patient resided in an institutional setting, caregivers were more inclined to use avoidant/evasive and regressive coping behaviors, all of which were associated with greater burden levels and lower life satisfaction levels for caregivers in this study.

It is not possible to determine causality in the chain of relationships just mentioned, but the implications are clear. Family members, friends and professional workers need to be aware that the institutional process can be very detrimental to the primary family caregiver. Caregivers were more likely to utilize maladaptive coping behaviors which were associated with maladaptive outcomes when the dementia patient was institutionalized. Therefore, counselors, social workers, and nursing home staff, and other related family members should be sensitive to the needs of the primary caregiver even after the decision to institutionalize.

However, sensitivity may not mean exclusively promoting internal control orientations or problem-solving coping efforts in caregivers after their decision to institutionalize the dementia patient. For example, Folkman (1984) has indicated that problem-oriented coping behaviors and direct control may actually increase the overall stress and burden experiences if the characteristics of the event (e.g., institutionalization) are beyond the control of the individual. In this case, the investment of energy for the caregiver could be directed in both reframing coping strategies (where the caregiver is helped to cognitively view the situation in an alternate way which makes the situation more manageable and understandable) and problem-solving strategies. Interventions directed toward increasing the use of reframing strategies may prove to be beneficial for the well-being of the caregiver, particularly because reframing coping efforts were associated with higher degrees of satisfaction in the caregiving role.

Another important finding for practioners, particularly support group leaders, was that caregivers who were members of a support group actually had significantly higher burden scores than caregivers who were not members. In the discussion section of this paper, it was mentioned that the functional level of the dementia patient did not significantly differ for caregivers in support groups compared to those not in support groups. This discounts as a possible explanation that caregivers in support groups were

more burdened because the dementia patient was more functionally impaired than for caregivers not in support groups. An alternate explanation is that support groups attract those caregivers who are in most need of support and thus the higher burden scores for caregivers in support groups reflected this need. Obviously, the present research design cannot validate nor confirm this interpretation, yet the finding has important implications for support group caregiver dynamics. Several studies have indicated that social support groups can assist in alleviating the stressors of caregiving by providing a supportive environment which allows the caregiver to "ventilate and validate" their experiences with others (Barnes et al., 1980; Lazarus et al., 1981). However, social "support" can have maladaptive consequences, particularly when the "support" is claimed to be available and offered, yet fails to meet the expectations of the individual who is in need of support (Fiore et al., 1983). The higher burden scores found for caregivers in support groups do not imply that support groups fail to provide support. Rather these findings suggest that more evaluative information is needed to determine how support groups function in order to accomplish their goals and objectives (Glosser & Wexler, 1985). Support group leaders cannot assume that mere membership and attendance in support groups will reduce or alleviate the overall burden associated with caregiving.

More qualitative issues were also raised about support

groups. For example, many caregivers reported that they were satisfied with the emotional support and knowledge that support groups had to offer, yet several reported in anecdotal information that the support group meetings were "depressive and pessimistic". Caregivers stated that they had just left an environment where the situation was already burdensome, and then participated in meetings where "the problem" appeared again in the form of discussions about what other caregivers were going through. These anecdotal reports again highlight the need for more evaluative research regarding the effectiveness of social support programs (Glosser & Wexler, 1985).

The regression analyses demonstrated that personal resources characteristics (e.g., control beliefs) were predictive of both coping behaviors and adaptational outcomes. Internal control beliefs were significant predictors of both problem-oriented and reframing coping efforts, while chance and powerful others control beliefs were predictive of avoidant/evasive coping efforts. Collectively, these findings support other researchers in suggesting that personal resource characteristics influence coping behaviors (Fleishman, 1984; Shoeneman & Reznikoff, 1983; Wheaton, 1983). These findings lend support for intervention programs that assist caregivers to develop the skills necessary for coping with the possible long-term role of careprovider. Wheaton (1983) further elaborated on the potential goal of such interventions:

"Stressors often occur beyond the control of friends, family and coworkers, where the therapist cannot easily reduce the environmental stressors, however, they can work with the more immediate facets of personality and cognitive orientations which influence coping and they may be effective in reducing the effects of environmental stress" (p. 222).

Intervention programs could assist caregivers to gain more internal control orientations and decrease perceptions of events being controlled by external forces such as chance or powerful others. Furthermore, programs could also focus on the cognitive skills which emphasize reframing coping efforts. Clearly, more research studies are needed to assess the impact and effectiveness of intervention programs which emphasize cognitive coping skills.

In a recent study, caregiver strain and the desire to institutionalize family members with Alzheimer's disease, the intensity of family strain was best predicted by the availability of social support to the caregiver (Morycz, 1985). More concisely, less support implied more strain. In the present study, similar results were found. The pervasive influence of social support was found to be predictor of positive adaptational outcomes for caregivers. These findings indicate the strong relationship between social networks and a family's adaptation to stressor events. These findings also underscore the connection between formal and informal support networks:

"family counselors, educators and medical professionals and policy makers need to consider the social contexts in which families function when designing and providing professional services" (Unger & Powell, 1980; p. 571).

Therefore, professionals who design intervention programs for caregivers of dementia patients should work to bridge the support available within the informal system and the formal support system. However, those who would bridge the formal and informal systems would also need to consider the ecological notion of the "fit" between characteristics of the person and the environment (Potaszniak & Nelson, 1984).

### Suggestions for Future Research

The present study was cross-sectional and therefore did not capture the dynamics of coping and adaptational outcome as a process (Lazarus & Folkman, 1984). Future research designs which target caregivers of dementia patients as subjects, need to implement longitudinal data analysis in order to accurately assess coping and adaptation over time (Ory, 1985). Some current studies have begun to assess adaptational outcomes (caregiver burden) over time (Todd, Zarit, & Zarit, 1985), but there is still the need for large samples which avoid the methodological drawbacks of self-selected and non-representative samples (Ory, 1985).

Future research studies should continue to utilize person-situation variables when investigating coping and adaptational outcomes. This study has shown that both personal and environmental characteristics were significant predictors of both coping and adaptational outcomes in caregivers of dementia patients. Future research designs should therefore consider ecological frameworks similar to

those proposed by Holahan and Spearly (1980) in order to capture the complexity of reciprocal factors in association with coping and adaptational outcomes.

Future research efforts should also concentrate on experimental designs to evaluate the effectiveness of support group goals and objectives. This research would be beneficial to the caregivers who need comfort and respite from the "36 hour day" (Mace & Rabins, 1981) associated with the caregiving role. Ory (1985) has indicated that there has been a proliferation of mutual aid groups for Alzheimer's families, but little is known about how effective these groups are.

Another area that bears investigation is the conceptualization and operationalization of the construct of coping. Results from this study have supported the multi-dimensional conceptualization of coping. However, the four factor solution for the Jaloweic Coping Scale (Jaloweic et al., 1980) should be tested on other samples to validate the conceptual domains as proposed in this study. The construct of coping will continue to receive rigorous investigation because the construct is still in a state of theoretical flux.

Many other areas of interest for future research can be suggested. Theoretical models which attempt to capture the causal ordering of latent constructs should choose indicator variables with careful theoretical justification. This study has shown that the development and testing of theoretical



constructs is an ongoing process of revision. Continued efforts should be directed at building theoretical models which integrate person-situation variables in the design, as well as proposals which include the a priori causal ordering of the theoretical constructs. The relationship between theory and research is a dynamic process and Pedhauzur's (1982) crystallization of the process bears repeating:

"the analysis of the data is designed to shed light on the question of whether or not the causal model is consistent with the data. If the model is inconsistent with the data, doubt is cast about the theory that generated it... consistency of the model with the data ... does not constitute proof of the theory... it only lends support to it." (p. 579).

## Concluding Statement

This study constructed and assessed a theoretical model which investigated the effects of personal and situational characteristics of the caregiver on coping behavior and adaptational outcomes. The theoretical model was found to be inconsistent with the data and therefore subsequent analyses were performed. These analyses assessed the validity of the proposed constructs and the relationships among the constructs. Several important findings have been discussed and applications for intervention programs and future studies have also been suggested.

It is only hoped that the results can help to assist caregivers and their families adjust to the "human tragedy of Alzheimer's Disease" and other dementias. This dilemma confronts all of us as individuals, as families, as communities, and as a society...

"as research tries to unravel the mystery of the disease, reflection and research are needed to better understand all of its human dimensions both as it effects the person with the disease and those who surround him"

