THE RELATIONSHIPS OF PERCEIVED STRESS, COPING STRATEGIES, AND SPECIFICALLY RELIGIOSITY ON SUBJECTIVE WELL-BEING OF FAMILY CAREGIVERS FOR INDIVIDUALS AFFECTED BY ALZHEIMER'S DISEASE

DISSERTATION

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BY

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To the special men in my life:
Tom, my husband and life time partner,
and our sons Brian and Sean.
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# TABLE OF CONTENTS

ACKNOWLEDGEMENTS ........................................ iii
VITA ....................................................... ix
LIST OF TABLES ......................................................... xii
LIST OF FIGURES ......................................................... xiii

CHAPTER I - INTRODUCTION ................................. 1
  Significance of the Study ................................. 1
  Problem Statement ......................................... 4
  Hypotheses .................................................. 4
  Definition of Terms ......................................... 5
  Limitations of the Study .................................... 8
  Basic Assumptions ............................................ 8
  Delimitations ................................................ 9

CHAPTER II - REVIEW OF THE LITERATURE ............. 10
  Introduction ................................................. 10
  The AD Caregiver and Subjective Well-Being .......... 10
  Theoretical Frameworks .................................... 28
  Caregiver Coping and Religiosity ........................ 37
  Conclusions .................................................... 45

CHAPTER III - PROCEDURES ................................. 48
  Research Design ............................................. 48
  Subject Selection ........................................... 49
  Measures ..................................................... 51
  Conditions of Testing ...................................... 58
  Data Analysis ................................................ 59

CHAPTER IV - RESULTS AND DISCUSSION ................. 64
  Description of Responding Sample ........................ 64
  Descriptive Statistics for Measured Variables ........ 76
  Hypothesis Testing .......................................... 76
  Summary of Findings ........................................... 93
CHAPTER V - DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS .................. 95

Introduction .................................................. 95
Discussion ..................................................... 95
Implications for practice ................................. 108
Recommendations for future research .............. 113

APPENDICES ...................................................... 117

A. Cover letter ............................................... 118
B. Postcard .................................................... 120
C. Letters of permission to use measures .......... 122
D. Human Subjects Review Approval .............. 128
E. AA Chapter Research Agreement for Member
   Participation .............................................. 130
F. Instruments ............................................... 132
G. Research participant questionnaire ............ 159
H. Verbal Address .......................................... 187

LIST OF REFERENCES .......................................... 189
## LIST OF TABLES

<table>
<thead>
<tr>
<th>TABLE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Frequency Distributions of Demographic Variables</td>
</tr>
<tr>
<td>2</td>
<td>Frequency Distributions of Caregiving Related Characteristics</td>
</tr>
<tr>
<td>3</td>
<td>Religious Affiliation of Caregivers</td>
</tr>
<tr>
<td>4</td>
<td>Descriptive Statistics for Measured Variables</td>
</tr>
<tr>
<td>5</td>
<td>Partial Correlations for Hypothesized Relationships</td>
</tr>
<tr>
<td>6</td>
<td>Correlation Matrix of the Dependent, Independent, Control and Interaction Variables</td>
</tr>
<tr>
<td>7</td>
<td>STEP 1 Simultaneous Multiple Regression Analysis: Explaining the Variance in Subjective Well-Being</td>
</tr>
<tr>
<td>8</td>
<td>STEP 2 Multiple Regression Analysis: Hierarchical Entry of Significant Independent Variables with Subsequent Simultaneous Entry of Control and Paired-Interaction Variables to Explain the Variance in Subjective Well-Being</td>
</tr>
<tr>
<td>9</td>
<td>STEP 3 Multiple Regression Analysis: Hierarchical Entry with Subsequent Simultaneous Entry to Explain the Variance in Subjective Well-Being</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>FIGURE</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Hypothesized Conceptual Model for Family AD Caregivers</td>
</tr>
<tr>
<td>2</td>
<td>A Schematic Representation Based on the Transactional Stress and Coping Theory</td>
</tr>
<tr>
<td>3</td>
<td>A Schematic Representation Based on the Continuity Theory of Aging</td>
</tr>
<tr>
<td>4</td>
<td>Graphic Representation of Frequency Distributions of Demographic Variables</td>
</tr>
<tr>
<td>5</td>
<td>Graphic Representation of Frequency Distributions of Caregiving Related Characteristics</td>
</tr>
<tr>
<td>6</td>
<td>Graphic Representation of the Religious Affiliation of Caregivers</td>
</tr>
<tr>
<td>7</td>
<td>Graphic Representation of the Variance in the Dependent Variable Explained by the Hypothesized Variables</td>
</tr>
</tbody>
</table>
CHAPTER I
INTRODUCTION

Significance of the Study

Dementing disorders constitute a major national and international health problem. Between 4 and 4.5 million Americans suffer from dementia of varying severity, with an estimated societal cost of $90 billion for the year 1990 alone (Markesbury, 1989; Cohen, 1991). The most common cause of dementia is Alzheimer's Disease (AD), as it accounts for up to 75 percent of all dementias and is the fourth leading cause of death among adults over the age 65 (Appel, 1981). It is estimated that the lives of at least 15 million family members are also affected (Markesbury, 1989).

Today, it is known that the symptoms of AD are due to irreversible neurological changes, with reduced production of multiple neurotransmitting chemicals in the brain. AD is a progressive and incurable form of dementia, involving degeneration of cortical brain cells and consequent mental deterioration. Symptoms emerge and progress gradually, including, changes in
personality, mood, memory, judgement, and the ability to communicate and perform necessary daily care tasks (Markesbury, 1989; Hawkins, 1987). The progression of the disease is a continuum of worsening dysfunction.

Research findings have demonstrated and confirmed the strength of the informal, family-support system in caring for the dependent older adult in the community. It is family support that provides 80 percent of the care needed by non-institutionalized older adults (Ohio Department of Aging, 1989). A particularly significant ramification of AD is that families provide the care and are responsible for their loved ones over a prolonged period of time, for an average of six to ten years. Many studies of AD caregiving have shown that most AD individuals are cared for in the home until the later stages of the disease process. Of significance, however is that the stress of caregiving is not reduced via the institutionalization of the AD individual (Baldwin, 1988; Pierce, et al., 1989).

Advances in the understanding of particular attitudes and behaviors that maximize coping and enhance well-being are particularly important for AD caregivers, as there currently is no cure or effective treatment for AD (Markesbury, 1989). This study was designed to explain the variable of religiosity for its possible role as a coping strategy for AD caregivers.
Research indicates that religiosity is a variable in coping with stress, adversity, and life changes among adults over the life course (Levin & Vanderpool, 1991; Hathaway & Pargament, 1991; Schaefer & Gorsuch, 1991; Koenig, et al., 1988a,b,c). Although research had generated data regarding the relationship between religiosity, coping and well-being among older adults, there was no prior comprehensive description of religiosity or its relationship to coping specifically among AD caregivers.

Further, due to AD's association with aging, and the known demographics of the aging population through 2050, this problem will only continue to increase. For instance, it has been estimated that because AD is most prevalent among those 85 and older, and this age group will grow by five times between 1990 and 2050, the prevalence of AD could triple in this age group alone (Meier-Ruge, 1990). The demonstration of positive relationships between religiosity and well-being, and/or religiosity and caregiver coping, would seem to reinforce the important role and potential for enhancement of the widespread religious community resources for this group.
Problem Statement

The purpose of this study was to investigate the perceived stresses of AD family caregivers, their coping strategies, and specifically the suggested coping strategy of religiosity, as they related to the subjective well-being of AD caregivers. Research questions asked included the following. Is religiosity related to the well-being of the AD caregiver? Also, is religiosity related to the caregiver’s perception of stress and coping within the caregiving situation? This study was based upon the Transactional Perspective of Stress and Coping Theory (Lazarus & Folkman, 1984), and the psychosocial framework of the Continuity Theory of Aging (Atchley, 1989).

Hypotheses

After controlling for the variables cited in the literature as influencing AD caregiver subjective well-being (See Figure 1), the following hypotheses were tested.

1. There will be an inverse relationship between family caregiver level of subjective well-being and perceived stress.

2. There will be a positive relationship between family caregiver level subjective well-being and coping.

3. There will be a positive relationship between the level of family caregiver subjective well-being and religiosity.
4. There will be a positive relationship between family caregiver religiosity score and overall coping.

5. A significant proportion of the variance in subjective well-being will be explained by a linear combination of the tested independent variables.

6. A significant proportion of the variance in family caregiver's subjective well-being will be explained by a linear combination of the independent variables and their interactions.

Figure 1. depicts the schematic representation of the above hypotheses being tested in this research study.

Definition of Terms

For the purpose of this research study, the following terms were conceptually and operationally defined.

Subjective Well-being is the caregiver's perceived health including constructs of anxiety, depression, positive (mental) well-being, self-control, general (physical) health, and vitality. This dependent variable will be operationally defined as the subject's score on the Current HIS Mental Health Battery: General Well-being (Ware, et al., 1987).

Stress is defined here as "any event in which environmental or internal demands (or both) tax or exceed the adaptive resources of the individual, social system or tissue system." (Lazarus & Launier, 1978,
p.29). This independent variable will be measured as the subject's score on the Caregiving Hassles Scale (Kinney, 1989).

Coping strategy is defined here as an internal or external cognitive and behavioral effort aimed at managing the perceived caregiving stressors. This independent variable will be measured as the subject's score on the Family Crisis Oriented Personal Evaluation Scales (F-COPES) (McCubbin, 1981).

Religiosity is defined as the extent to which a person is committed to a set of religious beliefs and is involved in organized and/or non-organized religious activities (Simons & West, 1985). This independent variable will be measured as the subject's score on Koenig's (1988) Springfield Religiosity Schedule.

Family Caregiver is defined as the family member or significant other involved and responsible for providing/coordinate the resources required by the AD affected individual (Pierce et al., 1989), and is not receiving financial reimbursement for these caregiving activities. This will be measured here with a single demographic item.
* The following variables will be measured and statistically controlled:

- Time as a family caregiver
- Caregiver perception of AD individual's functional dementia level
- AD affected individual's place of residence
- Care recipients' relationship to family caregiver

Hypothesized Conceptual Model *
For Family AD Caregivers

Figure 1
AD Individual is an individual who is affected by progressive, irreversible Alzheimer's dementia or related disorder. Level of functional impairment resulting from the dementia will be operationalized as the individual's score on Moore's Functional Dementia Scale (1983).

Limitations of the Study

Subjects included a convenience and volunteer sample, and thus may not be representative of AD caregivers.

Subjects were selected from only the Central-Ohio area, and thus may not be representative of AD caregivers living elsewhere.

In addition, it is recognized that caregivers who participate in the AD support group program may have different coping characteristics than caregivers who do not seek such support.

Further, the caregiver's responses were based on self-report instruments, and not on objective criteria.

Basic Assumptions

It is assumed that family caregivers answered the questions on the instruments truthfully, and did not attempt to use what would seem to be desirable answers.
**Delimitations**

The following delimitation was set for this study. Family caregivers needed to be responsible for the care or management of the AD-affected individual (without financial remuneration) in order to meet eligibility requirements of participation in the study. The receiving of in-kind resources, such as housing or room and board, etc., are not considered to be financially remunerative, and thus are not exclusion criteria.
CHAPTER II
REVIEW OF THE LITERATURE

Introduction
This review provides an overview of the AD family caregiving situation and related effects on caregiver well-being, exploring the concepts of stress and coping, and how potential stressors impact the AD caregiver. The review continues with a study of the theoretical and conceptual dimensions of stress and coping, using Lazarus and Folkman’s (1984) Transactional Perspective of Stress and Coping. The Continuity Theory of Aging (Atchley, 1989) is examined to help explain the role of religiosity in the process of adapting to changes and the demands across the lifespan (as in the caregiving role).

The AD Caregiver and Subjective Well-Being
AD presents a multifaceted challenge to the familial and social supports of the affected individual. Goldman (1982) called the well-being of the burdened AD family caregiver "the major public health issue of the next decade" (p. 94). The majority of the
caregiver literature attempts to describe and/or determine correlates of subjective well-being for the primary family caregiver for those with AD. For the most part, the primary caregiver has been defined as the individual who carries the primary responsibility for providing a wide-range of care to the AD affected individual at home and is not receiving financial reimbursement for these caregiving activities. Primary caregivers are predominantly females, in their mid to later years of life. The caregiving role entails coping with a multitude of emotional, physical, and financial changes and responsibilities. Existing literature relates the caregiving role to mental and physical symptoms of stress and burden, as well as varying degrees of coping and well-being.

Before discussing caregiver well-being however, it is important to discuss the measurement of adult subjective well-being overall, as this literature seems to have similar trends and weaknesses. It is well recognized that although subjective well-being is a commonly studied variable in the mental health and gerontological research, it has been vaguely defined conceptually, and theoretically (Larson, 1978; George, 1981; Sauer & Warland, 1982; Carp & Carp, 1983). Definitional problems are seen to stem from unidimensional and inconsistent measurement of the
construct subjective well-being (George, 1981). As Lund, et al. (1989) indicate, "subjective well-being is generally regarded as a multidimensional construct that encompasses both stable and transitory dimensions, as well as global and specific indicators" (p.4). Regardless, traditional research has tended to use unidimensional concepts as proxy measures, label findings as indicative of subjective well-being, and compare their results with studies that were conceptually and operationally incompatible. George (1981) categorizes proxy measures into four general areas, including life satisfaction, morale, happiness, and psychiatric symptoms. She notes that each differ with regard to meaning, time referent, stability over time, scope, and cognitive versus affective nature. In addition, this global variable can also be identified by its positive versus negative perspectives. Positive concepts would include measures of satisfaction, happiness, adjustment, positive affect, hopefulness, stability, mental health, self-control, and vitality. Negative measures include depression, anxiety, burden, loneliness, negative affect, sadness, despair, and helplessness.

In addition, the vague nature of what we know about subjective well-being has been attributed to a more basic problem in the investigation of the construct (Sauer & Warland, 1982). Historically, the
initial research focusing on the subjective well-being of older adults has studied this variable from an applied or problem-solving standpoint, rather than establishing it as a theoretical construct. This focus diverted attention away from studies that would have clearly defined the multidimensional nature of subjective well-being. Hence, what followed in the research was the development of many instruments, each measuring specific aspects of subjective well-being, but often having little in common with each other, and offering narrow, unequal and superficial reflections of the underlying construct they were meant to represent. The following are examples of proxy measures for subjective well-being that have been commonly used and compared in the literature (Sauer & Warland, 1982; Himmelfarb & Murrell, 1983): Attitude Inventory (Cavan, 1949); Kutner Morale Scale (Kutner, et al., 1956); Dean Morale Index (Cumming, et al., 1958); Adjustment Scale (Thompson, et al., 1960); Life satisfaction Index-A (Neugarten, et al., 1961); Morale Scale (Clark and Anderson, 1967; Pierce and Clark, 1973) Affect Balance Scale (Bradburn, 1969); Trait Anxiety Inventory (Spielberger, et al., 1970); Philadelphia Geriatric Center Morale Scale (Lawton, 1972); single item indicators of life satisfaction and happiness (Rose, 1955; Davis, 1974); and the Center for Epidemiological Studies Depression
Scale (Husaini, et al., 1980).

Regardless of instrument, measures of well-being among adults appear to be stable over time, and significantly related to several other variables, including financial status, quality and quantity of social resources, psychological resources related to personality, and religiosity as a specific personal and social support (Zautra & Hempel, 1984; Simons & West, 1985). Larson’s thirty year literature review for the construct of subjective well-being reported that health \( r = .2 \) to .4; \( r^2 = 4 \) to 16\%, socioeconomic factors \( r = .1 \) to .3; \( r^2 = 1 \) to 9\%, and degree of social interactions \( r = .1 \) to .3; \( r^2 = 1 \) to 9\% were most strongly correlated with this measure (Larson, 1978). Poor physical health and low income were predictive of lower levels of well-being; while age, race, and gender showed no consistent independent relationship with well-being.

Since Larson’s 1978 review of the literature, research efforts have been undertaken to determine how best to measure the multidimensional nature of subjective well-being and define it theoretically (Markides & Martin, 1979; Carp & Carp, 1983; Himelfarb & Murrell, 1983; Liang, 1985; Wolinsky, et al., 1985; Costa, et al., 1987; Shmotkin, 1990). Results of the different studies confirm the need to measure subjective well-being comprehensively, with valid and
reliable instruments.

A major effort was conducted by Ware, et al. (1987) in developing an instrument using items from many general and construct-specific measures of well-being. These authors performed a content analysis of tools measuring the concepts of anxiety, depression, positive well-being, self-control and perceptions of health. This analysis provided information regarding face and content validity, the polarity of certain dimensions, and operational definitions used in earlier overall measures. An instrument was created encompassing the six concepts based on content and statistical analysis, to include all content without overlap. While the Health Insurance Study-General Well Being (HIS-GWB) tool has established acceptable validity and reliability scores for the general population, it has not been confirmed for the older adult population. Further studies are needed to establish that this instrument will show similar trends in levels of subjective well-being and relationships with other variables in this group as those measures more commonly used with older adults. Brook, et al. (1979) indicate however that the GWB-HIS reflects a state-of-the-art measure of the intended construct, representing improvement in conceptualization and measurement of subjective well-being.
When the AD caregiver literature is reviewed, subjective well-being is the most frequently studied outcome or dependent measure. However, in these studies, it is normally assessed in terms of negative affect alone; most often as burden, depression, frustration, strain and distress (Zarit et al., 1980; Pierce, et al., 1989; Pruchno & Resch, 1989; Borden & Berlin, 1990; Harper & Lund, 1990; Dillehay & Sandys, 1990).