Msgr. Charles Fahey  
Third Age Center  
Fordham Univeristy  
1984

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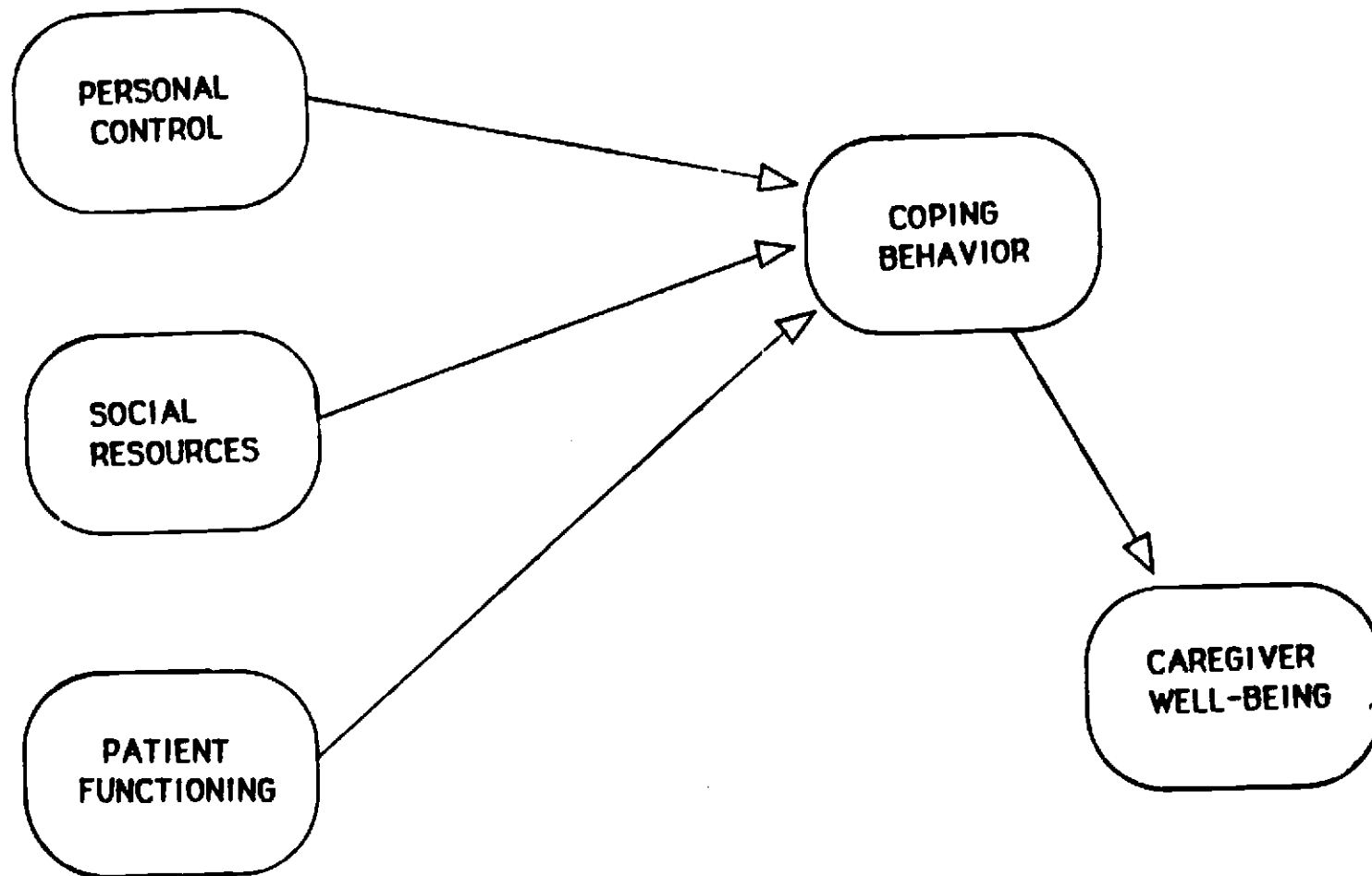
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**APPENDICES**



## APPENDIX A

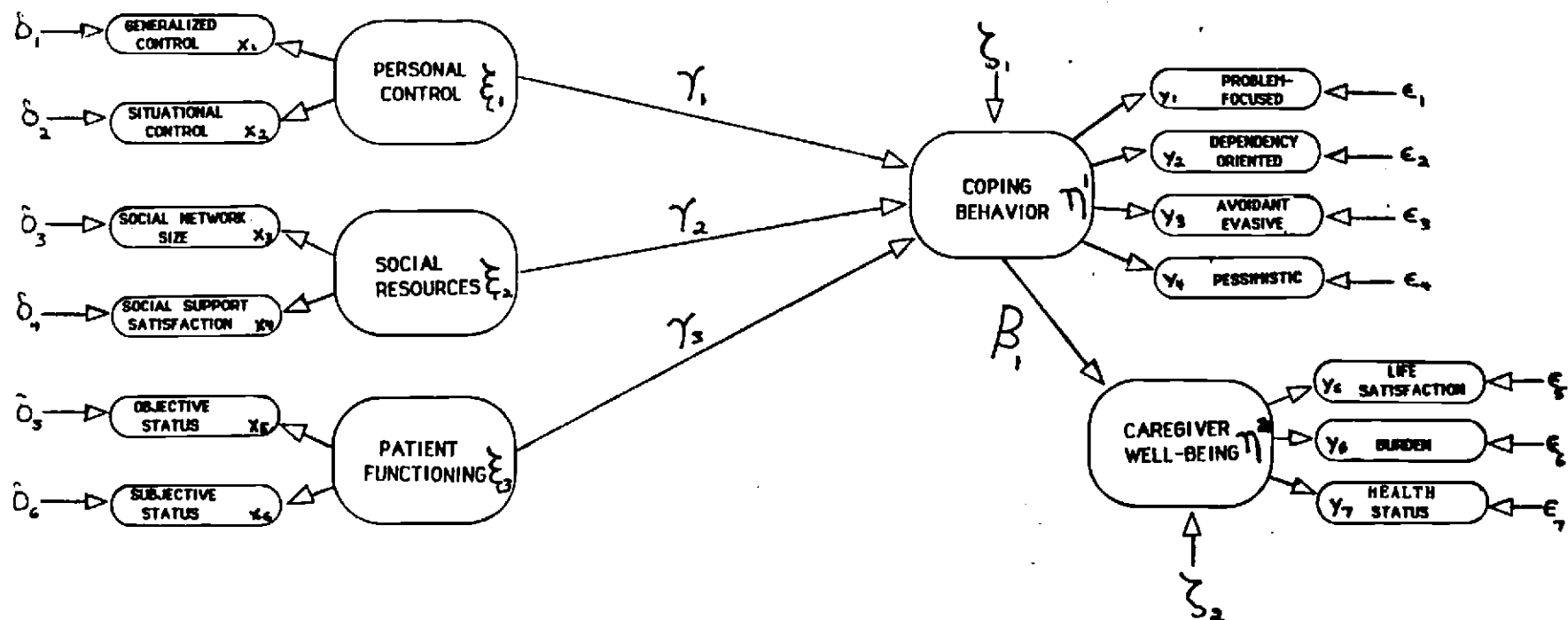
## THEORETICAL MODEL



**THEORETICAL MODEL FOR PREDICTING COPING  
BEHAVIOR AND CAREGIVER WELL-BEING**

## APPENDIX B

## LISREL MODEL



LISREL MODEL FOR PREDICTING COPING BEHAVIOR AND CAREGIVER WELL-BEING

## APPENDIX C

## COVER LETTER FOR QUESTIONNAIRE

Summer, 1985

Dear Caregiver:

We are writing to ask for your assistance with an important research project on Alzheimer's Disease and related disorders which is being conducted by the Intermountain West Long Term Care Gerontology Center at the University of Utah. The primary objectives of this project are to learn more about the problems that caregivers have, what kinds of help they receive from others and how others can be more helpful. Your name was obtained from the support group in your local area because your relative or friend might have Alzheimer's Disease or some related disorder.

Enclosed is a questionnaire that we would like you to complete and mail back to us in the envelope provided. You are not under any obligation to answer any of the questions, but it would be very helpful to us if you would. If you find the questionnaire to be tiring, we suggest that you take a day or two to complete it. Be assured that any information you share with us is completely confidential. We will make our conclusions available to other professionals but you will never be identified with your specific comments inasmuch as several hundred people throughout an eight-state area will be receiving this letter.

We hope that you will help us with this project. We want to learn more about the impact on families and friends who care for persons with dementia, and we want to assist families in obtaining resources to help cope with their situations. However, before we can be of much help, we need to learn more from those who are affected by these disorders. We will appreciate your help in providing this necessary information. If you have any questions, I can be reached at the above address. Thank you for your help.

Sincerely,

Enclosure

APPENDIX D

QUESTIONNAIRE

Group No. \_\_\_\_\_

1. Caregiver Profile: Please answer the following questions about yourself and your family.

1. What is your age? \_\_\_\_\_
2. What is your sex? \_\_\_\_\_(1) Male \_\_\_\_\_(2) Female
3. What is your racial/ethnic background?

☐ White  
☐ Black  
☐ Spanish American  
☐ Native American  
☐ Other: (specify)

4. What is your relationship to your impaired family member or friend?

\_\_\_\_\_ (1) Son  
 \_\_\_\_\_ (2) Daughter  
 \_\_\_\_\_ (3) Son-in-law  
 \_\_\_\_\_ (4) Daughter-in-law  
 \_\_\_\_\_ (5) Brother (or in-law)  
 \_\_\_\_\_ (6) Sister (or in-law)  
 \_\_\_\_\_ (7) Grandson  
 \_\_\_\_\_ (8) Granddaughter  
 \_\_\_\_\_ (9) Spouse  
 \_\_\_\_\_ (10) Other (specify): \_\_\_\_\_

5. How close would you describe your relationship to be with your impaired family member or friend according to the scale below? (Circle a number.)

1	2	3	4	5	6	7
Distant						Very Close

6. What is the highest level of your education?

☐ less than 7th grade  
☐ Junior High School (9th grade)  
☐ Partial High School (10th or 11th grade)  
☐ High School Graduate  
☐ Partial College (at least one year) or specialized training  
☐ Standard College or University graduation  
☐ Graduate professional training (graduate degree)



7. What is your annual household income from all sources?

- \_\_\_\_ (1) Below \$10,000
- \_\_\_\_ (2) \$10,000 - \$19,999
- \_\_\_\_ (3) \$20,000 - \$29,999
- \_\_\_\_ (4) \$30,000 - \$39,999
- \_\_\_\_ (5) \$40,000 - \$49,999
- \_\_\_\_ (6) \$50,000 - \$59,999
- \_\_\_\_ (7) \$60,000 - \$69,999
- \_\_\_\_ (8) \$70,000 and above.

8. What percentage of the health care costs of your impaired family member or friend are paid by you? \_\_\_\_\_% of total costs.

9. a. Of all the caregiving responsibilities what percentage do you feel that you provide to the impaired person? \_\_\_\_\_%

b. If you provide less than 50% of the caregiving responsibilities could you give us the names and mailing addresses of the other family or friends who are major caregivers and have not completed this questionnaire. We would like to send them a similar questionnaire.

Names	Relationship to Impaired Person	Address
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

10. How many hours per day do you, as the caregiver, need to be with or use in preparing to provide care to the patient?

- \_\_\_\_ (1) less than two hours
- \_\_\_\_ (2) 2 to 5 hours
- \_\_\_\_ (3) 6 to 10 hours
- \_\_\_\_ (4) 11 to 15 hours
- \_\_\_\_ (5) 16 to 20 hours
- \_\_\_\_ (6) 21 to 24 hours

11. How long have you been providing care to the person with dementia?  
\_\_\_\_\_ months and/or years.

12. What is your present marital status?

- \_\_\_\_ (1) Never married
- \_\_\_\_ (2) Married
- \_\_\_\_ (3) Divorced
- \_\_\_\_ (4) Separated
- \_\_\_\_ (5) Widowed

13. Are you presently: (check one)

- ☐ (1) Employed full-time  
☐ (2) Employed part-time  
☐ (3) Unemployed  
☐ (4) Retired  
☐ (5) Full-time homemaker

14. What is your religious affiliation?

- \_\_\_\_\_ (1) Catholic  
 \_\_\_\_\_ (2) Protestant  
 \_\_\_\_\_ (3) Jewish  
 \_\_\_\_\_ (4) Greek Orthodox  
 \_\_\_\_\_ (5) L.D.S.  
 \_\_\_\_\_ (6) Other: \_\_\_\_\_  
 \_\_\_\_\_ (7) None

15. It is important for us to know more about those WHO LIVE IN THE HOUSEHOLD WITH YOU. Please complete the following chart. Please include only those who live in the same home as you.

### Household Residents

<u>Relationship to the Alzheimer's Victim</u> (Son, Daughter, Spouse Grandchild, Friend, Etc.)	<u>Sex of Person</u> (M = Male F = Female)	<u>Age of Person</u>
1. _____	_____	_____
2. _____	_____	_____
3. _____	_____	_____
4. _____	_____	_____
5. _____	_____	_____
6. _____	_____	_____
7. _____	_____	_____

16. What do you believe is the probability that this person with dementia will be living in a nursing home one year from now? Use the scale below to indicate this possibility. (Circle a number from 1-7.)

1	2	3	4	5	6	7
Definitely Not						Definitely Yes

**Any Comments?**

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17. At the present time, how would you rate your desire to have this person placed in a nursing home? (Circle a number from 1-7.)

1      2      3      4      5      6      7  
No Desire    High Desire

18. How have your feelings toward this person changed (if at all) as a result of his/her having developed the impairment?

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

19. How has the presence of this disorder changed (if at all) your own feelings about growing older?

\_\_\_\_\_

\_\_\_\_\_

20. Use the space below to identify your most important needs/problems related to your caring for the impaired person.

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

21. Before the start of your caregiving role, would you say your physical health was:

_____	Excellent
_____	Good
_____	Fair
_____	Poor

22. How would you rate your health at the present time?

_____	Excellent
_____	Good
_____	Fair
_____	Poor

23. If your health status has changed do you feel caregiving has affected that change?

\_\_\_\_\_ A great deal  
\_\_\_\_\_ A little  
\_\_\_\_\_ Not at all

24. Are you now a member of a support group for caregivers of patients with Alzheimer's Disease or other disorders?

\_\_\_\_\_ Yes (If so, please answer the following questions.)  
 \_\_\_\_\_ No (If no, were you before? \_\_\_\_\_ Yes \_\_\_\_\_ No)

- a. How long have you been a member of this support group?  
 \_\_\_\_\_ months and/or years

- b. How helpful has this group been to you in providing  
 KNOWLEDGE/INFORMATION?

\_\_\_\_\_ Not at all helpful  
 \_\_\_\_\_ Not very helpful  
 \_\_\_\_\_ Helpful  
 \_\_\_\_\_ Very Helpful  
 \_\_\_\_\_ Too soon to tell  
 \_\_\_\_\_ Don't know

- c. How helpful has this group been to you in providing EMOTIONAL  
 SUPPORT?

\_\_\_\_\_ Not at all helpful  
 \_\_\_\_\_ Not very helpful  
 \_\_\_\_\_ Helpful  
 \_\_\_\_\_ Very Helpful  
 \_\_\_\_\_ Too soon to tell  
 \_\_\_\_\_ Don't know

- d. Approximately how many group meetings have you attended? \_\_\_\_\_

- e. How many other friends or relatives regularly attend these meetings  
 with you? \_\_\_\_\_

- f. Do these support groups meet your expectations?

\_\_\_\_\_ Most of the time  
 \_\_\_\_\_ Some of the time  
 \_\_\_\_\_ Very little of the time  
 \_\_\_\_\_ None of the time

- g. What do you like the most about the support groups?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

- h. What do you dislike about the support groups?

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

II. Dementia Patient Profile: Please answer the following questions about the impaired person.

1. Age of the impaired family member or friend: \_\_\_\_\_
2. Sex of the impaired person:  
 \_\_\_\_\_(1) Male      \_\_\_\_\_(2) Female
3. What is his/her racial/ethnic background?  
 \_\_\_\_\_ White  
 \_\_\_\_\_ Black  
 \_\_\_\_\_ Spanish American  
 \_\_\_\_\_ Native American  
 \_\_\_\_\_ Other (specify): \_\_\_\_\_
4. What is the highest level of education that he/she completed?  
 \_\_\_\_\_ Less than 7th grade  
 \_\_\_\_\_ Junior High School (9th grade)  
 \_\_\_\_\_ Partial high school (10th or 11th grade)  
 \_\_\_\_\_ High School Graduate  
 \_\_\_\_\_ Partial college (at least one year) or specialized training  
 \_\_\_\_\_ Standard college or university graduate  
 \_\_\_\_\_ Graduate professional training (graduate degree)
5. What were the major occupation(s) of the impaired person ?  
 \_\_\_\_\_  
 \_\_\_\_\_
6. What is his/her marital status?  
 \_\_\_\_\_(1) Married  
 \_\_\_\_\_(2) Widowed  
 \_\_\_\_\_(3) Separated  
 \_\_\_\_\_(4) Divorced  
 \_\_\_\_\_(5) Never Married
7. What is his/her religious affiliation?  
 \_\_\_\_\_(1) Catholic      \_\_\_\_\_(5) L.D.S.  
 \_\_\_\_\_(2) Protestant      \_\_\_\_\_(6) Other: \_\_\_\_\_  
 \_\_\_\_\_(3) Jewish      \_\_\_\_\_(7) None  
 \_\_\_\_\_(4) Greek Orthodox
8. What are the sources of financial support that the impaired person receives? (Check all that apply.)  
 \_\_\_\_\_(1) Welfare      \_\_\_\_\_(6) Savings  
 \_\_\_\_\_(2) Medicare      \_\_\_\_\_(7) Stocks/Bonds  
 \_\_\_\_\_(3) Medicaid      \_\_\_\_\_(8) Family Support  
 \_\_\_\_\_(4) Social Security      \_\_\_\_\_(9) Other: \_\_\_\_\_  
 \_\_\_\_\_(5) Retirement Pension

9. Where does the dementia patient live?

- ☐ (1) In the same household as you  
☐ (2) In a home separate from you  
☐ (3) In a nursing home or adult residential care facility  
☐ (4) Other: (specify) \_\_\_\_\_

10. How long has he/she resided at the above location?  
                                 \_\_\_\_\_ years          \_\_\_\_\_ months

11. How long ago did you first notice changes in your family member or friend?  
 \_\_\_\_\_

12. What were the first signs of the impairment?  
 \_\_\_\_\_  
 \_\_\_\_\_

13. Has the course of the impairment been gradual or rapid?

- ☐ (1) gradual                      ☐ (2) rapid

14. When was the impairment first diagnosed by a doctor?  
 Number of years/months ago: \_\_\_\_\_

15. What was the diagnosis?  
 \_\_\_\_\_  
 \_\_\_\_\_

16. Do you know what tests were done?

- A. CAT SCAN    ☐ (1) Yes    ☐ (2) No    ☐ (3) Don't Know  
 B. EEG           ☐ (1) Yes    ☐ (2) No    ☐ (3) Don't Know

17. How would you rate the patient's emotional health status?

- ☐ Excellent  
☐ Good  
☐ Fair  
☐ Poor

18. How would you rate the patient's physical health status?

- ☐ Excellent  
☐ Good  
☐ Fair  
☐ Poor

### III. Current Functioning of Impaired Family Member

In order to find out the seriousness of the impairment it would be very helpful if you would rate your impaired family member from 1-4 on each of the following statements.

Circle one rating for each item according to these choices:

- 1 = None or little of the time.  
 2 = Some of the time.  
 3 = Good part of the time.  
 4 = Most or all of the time.

<u>Choices</u>					<u>Statements</u>
1	2	3	4		1. Has difficulty in completing simple tasks on own, e.g., dressing, bathing, doing arithmetic.
1	2	3	4		2. Spends time either sitting or in apparently purposeless activity
1	2	3	4		3. Wanders at night or needs to be restrained to prevent wandering.
1	2	3	4		4. Hears things that are not there.
1	2	3	4		5. Requires supervision or assistance in eating.
1	2	3	4		6. Loses things.
1	2	3	4		7. Appearance is disorderly if left to own devices.
1	2	3	4		8. Moans.
1	2	3	4		9. Cannot control bowel function.
1	2	3	4		10. Threatens to harm others.
1	2	3	4		11. Cannot control bladder function.
1	2	3	4		12. Needs to be watched so doesn't injure self, e.g., by careless smoking, leaving the stove on, falling.
1	2	3	4		13. Destructive of materials around him/her, e.g., breaks furniture, throws food trays, tears up magazines.
1	2	3	4		14. Shouts or yells.
1	2	3	4		15. Accuses others of doing him/her bodily harm or stealing his possessions when you are sure the accusations are not true.
1	2	3	4		16. Is unaware of limitations imposed by illness.
1	2	3	4		17. Becomes confused and does not know where he/she is.
1	2	3	4		18. Has trouble remembering.
1	2	3	4		19. Has sudden changes of mood, e.g., gets upset, angered, or cries easily.
1	2	3	4		20. If left alone, wanders aimlessly during the day or needs to be restrained to prevent wandering.