It is understandable that caregiver well-being would be measured in terms of negative affect. The AD caregiving situation has been reported as being even more stressful than other caregiving situations (Rabins, et al., 1982; Gwyther & Matteson, 1983; Chenowith & Spencer, 1983; Gurland, 1984; Zarit, et al., 1986; Gonzalez-Lima & Gonzalez-Lima, 1987; Stephens, et al., 1991). The behavioral problems and the cognitive and memory losses associated with AD leave the affected individual unable to show recognition or appreciation for the help they have received. Caregiver feelings associated with stress include guilt, anger, frustration, isolation, grief, and resignation (Gonzalez-Lima & Gonzalez-Lima, 1987). However, it should be recognized that measuring well-being unidimensionally and only in terms of negative outcome would not capture the complex nature of subjective
well-being, with the possibility of adaptation and positive levels of well-being among caregivers, and may only tend to skew our view of AD caregiving itself.

Regardless of the measure used, the literature provides consistent information regarding AD caregivers and their subjective well-being. Pruchno and Postashnik (1989) describe the overall characteristics of persons caring for individuals with AD, as compared to a national, large-scale survey of non-caregivers (National Health Interview Study). Caregivers are characteristically more depressed, express higher levels of negative affect, are more likely to use psychotropic drugs themselves, and have more signs and symptoms of emotional distress. Physically, such caregivers report substantially poorer health, use medical services less often, experience fewer hours of sleep, and have higher rates of reported chronic disease states (i.e., arthritis, ulcers, hypertension, heart disease, etc). Thus, caregivers of AD individuals are susceptible to a wide range of mental and physical health problems related to their level of affective coping with the stresses of caregiving.

This research seems to be supported by several other AD caregiver studies, comparing AD caregivers with other caregiving groups (Birkel, 1987; Gatz, et al., 1990). For instance, Dura, et al. (1990) reported
30 percent of AD caregivers experiencing depression compared to only one percent in matched controls during the same time period. They concluded that "chronic strains of caregiving appear to be linked to the onset of depressive disorders in older adults with no prior evidence of vulnerability" (p.284). Such depression has been demonstrated among AD caregivers in many studies, including Lovett and Gallagher (1988) with depression detected among 26 percent of their subjects; Haley, et al. (1987) with 43 percent of caregivers reporting depression; and Anthony-Bergstone, et al. (1988) reporting clinical depression symptoms with anxiety and hostility even more apparent than depression alone. Liptzin, et al. (1988) further found family of patients with dementia equally burdened compared to families of depressed elderly.

Ory, et al. (1985) and several other investigators have associated circumstances of the caregiving situation with the AD caregiving experience that potentially lead to stress, strain, burden and depression (Zarit & Zarit, 1982; Wright, et al., 1985; Haley, et al., 1987; Pratt, et al., 1987; Given, 1988; Wilson, 1989; Stephens, et al, 1991). These circumstances include, but are not limited to the following: isolation related to the need for constant supervision and being increasingly homebound due to
disease progression; little backup support and the need for respite; the disruption of normal personal and household related activities; conflicting multiple role demands including familiar roles and the assumption of new roles formerly held by the AD individual; lack of information or the provision of misinformation, and a perceived abandonment by health care workers; a lack of support networks for medical, social and information services; lack of hope for cure or improvement in the AD individual’s condition; realization of loss of relationship with the AD family member/spouse and the AD individual’s quality of life (a "funeral that never ends" [Chiverton & Goldenberg, 1986, p. 20]); loss of identity to the caregiving role and to the AD individual; the catastrophic reactions of the AD individual involving demanding, critical, paranoid and/or aggressive behaviors; and, the guilt and ambiguity associated with the caregiving decision and any decision related to respite care or institutionalization that continues even with the AD individual’s death. As Wilson (1989) indicates, "the caregiving experience consists of coping with negative choices wherein all possible alternatives are undesirable" (p. 94).

The literature surrounding caregiver burden and stress delineates specific demographic and caregiving
situation variables that contribute to negative caregiver outcomes, including level of functional dementia, social support and religiosity, marital status and family relationship, living arrangements, and time in the caregiving role.

Controversy exists in the literature regarding the effect of functional disabilities related to the dementia process on subjective well-being, and particularly that including aberrant behaviors on the part of the AD individual. Zarit, et al. (1980), Zarit and Zarit (1982), George and Gwyther (1985), Ory, et al. (1985), and Given (1988) suggest that caregiver stress levels are less dependent upon the actual degree of functional disability of the AD individual, and more related to caregiver perception of the level of burden. Indeed, Rabins, et al. (1982) suggest that certain behaviors associated with the degree of dementia were perceived as particularly problematic and stressful for family caregivers. This explanation of dementia-related problematic behaviors and resulting caregiver stress is supported in the literature (Zarit, et al., 1986; Niederehe & Funk, 1987; Silliman & Sternberg, 1988). Gwyther and Matteson (1983) identified these dementia-related problem-behaviors as combativeness, shadowing the caregiver, suspiciousness, accusations, threats, and denials of relationships (ex., 'You are not my
wife.'). It is interesting to note that gender differences seem to exist with regard to the perception of problem behavior related stress. Harper and Lund (1990) found that men caring for their wives were more bothered by wandering and loss of memory, while women tended to be more burdened by aggressive behaviors on the part of their AD affected husbands.

It would seem that the controversy surrounding functional status and stress stems from how functional disability is measured, where the subjective appraisal of functional dementia by the caregiver shows less relationship to negative levels of subjective well-being than more objective, professional classifications of levels and stages by some researchers (Novak & Guest, 1989a,b; Quaghen & Quaghen, 1989). One explanation for this is that as the disease process progresses, it is different for each individual and is refractory to grouping these dysfunctions into well-defined stages and levels. Also, the behaviors associated with the cognitive deterioration change, so that the stress associated with these behaviors is not linear but an evolving process. For instance, the wandering and hiding of objects frequently seen earlier in the disease process discontinues as mobility declines, and the difficulties with accusations and repetitive statements by the AD individual discontinue
when language abilities are lost with further declines in the disease process.

Zarit, et al. (1980), Zarit, et al. (1986), George and Gwyther (1986), and Gatz, et al. (1990) have consistently identified social supports collectively as a powerful mediator of caregiver stress, related to lower levels of burden and higher levels of morale. For instance, Zarit, et al.s’ 1980 study indicated that lower levels of perceived burden were related to the amount of social support (specifically, visits by family members) and the caregivers’ perceived capability of coping with caregiving demands. Motenko (1989) related the caregiver’s sense of well-being to their original motivations for undertaking the caregiving role. Motivations related to love, affection, and commitment were related to higher levels of perceived well-being. In addition, Motenko found that more gratification and less frustration was found to exist for caregivers who maintained their social supports and continuity in their life patterns, despite the AD individual’s illness and characteristics.

It must be recognized, as Dillehay and Sandys (1990) indicate in their critical review of the literature, that there are inherent methodological weaknesses in studying and drawing conclusions regarding the effect of social support on caregiver
well-being. In essence, there is wide variability in the conceptualization and operationalization of social support. Investigators differ in measuring social support in terms of quality and quantity, and in terms of the implications drawn from results. The best analysis cited utilized a five-dimension measure of support systems, including cognitive guidance, emotional support, socializing, tangible assistance, and the availability of a confidant (Fiore, et al., 1983, in Dillehay & Sandys, 1990.) This study includes religiosity as an independent variable with the assumption that its multidimensional nature (including beliefs, attitudes, organizational and nonorganizational activities) transcends all five of these support system dimensions (Wright, et al., 1985; Pratt, et al., 1987; Koenig, et al., 1988a-d), thus mediating the perception of burden and negative resulting outcomes. This assumption seems to be supported by qualitative findings observed by Whitlatch and Langhout (1990), where caregiving individuals identified religious faith and practices, including in their discussions examples of each support system dimension delineated by Fiore, et al. (1983, in Dillehay and Sandys, 1990). This is further supported by Pargament (1990) who emphasizes that there are definitive variations in the styles of religious coping
that can be grouped similarly into categories including: interpersonal, behavioral, emotional, motivational and intimacy.

Marital status and family relationships seem to influence the degree and type of stress identified by AD caregivers. In her spousal caregiving study (n=315), Pruchno (1990) found that even though spouses were often frail and elderly, they continued to provide the bulk of care (with a mean of 74.7 hours per week). They found no relationship between task supports or social supports with the mental health of the spousal caregiver. This study suggest an actual lack of family support for elderly caregivers, where 53 percent of those with at least one daughter living nearby had no visits or assistance with tasks during a one month period, whereas 69 percent reported no help from their son. The average assistance per week to these spousal caregivers was reportedly 3.4 hours from daughters and 1.4 hours from sons.

George and Gwyther (1986), using mailing lists from the Duke University Family Support Group Program in their AD Family Support Group Study, found that spousal caregivers exhibited even lower levels of well-being, higher levels of stress, and greater likelihood of psychotropic drug use than any other family caregiver group. Higher stress levels among spousal
caregivers was supported by Harper and Lund (1990) where increased stress was noted among female spouses of AD demented males; and by Cantor (1983), who emphasized the increased vulnerability of spousal caregivers, citing that the closer the marital bond, the more stressful the caregiving role.

The living arrangement for caregivers and their AD care-recipients (institutionalized vs noninstitutionalized) is a common factor discussed in the literature with varying effects on caregiver stress, burden, and health status. Stephens, et al. (1991) found no difference between levels of stress and well-being among family members who care for AD individuals in their home and those who have placed their family member in an institution. This finding is supported by several studies (Baldwin, 1988; Pierce, et al., 1989; Harper and Lund, 1990) with the possible implication being that caregivers of institutionalized AD individuals continue to provide care and spend a great proportion of their time involved in managing the care for their family member. In addition, financial concerns and the loss of control over how care is provided seem to complicate the caregiving situation for those with institutionalized care-recipients, and equalize their stress compared to those providing care in the community. When co-residence with the AD
affected individual is associated with decreased
caregiver well-being, it tends to be in the areas of
mental health, financial security and social
participation (George & Gwyther, 1986). Indeed, Pratt,
et al. (1987) actually found that the signs and
symptoms of caregiver burden related to health status
worsened with the institutionalization of the AD family
member or spouse. These authors explain their findings
based on verbatim caregiver statements, indicating that
guilt, increased loneliness and feelings of separation,
lack of control over care management, and trauma
related to their feelings of failure to continue as
caregiver, seem to be factors that maintain or even
increase caregiver burden and decrease health status.

Another variable suggested as influencing
caregiver outcomes is the length of time spent as
caregiver (in number of years). For example, Deimling
and Bass (1986) and Lovett and Gallagher (1988) found
that time spent in the caregiving experience, and
specifically the time spent in overall tasks, were
significantly predictive of stress. Pruchno and Resch
(1989) further support these findings. These authors
examined length of time as caregiver in an attempt to
explain why their particular sample exhibited levels of
mental health complaints higher than other sample
groups in the literature. They determined that their
caregiving sample in their study had been in the AD caregiving role significantly longer (mean=8 years) than AD caregivers in other research samples. However, controversy seems to exist with regard to this factor as Zarit, et al. (1980), Novak and Guest (1989b), Quayhagen and Quayhagen (1989), and Gatz, et al. (1990) all note that the length of time as caregiver did not correlate with increased stress or with caregiver outcome measures of subjective well-being, when the effects of functional dementia, living arrangements, and social supports are controlled. This is not surprising given the variability of AD over time, and related differences in the caregiving experience.

A review of the AD caregiving literature reveals the complex nature of the caregiving experience and caregiver outcomes. It seems to support the inclusion of stress, coping and religiosity as independent variables; and functional dementia, living arrangements, time as caregiver and family relationship as control variables in this study to investigate their relationship to and explanatory value in predicting subjective well-being among AD caregivers. It further supports the need to measure the dependent and independent variables multidimensionally and from the caregivers perspective. The following discussion will describe a theoretical framework that proposes the
relationships between stress and coping in the AD experience, and the role of religiosity as a mediating factor in the subjective well-being among AD caregivers.

Theoretical Frameworks

Lazarus and Launier's (1978) Stress and Coping Framework and Atchley's (1989) Continuity Theory of Aging are useful theories in any attempt to conceptualize and measure the stresses of the AD caregiving situation, and caregiver coping and well-being within that situation. First, Lazarus and Launier's (1978) Stress and Coping Framework conceptualizes stress in terms of daily hassles of living, as well as catastrophic life events. This framework matches not only the daily hassles and tasks of caring for an AD individual, but also the long-term nature of caregiving and losses particular to the AD caregiving experience (ex., the loss of the spousal or familial affectional relationship, social isolation, disruption of other family ties, employment, etc.). These authors define stress as "any event in which environmental or internal demands (or both) tax or exceed the adaptive resources of the individual, social system or tissue system" (Lazarus & Launier, 1978, p.29). Environmental demands are events external to the
individual and consisting of the individual's environmental-related goals, commitments, or values according to Lazarus and Launier's model. If these demands are put off or delayed, negative consequences (lack of adaptation) will occur to the individual. In response to perceived stress, the individual looks to available resources to assist in meeting the demands. According to this model, the use of resources constitutes an adaptive response having the capacity to assist with the demands, and therefore prevent the negative consequences of stress. A balance between the perceived demands and resources determines whether or not an exchange is stressful.

According to Lazarus and Folkman's (1984) transactional model of stress and coping (see Figure 2), instead of viewing stress within the traditional major life-events frameworks, it is conceptualized in terms of the ordinary daily hassles of living, as well as catastrophic or major life-events. Lazarus and Folkman (1984) believe that the responses to potential daily hassles vary within an individuals's appraisal of that specific event. Cognitive appraisal is defined as an evaluative process that determines why and to what extent a transaction between a person and the environment is noted as stressful (Lazarus & Folkman, p.19, 1984). Appraisal of both stress and coping,
A Schematic Representation Based on the Transactional Stress and Coping Theory
Lazarus and Folkman (1984)

Figure 2
affect an individual's well-being. Cognitive appraisal intervenes between an encounter and an individual's reaction to the encounter. The process is evaluative, focusing on the meaning or significance events hold for individuals. Personal factors and situational factors influence how an event is cognitively appraised by an individual. Lazarus cites beliefs and commitments as the person factors that influence appraisal. Beliefs are concerned with what one thinks are true, whether one likes it or not. Beliefs are affectively neutral, whereas commitments reflect values, and include a motivational, emotional quality. Within the transactional theory, the person factors of beliefs and commitments explain the individual difference in appraisal. A person may generate several interpretations of an event depending on facets of the encounter. Situational factors also contribute to the appraisal of an event. Situation factors such as novelty, predictability, imminence, duration, uncertainty, and timing of events influence the appraisal of an event. Therefore "processes within the person and within the environment combine to determine the relationship between the two" (Lazarus & Folkman, p.114). Lazarus and Folkman (1984) maintain that individually, hassles or microstressors, demonstrate a weak threat; but chronic stressors can impact on the
long-term health and well-being of individuals.

Lazarus and Folkman (1984) define coping as "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" (p.141). By defining coping as a process, the expectation is that with each stressful situation, there may be a change in the way individuals cope. Also, coping becomes more than an outcome of the stress situation; rather it is all efforts by the individual to manage a stressful situation. Thus, coping has two main functions: 1) to regulate the emotional response to the problem, and 2) to manage stressful situations by mastering, reducing, or tolerating stressors. Their theory defines coping as process-oriented rather than trait-oriented. "The dynamics and change that characterize coping as a process are not random. They are a function of continuous appraisals and reappraisals of the shifting person-environment relationships" (Lazarus & Folkman, p.142). The major categories of coping resources, according to this transactional theory include: 1) physical resources of health and energy, 2) positive beliefs such as justice, free-will, and God, 3) problem-solving skills, 4) social skills, particularly communication, social resources, emotional,
informational, and tangible supports, 5) material resources including money and goods. However, Lazarus argues that it is more important to focus on coping processes rather than resources, and the factors that determine their use. Then one can "more easily identify the mechanism through which the stress-relationship is mediated" (Lazarus & Folkman, p.170).

The Continuity Theory of Aging is also useful in explaining AD caregiver coping and well-being (See Figure 3). This theory was initially proposed by Havighurst, et al. (1968), when results of gerontological research failed to accurately account for the findings related to life satisfaction across the life span and across individuals, using the more simplistic, linear theories of activity or disengagement. The Continuity Theory suggests that successful aging as evidenced by higher levels of life satisfaction, is characteristic of those who continue roles and activities over the life span or to find meaningful substitutes (Howe, 1987). Atchley (1989) describes the "central premise" of the Continuity Theory in the following way:

"...in making adaptive choices, middle-aged and older adults attempt to preserve and maintain existing internal and external structures and that they prefer to accomplish this objective by using continuity (i.e., applying familiar strategies in familiar arenas of life)." (p. 183)
Lettering in bold represents Atchley's theoretical framework of the Continuity Theory of Aging, with lettering in regular print (smaller box) representing the independent variables of the study within language of the Stress and Coping Theory (Lazarus & Folkman, 1984)

A Schematic Representation Based on
The Continuity Theory of Aging
(Atchley, 1989)

Figure 3
Adaptive choices are supported by both individual preferences and social sanctions.

This theory attempts to explain the choices made by adults to cope with the changes that accompany the normal aging process. Internal continuity is described as the foundation for individual mastery and competence on an everyday basis, where the individual operates "in relation to a remembered inner structure such as ... preferences, skills, [and] affect" (p. 184). Internal continuity is essential for maintaining ego integrity; it meets the need of self-esteem. Atchley further explains that external continuity of relationships is "motivated by desire for predictable social support" (p. 186). External continuity is concerned with the individual's past role performances related to their environment (for example, how we present ourselves to others and fulfill goals within known and dependable societal structures, and the predictability of feedback that is received from others related to social roles.).

Continuity for the individual, both internal and external, is seen as a preferred strategy for coping with the changes associated with aging, whereby individuals maintain their strengths and minimize the deficits. According to Atchley (1989), "continuity is a dynamic process within a basic structure of life that involves both internal aspects (such as one's sense of
identity) and external aspects (such as one's enduring relationships)" (p.186). This theory has been applied to
the process of adapting to changes that occur with age
across the life span. In middle and old age, continuity
may be disrupted by a series of life changes such as
loss of employment, retirement, moving, losing one's
friends or spouse, or a serious illness, and role
ambiguity that accompanies change (Kimmel, 1990).