\* Which one or two of the above behaviors is/are the most difficult for you to cope with? \_\_\_\_\_ (Put the number of the statement (1-20) in the blanks.)

#### IV. Caregiver Assessment

Instructions: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers. Check the response which best reflects how you feel.

Statements	Never	Rarely	Some- times	Quite Frequently	Nearly Always
1. Do you feel that this person asks for more help than he/she needs?					
2. Do you feel that because of the time you spend with this person that you don't have enough time for yourself?					
3. Do you feel stressed between caring for this person and trying to meet other responsibilities for your family or work?					
4. Do you feel embarrassed over this person's behavior?					
5. Do you feel angry when you are around this person?					
6. Do you feel that this person currently affects your relationship with other family members or friends in a negative way?					
7. Are you afraid what the future holds for this person?					
8. Do you feel this person is dependent upon you?					
9. Do you feel strained when you are around this person?					
10. Do you feel your health has suffered because of your involvement with this person?					
11. Do you feel that you don't have as much privacy as you would like because of this person?					
12. Do you feel that your social life has suffered because you are caring for this person?					



Statements

	Never	Rarely	Some- times	Quite Frequently	Nearly Always
13. Do you feel uncomfortable about having friends over because of this person?					
14. Do you feel that this person seems to expect you to take care of him/her as if you were the only one he/she could depend on?					
15. Do you feel that you don't have enough money to care for this person, in addition to the rest of your expenses?					
16. Do you feel that you will be unable to take care of this person much longer?					
17. Do you feel you have lost control of your life since this person's illness?					
18. Do you wish you could just leave the care of this person to someone else?					
19. Do you feel uncertain about what to do about this person?					
20. Do you feel you should be doing more for this person?					
21. Do you feel you could do a better job in caring for this person?					
22. Overall, how burdened do you feel in caring for this person?					

### V. Opinions About Older People

The following are 22 statements of opinions about older people in general. Please indicate in the boxes opposite each of these statements the extent to which you agree or disagree with the statement. Again, there are no right or wrong answers.

<u>Statements</u>	<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Uncertain</u>	<u>Agree</u>	<u>Strongly Agree</u>
1. The best neighborhoods are those where young families intermingle with retired people.					
2. You can't expect other people to take care of you when you no longer can take care of yourself.					
3. No one who is retired and over 70 should be allowed to drive a car.					
4. The older people get, the more they think only of themselves.					
5. Most times I feel relaxed in the company of elderly people.					
6. Old age is O.K. for those who are financially independent.					
7. There is no point in talking about personal matters with people who are much older or much younger than yourself.					
8. You can't cope with things the way you used to if you live to be a ripe old age.					
9. Retired people are happiest in the company of people who are their own age.					
10. Anyone could keep young if he/she only tried.					
11. You're likely to get bogged down if you let elderly people help you with your projects.					
12. No matter what the community can do it is up to the children to see that their aging parents have every comfort.					

<u>Statements</u>	Strongly Disagree	Disagree	Uncertain	Agree	Strongly Agree
13. I cannot help feeling depressed at the thought of getting old.					
14. You can't expect old people to exert themselves.					
15. When you retire you realize that the best years of life are yet to come.					
16. You'll never get old if you don't let yourself go.					
17. It is rather sad to be still alive after all your friends are gone.					
18. The future is so uncertain that there is little point in thinking or planning ahead.					
19. People who spend all they make cannot expect much when they are no longer earning a living.					
20. All community organizations should have some older persons on their boards.					
21. It must be quite a shock to look in the mirror and find that you are showing signs of aging.					
22. Relatives who were close to their parents in former years rightly expect the children to care about their well being if they live a very long life.					



### VII. Coping Questions

How often do you use the following attitudes or behaviors to cope with your role as a caregiver to a dementia patient. (Check the box that best represents how you feel or what you do.)

<u>Question</u>	<u>Almost Always</u>	<u>Often</u>	<u>Undecided</u>	<u>Rarely</u>	<u>Never</u>
1. Hope that things will get better.					
2. Try to maintain some control over the situation.					
3. Find out more about the situation so you can handle it better.					
4. Think through different ways to handle the situation.					
5. Look at the problem objectively.					
6. Eat; smoke; chew gum.					
7. Try out different ways to solve the problem to see which works the best.					
8. Draw on past experiences to help you handle the situation.					
9. Try to find meaning in the situation.					
10. Pray; trust God.					
11. Get nervous.					
12. Worry.					
13. Break the problem down into "small pieces."					
14. Seek comfort or help from family or friends.					
15. Set specific goals to help solve the problem.					
16. Accept the situation as it is.					
17. Want to be alone.					
18. Laugh it off, figuring things could be worse.					

Question	Almost. Always	Often	Undecided	Rarely	Never
19. Try to put the problem out of my mind.					
20. Daydream, fantasize.					
21. Get prepared to expect the worst.					
22. Talk the problem over with someone who has been in the same situation.					
23. Actively try to change the situation.					
24. Get mad; curse; swear.					
25. Cry; get depressed.					
26. Go to sleep figuring things will look better in the morning.					
27. Don't worry about it, everything will probably work out.					
28. Withdraw from the situation.					
29. Work off tension with physical activity.					
30. Settle for the next best thing.					
31. Take out your tensions on someone or something else.					
32. Drink alcoholic beverages.					
33. Resign yourself to the situation because things look hopeless.					
34. Do nothing in the hope that the problem will take care of itself.					
35. Resign yourself to the situation because it is your fate.					
36. Do anything just to do something.					
37. Blame someone else for your problems.					
38. Meditation, yoga, biofeedback.					
39. Let someone else solve the problem.					
40. Take drugs.					

### VIII. Caregiver Opinions

Listed below are a series of attitude statements, each represents a commonly held opinion. There are no right or wrong answers. We are interested in the extent to which you agree or disagree with such matters of opinion. First impressions are usually best. (Check one box for each statement.)

Statement	Strongly Agree	Agree	Uncertain	Strongly Disagree	Disagree
1. Whether or not I get to be a leader depends mostly on my ability.					
2. To a great extent my life is controlled by accidental happenings.					
3. I feel like what happens in my life is mostly determined by powerful people.					
4. Whether or not I get into a car accident depends mostly on how good a driver I am.					
5. When I make plans, I am almost certain to make them work.					
6. Often there is no chance of protecting my personal interest from bad luck happenings.					
7. When I get what I want, it's usually because I'm lucky.					
8. Although I might have good ability, I will not be given leadership responsibilities without appealing to those in positions of power.					
9. How many friends I have depends on how nice a person I am.					
10. I have found that what is going to happen will happen.					
11. My life is chiefly controlled by powerful others.					
12. Whether or not I get into a car accident is mostly a matter of luck.					

Statement	Strongly Agree	Agree	Uncertain	Strongly Disagree	Disagree
13. People like myself have very little chance of protecting our personal interests when they conflict with those of strong pressure groups.					
14. It's not always wise for me to plan too far ahead because many things turn out to be a matter of good or bad fortune.					
15. Getting what I want requires pleasing those people above me.					
16. Whether or not I get to be a leader depends on whether I'm lucky enough to be in the right place at the right time.					
17. If important people were to decide they didn't like me, I probably wouldn't make many friends.					
18. I can pretty much determine what will happen in my life.					
19. I am usually able to protect my personal interests.					
20. Whether or not I get into a car accident depends mostly on the other driver.					
21. When I get what I want, it's usually because I work hard for it.					
22. In order to have my plans work, I make sure that they fit in with the desires of the people who have power over me.					
23. My life is determined by my own actions.					
24. It's chiefly a matter of fate whether or not I have a few friends or many friends.					
25. I feel I have very little control over my life now that I am a caregiver.					



Statement	Strongly Agree	Agree	Uncertain	Strongly Disagree	Disagree
26. The caregiver role is a very satisfying and fulfilling responsibility.					
27. The role of caregiver is the most stressful situation that has happened in my life.					

IX. Support Questions:

1. If you were to list the names of the relatives and friends that are available to you for support in your caregiving responsibilities, how many people would you list?  
       \_\_\_\_\_ people
2. How easy is it for you to contact these people? (Check one answer.)  
       \_\_\_\_\_ Very difficult  
       \_\_\_\_\_ Fairly difficult  
       \_\_\_\_\_ Neither difficult nor easy  
       \_\_\_\_\_ Fairly easy  
       \_\_\_\_\_ Very easy
3. As a group, how often do they help you?  
       \_\_\_\_\_ Never  
       \_\_\_\_\_ Not very often  
       \_\_\_\_\_ Sometimes  
       \_\_\_\_\_ Quite often  
       \_\_\_\_\_ Very often
4. How satisfied are you with the support that you receive from these people?  
       \_\_\_\_\_ Not at all satisfied  
       \_\_\_\_\_ Satisfied a little  
       \_\_\_\_\_ Somewhat satisfied  
       \_\_\_\_\_ Quite satisfied  
       \_\_\_\_\_ Very satisfied
5. Of all these people, is there one specific person that you can share your most personal thoughts and feelings with?  
       \_\_\_\_\_ No  
       \_\_\_\_\_ Yes (If yes, is this person readily available? \_\_\_\_\_ Yes \_\_\_\_\_ No)

X. Community Services

1. Other than your local support group for caregivers, are there community services available to help you with any of your caregiving responsibilities?

☐ (1) No  
☐ (2) Don't know  
☐ (3) Yes (What are they?)

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2. If there are services, have you made use of any of them?

☐ (1) No.... Why not? \_\_\_\_\_  
☐ (2) Yes a. What services? \_\_\_\_\_

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b. How often do you use them?  
☐ (1) Not very often  
☐ (2) Sometimes  
☐ (3) Regularly

3. What single type of community service would you most like to have available?

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We realize that this questionnaire required a great deal of effort and we appreciate it very much. Please use the envelope that we provided to send it back to us. If the envelope was lost our mailing address is:

Gerontology Center  
 College of Nursing  
 University of Utah  
 Salt Lake City, UT 84112

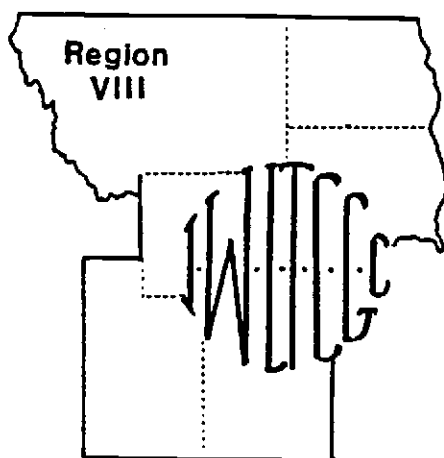
## APPENDIX E

## SUPPORT GROUP DIRECTORIES

## ALZHEIMER'S DISEASE FAMILY SUPPORT GROUP DIRECTORY

### HHS REGION VIII

Colorado  
Montana  
North Dakota  
South Dakota  
Utah  
Wyoming



Intermountain West Long Term Care Gerontology Center  
316 College of Nursing  
University of Utah  
Salt Lake City, UT 84112  
(801) 581-8198

First Edition

FEBRUARY 1985

Compiled by: Dale A. Lund and Michael S. Caserta

## UPDATE

Two of the Planning Centers listed on the inside front page have become fully funded operational centers since publication of this brochure.

The Intermountain West Long Term Care Gerontology Center  
University of Utah — College of Nursing  
Room 316  
Salt Lake City, Utah 84112  
(801) 581-8198

The Southwest Long Term Care Gerontology Center  
University of Texas Health Science Center at Dallas  
5323 Harry Hines Boulevard  
Dallas, Texas 75235  
(214) 688-2820

This means that every HHS region in the United States now has the resources of a Long Term Care Gerontology Center.

### **INTERMOUNTAIN WEST LONG TERM CARE GERONTOLOGY CENTER** **UNIVERSITY OF UTAH, SALT LAKE CITY, UTAH**

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With the extension of the average life span and the high cost of maintaining individual homes in today's economy, many older persons are looking for options in housing arrangements. Some are not physically able to maintain their own homes, yet could avoid institutionalization with the help of a younger live-in person; others are active seniors with independent lifestyles who are looking for a way to reduce expenses, prevent loneliness, and enjoy a family-type setting without going to live with adult children; still others are financially able to maintain their own homes but would like to share a home with another older person for the sake of companionship.

The Intermountain West Long Term Care Gerontology Center, has focused on providing housing options for the elderly within HHS Region VIII. A Student/Senior model matches University students with elderly home providers. Students receive free room and board in exchange for companionship, protection, and assistance with household and yard chores. However, since many students are required to work part-time while attending school, some elderly are left with fewer hours of companionship than they desire.

For this reason, a second model program is in the implementation stage where younger old people (60-75) are recruited to live with older more frail home providers in a similar arrangement.

Another viable housing alternative meets the needs of the well elderly who desire to reduce living expenses and still have the atmosphere of a private home. The Center has initiated a project of homesharing, called "Group Living." A large home is purchased, remodeled, and maintained by a local housing authority. Persons with reasonably good health who meet the income requirements of \$15,000/year or less can participate.

The IWLTCCG is one of the youngest of the Long Term Care Centers but has already established a reputation for excellence as a resource to the aging network of Region VIII. In addition to establishing service models on housing, the Center has made major research contributions in the area of grief and bereavement and in the development of medical curricula.

# Alzheimer's Disease Family Support Groups

HHS Region VIII

(Sponsoring Agencies and Contact Persons)

## COLORADO

ADRDA - Metro Denver Chapter  
4567 East Ninth Avenue  
Denver, CO 80220

Contact: Rosie Riek  
2042 West 101st Street  
Denver, CO 80221

Marjorie Fitzgerald  
4824 South Jason St.  
Englewood, CO 80110

St. Mary-Corwin Hospital  
Regional Medical and Health Ctr  
1008 Minnequa Avenue  
Pueblo, CO 81004

Contact: Elaine Pacheco, ACSW

Colorado Springs Steering Committee  
Penrose Hospital  
2215 N. Cascade Avenue  
Colorado Springs, CO 80907

Contact: Mrs. James V. Carris  
1334 Culebra Ave  
Colorado Springs, CO 80903

No Sponsoring Agency:

Contact: Stella B. Rector  
1441 Patterson Road #801  
Grand Junction, CO 81501

## MONTANA

RSVP  
333 North Washington  
Missoula, MT 59802

Contact: Kathleen T. Reynolds  
#226 2400 Fort Rd.  
Missoula, MT 59801

V.A. Medical Center  
210 South Winchester  
Miles City, MT 59301

Contact: Marielaine Hegel

Montana Deaconess So. Medical Ctr  
1101 26th Street So.  
Great Falls, MT 59405

Contact: Chuck Cerny, Ed. Dir.

SOUTH DAKOTA

ADROA - Siouxland Chapter  
1600 Edgewood Road  
Sioux Falls, SD 57103

Contact: Eileen Devick

No Sponsoring Agencies:

Contact: Cheryl A. Hamm  
P.O. Box 2440  
Rapid City, SD 57709

Contact: Judy Bergan  
116 South Lake Drive  
Watertown, SD 57201

UTAH

Logan Support Group  
1575 North 1600 East  
Logan, UT 84321

Contact: Jeanne S. Weeks

Sevier County Council on Aging  
P.O. Box 612  
Richfield, UT 84701

Contact: LaRae Ogden  
260 North 100 East  
Richfield, UT 84701

ADROA - Salt Lake Chapter  
1481 Woodland Avenue  
Salt Lake City, UT 84106

Contact: A.B. Blake

Utah County Branch of ADROA  
1161 East 300 North  
Provo, UT 84601

Contact: Bobbie Pillar

Hillhaven Convalescent Center  
41 South 900 East  
Salt Lake City, UT 84102

Contact: Ryan P. Thorn

WYOMING

Newcastle Alzheimer's Family  
Support Group  
Box 656  
Newcastle, WY 82701

Contact: Mary A. Capps

No Sponsoring Agency:

Contact: Darlene Rolf, BSW  
4776 Maple Way  
Cheyenne, WY 82009

Billings Alzheimer's Family  
Support Group  
c/o Bobbie Lavers - President  
1215 Avenue D  
Billings, MT 59102

Contact: Sherry Nickoloff, Director  
Social Services  
St. John's Lutheran Home  
3940 Rimrock Road  
Billings, MT 59102

Case Management Services  
300 North Willson Suite 11  
Bozeman, MT 59715

Contact: Therese Bosch  
Kountz Trailer Ct. #64  
Bozeman, MT 59715

The Retired/Volunteer Program  
807 North Tracy  
Bozeman, MT 59715

#### NORTH DAKOTA

Bethel Lutheran Home  
7515 2nd Avenue West  
P.O. Box 1828  
Williston, ND 58802

Contact: Beverly Bjella

Marion Manor  
Glen Ullin, ND 58631

Contact: Janet Auer, RN

St. Aloisius Hospital  
325 East Brewster  
Harvey, ND 58341

Contact: Donna Corneliusen

Lutheran Social Services  
1325 South 11th Street  
Fargo, ND 58103

Contact: Lenore Wermager  
102 21st Ave. North  
Fargo, ND 58102

St. Alexis Medical Center  
900 East Broadway Avenue  
Bismarck, ND 58501

Contact: Nancy Nelson or  
LaVonne Hastings

No Sponsoring Agency:

Contact: Marjorie Rykken  
UNO College of Nursing  
Grand Forks, ND 58202



# ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOCIATION OF COLUMBIA-WILLAMETTE

## "local support groups"

ALBANY	Julie Womack	LinnCare Convalescent Ctr. 1023 W. 6th Albany, Oregon 97321	
BAKER	Wes Brown	Route 1, Box 133 Baker, Oregon 97814	
	Sandy Kuroski 523-6461	St. Elizabeth Community Hosp. Box 766 Baker, Oregon 97814	
BEND	Virginia Martynowicz	95 N.W. Xermes Bend, Oregon 97701	or Doris Edmunson 389-5071
BURNS	Helen Sargeant 573-7281	557 W. Washington Burns, Oregon 97720	
CORVALLIS	Don Mangelli 754-6454 (H) 757-6844 (W)	Benton County Mental Health 530 N.W. 27th Corvallis, Oregon - 97330	
THE DALLES/ HOOD RIVER	Jan Stanfield (509)493-1297	Box 552 White Salmon, WA 98672	or Virginia Klindt 296-2056
EUGENE	Virginia Gates 484-9264 (H) 686-7162 (W)	3536 W. 15th Ave. Eugene, Oregon 97405	
GRANTS PASS	Margaret Bray 476-7180 (H) 479-9797 (W)	825 Trollview Road Grants Pass, Oregon 97526	
HERMISTON	Sally Peatow, R.N. 567-6483	Good Shepherd Hospital 685 Orchard Avenue Hermiston, Oregon 97838	
KLAMATH FALLS	Kris Riggs	891 Kane St. Klamath Falls, Oregon 97601	or Jane Pickett 882-7291
LA GRANDE	Norma Cooney 963-8421	Director of Education Grand Ronde Hospital 900 Sunset Drive LaGrande, Oregon 97850	
LEBANON	Susan Dahlen	Lebanon Community Hospital 525 N. Santiam Hwy. Lebanon, Oregon 97355	1st Thursday, 1:00 pm 3rd Thursday, 7:30 pm
LINCOLN CITY	Wilma Kiefer 994-3661		97367
MADRAS	Dorothy Saunders 475-3882 ext. 22	Mountain View Nursing Home 1270 "A" St. Madras, Oregon 97741	
MEDFORD	Chris Parfitt 773-6281	Community Relations Coord. Mental Health Unit Rogue Valley Memorial Hosp. 2825 Barnett Road Medford, Oregon 97501	