The two frameworks discussed above help provide a
model (see Figure 1) in which to view the AD caregiving
situation as a series of life changes (major life
events), while also viewing the AD caregiving
experience as a dynamic process involving the stress
and coping with day-to-day changes and hassles, with
caregiver subjective well-being as the outcome. The
Continuity Theory would suggest that the AD caregiver,
as a middle or older adult, appraises the stress of
their situation and copes with that stress within
familiar internal and external structures (example,
personality traits; self-esteem; occupational,
community and familial roles, etc.). These structures
have evolved and are internalized over the lifespan,
and would seem therefore to be similar to those used by
other adults to cope with life changes.
Caregiver Coping and Religiosity

In reviewing the literature regarding religiosity in later life, Peterson and Roy (1985) and Witter, et al. (1985) have determined it to be reasonable to suggest religiosity as a coping resource, having a positive effect on subjective well-being and a modifying effect on stress. Efforts made to measure religiosity over the past 25 years have evolved from measuring only organized religious behaviors and activities with single items, to measuring the multidimensionality of the concept including internal and external manifestations and motivations (Glock & Stark, 1965; Hoge, 1972; Moberg, 1965, 1970, 1971, 1972; Wilson, 1978; Mindel & Vaughn, 1978; Hunsberger, 1985; Koenig, et al., 1988a-d; Kirkpatrick, 1989; Gorsuch & McPherson, 1989). When measured as a characteristic, religiosity has predominantly been limited to the measurement of church attendance, or religious affiliation, or items lacking tests of validity or reliability.

Allport was the first to conceptualize the underlying motivation for religiousness in terms of intrinsic and extrinsic factors (Allport & Ross, 1967). Intrinsic factors dealt with religious beliefs and values, where extrinsic factors were more related to religious behaviors including religious affiliation,
church attendance, prayer, bible studies, etc. This thinking expanded the appreciation for the role of religion in individual lives, beyond the traditional measurement of religious affiliation and church attendance. Hoge (1972) further contributed to the development of the religiosity concept by developing a 10-item tool focusing on religious beliefs and attitudes (intrinsic religiosity).

While Mindel and Vaughn (1978) continued the study of religiosity among older adults with Allport's more comprehensive attitude, they further expanded the idea of religious behaviors by grouping them into organized and nonorganized religious activity. They found that although older adults participate less frequently in organized religious activities, they seem to increasingly depend upon nonorganized activities in coping with their lives. The drawback to their research, however involved their use of only a three-item measurement tool.

Koenig, et al.s' 1988 research demonstrates the latest evolution of the conceptualization and operationalization of religiosity, as identified in the Springfield Religiosity Scale. This instrument encompasses the original ideas set forth by Allport (Allport & Ross, 1967) including both intrinsic and extrinsic factors, using Hoge's 1972 items for
intrinsic religiosity, and Mindel and Vaughn's (1978) conception of organized and nonorganized religious behavior and activities. Koenig's research (1988a-d) at this time represents the most current and comprehensive measurement for the religiosity variable. Religiosity may thus be defined as the extent to which a person is committed to a set of religious beliefs and is involved in organized and/or non-organized religious activities (Simons & West, 1985). Several authors present critical review of the literature, clearly demonstrating that only when religiosity is studied in the comprehensive fashion is there consistency across studies in the measure of this variable and in its association with other constructs (Donahue, 1985; Haitsma, 1986; Levin & Vanderpool, 1987; Schaffer & Gorsuch, 1991). The literature surrounding religiosity among older adults indicates a significant association with subjective well-being, shows that religiosity serves as a coping mechanism in the aging process, and suggests that religiosity may even serve as a modifier in the appraisal of stress related to major life events. The following will be a discussion of this literature.

The religiosity construct has been associated with subjective well-being, regardless of how subjective well-being is measured in the older adult literature. Research by Blazer and Palmore (1976) from the Duke
Longitudinal Study of Aging, Beckman and Houser (1982) using cross-sectional samples, Moberg (1965, 1971, 1972), and Hunsburger (1985) have demonstrated correlations between religious beliefs/attitudes and subjective well-being ranging between $r = .18$ to $r = .45$. Idler (1987) studied religious involvement and the health of elderly using data from the Yale Health and Aging Project ($N = 2,811$). Controlling for demographic variables and physical health status, cross-sectional analysis showed higher levels of religious involvement associated with lower levels of functional disability and depression.

Koenig and his associates have studied religiosity extensively for its relationship to subjective well-being among the elderly, in a variety of settings and population groups (1988a-d). Their reviews of the literature (1988a,b) found a limited amount of research regarding religiosity as a unique and important variable correlated with life satisfaction and well-being. Their 1988a study indicates strong correlations between morale and three measurements of religiosity: (1) organizational activity (ORA); (2) non-organizational religious activity (NORA); and (3) intrinsic religiosity (IR), a concept originally developed by Allport (1967). However, Koenig et al. (1988b) also concluded that religious attitudes and
activities may influence the complex interactions of health, financial status, and social support affecting morale and well-being.

Koenig, et al. (1988c) further explored the relationship between religiosity and well-being among 836 community dwelling elderly. In the 75 and older group, religiosity explained 25 percent of the variance in well-being, and contributed more than any other separate variable except health.

Ruffing-Rahal (1989) studied characteristics of community-dwelling elderly to determine core themes that contributed to their sense of well-being, using qualitative data collected by interviews. She found that spirituality and religion played a major role for the core theme of affirmation. Individuals that scored highly on the measure for well-being frequently made statements alluding to strongly held religious and spiritual values.

Pargament, et al. (1990) further investigated religiosity (beliefs, practices and motivations) for its importance among individuals who tend to turn to religion in coping with major negative life events, with mental health as their outcome measure. Seventy-eight percent of their sample reported that religion was involved in understanding or dealing with their significant negative event (widowhood, illnesses,
divorce, work-related problems, etc.). In this study, religious coping explained 20 percent of the variance in well-being, while non-religious coping explained 10 percent. Thus it seems that religious involvement in coping has implications for outcomes that are not limited to the religious realm. Rather the implications extend to the resolution of the problem and the mental health status of the individual. They concluded that religious coping efforts, like more general religious dispositions, appear to be multidimensional in nature and interact with non-religious coping strategies.

Hathaway and Pargament (1991) used Lazarus' stress and coping framework to evaluate religiosity research, in order to address two general questions: 1) "When is religion involved in coping"; and 2) "How is religion involved in coping" (p. 65). Their review supports the trends and criticisms discussed above. Based on their review, the role of religiosity in the coping process is very complex and becomes difficult to discern due to the inconsistent and oversimplistic measure of this variable.

Since both religiosity and coping are complex human phenomenon, with "varieties of ways of being religious and varieties of coping" (p. 73), religiosity serves a coping mechanism in a variety of ways and situations. Religiosity may function in a proactive
manner by modifying the individual's appraisal of stress associated with major life events and daily hassles (Hathaway & Pargament, 1991). Roden et al. (1985) suggest that the role of religion in reducing stress among the elderly is extremely important because other coping mechanisms may diminish with age and disability. Sanua (1969), Veroff, et al. (1981), and Cohen (1990) all support the contention that religion acts as a coping resource, as they found it to play an important role in the management of life crises. Further, Peterson and Roy (1985) argue that religiosity serves to reassure people that the problems (stressors) of life can be overcome.

Koenig, et al. (1988d) studied interview of participants in the second Duke longitudinal study, consisting of a stratified random sample (n=100) ranging in age from 55 to 80. Participants in this study were questioned about three stressful event. Forty-five percent of this sample identified religious coping behavior for at least one of the three events. It is important to note, as indicated in this study, that religiosity is stable as a stress modifier and coping mechanism in promoting subjective well-being across socio-demographic variables including gender, education level, and income.
Two specific studies discuss the role of religiosity in the stress and coping process for ethnic minority populations. Gallego (1988) in his study of Hispanic elderly, explored the role of religiosity as a coping mechanism and found that religiosity helps make life bearable by explaining the unexplainable and enhancing self-importance. This can also be seen in Krause and Van Tran's (1989) national sample of older Black Americans, where although stress tended to erode feelings of self-worth and mastery, negative effects were offset by increased religious involvement.

In examining how religiosity acts in coping processes, Pargament, et al. (1990) point to important aspects of the religiosity-stress-coping relationships. Pargament, et al. emphasize that it is important to integrate religious constructs into the coping measures and literature as both religious and nonreligious activities appear to be involved and interrelated in the coping process, at least for those who are religious. They further summarize by indicating that "it appears that religious involvement in coping with significant, negative events is commonplace rather than unusual" (p.818).

This seems particularly applicable to the caregiving situation where the AD caregiving experience involves coping with both a major negative life event
(major family dementing illness and loss of relationship) and daily hassles of AD caregiving. Religiosity would seem to act in both an internal and external adaptive function, helping the adult to cope with life changes and discontinuity through familiar attitudes, beliefs, activities that enhance their identity and meaning of life. A person, and particularly a caregiver, with strong religiosity may become less discouraged and more likely believe that the effects of life stressors can be overcome and controlled.

**Conclusions**

This review provided an overview of the AD family caregiving situation and related effects on caregiver well-being, exploring the concepts of stress and coping, and how potential stressors impact the AD caregiver. The majority of the caregiver literature attempts to describe and/or determine correlates of subjective well-being for the primary family caregiver for those with AD. It is well recognized that although subjective well-being is a commonly studied variable in the mental health and gerontological research, it has been vaguely defined conceptually, and theoretically. Traditional research has tended to use unidimensional concepts as proxy measures and label findings as indicative of subjective well-being.
Subjective well-being is the most frequently studied outcome or dependent measure in the AD caregiver literature, normally assessed in terms of negative affect alone; most often as burden, depression, frustration, strain and distress. It is understandable that caregiver well-being would be measured in terms of negative affect. The AD caregiving situation has been reported as being even more stressful than other caregiving situations.

Lazarus and Launier's (1978) Stress and Coping Framework and Atchley's (1989) Continuity Theory of Aging are useful theories in any attempt to conceptualize and measure the stresses of the AD caregiving situation, and caregiver coping and well-being within that situation. While stress and coping are common concepts studied in the caregiving literature, to this point religiosity has not been studied comprehensively as a significant variable in the caregiving literature. As a variable affecting the caregiving experience, religiosity has only recently been cited by authors who have extracted and analyzed specific religiosity items from their coping measures (Wright, et al., 1985; Pratt, et al., 1987). The literature surrounding religiosity and subjective reports of well-being in middle and late adulthood however suggests that religious attitudes, beliefs, and
activities are important to coping with stressful life events. This seems particularly applicable to the caregiving situation where the AD caregiving experience involves coping with both a major negative life event (major family dementing illness and loss of relationship) and daily hassles of AD caregiving.

A review of the AD caregiving literature revealed the complex nature of the caregiving experience and caregiver outcomes. It seemed to support the inclusion of stress, coping and religiosity as independent variables; and functional dementia, living arrangements, time as caregiver and family relationship as control variables in this study to investigate their relationship to and explanatory value in predicting subjective well-being among AD caregivers. It further supported the need to measure the dependent and independent variables multidimensionally and from the caregivers' perspective. The demonstration of positive relationships between religiosity and well-being, and/or religiosity and caregiver coping, would seem to reinforce the important role and potential for enhancement of the widespread religious community resources for this group.
CHAPTER III
PROCEDURES

Research Design

This study involved an ex-post facto research approach, with a static-group-comparison research design. This design examines variables that have occurred in a natural setting and cannot be created in an experiment. Data were collected by mailed self-report instruments.

A pilot study for the entire questionnaire was conducted prior to initiating data collection. It was determined that one support group would be selected by the Alzheimer's Association (AA) Chapter liaison to serve as the pilot group, whose usual attendance included at least 10 to 12 members. The pilot was conducted to determine face validity, readability and internal consistency of the survey instrument for this population. The survey instrument and procedures were revised according to Human Subjects Review comments. A pilot study was conducted on June 12, 1993 with one support group from the Central Ohio Chapter. Participants (n=11) offered suggestions regarding the
rewording of directions for the Hassles Scale to ease in their understanding. They took between 20 and 30 minutes to complete the questionnaire and stated that they did not find the questionnaire taxing. In fact, these participants requested an additional format for the option of discussing their caregiving situations further. These adjustments were made in the questionnaire. Cronbach alphas were computed for pilot data, ranging between .83 and .98 for the separate tools used in the questionnaire, representing acceptable internal consistency.

Subject Selection

The study population included members of the Central-Ohio Alzheimer's Association and Related Disorders' support group program. A prior study of this Alzheimer's Association Chapter's support group program indicated that members hold diverse characteristics with regard to caregiving status, length and regularity of group membership, age, relationship to the AD individual, and support service needs (Whitlatch & Langhout, 1990). Thus, although this population seems to be limited in its generalizability, prior research
with this particular population demonstrated no
difference in the demographics of these AD caregivers
(Whitlatch & Langhout, 1990; Whitlatch, et al., 1992)
compared to known AD caregiver demographic statistics.

A cluster sampling of the 23 support groups from
the Central-Ohio Alzheimer’s Disease and Related
Disorders Association included 15 groups. This sampling
method was chosen due to the researcher’s lack of
access to a mailing list of individual caregiver
members of AA support groups. It was the researcher’s
intention to study groups both in urban and rural areas
as research indicates differences between these groups
with regard to available community and respite
resources (Whitlatch & Langhout, 1990). It has been
estimated that individual support group attendance in
this chapter ranges from 4 to 23 members, having
sampled six of 23 groups (Whitlatch & Langhout, 1990)
and a subsequent review of 1992 attendance records. The
staff administrator for the Alzheimer’s Association
(AA) served as liaison for the researcher in initiating
contact with the selected sample support groups’
leaders. This AA liaison informed support group leaders
(SGLs) of the association’s formal approval of the
research, encouraging cooperation with the researcher.
The researcher subsequently contacted individual SGLs
to schedule attendance for the purpose of data
collection. At these meetings the researcher requested voluntary participation of group members. Member eligibility was based upon family (or significant other) caregiver status of an AD affected care-recipient. Therefore, this study involved a volunteer, cluster sample of AD caregivers. A minimal number of subjects was needed in this study, calculated at n=91; based on the critical effect size of .30 and power=.90, and a one-tail test.

**Measures**

Written permission was sought and received for the use of all measures to be included in this study. Letters of permission have been included as Appendix C.

**Well-being**

The dependent variable, subjective well-being, was measured by using the *Current HIS Mental Health Battery: General Well-being* (Current HIS-GWB). The instrument was originally designed to measure the effects of different health care financing arrangements on the health status of the population in the Rand Health Insurance Study, with health status operationally defined as general well-being. This instrument consists of 38 items, grouped into six summated subscales representing anxiety, depression, positive-
well-being, self-control, general health, and vitality (Ware, et al, 1987). These subscales were formed by examining the content of accepted tools for measuring well-being. The intent was to include both positive and negative states or aspects most often associated with or used to determine mental health and general well-being.

The authors of the HIS-GWB developed the subscales by examining, comparing and including the content of many accepted tools, retaining items that best measured each subscale without redundancy. The item groupings that were hypothesized to define the summated rating scales measuring the six constructs for general well-being were tested by subjecting them to the criteria of multi-trait scaling. Multi-trait scaling was used to test both the internal consistency of the hypothesized summated rating scales and the discriminant validity of items in those scales. It was determined that the criterion was satisfied for all six subscales, correcting for overlap between items.

The tool that was used in this study is Form E, including 38 of 46 items. Face validity for content of all items was judged to be adequate by the authors of the original instrument. Eight items testing for social desirability of response were eliminated as they were not part of or important to validity and reliability
studies, and because it was felt that they were potentially offensive in content and might reduce response.

Two methods were used to estimate the reliability of the HIS-GWB scales. First, Ware, et al. (1987) report ample internal-consistency reliability coefficient for the Current HIS-GWB, with values above .90. Further, test-retest estimates of reliability tend to range from .70 to .80, depending upon the time between administration. The trend suggests that stability is best during periods of up to one month.

**Perceived Stress**

Stress, an independent variable, was assessed using Kinney’s (1989) Caregiving Hassles Scale designed to measure the daily hassles (events identified as stressful) of caring for a family member with dementia. This tool was based on the transactional perspective of stress (Lazarus & Folkman, 1984). Items were derived from the literature on caregiving and from discussions with caregivers. This forty-two item scale consists of five subscales including hassles associated with activities of daily living (ADL), assistance with instrumental activities (cooking, shopping, etc.) of daily living (IADL), care-recipient’s cognitive status, care-recipient’s behavior, and caregiver’s social
network. The test-retest reliability coefficient was reported as $r = .83$, and internal consistency was reported at alpha = .91 (Kinney & Stephens, 1989). Construct validity was established in a two step process. The total hassles score is computed by summing intensity ratings across all items, and subscale scores are computed by summing ratings across all items in that subscale (see Appendix F).

**Coping Strategies**

Coping strategies, another independent variable, was assessed using the thirty-item Family Crisis Oriented Personal Evaluation Scales (F-Copes) (McCubbin et al., 1981). There are several reasons for choosing this instrument over Lazarus’s 68-item Ways of Coping Checklist. First, the F-Copes results in interval data in the form of a mean score, where Lazarus’s checklist results in bivariate responses of yes and no to each item and a subscale for each coping strategy (Gass, 1989). Second, the F-Copes was preferred in length with 30 items, over the comparatively long checklist tool. In addition, the F-Copes instrument tended to have higher reliability scores in the literature (ranging from .81 to .86), than the checklist tool (ranging from subscores from .34 to .74) (Gass, 1989). Finally, the F-Copes tool was created and revised specifically to

This 30 item tool divides its focus on two levels. They are: 1) ways in which family members cope internally with demands, and 2) ways in which family members cope externally with difficulties or demands. Internal family coping strategy subscales are identified under three major patterns: confidence in problem-solving, reframing problems, and passivity (avoidance behaviors based on a lack of confidence) (McCubbin et al., 1981). The external subscales are identified under five major patterns: church/religious resources, extended family, friends, neighbors, and community resources (McCubbin et al., 1981). The F-COPES Scale overall, has an alpha reliability of .86 and test-retest reliability of .81 (Olsen et al., 1983) (see Appendix F).