NORTH BEND	Deloras Hart 756-7769	701 W. Way North Bend, Oregon 97459	
ONTARIO	Evelyn Vanca (208)452-4193  Cathy Braasch 889-5331	P.O. Box 4 Fruitland, Idaho 83619  Holy Rosary Hospital Public Affairs 351 S.W. 9th Ontario, Oregon 97914	
OREGON CITY	Marty Schippers 657-5856  Pat Howard		4th Tuesday  meet in Board Room 4th Tuesday
PENDLETON		Willamette Falls Community Hosp. 1500 Division St. Oregon City, Oregon	97045
PORTLAND METRO AREA	<u>Beaverton</u> Jackie May 646-8468 (eve.)  <u>East/Northeast</u> Sharon Moody 232-0306  <u>Gresham</u> Carol Nightengale or Rita- 665-1151  <u>Hillsboro</u> Joyce Gallovich 648-8588  <u>Lake Oswego</u> Nancy Paulk 636-9614  Cindy Reisler 635-3758  <u>Milwaukie/ Clackamas</u>  <u>Tigard</u> 620-4613  <u>West/Southwest</u> Bob Shears 246-7378	Elsie Stuhr Adult Ctr. 555 S.W. Hall Portland, Oregon 97005  First Covenant Church 45th and E. Burnside 97208  Rest Harbor Extended Care Ctr. P.O. Box 525 97030  Oak Villa Nursing Home 650 E. Oak Hillsboro, Oregon 97123  Mountain Park Convalescent Ctr. P.O. Box 527 Lake Oswego, Oregon 97034  Lake Oswego Adult Community Ctr. 505 G Avenue Lake Oswego, Oregon 97034  Milwaukie Center 5440 S.E. Kellogg Creek Dr. Milwaukie, Oregon 97222  Tigard Senior Center 8815 S.W. Omara Tigard, Oregon 97042  Multnomah School (Senior Ctr.) 7688 S.W. Capital Highway Portland, Oregon 97219	1st Monday, 2:30 pm Ann Hilles - 643-2654  4th Tuesday, 7:00 pm             meetings at Hillsboro Senior Center  1st Monday, 7:00 pm     4th Tuesday, 7:00 pm   4th Tuesday, 7:00 pm
ROSEBURG			
ST. HELENS	Donna Tewksbury 397-1188 ext. 222	Director of Social Services Columbia District Hospital St. Helens, Oregon 97051	

<u>SALEM</u>	Barbara Nelson 364-9361 Major Longdon 399-0206	Salvation Army Headquarters Market/Winter St. NE Salem, Oregon 97302	3rd Thursday
SEASIDE	Janet Howell 738-5533	317 S. Columbia Seaside, Oregon 97138	
SILVERTON	Joan Rader	Mt. Angel Home 514 W. Main Silverton, Oregon 97381	
SUBLIMITY	Joan Kerns 378-9077 (H) 769-3499 (W)		
WOODBURN	William Cooper	950 N. Cascade Drive #132 Woodburn, Oregon 97071	

WASHINGTON

Ranier/ Longview-Kelso	Joyce Dick	606 Ostrander Kelso, WA 98526	
Vancouver	694-6300	Alzheimer's Caregivers Assn. 4420A St. John's Blvd. Vancouver, Washington 98663	open 12:00-3:00

Region VIAlzheimer's Disease Family Support GroupsArkansas

1. Alzheimer's Disease Support Group of Central Arkansas, Inc.  
 Contact/Location of Meetings:  
 Marie Nolen  
 Tel (501) 664-3117  
 University of Arkansas Medical  
 Sciences Campus  
 Education 2 Building, Room 6132  
 Little Rock, AR
  
2. Alzheimer's Disease Support Group  
 Contract/Location of Meetings:  
 Teresa Miller  
 Tel (501) 623-5037  
 Garland Towers  
 126 Oriole  
 Hot Springs, AR 71901
  
3. Alzheimer's Disease Support Group  
 Contract/Location of Meetings:  
 Perry Myun  
 Tel (501) 862-7921  
 South Arkansas Regional  
 Health Center  
 715 North College  
 El Dorado, AR 71730
  
4. Alzheimer's Disease Support Group  
 Contract/Location of Meetings:  
 Liz Vallance  
 Tel (501) 362-8137  
 Geriatrics Nursing Center  
 1040 Wedding Ford Road  
 Heber Springs, AR 72543
  
5. Alzheimer's Disease Support Group  
 Contract/Location of Meetings:  
 Louis Helverston  
 Tel (501) 425-6316  
 Chastain's Nursing Home  
 1100 Pine Tree Lane  
 Mountain Home, AR 72653

Support Groups (continued):

3. Bill Hugg  
P. O. Box 1846  
Clovis, NM 88101  
Tel (505) 762-5592

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4. Joe Fallon  
405 DeKalb Avenue, Apt  
Farmington, NM 87401  
Tel (505) 326-5373

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5. Mrs. Hildur Benting  
2060 Garrison  
Las Cruces, NM 88001

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6. Doris Krause  
5 Camino Pequeno  
Santa Fe, NM 87501  
Tel (505) 582-5906

TexasAlzheimer's Disease and Related Disorders  
Association (ADRDA) ChaptersContact/Location:

1. Becky McGee  
Tel (806) 381-1010 (Amarillo)  
c/o Panhandle Area Agency on Aging  
~~901 Capitol Building, Suite 200~~  
Amarillo, TX 79105  
Tel (806) 372-3381

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2. Clay Walker  
Tel (512) 886-4445 (Corpus Christi)  
c/o Coastal Bend Area Agency on Aging  
2910 Leopard Street  
P. O. Box 9909  
Corpus Christi, TX 78408  
Tel (512) 883-5743

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3. Michael Luyt  
Tel (214) 424-1929 (Dallas)  
or  
Jo Ann Ray (Dallas)  
Tel (214) 270-9604 or (214) 948-7973  
c/o Dallas County Area Agency on Aging  
1900 Pacific Building, Suite 75201  
Tel (214) 741-5851

- 
6. Foothills Alzheimer's Support Group  
 Contact/Location of Meetings:  
 Patti Goff  
 Tel (501) 268-0233  
 Searcy Housing Authority Building  
 501 So. Fir Street  
 Searcy, AR 72143

- 
7. Alzheimer's Disease Support Group  
 Contact/Location of Meetings:  
 Stan Krueger  
 Tel (501) 521-1694  
 First United Methodist Church  
 206 West Johnson  
 Springdale, AR 72764

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New Mexico

- 
1. Alzheimer's Disease Support Group  
 Contact/Location of Meetings:  
 Jane Levy  
 Tel (505) 266-2195  
 Highland Senior Center  
 131 Monroe NE  
 Albuquerque, NM 87108
- 
2. Alzheimer's Disease Support Group  
 Contact/Location of Meetings:  
 Milton R. Wolfson  
 Tel (505) 437-8071  
 Counseling Center  
 1408 Eighth Center  
 Alamogordo, NM 88310

Alzheimer Support Group Contacts:

(Listing represents local contacts which will provide information on support groups and/or hold meetings on an irregular basis).

1. Harold Dunagan  
 P. O. Box 828  
 Bayard, NM 88023  
 Tel (505) 537-5787
2. Barbara Bryan  
 302 Riverside Drive  
 Carlsbad, NM 88220  
 Tel (505) 885-4048

4. Grace Braly  
Tel (915) 587-4926 (El Paso)  
or  
Virginia Fisk  
Tel (915) 584-1762 (El Paso)  
c/o West Texas Area Agency on Aging  
#2 Civic Center Plaza  
8th Floor  
El Paso, TX 79999  
Tel (915) 541-4972
5. Mary Jane Carpenter  
Tel (713) 721-6331 (Houston)  
or  
Lorene Wyatt  
Tel (713) 780-0811 (Memorial City)  
or  
Muriel Kuykendall  
Tel (713) 473-1771 (Ext 535) (Pasadena)  
c/o Harris County Area Agency on Aging  
402 Pierce Street  
Houston, TX 77002  
Tel (713) 757-7822
6. Gerald Boelter  
Tel (817) 297-1396 (Fort Worth)  
or  
(817) 297-1396 (Fort Worth)  
or  
(817) 738-7727  
c/o Tarrant County Area Agency on Aging  
210 E. Ninth Street  
Fort Worth, TX 76102  
Tel (817) 335-3473

Satellite Alzheimer's Disease Family Support Groups:

Contact/Location:

1. Vicki Strader  
Tel (512) 447-4141 (Austin)  
or  
Roy Craig  
Tel (512) 453--4375  
c/o Capital Area Agency on Aging  
2520 Interstate Hwy 35 South  
Suite 100  
Austin, TX 78704

2. Leona Cook  
Tel (713) 334-4157 ("Bay Area")  
or  
Ed Rauch  
Tel (713) 482-1700  
c/o Harris County Area Agency on Aging  
402 Pierce Street  
Houston, TX 77002  
Tel (713) 757-7822
3. Beverly Smythia  
Tel (409) 898-0836 (Beaumont-Port Arthur)  
c/o South East Texas Area Agency on Aging  
3006 E 29th Street  
P. O. Drawer 4128  
Bryan, TX 77805  
Tel (409) 822-7421
4. Jane Donaldson  
Tel (409) 822-7421 (Bryan-College Station)  
c/o Brazos Valley Area Agency on Aging  
3006 E. 29th Street  
P. O. Drawer 4128  
Bryan, TX 77805  
Tel (409) 822-7421
5. Jo Scott  
Tel (409) 763-6022 (Galveston)  
or  
(713) 488-0671 (Ext 29)  
c/o Houston-Galveston Agency on Aging  
3701 W. Alabama  
P. O. Box 22777  
Houston, TX 77027  
~~Tel (713) 627-3200~~ 443-3370
6. Mary Glenn Allison  
Tel (713) 862-8805 (Humble)  
or  
(713) 376-3472  
c/o Harris County Area Agency on Aging  
Pierce Street  
Houston, TX 77002  
~~Tel (713) 757-7822~~
7. Ann Pratt  
Tel (409) 384-5704 (Jasper)  
c/o Deep East Texas Area Agency on Aging  
272 East Lamar Street  
P. O. Drawer 1170  
Jasper, TX 75951  
Tel (409) 384-5704



8. Mary Lou Lock  
Tel (214) 297-7268 (Longview)  
c/o East Texas Area Agency on Aging  
3800 Stone Road  
Kilgore, TX 75662  
Tel (214) 984-8641
9. Eva Walraven  
Tel (915) 653-9360 (San Angelo)  
or  
c/o Concho Valley Area Agency on Aging  
5002 Knickerbocker Road  
P. O. Box 60050  
San Angelo, TX 76906  
Tel (915) 944-9666
10. Mary Fletcher  
Tel (915) 653-9360 (San Angelo)  
or  
c/o Bexar County Area Agency on Aging  
118 Broadway, Suite 400  
San Antonio, TX 78205  
Tel (512) 225-5201
11. Karen Houston  
Tel (817) 778-4811 (Temple)  
c/o Central Texas Area Agency on Aging  
100 So. East Street  
P. O. Box 729  
Belton, TX 76513  
Tel (817) 939-1886 and 1887
12. Audrey Beason  
Tel (817) 778-4811 (Texas City)  
c/o Houston-Galveston Area Agency on Aging  
3701 West Alabama  
P. O. Box 22777  
Houston, TX 77027  
Tel (713) 627-3200
13. Pat Cook  
Tel (214) 592-5203 (Tyler)  
c/o East Texas Area Agency on Aging  
3800 Stone Road  
Kilgore, TX 75662  
Tel (214) 984-8641

14. Risa Stewart  
Tel (512) 576-2189 (Victoria)  
c/o Golden Crescent Area Agency on Aging  
715 So. Main  
P. O. Box 2028  
Victoria, TX 77902  
Tel (512) 578-1587
15. Howard Gruetzner  
Tel (817) 752-3451 (Waco)  
c/o Heart of Texas Area Agency on Aging  
320 Franklin Avenue  
Waco, TX 76701  
Tel (817) 756-6631

## ALZHEIMER'S SUPPORT GROUPS

## LOUISIANA

BATON ROUGE

Mona J. Romaine  
Medical Personnel Pool  
P.O. Box 14351  
Baton Rouge, LA 70898-4351  
Phone (504) 928-2888

MONROE

Christopher Johnson  
Northeast Louisiana University  
Monroe, LA  
Phone (318) 342-2039

NEW ORLEANS

Diane Young, President  
ADRDA  
DePaul Hospital  
1040 Calhoun  
New Orleans, LA. 70118  
Phone (504) 895-6223

SHREVEPORT

Ann Eddy  
4015 Greenwood  
Shreveport, LA 71109  
Phone (318) 636-7956

JEFFERSON PARISH

Jefferson Caregiver's Support Group 102  
2301 Idaho-Westminister Towers  
Kenner, LA 70062

Oklahoma

1. Alzheimer's Disease and Related Disorders Association, Inc.  
Contact:

Jerry Robinson, President  
Tel. (405) 843-4680  
1613 Andover Court  
Oklahoma City, Oklahoma 73120

2. Alzheimer's Disease Family Support Group  
Contact/Location of Meetings:

Kay Galliland  
Tel. (405) 772-5427  
Weatherford City Hall  
Weatherford, Oklahoma 73624

3. Day by Day Alzheimer's Group  
Contact/Location Meetings:

Rod Donley  
or  
Arlene Adams  
Tel. (405) 256-5511  
Woodward Memorial Hospital  
1014 17th Street  
Woodward, Oklahoma 73801

4. Alzheimer's Disease Support Group  
Contact/Location of Meetings:

Senior Citizens Center  
Tel. (405) 256-9263  
1420 South Downs  
Woodward, Oklahoma 73801

5. Alzheimer's Disease Family Support Group  
Contact:

Mrs. Ester Mary Reiswig  
Tel. (405) 625-3616  
602 Avenue J  
Beaver, Oklahoma 73932

Oklahoma (Continued)

6. Elders Family Circle  
Contact/Location of Meetings:

Jacqueline Cook  
Tel. (405) 524-6363  
Oklahoma County Mental Health Center  
5401 N. Francis, Suite B  
Oklahoma City, Oklahoma 73118

7. ADRDA Support Group  
Contact:

Judy Carella, M.A., MPH  
Tel. (405) 524-7711  
Red Rock Mental Health Center  
214 East Madison  
Oklahoma City, Oklahoma 73105

## APPENDIX F

## INQUIRY LETTER TO SUPPORT GROUP LEADERS

THE  
UNIVERSITY  
OF UTAH

GERONTOLOGY PROGRAM  
UNIVERSITY OF UTAH  
316 COLLEGE OF NURSING  
SALT LAKE CITY, UTAH 84112  
(801) 581-8198

June 7, 1985

Dear Support Group Leader:

The Intermountain West Long Term Care Gerontology Center is initiating a major study of Alzheimer's Disease (and other related disorders) caregivers and we need your assistance to ensure that we have a high quality study. We are interested in studying the caregivers' coping strategies, and to see if we can identify the factors that are most strongly related to the likelihood of future institutionalization. We have already pilot tested a questionnaire that we would like to have completed by over 1,000 caregivers.

In order to identify the caregivers we have decided to ask for your help. We are asking all of the contact people of the A.D. family support groups in MHS Region VIII, Region VI and the States of Oregon and Washington, to send us a list of all the caregivers who attend or belong to their support group. We need to have their names and mailing addresses so that we can send them a questionnaire. None of the people will be identified by name or in any other way in the published reports on the study. Their confidentiality will be guaranteed.

Ms. Ann Bayne Jones, with the Administration on Aging in Region VI is supportive of this study. She has helped us to identify the support groups in your local area.

We hope to learn some valuable information from this study that will be helpful to these caregivers. We will also send you copies of any published or printed materials that result from this study. I hope that you will be able to assist us in this important project. If you have any questions, please let me know.

Sincerely,

## APPENDIX G

## FOLLOW-UP LETTER



July 19, 1985

Dear Support Group Leader:

This letter is being sent as a follow up to our original letter sent on June 20, 1985 regarding our research study initiated through the Intermountain West Long Term Care Gerontology Center. In that original letter we had asked support group leaders (like yourself) to send us a mailing list of all the caregivers who attend or belong to your support group. We had requested this list with names and addresses so that we could send them a questionnaire which would identify factors to enhance caregiver coping abilities and also influence the likelihood of future institutionalization. This study will also provide some information on how these caregivers view their support group experience. We had emphasized that confidentiality would be guaranteed and that none of the caregivers involved in this study would be identified by name or in any other way in published reports of the study.

The research study that we are conducting represents a major effort in understanding how caregivers of dementia patients adapt and cope in the careproviding role. In fact, this project is the first major study to include caregivers from an 15 state region. We have already received mailing lists from over 30 different support groups (throughout the 15 state region), but because we have not received any indication of your intent to participate, we are again requesting your assistance. With your cooperation and the caregivers' participation in this project we can be assured of a high quality study that will provide valuable information that will be helpful to all caregivers of dementia patients.

We hope that you will be able to assist us in this important project by sending us this mailing list. If you have any questions, please let me know by writing or calling at the phone number and address below. Thank you very much.

Sincerely,

jkb

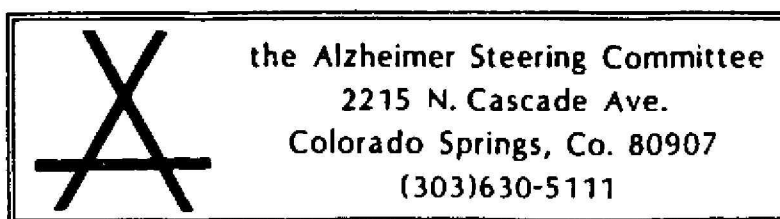
## APPENDIX H

## SUPPORT GROUP RESPONSE

Corvallis	Williston
The Dalles/Hood River	Harvey
Klamath Falls	Fargo
Lebanadon	Bismarck
Medford	Grand Forks
Oregon City	East/Northwest (Portland)
Silverton	West/Southeast (Portland)
Woodburn	Dallas
Ranier/Kelso	Beaumont
Sioux Falls	San Antonio
Salt Lake City	Monroe
Denver	Shereveport
Pueblo	Heber Springs
Colorado Springs	Searcy
Grand Junction	Springdale
Alturas	Farmington
Cheyenne	Las Cruces
Miles City	Santa Fe
Great Falls	Albuquerque

APPENDIX I

LETTER: CONCERN FOR CONFIDENTIALITY



June 11, 1985

Dear Friend of the Colorado Springs Alzheimer Support Group:

Our committee has been asked to cooperate with a study being made by the University of Utah , Program of Gerontology.

We are eager to cooperate in any way possible to further the cause of Alzheimer's disease; however, because our committee feels that your names, as caregivers on our files, are confidential, we have requested that we do the mailing. In other words, your name has not been given to the University of Utah but the materials have been sent to us to mail to you.

We do believe this study is important for you and your loved one and those in the future who may be afflicted with Alzheimer's disease. We do encourage you to complete the questionnaire with as much care and accuracy as possible. Please know that your cooperation will make a difference. It is only through total teamwork that we can surmount this difficult social, medical, financial and national problem.

Thank you in advance for your prompt participation in this project.

Sincerely yours  
Redacted for Privacy  
Flo W. Carris,  
[Mrs. James V.]  
Coordinator

July, 1985  
Cheyenne, WY

Dear Caregiver:

Our local support group, the "Alzheimers Care Team" is cooperating with the University of Utah in their efforts to learn more about the problems confronting caretakers.

They would like each of our members/contacts to fill out a questionnaire (enclosed). Rather than give out your names and addresses, as requested, we asked that the University send the appropriate materials to us and allow us to do the mailing to our membership.

Please read the cover letter from the University, complete the questionnaire and process it as requested. I sincerely hope you will give your support and cooperation to this project.