Religiosity

Religiosity, an independent variable, was assessed using the Springfield Religiosity Schedule (SRS) (Koenig et al., 1988c). This tool includes: (1) an intrinsic factor that includes the ten items from the
Intrinsic Religious Motivation Scale (IRM) (Hoge, 1972) and (2) a ritual factor from Glock and Stark’s ritual items including both organizational and non-organizational activities from the Koenig et al.’s scales (1988a, 1988b) Organizational Religious Activity scale (ORA) and the Non-organizational Religious Activity scale (NORA). This scale includes both objective and subjective dimensions of religiosity. The three separate measures of religiosity have demonstrated high internal consistency and reliability, with Cronbach alphas of .61 (ORA), .63 (NORA), and .87 (IR) (Hoge, 1972; Koenig et al., 1988). Scoring on this tool ranges from 15 to 75. Also included in this study were two additional items, which were not included in the scoring of the Religiosity scale. Respondents were asked to identify their religious preference for a list of possible religious affiliations, including catholic, protestant, jewish, other and none of the above as choices. In addition, caregiver respondents were asked to indicate whether their religious beliefs or practices had changed since taking on their caregiving role, by answering yes or no. If the respondents answered affirmatively, they were asked to explain the nature of that change.
Dementia Impairment

Severity of AD individual impairment was measured by the Functional Dementia Scale (FDS) (Moore, et al., 1983) and used as a control variable in this study. This scale includes 20 items designed to be completed by the caregiver concerning their perception of the affected individual's impairment in the activities of daily living, affect, and orientation. Cronbach's alpha coefficient of internal consistency as applied by Moore, et al (1983) was .90. The test-retest correlation was .88. Content validity was achieved by piloting the instrument with nurses. In addition, Moore, et al. (1983) found this instrument to correlate highly with two widely accepted tests of cognitive function (the Short Portable Mental Status Questionnaire (SPMSQ), and the SET test a rapid test of mental function to assess mental function, in order to establish construct and concurrent validity (see Appendix F).

Demographic Characteristics

Several items were included to gain information regarding caregiver demographic characteristics and resources. Items regarding caregiver characteristics involved questions about caregiver age, gender, marital status, race, education level, and employment status.
In addition, control variables related specifically to characteristics of the caregiving situation, including, length of time as family caregiver for and relationship to the affected AD individual, the AD affected individual’s place of residence. The respondents were also asked to indicate whether their care-recipient had been diagnosed with Alzheimer’s or other type of dementia. All demographic items were piloted during a previous study (Whitlatch & Langhout, 1990).

**Conditions of Testing**

As eligible subjects voluntarily agreed to participate in this research, each one received the questionnaire packet (with a cover letter and pre-addressed, stamped envelope). Completion of the tool was considered to represent the respondents’ willingness to participate in this study. The cover letter included the purpose of the research, general directions for completing and returning the questionnaire, a request for response within two weeks, and assured anonymity of individual responses to the researcher.

Non-response was handled in the following manner. Eligible, volunteer members were given the packet, and instructed to sign their name and address on a numbered member roster. Roster numbers corresponded with number
coded packets. This roster remained with the support group leader (SGL). After the two week deadline, the researcher called the SGL and identified the nonrespondents by code number. The SGL was instructed to mail out the prepared reminder postcards (see Appendix B) to the nonrespondents. In this fashion, anonymity was maintained between participants and the researcher, adhering to the agreement previously established with AA chapter staff; that the researcher would at no time obtain or use names and addresses of the family support group members.

In order to maximize response, a second mailing was planned for two weeks following the postcard reminder period. This mailing was handled in a similar manner to the postcard mailing, using the number coded system. Following two more weeks, the researcher called the SGLs and requested demographic information (permitted by the AA Chapter for release) in order to describe identified nonrespondents' characteristics (gender, age, relationship to AD affected individual, and an estimate of how long they have been a caregiver).

Data Analysis

Data were analyzed using the Statistical Package for the Social Sciences (SPSSx) on The Ohio State
University main computer system. The level of significance for this study was established a priori at \( \alpha < 0.05 \). Individual scores were computed for the following variables: 1) subjective well-being; 2) overall perceived stress level; 3) coping; 4) level of religiosity; and 5) degree of functional impairment of the AD individual.

Frequency distributions and appropriate descriptive statistics were computed for all data. Individual summary scores were determined for each scale used within the questionnaire, including subjective well-being, perceived stress, level of coping, religiosity, and level of functional dementia impairment. Mean and standard deviation scores were computed for the group using the summary scores on likert-scale tools. With demographic items, descriptive statistics included frequency scores and modes for nominal items, and median and ranges values for ordinal scaled items.

Pearson partial correlation values (pr's) were computed to determine the direction and magnitude of relationships between the dependent variable and each of the independent variables, and the relationships among the independent variables, while controlling for length of time as family caregiver for and relationship to the affected AD individual, the AD affected
individual's place of residence, and functional dementia score. This correlational analysis was performed to determine whether associations existed between subjective well-being and the independent variables of perceived stress, coping strategies, and religiosity measures, and functional dementia level of AD individual, and among the independent variables, in order to evaluate stated hypotheses one through four.

A three-step multiple regression analysis was applied to the data to determine the linear combination of independent variables that explained the greatest proportion of variance in the dependent variable. Thus, the null hypothesis was stated as follows: $R^2 = 0$. Semi-partial (part) correlations were computed to indicate the contribution of each independent variable to the explained variance, eliminating the linear effects of the other independent variables ($H_0: R^2 \text{ change} = 0$). The first of the three step analysis involved the simultaneous entry of independent and control variables into a linear combination, predicting variance in the dependent variable, in order to test Null Hypothesis 5 and to determine the order of entry for Step 2. From these results it was determined which variables would be entered hierarchically in Step 2, followed by the simultaneous entry of the remaining independent and control variables, in addition to the
two-way interaction variables (stress-coping, stress-religiosity, religiosity-coping). Once again, results of Step 2 were used to determine the hierarchical ordering of variables in step 3, to be followed by the simultaneous entry of all other variables including the three-way interaction variable (stress-coping-religiosity). In this way it was felt that the best linear combination of independent and interaction variables explaining the greatest proportion of variance in the dependent variable of subjective well-being could be determined, given the variables measured in this study.

In order to test for violation of assumptions using multiple regression analysis, the following were examined: 1) multicollinearity between the independent variables; and 2) residuals for normality, independence, and homoscedasticity. For multicollinearity, the correlation matrix was examined for any bivariate correlations close to \( r = 1.0 \), and by examining tolerance values for each variable for values significantly less than 1.0. Violation of assumptions regarding residuals in the analysis were determined by examining the following: 1) normality - visual examination of the normal probability plot of residuals, looking for all values falling along a diagonal with no substantial or systematic deviation;
2) independence - examination of Durbin-Watson statistic, where a value of close to 2.0 would indicate that the assumption has not been violated; and 3) homoscedasticity - visual examination of standardized scatterplots for each variable, where a horizontal band configuration for each plot indicates no trend in the data, and thus constancy of variance in the residuals.
CHAPTER IV

RESULTS

This ex post-facto, static-group-comparison study was designed to investigate the perceived stresses of AD family caregivers, their coping strategies, and specifically the suggested coping strategy of religiosity, as they relate to the subjective well-being of AD caregivers. Data were collected from a convenience sample of family caregivers who attended Central Ohio Alzheimer's Association support group program meetings from June 15 through September 6, 1993. Presentation of results of the data analysis, and interpretation of the data obtained by the methods described in the previous chapter, are discussed in this chapter. This presentation includes a description of the demographic caregiver and AD individual characteristics, and results of hypothesis testing. The findings are organized in tables and figures.

Description of the Responding Sample

During the 15 support group meetings, a total of 115 caregivers accepted questionnaires, with 105 (91%)
actually responding by returning the completed questionnaire. Examination of nonrespondents’ characteristics following the four-week nonresponse period demonstrated no systematic differences with respondents with regard to gender, age, support group location, time as caregiver and family relationship to the AD individual. Seventy percent of the non-respondent caregivers were female, white (90%), with 90 percent 50 years and older, caring for their mother (30%) or spouse (50%). The majority of these respondents have been a caregiver between one and five years (70%). These characteristics are similar to those of respondents in this study.

Frequency distributions of caregiver demographic variables are organized in Table 1 and Figure 4 for age, gender, race, marital status, education and employment. The mean age for this sample of family caregivers was 61.6 years, with a standard deviation of 14.9 years. The sample varied in age from 18 to 88 years, with the majority of respondents (78%) being 40 and older. The majority of caregivers were female (n=71; 67.6%), and married (n=92; 87.6%). With regard to race, all but one respondent was caucasian (n=104; 99%).

The sample distribution also indicates that the majority (97%) held at least a high school diploma, with 31 percent reporting some college experience.
TABLE 1

Frequency Distributions of Demographic Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (n)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-19</td>
<td>1</td>
<td>1.0%</td>
</tr>
<tr>
<td>20-29</td>
<td>1</td>
<td>1.0%</td>
</tr>
<tr>
<td>30-39</td>
<td>7</td>
<td>6.7%</td>
</tr>
<tr>
<td>40-49</td>
<td>14</td>
<td>13.3%</td>
</tr>
<tr>
<td>50-59</td>
<td>23</td>
<td>21.5%</td>
</tr>
<tr>
<td>60-69</td>
<td>23</td>
<td>21.5%</td>
</tr>
<tr>
<td>70-79</td>
<td>26</td>
<td>24.8%</td>
</tr>
<tr>
<td>80-89</td>
<td>10</td>
<td>9.5%</td>
</tr>
<tr>
<td>GENDER</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>34</td>
<td>32.4%</td>
</tr>
<tr>
<td>Female</td>
<td>71</td>
<td>67.6%</td>
</tr>
<tr>
<td>RACE</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>104</td>
<td>99.0%</td>
</tr>
<tr>
<td>Black</td>
<td>1</td>
<td>1.0%</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>0.0%</td>
</tr>
<tr>
<td>MARITAL STATUS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>92</td>
<td>87.6%</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>3.8%</td>
</tr>
<tr>
<td>Widowed</td>
<td>3</td>
<td>2.9%</td>
</tr>
<tr>
<td>Never Married</td>
<td>6</td>
<td>5.7%</td>
</tr>
<tr>
<td>EDUCATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grade School</td>
<td>3</td>
<td>2.5%</td>
</tr>
<tr>
<td>High School</td>
<td>49</td>
<td>46.7%</td>
</tr>
<tr>
<td>Some college</td>
<td>33</td>
<td>31.4%</td>
</tr>
<tr>
<td>Collegen Degree</td>
<td>15</td>
<td>14.3%</td>
</tr>
<tr>
<td>Graduate Degree</td>
<td>5</td>
<td>4.8%</td>
</tr>
<tr>
<td>EMPLOYMENT</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Work &gt; 30 hours</td>
<td>26</td>
<td>24.8%</td>
</tr>
<tr>
<td>Work &lt; 30 hours</td>
<td>17</td>
<td>16.2%</td>
</tr>
<tr>
<td>Retired</td>
<td>49</td>
<td>46.7%</td>
</tr>
<tr>
<td>Unemployed</td>
<td>12</td>
<td>11.4%</td>
</tr>
<tr>
<td>Disabled</td>
<td>1</td>
<td>1.0%</td>
</tr>
</tbody>
</table>

* x = 61.6 sd=14.9 range=18-88
Graphic Representation of Frequency Distribution of Demographic Variables
Figure 4
Figure 4 (continued)

MARITAL STATUS

- Married (87.62%)
  - Never Married (5.71%)
  - Widowed (2.86%)
  - Divorced (3.81%)

EDUCATION

- High School (46.67%)
  - Some college (31.43%)
  - Collg Degree (14.29%)
  - Grade School (2.86%)
  - Graduate Degree (4.76%)

EMPLOYMENT

- Work > 30 hours (24.76%)
  - Work < 30 hours (15.19%)
  - Retired (46.67%)
  - Unemployed (11.43%)
  - Disabled (0.95%)
Nearly 20 percent (n=20) held a college or graduate degree. When considering employment characteristics in this sample, 41 percent are employed on either a full- or part-time basis, with nearly 50 percent of the caregivers reporting retired status.

Table 2 and Figure 5 organize frequency distributions of caregiver-related characteristics. The respondents have been in the caregiving situation between one and seventeen years, with a mean of 4.81 years and a standard deviation of 3.34 years. Sixty-seven percent have been caregivers for at least three to ten years. The majority of care-recipients are either the caregivers' spouse (45%) or parent (41%), most often their mother. Other relationships included son, grandfather, aunt, and mother-in-law. When "other" was cited as a response to this item, three of five caregivers identified caring for both parents. For this sample, the care-recipients' dementia has been most often diagnosed as the Alzheimer's type. Over half (59%) of care-recipients are being cared for by family in the community, with the remaining 41 percent residing and cared for in an institutional setting.

Religious affiliation of caregivers are organized in Table 3 and Figure 6. Nearly all of the respondents (98%) reportedly identify themselves with a particular organized religious denomination, with the majority
### TABLE 2

**Frequency Distributions of Caregiving-Related Characteristics**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Frequency (n)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Length of Time as a Caregiver</strong> <em>(in years)</em></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2</td>
<td>28</td>
<td>26.7%</td>
</tr>
<tr>
<td>3-5</td>
<td>44</td>
<td>41.9%</td>
</tr>
<tr>
<td>6-10</td>
<td>27</td>
<td>25.7%</td>
</tr>
<tr>
<td>&gt;10</td>
<td>6</td>
<td>5.7%</td>
</tr>
</tbody>
</table>

| Care-recipient’s relationship to Caregiver     |               |             |
| Spouse                                        | 47            | 44.8%       |
| Mother                                        | 35            | 33.3%       |
| Father                                        | 8             | 7.6%        |
| Mother-in-law                                 | 5             | 4.8%        |
| Grandfather                                   | 2             | 1.9%        |
| Son                                           | 1             | 1.0%        |
| Aunt                                          | 1             | 1.0%        |
| Other                                         | 5             | 4.8%        |

| Differential Diagnosis of Dementia            |               |             |
| Alzheimer’s Disease                           | 81            | 77.1%       |
| All Other Dementias                           | 24            | 22.9%       |

| Residence of AD individual                    |               |             |
| In caregiver home                             | 41            | 39.0%       |
| In own home with caregiver                    | 14            | 13.3%       |
| With another family member                    | 7             | 6.7%        |
| In a nursing home                             | 41            | 39.0%       |
| In assisted-living center                     | 2             | 1.9%        |

\[ x = 4.81 \quad sd = 3.34 \quad range = 1-17 \text{ years} \]
Length of Time as a Caregiver
(in years)

- >10 (5.71%)
- 1-2 (26.67%)
- 3-5 (41.90%)
- 6-10 (25.71%

Care-recipient Relationship to Caregiver

- Spouse (45.19%)
- Mother (33.65%)
- Father (7.69%)
- Grandfather (1.92%)
- Mother-in-law (4.81%)
- Son (0.96%)
- Aunt (0.56%)
- Other (4.81%)

Graphic Representation of Frequency Distribution of Caregiving-Related Characteristics
Figure 5
Figure 5 (continued)

Differential Diagnosis of Dementia

- Alzheimer's Disease (77.14%)
- All Other Dementias (22.86%)

Residence of AD Individual

- In assisted-living center (1.90%)
- In a nursing home (39.05%)
- In caregiver home (39.05%)
- In own home with caregiver (13.33%)
- With another family member (6.87%)
### TABLE 3

**Religious Affiliation of Caregivers**

*(n=104)*

<table>
<thead>
<tr>
<th>Affiliation</th>
<th>Frequency (n)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catholic</td>
<td>12</td>
<td>11.4%</td>
</tr>
<tr>
<td>Jewish</td>
<td>4</td>
<td>3.8%</td>
</tr>
<tr>
<td>Protestant</td>
<td>86</td>
<td>81.9%</td>
</tr>
<tr>
<td>None</td>
<td>2</td>
<td>1.9%</td>
</tr>
</tbody>
</table>

Have your religious practices or beliefs changed since caregiving?

<table>
<thead>
<tr>
<th>Frequency (n)</th>
<th>Percent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>26</td>
</tr>
<tr>
<td>No</td>
<td>78</td>
</tr>
</tbody>
</table>
Religious Affiliation

None (1.92%)  Catholic (11.54%)  Jewish (3.85%)
Protestant (82.69%)

Change in Belief?

Yes (25.00%)  No (75.00%)

Graphic Representation of the Religious Affiliation of Caregivers
Figure 6
beliefs has changed since the onset of their caregiving responsibilities, the majority (n=78; 74.3%) denied any change (Table 3 and Figure 6). Of those who indicated that changes had occurred (n=26; 25%), several (n=5) cited a decreased ability to participate in formal religious activities due to the overwhelming nature of caregiving and a lack of respite care. As one respondent commented, "Can’t get away to attend services and programs." Yet another caregiver wrote, "I go to church less since my spouse stays home with care-recipient."

Several other caregivers (n=12) expressed an actual increase in their religious beliefs, with an increased need and/or desire for prayer. For instance, one respondent wrote: "I lean on God more - talk to him more - ask for guidance and wisdom more." Another indicated that he or she "spend(s) more time praying for strength, understanding, and patience."

Still other caregivers (n=3) expressed despair with their situations. One caregiver wrote, "While still a strong believer, I often wonder why we must suffer so much." Another wrote, "I don’t have much faith any more."
**Descriptive Statistics for Measured Variables**

Table 4 organizes descriptive statistics for each of the measured variables: dependent, independent and control variable measured separately in the caregiver questionnaire. Cronbach alphas were computed separately for the five measurement tools used in the questionnaire, representing acceptable internal consistency, with the following results: 1) subjective well-being, alpha=.9738; 2) religiosity, alpha=.9632; 3) stress, alpha=.9296; 4) coping, alpha=.8413; and functional dementia, alpha=.8649.

**Hypothesis Testing**

The six hypotheses were tested using partial correlation and a three-step multiple regression analysis. All were tested at the $\alpha=.05$ level of significance, controlling for family relationship of the care-recipient to the caregiver (recoded as spouse or nonspouse), time as a caregiver (in years), functional dementia score, and care-recipient place of residence (recoded as institutionalized or noninstitutionalized). The research hypotheses are being restated here as follows:

1. There will be an inverse relationship between family caregiver level of subjective well-being and perceived stress.
# TABLE 4

*Descriptive Statistics for Measured Variables*

<table>
<thead>
<tr>
<th>Variable</th>
<th>n</th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
<th>Possible Range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Dependent</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Subjective Well-Being</td>
<td>100</td>
<td>4.003</td>
<td>0.881</td>
<td>1.89-5.71</td>
<td>1-6</td>
</tr>
<tr>
<td><strong>Independent</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>101</td>
<td>0.591</td>
<td>0.453</td>
<td>0-2.43</td>
<td>0-3</td>
</tr>
<tr>
<td>Coping</td>
<td>97</td>
<td>3.490</td>
<td>0.506</td>
<td>2.43-4.60</td>
<td>1-5</td>
</tr>
<tr>
<td>Religiosity</td>
<td>99</td>
<td>3.612</td>
<td>0.999</td>
<td>1.04-5.11</td>
<td>0-6</td>
</tr>
<tr>
<td><strong>Control</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Functional Dementia</td>
<td>103</td>
<td>2.354</td>
<td>0.571</td>
<td>1.0-3.65</td>
<td>1-4</td>
</tr>
</tbody>
</table>
2. There will be a positive relationship between family caregiver level subjective well-being and coping.

3. There will be a positive relationship between the level of family caregiver subjective well-being and religiosity.

4. There will be a positive relationship between family caregiver religiosity score and overall coping.

5. A significant proportion of the variance in subjective well-being will be explained by a linear combination of the tested independent variables.

6. A significant proportion of the variance in family caregiver's subjective well-being will be explained by a linear combination of the independent variables and their interactions.

The results of the data analysis are described below, following the restatement of each hypothesis in its null form. Results of partial correlation analysis are organized in Table 5. Missing data for this analysis was handled by listwise deletion. Results of the multiple regression analysis are organized in Tables 6 through 8. Missing data for these analyses were handled by mean-substitution.

**Null Hypothesis 1: There will be no significant or a positive relationship between family caregiver level of subjective well-being and perceived stress.**

Partial correlation values support rejecting the null (H₀: ρ=0), where ρ=-.3218, at p=.001 (Table 5). Thus, the data indicate a significant moderate and inverse relationship between caregiver subjective
**TABLE 5**

*Partial Correlations for Hypothesized Relationships*

<table>
<thead>
<tr>
<th>Variables</th>
<th>n</th>
<th>pr</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWB and Stress</td>
<td>90</td>
<td>-0.3218</td>
<td>0.001</td>
</tr>
<tr>
<td>SWB and Coping</td>
<td>88</td>
<td>0.2795</td>
<td>0.004</td>
</tr>
<tr>
<td>SWB and Religiosity</td>
<td>89</td>
<td>0.3920</td>
<td>0.000</td>
</tr>
<tr>
<td>Coping and Religiosity</td>
<td>89</td>
<td>0.5602</td>
<td>0.000</td>
</tr>
</tbody>
</table>

*Controlling for Relationships to patient, Time in caregiving situations, AD individual's place of residence, and Functional Dementia Score.*
well-being and their level of perceived stress, as measured by the Hassles Scale, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the caregivers’ level of stress increases, their subjective well-being will decrease.

Null Hypothesis 2: There will be no significant or a negative relationship between family caregiver level of subjective well-being and coping.

Partial correlation values support rejecting the null ($H_0: r=0$), where $r=.2795$, at $p=.004$ (Table 5). Thus, the data indicate a significant low and positive relationship between caregiver subjective well-being and their level of coping, as measured by the F-COPES Instrument, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the caregivers’ level of coping increases, their subjective well-being will increase as well.

Null Hypothesis 3: There will be no significant or a negative relationship between family caregiver level of subjective well-being and religiosity.

Partial correlation values support rejecting the null ($H_0: r=0$), where $r=.3920$, at $p=.001$ (Table 5). Thus, the data indicate a significant moderate and positive relationship between caregiver subjective
well-being and their level of religiosity, as measured by the Springfield Religiosity Scale, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the greater the level of caregiver religiosity, the higher their subjective well-being.

**Null Hypothesis 4:** There will be no significant or a negative relationship between family caregiver level of religiosity and coping.

Partial correlation for hypothesized relationships support rejecting the null ($H_0: \rho \leq 0$), where $\rho = 0.5602$, at $p = 0.001$ (Table 5). Thus, the data indicate a significant substantial and positive relationship between caregiver level of religiosity and coping, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the greater the level of caregiver religiosity, the higher their level of coping.

**Null Hypothesis 5:** No significant proportion of the variance in family caregiver subjective well-being will be explained by the linear combination of the independent variables, including stress, coping and religiosity.

**Null Hypothesis 6:** No significant proportion of the variance in family caregiver subjective well-being will be explained by the linear combination of the independent variables (stress, coping and religiosity), and their interactions (stress-coping,

Table 6 displays the correlation matrix for all dependent, independent, control and interaction variables. A three-step multiple regression analysis was used to test Null Hypotheses 5 and 6.

The first step involved the simultaneous entry of independent and control variables into a linear combination, predicting variance in the dependent variable, in order to test Null Hypothesis 5 and to determine the order of entry for step 2. Results of this simultaneous multiple regression analysis are listed in Table 7. From these results it was determined which variables would be entered hierarchically in step 2, followed by the simultaneous entry of the remaining independent and control variables, in addition to the two-way interaction variables (stress-coping, stress-religiosity, religiosity-coping). Once again, results of step 2 were used to determine the hierarchical ordering of variables in step 3, to be followed by the simultaneous entry of all other variables including the three-way interaction variable (stress-coping-religiosity). In this way it was felt that the best linear combination of independent and interaction variables explaining the greatest proportion of variance in the dependent variable of subjective well-being could be determined, given the variables measured
### TABLE 6

**Correlation Matrix of Dependent, Independent, Control Variables and Interaction Variables**

(n=105)

<table>
<thead>
<tr>
<th>VARIABLE</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
<th>11</th>
<th>12</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 SWB</td>
<td>-0.317</td>
<td>0.258</td>
<td>0.360</td>
<td>0.072</td>
<td>0.028</td>
<td>-0.550</td>
<td>-0.008</td>
<td>-0.242</td>
<td>-0.142</td>
<td>0.357</td>
<td>-0.093</td>
</tr>
<tr>
<td>2 Stress</td>
<td>-0.011</td>
<td>0.037</td>
<td>0.043</td>
<td>-0.264</td>
<td>0.175</td>
<td>0.041</td>
<td>0.950</td>
<td>0.903</td>
<td>0.032</td>
<td>0.847</td>
<td></td>
</tr>
<tr>
<td>3 Coping</td>
<td>-0.545</td>
<td>-0.108</td>
<td>0.081</td>
<td>0.096</td>
<td>0.010</td>
<td>0.156</td>
<td>0.145</td>
<td>0.786</td>
<td>0.267</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Religiosity</td>
<td>-0.051</td>
<td>-0.007</td>
<td>0.195</td>
<td>0.015</td>
<td>0.153</td>
<td>0.374</td>
<td>0.931</td>
<td>0.445</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Time</td>
<td>-0.135</td>
<td>0.163</td>
<td>0.012</td>
<td>0.025</td>
<td>0.046</td>
<td>-0.014</td>
<td>0.041</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Residence</td>
<td>-0.130</td>
<td>0.088</td>
<td>-0.230</td>
<td>-0.234</td>
<td>0.019</td>
<td>-0.210</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Functional Dementia</td>
<td>-0.136</td>
<td>0.184</td>
<td>0.209</td>
<td>0.194</td>
<td>0.213</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Relationship</td>
<td>-0.097</td>
<td>0.058</td>
<td>0.007</td>
<td>0.106</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Stress-Coping</td>
<td>-0.907</td>
<td>0.165</td>
<td>0.922</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Stress-Religiosity</td>
<td>-0.336</td>
<td>0.970</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Religiosity-Coping</td>
<td>-0.426</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Stress-Coping-Religiosity</td>
<td>-</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## TABLE 7

**STEP 1** Simultaneous Multiple Regression Analysis Explaining the Variance in Subjective Well-Being

<table>
<thead>
<tr>
<th>Variables</th>
<th>SE Coefficient</th>
<th>$\beta$</th>
<th>Partial Correlation</th>
<th>t-value</th>
<th>p of t-value</th>
<th>Tolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress</td>
<td>0.181</td>
<td>-0.335</td>
<td>-0.315</td>
<td>-3.585</td>
<td>0.001</td>
<td>0.882</td>
</tr>
<tr>
<td>Coping</td>
<td>0.189</td>
<td>0.087</td>
<td>0.072</td>
<td>0.817</td>
<td>0.416</td>
<td>0.673</td>
</tr>
<tr>
<td>Religiosity</td>
<td>0.095</td>
<td>0.336</td>
<td>0.275</td>
<td>3.125</td>
<td>0.002</td>
<td>0.668</td>
</tr>
<tr>
<td>Time</td>
<td>0.023</td>
<td>0.038</td>
<td>0.036</td>
<td>0.414</td>
<td>0.680</td>
<td>0.927</td>
</tr>
<tr>
<td>Residence</td>
<td>0.164</td>
<td>-0.062</td>
<td>-0.058</td>
<td>-0.658</td>
<td>0.512</td>
<td>0.864</td>
</tr>
<tr>
<td>Functional</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia</td>
<td>0.143</td>
<td>-0.070</td>
<td>-0.066</td>
<td>-0.750</td>
<td>0.455</td>
<td>0.875</td>
</tr>
<tr>
<td>Relationship</td>
<td>0.153</td>
<td>0.014</td>
<td>0.015</td>
<td>0.167</td>
<td>0.867</td>
<td>0.974</td>
</tr>
</tbody>
</table>


*Multiple R = .502  
*R square = .252  
SE of estimate = .770

### Analysis of Variance - Summary Table

<table>
<thead>
<tr>
<th>Sum of Squares</th>
<th>df</th>
<th>Mean Squared</th>
<th>F-ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>19.405</td>
<td>2.772</td>
<td>4.676</td>
</tr>
<tr>
<td>Residual</td>
<td>57.483</td>
<td>0.593</td>
<td>(p=0.001)</td>
</tr>
</tbody>
</table>

*Analysis of Residuals:*
1. Independence: Durbin-Watson test = 1.64 with no linear trends on casewise plots of standardized residuals.
2. Normality: Histogram of standardized residual and normal probability plots indicate normality.
3. Homoscedasticity: Standardized scatter plots for all variables indicate no trends.
in this study.

Findings from Step 1 of the multiple regression analysis are organized in Table 7. The three main independent variables and four control variables were entered into the regression simultaneously. This step revealed that these variables together explained a significant proportion of the variance ($R^2=.252$; $F_{7,97}=4.68$ at $p<.001$) in subjective well-being. Examination of individual variables in the model, however, revealed that only religiosity and stress accounted for significant contributions to this regression model, when other variables are controlled ($Beta= .336$, $t=3.125$ and $-.335$, $t=-3.830$, respectively, at $p<.002$). This information was used to perform Step 2, involving the hierarchical entry of religiosity and stress, in that order. For this step, the remaining variables were entered simultaneously with the addition of the three two-way interaction variables. Findings from Step 2 are organized in Table 8. These results again reveal religiosity and stress as the only two significant variables explaining the variance in the dependent variable of subjective well-being.

The third multiple regression step involved the hierarchical entry of religiosity and stress, with the simultaneous entry of the remaining independent, interaction and control variables, this time including
### TABLE 8

**STEP 2  Multiple Regression Analysis: Hierarchical Entry of Significant Independent Variables with Subsequent Simultaneous Entry of Control and Paired-Interaction Variables to Explain the Variance in Subjective Well-being**

**Hierarchical Entry:**

<table>
<thead>
<tr>
<th>Variables</th>
<th>R squared</th>
<th>R squared change</th>
<th>F change</th>
<th>β</th>
<th>t</th>
<th>p</th>
<th>Tolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religiosity</td>
<td>0.1297</td>
<td>0.1297 (p&lt;.001)</td>
<td>15.35</td>
<td>0.36</td>
<td>3.919</td>
<td>0.0002</td>
<td>0.999</td>
</tr>
<tr>
<td>Stress</td>
<td>0.2392</td>
<td>0.1094 (p&lt;.001)</td>
<td>14.67</td>
<td>-0.31</td>
<td>-3.83</td>
<td>0.0002</td>
<td>0.999</td>
</tr>
</tbody>
</table>

**Multiple R = .48905**
**R square = .23917**
**SE of estimate = .75731**

---

**Analysis of Variance - Summary Table**

<table>
<thead>
<tr>
<th></th>
<th>Sum of Squares</th>
<th>d f</th>
<th>Mean Squared</th>
<th>F-ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>18.390</td>
<td>2</td>
<td>9.190</td>
<td>16.030</td>
</tr>
<tr>
<td>Residual</td>
<td>58.500</td>
<td>102</td>
<td>0.570</td>
<td>(p=0.0001)</td>
</tr>
</tbody>
</table>

α<0.05

*Analysis of Residuals:*
1. Independence: Durbin-Watson test = 1.67 with no linear trends on casewise plots of standardized residuals.
2. Normality: Histogram of standardized residual and normal probability plots indicate normality.
3. Homoscedasticity: Standardized scatter plots for all variables indicate no trends, and thus constant variance.
TABLE 8 (continued)

**Simultaneous Entry:**

<table>
<thead>
<tr>
<th>Variable</th>
<th>SE Coefficient</th>
<th>β</th>
<th>Partial Correlation</th>
<th>t-value</th>
<th>p of t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping</td>
<td>0.557</td>
<td>0.064</td>
<td>0.018</td>
<td>0.202</td>
<td>0.840</td>
</tr>
<tr>
<td>Stress-Coping</td>
<td>0.219</td>
<td>0.067</td>
<td>0.015</td>
<td>0.172</td>
<td>0.863</td>
</tr>
<tr>
<td>Stress-Religiosity</td>
<td>0.165</td>
<td>0.287</td>
<td>0.071</td>
<td>0.804</td>
<td>0.433</td>
</tr>
<tr>
<td>Religiosity-Coping</td>
<td>0.129</td>
<td>0.071</td>
<td>0.009</td>
<td>0.106</td>
<td>0.916</td>
</tr>
<tr>
<td>Time</td>
<td>0.024</td>
<td>0.043</td>
<td>0.041</td>
<td>0.465</td>
<td>0.643</td>
</tr>
<tr>
<td>Functional Dementia</td>
<td>0.146</td>
<td>-0.066</td>
<td>-0.061</td>
<td>-0.692</td>
<td>0.490</td>
</tr>
<tr>
<td>Residence</td>
<td>0.166</td>
<td>-0.065</td>
<td>-0.061</td>
<td>-0.685</td>
<td>0.495</td>
</tr>
<tr>
<td>Relationship</td>
<td>0.159</td>
<td>0.007</td>
<td>0.006</td>
<td>0.073</td>
<td>0.942</td>
</tr>
</tbody>
</table>

Multiple R = .509
R square = .259
SE of estimate = .779

R square change = .0157
F change = .2835 (p=.959)

α<0.05

**Analysis of Variance Summary Table**

<table>
<thead>
<tr>
<th>Source</th>
<th>Mean Square</th>
<th>F-ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Regression</td>
<td>1.089</td>
<td>0.328</td>
</tr>
<tr>
<td>Residual</td>
<td>0.006</td>
<td>(p=.001)</td>
</tr>
</tbody>
</table>
the three-way interaction variable (stress-coping-religiosity). These results are displayed in Table 9 and Figure 7. Again, in examining each partial regression coefficient and related t-value for the remaining variables, and thus testing $H_0: B_k=0$, individually these variables do not contribute significantly to the regression when the effects of other variables are controlled. In addition, the simultaneous entry of variables other than religiosity and stress in Steps 2 and 3 do not produce significant change in $R^2$, as evidenced by nonsignificant F-change values (See Tables 8 and 9).

Information regarding the analysis of residuals is listed in footnotes for each multiple regression step in Tables 7, 8, and 9. Examination of this information indicates no violation of assumptions regarding residuals, including independence, normality, and homoscedasticity.

Data were also examined for the violation of multicollinearity. Initially, the correlation matrix was examined for intercorrelation among independent and interaction variables. No zero-order correlations above $r=.545$ (for coping and religiosity) were detected when considering only Step 1 variables. Tolerance values for Step 1 independent variables ranged from .668 to .882, considered acceptable for ruling out multicollinearity.
### TABLE 9

**STEP 3**

Multiple Regression Analysis: Hierarchical Entry with Subsequent Simultaneous Entry to Explain the Variance in Subjective Well-Being

Hierarchical Entry:

<table>
<thead>
<tr>
<th>Variables</th>
<th>R squared</th>
<th>R squared change</th>
<th>F change</th>
<th>β</th>
<th>t</th>
<th>p</th>
<th>Tolerance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Religiosity</td>
<td>0.1297</td>
<td>0.1297</td>
<td>15.35</td>
<td>0.36</td>
<td>3.918</td>
<td>0.0002</td>
<td>0.999</td>
</tr>
<tr>
<td>Stress</td>
<td>0.2392</td>
<td>0.1094</td>
<td>14.67 (p&lt;.001)</td>
<td>-0.331</td>
<td>-3.83</td>
<td>0.0002</td>
<td>0.999</td>
</tr>
</tbody>
</table>

Multiple R = .5125
R square = .2627
SE of estimate = .7807

R square change = .0190
F change = .299
(p=.965)

\[ \alpha < 0.05 \]

*Analysis of Residuals:
1. Independence: Durbin-Watson test = 1.69 with no linear trends on casewise plots of standardized residuals.
2. Normality: Histogram of standardized residual and normal probability plots indicate normality.
3. Homoscedasticity: Standardized scatter plots for all variables indicate no trends, with constant variance.
Graphic Representation of the Variance in the Dependent Variable Explained by the Hypothesized Variables

Figure 7
For Steps 2 and 3, the tolerance values for religiosity and stress (the two significant variables) was .999 (see Tables 8 and 9).