If you have any questions, please feel free to contact me. Thank you for your assistance.

Sincerely,

Redacted for Privacy

Darlene Rolf, B.S.W.  
Facilitator  
632-3288

*Alzheimer's Disease and Related Disorders Assn*  
*Albuquerque, New Mexico 87103*  
*PO Box 1368 (505) 266-2195*

Dear Sir,

As phone co-ordinator for the New Mexico Chapter ADRDA, I have a comprehensive list of the care givers with whom we are in regular contact.

Before forwarding a list to you, I would like a copy of the questionnaire sent to me at the above address. Then our board of directors could look it over. Some of our caregivers have gotten letter shy by getting on the mailing of some not so honest people.

I would also need an assurance in writing that this list would be confidential and not sold or lent to commercial entities.

We really feel that you might be on the right track in doing your study, and hope something good comes out of it. We would really appreciate hearing from you when your study is done.

Thank You.

Jane Levy

Communications co-ordinator

## APPENDIX J

LETTER EXPLAINING REMINDER POST CARD



THE  
UNIVERSITY  
OF UTAH

GERONTOLOGY PROGRAM  
UNIVERSITY OF UTAH  
316 COLLEGE OF NURSING  
SALT LAKE CITY, UTAH 84112  
(801) 581-8108

May 28, 1985

Mrs. Flo W. Carris  
The Alzheimer's Steering Committee  
2215 N. Cascade Ave.  
Colorado Springs, CO 80907

Dear Mrs. Carris:

Enclosed within the envelop you will find our questionnaires for the caregivers in your support group for the Colorado Springs area. We do appreciate your willingness to write a cover letter which would accompany each questionnaire. We agree that your local encouragement will help us acheive a better response rate.

At the top of each questionnaire you will notice that a two digit number is marked to indicate site location only. We would appreciate if you would assign a three digit code number to each questionnaire, so that it may be possible to send a polite reminder letter to those who do not return the questionnaire within three to four weeks. For example, each caregiver on the mailing list would receive a three digit identification number starting with 001..., 002..., and so on until each caregiver has a number. If you were to maintain a "master list" with the caregivers and their identification numbers, we would be able to tell you after a period of time which caregiver (identified by I.D. number only) had not returned their questionnaire. This would enable us to send them (through your cooperation) a polite reminder letter.

You will also find enclosed within this envelop stamps, envelopes for mailing, and envelopes for returning the questionnaires.

We would like to finally add, that your cooperation is most encouraging. Your willingness to distribute the questionnaires to the caregivers in your area will help to make this research project a great success. It is our hope that with the cooperation of dedicated people like yourself, the information we gain from the caregiver's responses will help caregivers of dementia patients to better adapt and cope with the care-providing role.

If there are any questions, or if there is any way we can help with the questionnaire distribution, please contact me at the Gerontology Program at the University of Utah.

Sincerely,

THE  
UNIVERSITY  
OF UTAH

GERONTOLOGY PROGRAM  
UNIVERSITY OF UTAH  
310 COLLEGE OF NURSING  
SALT LAKE CITY, UTAH 84112  
(801) 581-8108

June 13, 1985

Mr. Charles Cerny  
Assistant Vice President  
Director of Education  
Montana Deaconess Medical Center  
1101 Twenty-sixth St. South  
Great Falls, MT 59405-5193

Dear Mr. Cerny:

Enclosed you will find our questionnaires for the caregivers in your Great Falls support group. We do appreciate your willingness to assist in the distribution of the questionnaires. We believe your local encouragement will help us achieve a better response rate.

At the top of each questionnaire you will notice a three-digit number is marked to indicate "site" location only. We would appreciate if you would assign a three digit number to each questionnaire (perhaps on the back of the last page), so that it might be possible to send a reminder letter to those who do not return the questionnaire within three to four weeks. For example each caregiver on the mailing list would receive a three digit identification number starting with 001, 002, and so on until each caregiver has a number.

If you would maintain a "master list" with the caregivers and their identification numbers, we would be able to tell you after a period of time which caregivers (identified by I.D. number only) had not returned their questionnaire. This would enable us to send them (through your cooperation) a polite reminder letter.

You will also find enclosed sheets that contain enough postage stamps to mail questionnaires out to the caregivers who do not attend support group meetings, postage for returned responses, mailing labels and return envelopes. By our calculations, questionnaires mailed out to caregivers should have 90¢ of postage on each envelope. The "return" envelope should have 73¢ of postage. We would also appreciate the return of any stamps, envelopes, etc. not used after the distribution of the questionnaires.

We would like to finally add that your cooperation is most encouraging. Your assistance will help to make this research project a great success. It is our hope that with the cooperation of dedicated people like yourself, the information we gain from the caregiver's responses will help caregivers of dementia patients to better adapt and cope with the care providing role.

If there are any questions or if there is any way we can help to facilitate the questionnaire distribution, please contact me at the Gerontology Program at the University of Utah.

Sincerely,

APPENDIX K  
MAILING DATES

June 4, 1985	First Mailing Wave
June 18, 1985	Second Mailing Wave
July 1, 1985	Third Mailing Wave
July 25, 1985	Fourth Mailing Wave

## APPENDIX L

## REMINDER POST CARD

Dear Caregiver:

We are contacting you to remind you of our research project which studies the impact of family caregiving on for persons with dementia. Because we have not received your questionnaire yet, we are again requesting your assistance. If you have misplaced or lost the questionnaire, we would be glad to send you another. If you have not completed the questionnaire, we would like to encourage you to complete it so that we can be assured of a high quality study that will provide valuable information that will be helpful to all caregivers of dementia patients.

Thank you,

UNIVERSITY OF UTAH  
GERONTOLOGY PROGRAM  
SALT LAKE CITY, UTAH 84112

NON-PROFIT ORG.  
U. S. POSTAGE PAID  
PERMIT NO. 1529  
SALT LAKE CITY, UTAH

## APPENDIX M

## CORRELATION MATRIX

	Internal	Powerful Others	Chance	Situational Control	Role Satisfaction	Role Stress	Objective Evaluation	Patient Emotional Status	Patient Physical Status	Network Size	Ease of Contact
Internal	1.0000										
Powerful Others	-.0451	1.0000									
Chance	-.1115	.6017	1.0000								
Situational Control	-.0998	.3378	.3344	1.0000							
Role Satisfaction	.0398	.0039	.0786	-.2147	1.0000						
Role Stress	-.0377	.0892	.1366	.2481	-.3153	1.0000					
Objective Evaluation	-.0996	.0218	.1416	.1539	-.0561	.1599	1.0000				
Patient Emotional Status	.0996	.0387	-.0521	-.1463	.1252	-.1657	-.4265	1.0000			
Patient Physical Status	-.0032	-.0859	-.1327	-.0575	-.0590	-.0394	-.2326	.3913	1.0000		
Network Size	.0667	-.0628	-.0975	-.1010	.1196	-.0778	-.0286	.0149	.1111	1.0000	
Ease of Contact	.0477	-.1197	-.1537	-.2000	.1006	-.1222	-.0198	.0918	.1076	.0359	1.0000
Degree of Contact	.0365	.0004	.0002	-.0778	.1321	-.1148	.0547	-.1186	-.0265	-.1124	-.3463
Support Satisfaction	.0611	-.0922	-.0634	-.2059	.2563	-.1542	.0166	.0549	.0398	.1560	.4044
Problem Oriented	.1311	-.0192	-.0634	-.0770	.1275	-.0755	.0828	-.0240	-.0486	-.0017	.0124
Avoidant/ Evasive	-.1108	.2988	.3723	.3831	-.2585	.3573	.2733	-.2407	-.1402	-.0816	-.2214
Reframing	.1211	.1030	.0960	-.0103	.1580	-.0603	.0625	-.0117	-.0592	.0358	-.0074
Aggressive	-.0930	.0844	.0940	.1938	-.2112	.2174	.0773	-.0928	-.0361	-.0069	-.1891
Burden	-.0224	.1477	.1263	.3748	-.3464	.4189	.2672	-.2156	-.0687	-.0942	-.3181
Life Satisfaction	.2780	-.3265	-.4014	-.4187	.1405	-.2290	-.1119	.1367	.1611	.1435	.1930
Health Status Before	.0960	-.0595	-.1160	-.1323	.0149	-.0340	-.0326	.1171	.0907	.1516	.0178
Health Status Present	.0816	-.1616	-.1808	-.2571	.0899	-.1574	-.2170	.2333	.2153	.1159	.1667
Change in Health Status	-.0248	.2349	.1902	.2551	-.1781	.3099	.3073	-.1528	-.1859	-.0777	-.1535



	Degree of Contact	Support Satisfaction	Problem Oriented	Avoidant/ Evasive	Reframing	Regressive	Burden	Life Satisfaction	Health Status Before	Health Status Present	Health Status
Internal											
Powerful Others											
Chance											
Situational Control											
Role Satisfaction											
Role Stress											
Objective Evaluation											
Patient Emotional Status											
Patient Physical Status											
Network Size											
Ease of Contact											
Degree of Contact	1.0000										
Support Satisfaction	.5770	1.0000									
Problem Oriented	.0696	.1463	1.0000								
Avoidant/ Evasive	-.0628	-.1818	-.0269	1.0000							
Reframing	.0718	-.0051	.2783	.1566	1.0000						
Regressive	-.1363	-.2157	-.0139	.4898	.1096	1.0000					
Burden	-.2583	-.2501	.0240	.4788	.0836	.3724	1.0000				
Life Satisfaction	.0643	.2116	.1974	-.4375	.1275	-.2668	-.2543	1.0000			
Health Status Before	-.0392	-.0043	.1117	-.1378	.0836	-.0850	-.0016	.2200	1.0000		
Health Status Present	-.0087	.1002	.0397	.3176	-.0042	-.1347	-.3428	.3846	.5909	1.0000	
Change in Health Status	-.0518	-.1366	.0670	.3891	.0849	.1963	.5652	-.2993	-.0812	-.3043	1.0000