Not surprisingly, with the addition of interaction variables, several correlation values exceeded $r= .90$, with tolerance values ranging from .02 to .06. This indicated significant multicollinearity for these variables with each other and the main independent variables. However, since none of these interaction variables contributed significantly to the regression models in Steps 2 and 3 beyond the Step 1 analysis, these high intercorrelations are considered irrelevant. Thus, there is no concern for multicollinearity in this data.

Conclusions drawn from these multiple regression analyses regarding Null Hypotheses 5 and 6 are as follows. Coefficient of determination ($R^2$) values support rejecting Null Hypothesis 5 ($H_0: R^2=0$), where $R^2=.2392$, $F=16.032$ at $p=.000$, given the control of coping and the remaining four control variables. The variables of religiosity and stress explain a significant proportion of variance in the dependent variable subjective well-being.

Findings from Step 2 and 3 analyses support accepting Null Hypothesis 6 ($H_0: R^2=0$ and $B_x=0$), as the interaction variables do not contribute significantly
to explaining variance in the dependent variable subjective well-being beyond that explained by the religiosity and stress variables.
Summary of Findings

The typical caregiver in this sample is a white, protestant female, over 50 years of age, married and caring for her spouse or mother. Caregivers most often have a high school education, with at least some college experience, and work either full- or part-time. The typical respondent has been a caregiver for 4.8 years, for a community-dwelling individual diagnosed with dementia of the Alzheimer's type.

Findings presented in this chapter address each of the research hypotheses. Statistically significant and positive partial correlations were revealed between subjective well-being and the variables religiosity (pr=.3920) and coping (pr=.2795). A statistically significant and negative partial correlation (pr=-.3218) was found between subjective well-being and stress. In addition, a statistically significant and positive partial correlation (pr=.5602) was detected between the variables religiosity and coping.

Therefore, research hypotheses one through four were supported. It may be said that caregivers who display higher levels of religiosity and coping, with lower levels of stress, tend to demonstrate higher subjective well-being. In addition those with higher religiosity also tend to demonstrate higher levels of coping.
When the three independent (stress, coping and religiosity) and control variables were entered simultaneously during Step 1 multiple regression analysis, 25.2 percent of the variance in subjective well-being was accounted for among these caregivers. Religiosity explained 13 percent and stress explained 11 percent of the variance in subjective well-being.

No significant additional explanations for the variance in subjective well-being were found in Steps 2 or 3, when including the two- and three-way interactions of the independent variables and the control variables. Therefore, research hypothesis 5 was supported with the condition that coping does not tend to explain a significant proportion of the variance in subjective well-being. Research hypothesis 6 was rejected as no further variables contributed significantly to the regression model beyond the independent variables of religiosity and stress.
CHAPTER V

DISCUSSION, IMPLICATIONS AND RECOMMENDATIONS

Introduction

This study was undertaken to describe and analyze the relationships of stress, coping and religiosity with subjective well-being, and coping with religiosity for family caregivers of AD affected individuals. Specific characteristics of the caregiving situation were measured and statistically controlled, including family relationship, time as a caregiver, functional dementia and living arrangement. Selected demographic and religious characteristics of family caregivers were also described.

Discussion

The typical caregiver in this sample is a white, protestant female, over 50 years of age, married and caring for her spouse or mother. Caregivers most often have a high school education, with at least some college experience, and work either full- or part-time. The typical respondent has been a caregiver for 4.8 years, for a community-dwelling individual diagnosed
with dementia of the Alzheimer's type.

The sample described in this study is similar to other studies of AD caregivers with regard to mean age, gender, marital status and length of time as caregiver (Lawton et al., 1989; Pratt, et al., 1989; Novak & Guest, 1989; Scott, et al., 1989; Pearlin, et al., 1990; Whitlatch & Langhout, 1990). They tend to differ from descriptions of other AD caregiver samples by being more educated with more individuals with high school diplomas and at least some college; employment status, with more working caregivers in this sample; living arrangement of the care-recipient, with fewer caregivers actually living with the care-recipient; and race, with negligible representation of ethnic minorities (n=1).

It must be noted that this sample is limited by its volunteer nature, and support group membership. It is difficult to determine why these differences may have occurred, except for the lack of ethnic minority representation. It is recognized in the literature that, particularly for blacks, minority groups tend to have extensive support networks of family, friends and church. As Ebersole and Hess (1990) indicate, "Church members are an important source of support to elderly blacks. They develop a hierarchy of assistance: from family to friends and then neighbors and church members
before they seek help from formal organizations" (p. 670). In addition, Ballard, et al. (1993) indicate that even with adequate potential access to the black population, recruitment of black elderly for clinical research studies of dementia is difficult. Both trends have been attributed to the lower education and income levels, and the tendency for blacks to seek support from informal systems. One might speculate that had the black component of this sample been more in line with other caregiver studies, the differences with regard to education, employment, and living arrangements may have lessened.

The control variables in this study demonstrated no significant relationship with subjective well-being, including time as a caregiver (in years), living arrangements of the care-recipient (institutionalized versus noninstitutionalized), functional dementia score, and relationship to care-recipient (spouse versus nonspouse).

The non-association between time as a caregiver and subjective well-being agrees with the findings of Zarit, et al. (1980), Novak and Guest (1989b), Quayhagen and Quayhagen (1989), and Gatz, et al. (1990) who all noted that the length of time as caregiver did not correlate with increased stress or with caregiver outcome measures of subjective well-being, when the
effects of functional dementia, living arrangements, and social supports are controlled. Again, this is not surprising given the variability of AD over time, and related differences in the caregiving experience.

The lack of relationship between living arrangement of the care-recipient also agrees with the findings of several investigators in the literature, who determined no differences in the subjective well-being or reported stress between caregivers of institutionalized and noninstitutionalized AD individuals (Baldwin, 1988; Pierce, et al., 1989; Harper and Lund, 1990; Stephens, et al., 1991). Again, it would seem possible that caregivers of institutionalized AD individuals continue to provide care and spend a great proportion of their time involved in managing the care for their family member. In addition, financial concerns and the loss of control over how care is provided seem to complicate the caregiving situation for those with institutionalized care-recipients, and equalize their stress compared to those providing care in the community.

In this sample, no relationship was detected for the caregivers’ subjective perception of functional dementia, when the effects of coping, religiosity, stress and other variables were controlled. This seems to agree with the notion that it is not the degree of
disability exhibited by the AD individual that is associated with lower levels of subjective well-being, but the caregiver's appraisal or perception of the AD individual's behavior or disability as stressful (Zarit, et al., 1980; Zarit & Zarit, 1982; George & Gwyther, 1985; Ory, et al., 1985; and Givens, 1988).

Finally, no association was detected with relationship between the caregiver and care-recipient for either subjective well-being or stress. This contradicts findings by George and Gwyther (1986) and Harper and Lund (1990) who determined higher levels of stress among spousal caregivers than other family caregivers. One possible explanation for this might be the relatively high number of institutionalized care-recipients in this sample and thus fewer caregivers actually having day-to-day caregiving responsibilities. Another potential explanation may be that more caregivers in this sample are employed, which for many caregivers is a type of respite from caregiving responsibilities (Heany, 1991).

The findings of this study pertinent to the six research hypotheses indicated the following. There was a significant negative relationship between subjective well-being and the independent variable of stress. In addition, findings indicated significant positive relationships between subjective well-being and the
independent relationships of coping and religiosity, and between coping and religiosity. Multiple regression analysis revealed that religiosity explained 13 percent and stress explained 11 percent of the variance in the dependent variable subjective well-being. The research hypotheses together with the findings were as follows:

H1 There will be an inverse relationship between family caregiver level of subjective well-being and perceived stress. The partial correlation coefficient (pr=-.32) was significant at the p=.001 probability level. The hypothesis was therefore accepted.

H2 There will be a positive relationship between family caregiver level subjective well-being and coping. The partial correlation coefficient (pr=.28) was significant at p=.004. The hypothesis was therefore accepted.

H3 There will be a positive relationship between the level of family caregiver subjective well-being and religiosity. The partial correlation coefficient (pr=.39) was significant at the p=.001 probability level. The hypothesis was therefore accepted.

H4 There will be a positive relationship between family caregiver religiosity score and overall
coping. The partial correlation coefficient (pr=.56) was significant at the p=.001 probability level. The hypothesis was therefore accepted.

H5 A significant proportion of the variance in subjective well-being will be explained by a linear combination of the tested independent variables. Coefficient of determination (R²) values support accepting the hypothesis, where R²=.2392, F=16.032 at p=.000, given the control of coping and the remaining four control variables.

H6 A significant proportion of the variance in family caregiver's subjective well-being will be explained by a linear combination of the independent variables and their interactions. R²change values support rejecting the hypothesis, as the interaction variables do not contribute significantly to explaining variance in the dependent variable subjective well-being beyond that explained by the religiosity and stress variables, as evidenced by F-change values.

Subjective Well-Being and Stress

The data indicate a significant moderate and inverse relationship between caregiver subjective well-being and their level of perceived stress, as measured by the Hassles Scale, controlling for family
relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the caregivers' level of stress increases, their subjective well-being will decrease. This has been overwhelmingly and consistently supported in the AD caregiving literature, regardless of how subjective well-being is measured, including: 1) In the case where AD caregiver stress was determined to be greater that other caregiving situations, and subjective well-being was measured in terms of negative affect (Rabins, et al., 1982; Gwyther & Matteson, 1983; Chenowith & Spencer, 1983; Gurland, 1984; Zarit, et al, 1986; Gonzalez-Lima & Gonzalez-Lima, 1987; Stephens, et al., 1991); 2) In the case where AD caregivers' subjective well-being was measured in terms of depression (Birken, 1987; Haley, et al., 1987; Anthony-Bergstone, et al., 1988; Lovett & Gallagher, 1988; Liptzin, et al., 1988; Pruchno & Potashnik, 1989; Dura, et al., 1990; Gatz, et al., 1990); and 3) Where researchers identified the circumstances of the AD caregiving experience leading to stress, strain, and burden (Zarit & Zarit, 1982; Wright, et al., 1985; Ory, et al., 1985; Haley, et al., 1987; Pratt, et al, 1987; Given, 1988; Wilson, 1989; Stephens, et al, 1991).
Subjective Well-being and Coping

The data indicate a significant low and positive relationship between caregiver subjective well-being and their level of coping, as measured by the F-COPES Instrument, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the caregivers' level of coping increases, their subjective well-being will increase as well. This is congruent with Lazarus and Folkmans' (1984) definition of coping as "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" (p.141). By defining coping as a process, the expectation is that with each stressful situation, there may be a change in the way individuals cope. Also, coping becomes more than an outcome of the stress situation; rather it is all efforts by the individual to manage a stressful situation. Such efforts are readily apparent in the AD caregiving literature where caregivers utilize a variety of coping mechanisms including varying personal styles and social resources to adapt to the stressful caregiving situation, and maintain continuity in their life patterns, despite the AD individual's illness and characteristics (Zarit, et al., 1980; Fiore, et al.,

**Subjective Well-Being and Religiosity**

The data indicate a significant moderate and positive relationship between caregiver subjective well-being and their level of religiosity, as measured by the Springfield Religiosity Scale, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the greater the level of caregiver religiosity, the higher their subjective well-being. Except for two studies cited in the caregiving literature that have shown initial confirmation of this relationship by extracting a few religiosity items from their coping measures (Wright, et al., 1985; Pratt, et al., 1987), there exists no comprehensive information regarding this relationship. However, the gerontology literature consistently demonstrates the positive relationship between subjective well-being and the multidimensional measure of religiosity with correlations between religious beliefs/attitudes and subjective well-being ranging between $r = .18$ to $r = .45$ (Blazer & Palmore, 1976; Beckman & Houser, 1982; Moberg, 1965, 1971, 1972; Hunsburger, 1985; Idler, 1987; Koenig, et al., 1988a-d). The findings of this study are consistent
with the above investigations, lending support to the notion that religiosity potentially acts as a coping mechanism across the life span, modifying the perception of stress, and positively affecting subjective well-being as suggested in the Stress and Coping, and Continuity frameworks presented above.

Religiosity and Coping

The data indicate a significant substantial and positive relationship between caregiver level of religiosity and coping, controlling for family relationship, time as a caregiver, functional dementia and living arrangement. It can be stated that as the greater the level of caregiver religiosity, the higher their level of coping. These results support what is theorized in the gerontology research which suggests that religiosity may function in a proactive manner by modifying the individual’s appraisal of stress associated with major life events and daily hassles (Sanua, 1969; Veroff, et al., 1981; Peterson and Roy, 1985; Roden et al., 1985; Cohen, 1990; Hathaway & Pargament, 1991).

Kirkpatrick (1989) and Pargament, et al. (1990) surmise that religiosity serves as a unique coping mechanism in situations that cannot be personally controlled and those not amenable to traditional forms
of problem solving. The relationship between religiosity and coping seems particularly applicable to the caregiving situation where the AD caregiving experience involves coping with both a major negative life event (major family dementing illness and loss of relationship), daily hassles of AD caregiving, and negative choices. Again, religiosity would seem to act in both an internal and external adaptive function, helping the adult to cope with life changes and discontinuity through familiar attitudes, beliefs, activities that enhance their identity and meaning of life. A person, and particularly a caregiver, with strong religiosity may become less discouraged and more likely believe that the effects of life stressors can be overcome and controlled.

Variance Explained in Subjective Well-Being

The data indicate that the independent variables of religiosity and stress explain a significant proportion of variance in the dependent variable subjective well-being, where religiosity explained 13 percent and stress explained 11 percent of the variance in subjective well-being.

Limited information is available in the literature regarding the explanatory value of religiosity using multiple regression analysis. Pargament, et al. (1990)
found that religious coping explained 20 percent of the variance in well-being, while non-religious coping explained 10 percent. Thus, it seems that the apparent involvement of religiosity in coping has implications for outcomes that are not limited to the religious realm. Rather, the implications extend to problem resolution and the mental health status of the individual overall. Pargament, et al. (1990) concluded that religious coping efforts, like more general religious dispositions, appear to be multidimensional in nature and interact with non-religious coping strategies.

Although Ory, et al. (1985) and several other investigators have associated circumstances of the caregiving situation with the AD caregiving experience that potentially lead to stress, strain, burden and depression (Zarit & Zarit, 1982; Wright, et al., 1985; Haley, et al., 1987; Pratt, et al., 1987; Given, 1988; Wilson, 1989; Stephens, et al, 1991), the information we have regarding subjective well-being and stress tends to be inconsistent and confusing (Pearlin, et al, 1990). The instability in the literature has been attributed to inconsistent measurement, and to inconsistency in whether stress is hypothesized as predictive of well-being or as a proxy measure for well-being. Regardless, the findings of this study
agree with those reported by Pruchno and Resch (1989) who were able to explain 12 percent of the variance in mental health with their measure of stress. These investigators used Lazarus and Folkman's Stress and Coping Framework (1984), measured mental health multidimensionally with positive and negative concepts, and measured caregiver stress using a self-appraisal checklist for stressor events and responses.

**Implications for Practice**

The following implications for practice related to roles in health education and community nurse for client and family education are based on the findings from this study and the extensive findings from the gerontology and AD caregiver literature. Most implications relate to the need for better preparing the religious community for their role in the coping process of AD caregivers by designing and providing educational programs and increasing awareness. Implications are categorized as 1) education for increased awareness; 2) education for competency building; and 3) education for influencing traditionally non-religious affiliated organizations and practitioners.
Increasing Awareness

Health educators and others concerned with caregiver well-being must be proactive in targeting and disseminating mental health literature to the religious community to enhance their congregations’ awareness of the caregiver’s current life situation and with difficulties related to stress and coping. In addition, increasing the awareness among religious groups should involve the idea of building up and supporting members across difficult life events by providing relevant instruction within their own doctrines, to include Bible studies, sermons, conferences, and organized outreach programs that assist families. Outreach may involve the provision of services that serve as coping resources.

Effectively increasing awareness within congregations may also lead to organized financial and volunteer support for voluntary organizations such as the AA. Such participation can only improve outside organization services and resource provisions toward better services to caregivers.

Competency Building

The findings of this study seem to indicate a need to provide inservice education to empower religious community members (ministers, priests, rabbis, church
staff, and lay volunteer ministry) to promote one-on-one caregiving skills, including the following content specific to AD and in general for dealing with stress:

* knowledge of the disease process for AD including its signs, symptoms, clinical course and prognosis;
* knowledge regarding the AD caregiving situation, including the stresses and factors related to coping resources and styles, and well-being;
* assertiveness training;
* listening skills;
* dealing with affect;
* crisis intervention; and
* principles of confidentiality.

Such competency building efforts would enable the religious community members to offer the AD caregiver constructive assistance and proactive strategies when dealing with routine stressful events, thus avoiding a cycle of reactive crisis intervention assistance. Relevant educational materials would include religious instructional models for communication skills, interpersonal conflict, and maintaining family and social relationships.

In addition, religious communities may benefit in this effort from education regarding public and social service funding to develop more church-based respite
Influencing Organizations and Practitioners

Health educators and nurses could find many new avenues for education and health promotion through networking with religious communities. This can only occur if health educators and nurses are willing to become advocates in the spiritual dimension of health, overcoming stereotypes and misconceptions regarding the spiritual dimension of religiosity, such as: 1) that religion is no longer a part of people’s lives, since we know that between 68 and 95 percent of studied populations report religious involvement; 2) that religiosity is complex in nature, involving several dimensions beyond church attendance; and 3) that religiosity plays a role in coping with major life stressors and daily microstressors for many individuals, particularly in the AD caregiving experience.

Health educators and community nurses could also work within existing infrastructures to connect the religious community with outside non-profit voluntary association. For example, AD diagnosis centers need to include explicit religious dimensions in their holistic approach to client and family assistance by possibly hiring religious professionals on their staff to incorporate a spiritual growth plan into the health
care model.

In the past, organizations have been established out of the White House Conference on Aging (1971), to improve the quality of life for the aging within existing infrastructures such as religious communities (Hooijman & Kiyak, 1988). For instance, the National Inter-Faith Coalition on Aging (NICA) was established, with the goal of revitalizing the role of church and synagogue in supporting and providing services to the ever increasing aging population, at the local, regional and federal level. Health educators and nurses with concerns for AD caregivers must become aware of and participate in such organizations, promoting programs that support caregiver networks and resources.

Health educators in the state of Ohio must become politically active in health promotion activities, by lobbying for the establishment of a task force on AD. This task force would be charged with designing the following: 1) a statewide coordination system identifying existing services in the state; 2) a needs assessment of the AD individual and their family, and 3) a proposed plan for meeting AD individual and family caregiving needs. Such programs only exist currently in Michigan and California (Shope, et al., 1993).

Gwyther and George (1986) point out the need for a mix of services options for caregivers, since
1) caregivers are a heterogeneous group with regard to subjective perceptions, personal characteristics, and social resources; and 2) the demands and burdens of caregiving change overtime with the disease progression. This would suggest the need to form networks such as those discussed above, that provide caregivers with choices, beyond the negative choices they face day to day.

**Recommendations for Future Research**

Recommendations regarding the research design and for further study are as follows.

**Research Design and Sample**

1. Construct stratified sampling methods to allow for the inclusion of ethnic minority groups.
2. Design longitudinal studies to examine differences within individuals overtime with regard to religiosity and coping among AD caregivers.
3. Design longitudinal studies to examine the potentially dynamic relationship between functional dementia with its evolving behaviors, coping, and caregiver subjective well-being.
4. Design longitudinal studies to examine the stability of stress in predicting health and well-being outcomes among caregivers over time.
5. Replicate studies that measure subjective well-being and related constructs comprehensively to capture all their dimensions and maximize variance.

Further Study for Religiosity
1. Measure and analyze the ways in which coping is enhanced by religious beliefs and activities, and the interaction of religious and non-religious coping mechanisms among AD caregivers.
2. Replicate this study in other regions of the country.
3. Replicate this study with a population of early caregivers drawn from clinical settings, not yet participating in support group programs.

Further Study for Stress
1. Conduct caregiver stress studies measuring for the effect of specific situational related stressors on self-appraised stress levels and subjective well-being.
2. Conduct well-designed experimental studies of stress interventions beyond support groups, such as educational programs, relaxation training, respite services, etc.
3. Investigate how and to what degree social supports serve to mediate stress within Lazarus and Folkman’s Stress and Coping Theory.
4. Conduct more studies that utilize specific theoretical frameworks to describe the stress and coping process among caregivers.

**Conclusions from Recommendations**

Advances in the understanding of particular attitudes and behavior that maximize coping and enhance well-being are particularly important for AD caregivers, as there currently is no cure or effective treatment for AD. Regardless, the findings of this study agree with those reported by Pruchno and Resch (1989) who were able to explain 12 percent of the variance in mental health with their measure of stress. It can be stated that the greater the level of caregiver religiosity, the higher their subjective well-being. These results support what is theorized in the gerontology research which suggests that religiosity may function in a proactive manner by modifying the individual’s appraisal of stress associated with major life events and daily hassles.

The results of this study indicate the need for future investigation into a more exact description of how religiosity affects subjective well-being and
modifies the appraisal of stress suggested by the Stress and Coping Theory (Lazarus & Folkman, 1984). While this study measured religiosity comprehensively, the relationships and explained variance were not broken down further by type of religiosity, type of stress, or by how religiosity served as a coping mechanism. It is encouraging to note the response rate (91%) for this sample of caregivers, as well as this study’s findings that are consistent with the already existing body of knowledge. It is clear that AD caregivers are not only willing to participate in research that concerns them, but also are eager to find further answers to their caregiving-related problems.

Due to the associational nature of the study, the reader is cautioned against making cause-effect generalizations from its findings. However, the demonstration of positive relationships between religiosity and well-being, and between religiosity and caregiver coping, reinforce the important role and potential for enhancement of the widespread religious community resources for this group.
APPENDICES

A. Cover letter
B. Postcard
C. Letters of permission to use measures
D. Human Subjects Review Approval
E. AA Chapter Research Agreement for Member Participation
F. Instruments
G. Research Participant Questionnaire
H. Verbal Address
Appendix A

Cover Letter
August 17, 1993

Dear Research Participant,

Thank you for agreeing to participate in this study. Enclosed you will find a survey, with a pre-addressed, pre-stamped envelope for its return. Please return your completed survey by August 31. Your responses to this survey will be kept anonymous.

Thank you again for participating. Your responses will contribute to what we know about caregivers and how best to assist them. Study results will be published in your Chapter's newsletter.

Sincerely,

R. Carson Bates, EdD
Associate Professor
The Ohio State University
Health Education

Ann M. Whitlatch
Ann M. Whitlatch, MS, RN
Assistant Professor
Ohio Wesleyan University
School of Nursing
Appendix B

Postcard
Dear Member of the Alzheimer's Family Support Group

This is just a reminder to request that if you haven't already completed the CAREGIVER QUESTIONNAIRE given to you by Ann Whittatch at your last support meeting, would you please finish the questionnaire and mail back to me in the pre-addressed, pre-stamped envelope as soon as possible?  I greatly appreciate your time and assistance. Your contribution is important. Results of this caregiver study will be published in the Alzheimer's Newsletter.

Thank You,

Ann M. Whittatch
Ann M. Whittatch RN, MS, OSU Doctoral Candidate
Appendix C

Letters of Permission to Use Measures
June 12, 1992

Ann M. Whittlatch
5078 Doral Avenue
Columbus, OH 43218

Dear Ms. Whittlatch:

Permission is hereby granted, royalty-free, to your telephone request regarding use of material from:


It is understood that the material will be reprinted in your dissertation on coping strategies for caregivers of family members with Alzheimer's. The standard academic credit should be given.

Sincerely,

[Signature]

Denise Woerner
Rights and Permissions
Dr. Phyllis Kahnt  
Director of Copyright Permissions  
The Gerontological Society of America  
1275 K Street N.W.  
Suite 350  
Washington, D.C.  20005  

Dr. Kahnt:  

I am a doctoral candidate at The Ohio State University, in the College of Health Education, with a specialty in Gerontology. I am working on my dissertation proposal, entitled "Stress, Coping Strategies, and specifically the role of Religiosity on the perceived Well-being of Family Caregivers of Individuals Affected by Alzheimer's Disease".

I am writing to you to again seeking permission to use the Caregiving Hassles Scale cited in the 1989 journal article published in the *Gerontologist*, Vol. 29, No. 3, pp. 328-332, entitled "Caregiving Hassles Scale: Assessing the Daily Hassles of Caring for a Family Member With Dementia", written by Jennifer M. Kinney, PhD, and Mary Ann Farris Stephens, PhD.

I would like to use the measurement scale for testing the independent variable of perceived stress in caregiving as part of my dissertation study as described in their article. The manner in which they measured hassles is exactly how I want to measure perceived stress in my study.

I intend to reproduce all these tools only for the expressed purpose of using them to test my independent variable. My study population will include members of Alzheimer's Association Support Group Program from the mid-western region.

I would also ask that you include instructions on how I should document the copyright materials throughout my dissertation.

Thank you for your efforts,

Ann M. Whitlatch, M.S., RN
February 8, 1993

Anne Whalatch
5073 Doral Ave.
Columbus, OH 43213

Dear Ms. Whalatch:

I am pleased to give you my permission to use the F-COPES: Family-Crisis Oriented Personal Evaluation Scales (McCubbin, H., Olson, & D., Larsen, A.) instrument. We have a policy to charge $5.00 (one time charge only) per instrument to individuals who seek permission. We apologize for this necessity. We also ask that you please fill out the enclosed abstract form and return it to this office.

The manual, Family Assessment Inventories for Research and Practice, Second Edition should be cited when using the instrument. The publication was printed at the University of Wisconsin-Madison in 1991 and edited by Hamilton I. McCubbin and Anne I. Thompson. It is not advisable to use the Family Inventories manual by David Olson to score the instruments due to errors in its scoring section.

A sample copy of the instrument is enclosed. Additional copies can be obtained at this address for 10 cents each. When large quantities are requested, the cost of postage is also added to the order.

If I could be of any further assistance to you, please let me know.

Sincerely,

Hamilton I. McCubbin
Dean

HIM/ame

Enclosures
April 10, 1992

Ann M. Whitlatch MS, RN
5073 Doral Ave
Columbus, Ohio 43213

Dear Ms. Whitlatch,

You have my permission to use the ORA, NORA, and IMR in your study. These have been combined into a single instrument, "The Springfield Religiosity Schedule", whose test characteristics and validity have been established (Koenig, H. Smiley, M, Gonzales J. Religion, Health, and Aging. Greenwood Press). This is the reference you would cite in your manuscript. I have enclosed a flyer for this book with this letter. Good luck with your research. Very little good work has been done on the subject of religiosity and caregiver stress. Yours will be a significant contribution.

Sincerely,

Harold G. Koenig MD
Clinical Assistant Professor
Division of Geriatric Psychiatry
Duke University Medical Center
Box 3215
Durham, NC 27710
James T. Moore, M.D.
Halifax Medical Center
Halifax Psychiatric Center
303 N. Clyde Morris Blvd.
Daytona Beach, FL 32114-2732

May 15, 1992

Ann M. Whitleatch, MSRN
5073 Doral Avenue
Columbus, Ohio 43213

Dear Ms. Whitleatch:

Thank you for your letter of 14 April. I am pleased of your interest in using the Functional Dementia Scale in your dissertation. By all means feel free to do so. Citing the original references are all that I know as far as referring to it. I wish you success in your dissertation. A former colleague of mine at Duke, Dr. Phil Hinkle, is a geriatric psychiatrist at Hillside Hospital in Columbus and he might be able to be of some help to you in your project.

Sincerely,

James T. Moore, M.D.

JM:mf

cc: Dr. Phil Hinkle
Appendix D

Human Subjects Review Approval
BEHAVIORAL AND SOCIAL SCIENCES
HUMAN SUBJECTS REVIEW COMMITTEE
THE OHIO STATE UNIVERSITY

Research Involving Human Subjects

ACTION OF THE REVIEW COMMITTEE

With regard to the employment of human subjects in the proposed research protocol:

93B0149 RELATIONSHIPS OF PERCEIVED STRESS, COPEING STRATEGIES, AND SPECIFICALLY RELIGIOSITY TO SUBJECTIVE WELL-BEING OF FAMILY CAREGIVERS FOR INDIVIDUALS AFFECTED BY ALZHEIMER'S DISEASE, R. Carsen Bates, Ann M. Whitslach, Health, Physical Education and Recreation

THE BEHAVIORAL AND SOCIAL SCIENCES REVIEW COMMITTEE HAS TAKEN THE FOLLOWING ACTION:

____ APPROVED

X. APPROVED WITH CONDITIONS*

____ DISAPPROVED

X. WAIVER OF WRITTEN CONSENT GRANTED

* Conditions stated by the Committee have been met by the Investigator and, therefore, the protocol is APPROVED.

It is the responsibility of the principal investigator to retain a copy of each signed consent form for at least four (4) years beyond the termination of the subject's participation in the proposed activity. Should the principal investigator leave the University, signed consent forms are to be transferred to the Human Subjects Review Committee for the required retention period. This application has been approved for the period of one year. You are reminded that you must promptly report any problems to the Review Committee, and that no procedural changes may be made without prior review and approval. You are also reminded that the identity of the research participants must be kept confidential.

Date: May 21, 1993

Signed: [Signature]
(Chairperson)

HS-025B (Rev. 8/90)
Appendix E

AA Chapter Research Agreement for Member Participation
May 7, 1993

To Whom It May Concern:

The Alzheimer's Association of Central Ohio agrees to assist Ann Whitlatch in gathering data for her caregiver study.

It is our understanding that Ms. Whitlatch will abide by the Association's research guidelines.

Sincerely,

Pat Henderson, LSW
Family Service Coordinator
Appendix F

Instruments
HIS MENTAL HEALTH BATTERY
GENERAL WELL-BEING

THESE QUESTIONS ARE ABOUT HOW YOU FEEL, AND HOW THINGS
HAVE BEEN WITH YOU MOSTLY WITHIN THE PAST MONTH.
FOR EACH QUESTION, PLEASE CIRCLE A NUMBER FOR THE ONE
ANSWER THAT COMES CLOSEST TO THE WAY YOU HAVE BEEN
FEELING.

1. How happy, satisfied, or pleased have you been with
your personal life during the past month?

(circle one)

Extremely happy, could not have been more
satisfied.............................................. 1
Very happy most of the time.......................... 2
Generally satisfied, pleased........................... 3
Sometimes fairly satisfied, sometimes
fairly unhappy........................................ 4
Generally dissatisfied, unhappy...................... 5
Very dissatisfied, unhappy most of the time... 6

2. How much of the time have you felt lonely during
the past month?

(circle one)

All of the time .......................................... 1
Most of the time......................................... 2
A good bit of the time................................. 3
Some of the time....................................... 4
A little of the time.................................... 5
None of the time....................................... 6

3. How often did you become nervous or jumpy when
faced with excitement or unexpected situations during
the past month?

(circle one)

Always..................................................... 1
Very often................................................ 2
Fairly often............................................. 3
Sometimes............................................... 4
Almost never.......................................... 5
Never..................................................... 6

4. During the past month, how much of the time have
you felt that the future looks hopeful and promising?

(circle one)

All of the time....................................... 1
Most of the time..................................... 2
A good bit of the time.............................. 3
Some of the time.................................... 4
5. How much of the time, during the past month, has your daily life been full of things that were interesting to you?
   (circle one)
   All of the time ...................................... 1
   Most of the time .................................... 2
   A good bit of the time ............................... 3
   Some of the time ................................... 4
   A little of the time ................................. 5
   None of the time ................................... 6

6. How much of the time, during the past month, did you feel relaxed and free of tension?
   (circle one)
   All of the time ...................................... 1
   Most of the time .................................... 2
   A good bit of the time ............................... 3
   Some of the time ................................... 4
   A little of the time ................................. 5
   None of the time ................................... 6

7. During the past month, how much of the time have you generally enjoyed the things you do?
   (circle one)
   All of the time ...................................... 1
   Most of the time .................................... 2
   A good bit of the time ............................... 3
   Some of the time ................................... 4
   A little of the time ................................. 5
   None of the time ................................... 6

8. During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory?
   (circle one)
   No, not at all ........................................... 1
   Maybe a little .......................................... 2
   Yes, but not enough to be concerned or worried about it ........................................ 3
   Yes, and I have been a little concerned ...... 4
   Yes, and I am quite concerned ...................... 5
   Yes, and I am very much concerned about it ... 6

9. Did you feel depressed during the past month?
   (circle one)
   Yes, to the point that I did not care about
10. During the past month, how much of the time have you felt loved and wanted?

(circle one)

All of the time ........................................ 1
Most of the time ....................................... 2
A good bit of the time ................................. 3
Some of the time ....................................... 4
A little of the time ................................... 5
None of the time .................................... 6

11. How much of the time, during the past month, have you been a very nervous person

(circle one)

All of the time ........................................ 1
Most of the time ....................................... 2
A good bit of the time ................................. 3
Some of the time ....................................... 4
A little of the time ................................... 5
None of the time .................................... 6

12. When you got up in the morning, this past month, about how often did you expect to have an interesting day?

(circle one)

Always .................................................... 1
Very often ................................................. 2
Fairly often ............................................... 3
Sometimes ............................................... 4
Almost never ............................................ 5
Never ..................................................... 6

13. During the past month, how much of the time have you felt tense or "high-strung"?

(circle one)

All of the time ........................................ 1
Most of the time ....................................... 2
A good bit of the time ................................. 3
Some of the time ....................................... 4
A little of the time ................................... 5
None of the time .................................... 6

14. During the past month, have you been in firm
control of your behavior, thoughts, emotions, feelings?

(circle one)
Yes, very definitely ........................................ 1
Yes, for the most part .................................... 2
Yes, I guess so ............................................. 3
No, not too well ............................................ 4
No, and I am somewhat disturbed ..................... 5
No, and I am very disturbed ............................... 6

15. During the past month, how often did your hands shake when you tried to do something?

(circle one)
Always ......................................................... 1
Very often .................................................... 2
Fairly often .................................................. 3
Sometimes .................................................... 4
Almost never ............................................... 5
Never .......................................................... 6

16. During the past month, how often did you feel that you had nothing to look forward to?

(circle one)
Always ......................................................... 1
Very often .................................................... 2
Fairly often .................................................. 3
Sometimes .................................................... 4
Almost never ............................................... 5
Never .......................................................... 6

17. How much of the time, during the past month, have you felt calm and peaceful?

(circle one)
All of the time ............................................. 1
Most of the time .......................................... 2
A good bit of time ......................................... 3
Some of the time ......................................... 4
A little of the time ...................................... 5
None of the time ......................................... 6

18. How much of the time, during the past month, have you felt emotionally stable?

(circle one)
All of the time ............................................. 1
Most of the time .......................................... 2
A good bit of the time ................................... 3
Some of the time ......................................... 4
A little of the time ...................................... 5
19. How much of the time, during the past month, have you felt downhearted and blue?

(circle one)

All of the time .............................................. 1
Most of the time ............................................ 2
A good bit of the time .................................... 3
Some of the time .......................................... 4
A little of the time ...................................... 5
None of the time .......................................... 6

20. How often have you felt like crying, during the past month?

(circle one)

Always .......................................................... 1
Very often ........................................................ 2
Fairly often .................................................... 3
Sometimes ....................................................... 4
Almost never ................................................... 5
Never .............................................................. 6

21. During the past month, how often did you feel that others would be better off if you were dead?

(circle one)

Always .......................................................... 1
Very often ........................................................ 2
Fairly often .................................................... 3
Sometimes ....................................................... 4
Almost never ................................................... 5
Never .............................................................. 6

22. How much of the time, during the past month, were you able to relax without difficulty?

(circle one)

All of the time .............................................. 1
Most of the time ............................................ 2
A good bit of the time .................................... 3
Some of the time .......................................... 4
A little of the time ...................................... 5
None of the time .......................................... 6

23. During the past month, how much of the time did you feel that your relationships, loving and being loved, were full and complete?

(circle one)

All of the time .............................................. 1
Most of the time ............................................ 2
A good bit of the time .......................... 3
Some of the time ............................... 4
A little of the time ............................. 5
None of the time ............................... 6

24. How often, during the past month, did you feel that nothing turned out for you the way you wanted it to?  
(circle one)

Always ........................................... 1
Very often ......................................... 2
Fairly often ....................................... 3
Sometimes ......................................... 4
Almost never ....................................... 5
Never ................................................ 6

25. How much have you been bothered by nervousness, or your "nerves", during the past month?  
(circle one)

Extremely so, to the point where I could not take care of things ................. 1
Very much bothered ............................. 2
Bothered quite a bit by nerves ............. 3
Bothered some, enough to notice ........... 4
Bothered just a little by nerves ............ 5
Not bothered at all by this ................. 6

26. During the past month, how much of the time has living been a wonderful adventure for you?  
(circle one)

All of the time .................................. 1
Most of the time .................................. 2
A good bit of the time ........................... 3
Some of the time .................................. 4
A little of the time ................................ 5
None of the time .................................. 6

27. How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?  
(circle one)

Always ........................................... 1
Very often ......................................... 2
Fairly often ....................................... 3
Sometimes ......................................... 4
Almost never ....................................... 5
Never ................................................ 6

28. During the past month, did you ever think about taking your own life?  
(circle one)
Yes, very often ........................................ 1
Yes, fairly often ....................................... 2
Yes, a couple of times .................................. 3
Yes, at one time ........................................ 4
No, never .................................................... 5

29. During the past month, how much of the time have you felt restless, fidgety, or impatient? (circle one)
   All of the time ........................................ 1
   Most of the time ...................................... 2
   A good bit of the time ................................. 3
   Some of the time ...................................... 4
   A little of the time ................................... 5
   None of the time ...................................... 6

30. During the past month, how much of the time have you been moody or brooded about things? (circle one)
   All of the time ........................................ 1
   Most of the time ...................................... 2
   A good bit of the time ................................. 3
   Some of the time ...................................... 4
   A little of the time ................................... 5
   None of the time ...................................... 6

31. How much of the time, during the past month, have you felt cheerful, lighthearted? (circle one)
   All of the time ........................................ 1
   Most of the time ...................................... 2
   A good bit of the time ................................. 3
   Some of the time ...................................... 4
   A little of the time ................................... 5
   None of the time ...................................... 6

32. During the past month, how often did you get rattled, upset, or flustered? (circle one)
   Always .................................................. 1
   Very often .............................................. 2
   Fairly often ............................................ 3
   Sometimes .............................................. 4
   Almost never .......................................... 5
   Never ..................................................... 6

33. During the past month, have you been anxious or
34. During the past month, how much of the time were you a happy person?

(circle one)

- All of the time ........................... 1
- Most of the time ......................... 2
- A good bit of the time .................. 3
- Some of the time ........................ 4
- A little of the time ..................... 5
- None of the time ........................ 6

35. How often during the past month did you find yourself having difficulty trying to calm down?

(circle one)

- Always ...................................... 1
- Very often .................................. 2
- Fairly often ................................ 3
- Sometimes .................................. 4
- Almost never .............................. 5
- Never ....................................... 6

36. During the past month, how much of the time have you been in low or very low spirits?

(circle one)

- All of the time ........................... 1
- Most of the time ......................... 2
- A good bit of the time .................. 3
- Some of the time ........................ 4
- A little of the time ..................... 5
- None of the time ........................ 6

37. How often during the past month, have you been waking up feeling fresh and rested?

(circle one)

- Always, every day ........................ 1
- Almost every day ........................ 2
- Most days .................................. 3
- Some days, but usually not ............. 4
- Hardly ever .................................. 5
- Never wake up feeling rested .......... 6

38. During the past month, have you been under or felt you were under any strain, stress, or pressure?

(circle one)
(circle one)

Yes, almost more than I could stand or bear  1
Yes, quite a bit of pressure  2
Yes, some more than usual  3
Yes, some, but about normal  4
Yes, a little bit  5
No, not at all  6
CAREGIVING HASSLES SCALE

Jennifer M. Kinney and Mary Ann Parris-Stephens

THIS QUESTIONNAIRE LISTS THINGS THAT CAN BE HASSLES IN DAY-TO-DAY CAREGIVING. YOU WILL FIND THAT DURING THE PAST WEEK, SOME OF THESE HAVE BEEN HASSLES, WHEREAS OTHERS HAVE NOT.

FOR EACH ITEM, INDICATE WHETHER THE EVENT OCCURRED DURING THE PAST WEEK BY CHECKING YES OR NO. IF YOU CHECK "NO", GO ON TO THE NEXT ITEM. IF YOU CHECK "YES", INDICATE HOW MUCH OF A HASSLE IT WAS FOR YOU DURING THE PAST WEEK.

<table>
<thead>
<tr>
<th>EVENT</th>
<th>WAS IT A HASSLE?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Care-recipient criticizing or complaining</td>
<td>_yes--&gt;_not a hassle</td>
</tr>
<tr>
<td></td>
<td>_no</td>
</tr>
<tr>
<td></td>
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<tr>
<td>2. Care-recipient declining mentally</td>
<td>_yes--&gt;_not a hassle</td>
</tr>
<tr>
<td></td>
<td>_no</td>
</tr>
<tr>
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<td></td>
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<tr>
<td>3. Assisting care-recipient with walking</td>
<td>_yes--&gt;_not a hassle</td>
</tr>
<tr>
<td></td>
<td>_no</td>
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<tr>
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<tr>
<td>4. Extra expenses due to caregiving</td>
<td>_yes--&gt;_not a hassle</td>
</tr>
<tr>
<td></td>
<td>_no</td>
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<tr>
<td>5. Friends not showing understanding about caregiving</td>
<td>_yes--&gt;_not a hassle</td>
</tr>
<tr>
<td></td>
<td>_no</td>
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<td></td>
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<tr>
<td>6. Care-recipient losing things</td>
<td>_yes--&gt;_not a hassle</td>
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<tr>
<td></td>
<td>_no</td>
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<tr>
<td>7. Undesirable changes in care-recipient's personality</td>
<td>_yes--&gt;_not a hassle</td>
</tr>
<tr>
<td></td>
<td>_no</td>
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</tbody>
</table>
8. Assisting with care-recipient to toileting

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
<td>___</td>
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</table>

9. Transporting care-recipient to doctor/other places

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
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<tr>
<td>No</td>
<td>___</td>
<td>___</td>
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</table>

10. Conflicts between care-recipient and family

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
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<tr>
<td>No</td>
<td>___</td>
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11. Care-recipient not showing interest in things

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
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<td>___</td>
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</table>

12. Bathing care-recipient

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
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<tr>
<td>No</td>
<td>___</td>
<td>___</td>
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<td>___</td>
</tr>
</tbody>
</table>

13. Family not showing understanding about care-giving

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
<td>___</td>
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<td>___</td>
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</tbody>
</table>

14. Care-recipient yelling, swearing

<table>
<thead>
<tr>
<th>Porcelain</th>
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<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

15. Care-recipient not cooperating

<table>
<thead>
<tr>
<th>Porcelain</th>
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<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

16. Care-recipient forgetfulness

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

17. Assisting care-recipient with exercise/therapy

<table>
<thead>
<tr>
<th>Porcelain</th>
<th>Not a Hassle</th>
<th>Somewhat</th>
<th>Quite a Bit</th>
<th>A Great Deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
<tr>
<td>No</td>
<td>___</td>
<td>___</td>
<td>___</td>
<td>___</td>
</tr>
</tbody>
</table>

18. Doing care-recipient’s
19. Care-recipient leaving tasks uncompleted _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

20. Care-recipient being confused and not making sense _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

21. Lifting or transferring care-recipient _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

22. Not receiving caregiving help from friends _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

23. Care-recipient frowning, scowling _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

24. Care-recipient living in the past _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

25. Helping care-recipient eat _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

26. Picking up after care-recipient _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

27. Care-recipient verbally inconsiderate, not respecting others' feelings _yes-->__no _somewhat _not a hassle _quite a bit _a great deal

28. Being in care-recipient's presence _yes-->__no _somewhat _not a hassle _quite a bit
29. Care-recipient talking about things that aren't real
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

30. Dressing care-recipient
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

31. Not receiving caregiving help from family
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

32. Care-recipient asking repetitive questions
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

33. Care-recipient not recognizing familiar people
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

34. Giving medications to care-recipient
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

35. Preparing meals for care-recipient
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

36. Care-recipient wandering off
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

37. Care-recipient's agitation
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

38. Assisting care-recipient with health aids (ie., dentures, braces)
   __yes-->____not a hassle
   __no    ___somewhat
   ___quite a bit
   ___a great deal

39. Care-recipient
   __yes-->____not a hassle
requiring day supervision

<table>
<thead>
<tr>
<th></th>
<th>no</th>
<th>somewhat</th>
<th>quite a bit</th>
<th>a great deal</th>
</tr>
</thead>
</table>

40. Leaving care-recipient with others

|   | yes---> | not a hassle | somewhat | quite a bit | a great deal |

41. Care-recipient hiding things

|   | yes---> | not a hassle | somewhat | quite a bit | a great deal |

42. Care-recipient requiring night supervision

|   | yes---> | not a hassle | somewhat | quite a bit | a great deal |
F-COPES  
Family Crisis Oriented Personal Scales  
Hamilton McCubbin, David Olsen, and Andrea Larson  

Using the open statement underlined below as a preface, read each of the statements that follow to complete the sentence. Circle a response on the right that best describes how you feel about each statement using the following scale:  

1 = Strongly Disagree,  
2 = Moderately Disagree,  
3 = Neither Agree nor Disagree,  
4 = Moderately Agree,  
5 = Strongly Agree.  

<table>
<thead>
<tr>
<th>When I face problems or difficulties with my caregiving responsibilities, I respond by:</th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Sharing my difficulties with relatives</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>2. Seeking encouragement and support from friends</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>3. Knowing I have the power to solve major problems</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>4. Seeking information and advice from persons who have faced the same or similar problems</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>5. Seeking advice from relatives</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>6. Seeking assistance from community agencies and programs designed to help families in my situation</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>7. Knowing that I have the strength to solve my problems</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>8. Receiving gifts and favors from neighbors (e.g. food, taking in mail, etc.)</td>
<td>1 2 3 4 5</td>
<td></td>
</tr>
<tr>
<td>9. Seeking information and advice from the family physician</td>
<td>1 2 3 4 5</td>
<td></td>
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</tbody>
</table>

Please circle answer.
When I face problems or difficulties with my caregiving responsibilities, I respond by:

<table>
<thead>
<tr>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>please circle answer</td>
<td></td>
</tr>
</tbody>
</table>

10. Asking neighbors for favors and assistance
    1  2  3  4  5

11. Facing the problems "head-on" and trying to get solution right away
    1  2  3  4  5

12. Watching television
    1  2  3  4  5

13. Showing that I am strong
    1  2  3  4  5

14. Attending church services
    1  2  3  4  5

15. Accepting stressful events as a fact of life
    1  2  3  4  5

16. Sharing concerns with close friends
    1  2  3  4  5

17. Knowing luck plays a big part in how well I am able to solve caregiving problems
    1  2  3  4  5

18. Exercising with friends to stay fit and reduce tension
    1  2  3  4  5

19. Accepting that difficulties occur unexpectedly
    1  2  3  4  5

20. Doing things with relatives (get-togethers, dinners, etc.)
    1  2  3  4  5

21. Seeking professional counseling and help for caregiving difficulties
    1  2  3  4  5

22. Believing I can handle my own problems
    1  2  3  4  5
1 = Strongly Disagree,
2 = Moderately Disagree,
3 = Neither Agree nor Disagree,
4 = Moderately Agree,
5 = Strongly Agree.

When I face problems or difficulties with my caregiving responsibilities, I respond by:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Disagree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>please circle answer</td>
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</tbody>
</table>

23. Participating in church activities

24. Defining the caregiving problem in a more positive way so that I do not become too discouraged

25. Asking relatives how they feel about the problems I face

26. Feeling that no matter what I do to prepare, I will have difficulty handling problems

27. Seeking advice from a minister

28. Believing if I wait long enough, the problem will go away

29. Sharing problems with neighbors

30. Having faith in God
THE SPRINGFIELD RELIGIOSITY SCHEDULE

Harold G. Koenig, Mona Smiley, and Jo Ann Ploch-Gonzalez

There are no right or wrong answers. For the first item listed below, check the answer that best describes your feelings.

1. Which of the following statements comes closest to expressing what you believe about God?

<p>| | |</p>
<table>
<thead>
<tr>
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</thead>
<tbody>
<tr>
<td></td>
<td>I know God really exists, and I have no doubts about it.</td>
</tr>
<tr>
<td></td>
<td>While I have doubts, I feel that I do believe in God.</td>
</tr>
<tr>
<td></td>
<td>I don't believe in a personal God, but I do believe in a higher power of some kind.</td>
</tr>
<tr>
<td></td>
<td>I don't know whether there is a God or not, and I don't believe there is any way to find out.</td>
</tr>
<tr>
<td></td>
<td>I don't believe in God.</td>
</tr>
</tbody>
</table>

Circle the appropriate response for the frequency that you participate in each of the following activities:

2. How often do you attend church services?

<p>| | |</p>
<table>
<thead>
<tr>
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<tbody>
<tr>
<td></td>
<td>Several times a week</td>
</tr>
<tr>
<td></td>
<td>About once a week</td>
</tr>
<tr>
<td></td>
<td>Several times a month</td>
</tr>
<tr>
<td></td>
<td>Several times a year</td>
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<tr>
<td></td>
<td>Seldom</td>
</tr>
<tr>
<td></td>
<td>Never</td>
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</tbody>
</table>

3. How often do you participate in other religious group-related activities? (Bible study groups, prayer groups, adult Sunday school classes)

<p>| | |</p>
<table>
<thead>
<tr>
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<td></td>
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<td>Several times a year</td>
</tr>
<tr>
<td></td>
<td>Seldom</td>
</tr>
<tr>
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<td>Never</td>
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</table>

4. How often do you pray privately?

<p>| | |</p>
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<tbody>
<tr>
<td></td>
<td>Not at all</td>
</tr>
<tr>
<td></td>
<td>Only occasionally</td>
</tr>
<tr>
<td></td>
<td>Several times a week</td>
</tr>
<tr>
<td></td>
<td>Once a day</td>
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<tr>
<td></td>
<td>Twice a day</td>
</tr>
<tr>
<td></td>
<td>More than twice a day</td>
</tr>
</tbody>
</table>
5. How often do you read the bible or other religious literature (magazines, papers, books) at home?

___ Several times a day  ___ Several times a month
___ Daily  ___ Only occasionally
___ Several times a week  ___ Not at all

6. How often do you watch religious television programs or listen to religious radio programs?

___ Not at all  ___ Several times a week
___ Only occasionally  ___ Daily
___ Several times a month  ___ Several times a day

The next section of the questionnaire asks how much you agree or disagree with each item. Place a check next to the phrase which best describes your feeling for each item, where:
6 = Strongly Agree
5 = Moderately Agree
4 = Slightly Agree
3 = Slightly Disagree
2 = Moderately Disagree
1 = Strongly Disagree

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>6  5  4  3  2  1</td>
<td></td>
</tr>
</tbody>
</table>

7. I experience God’s love and care for me in my relationship with Him. 6 5 4 3 2 1

8. I believe that God is impersonal and not interested in my daily situations. 6 5 4 3 2 1

9. I have a personally meaningful relationship with God. 6 5 4 3 2 1

10. While dealing with difficult times in my life, I don't get much personal strength and support from God. 6 5 4 3 2 1

11. My relationship with God helps me not to feel lonely. 6 5 4 3 2 1
6 = Strongly Agree  
5 = Moderately Agree  
4 = Slightly Agree  
3 = Slightly Disagree  
2 = Moderately Disagree  
1 = Strongly Disagree  

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>12. Private prayer is</td>
<td>6 5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>important in my life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I do not experience</td>
<td>6 5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>God’s intervention in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>my life in any concrete</td>
<td></td>
<td></td>
</tr>
<tr>
<td>or personal way.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. God has revealed</td>
<td>6 5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>things to me about my</td>
<td></td>
<td></td>
</tr>
<tr>
<td>life, other people,</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Himself, or His Divine</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Plan.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Prayer does not help</td>
<td>6 5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>me to cope with</td>
<td></td>
<td></td>
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<tr>
<td>difficulties and stress</td>
<td></td>
<td></td>
</tr>
<tr>
<td>in my life.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I feel most</td>
<td>6 5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>fulfilled when I am in</td>
<td></td>
<td></td>
</tr>
<tr>
<td>close communion with</td>
<td></td>
<td></td>
</tr>
<tr>
<td>God.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Respond to the following statements by circling that response that best describes how you feel, where:

4 = definitely true of me,  
3 = tends to be true,  
2 = tends not to be true,  
1 = definitely not true of me,  
0 = unsure.

definitely  unsure  
true       
|                         |               |                   |
| 17. My faith involves   | 4 3 2 1 0     |               |
| all of my life.         |               |                   |
| 18. In my life I        | 4 3 2 1 0     |               |
| experience the presence  |               |                   |
| of the Divine.          |               |                   |
4 = definitely true of me,
3 = tends to be true,
2 = tends not to be true,
1 = definitely not true of me,
0 = unsure.

definitely true

please circle answer

19. Although I am a religious person, I refuse to let religious considerations influence my everyday affairs.  
   4 3 2 1 0

20. Nothing is as important to me as serving God as best I know how.  
   4 3 2 1 0

   4 3 2 1 0

22. My religious beliefs are what really lie behind my whole approach to life.  
   4 3 2 1 0

23. I try hard to carry my religion over into all of my other dealings in life.  
   4 3 2 1 0

24. My religious faith is the most important influence in my life.  
   4 3 2 1 0

The following section asks how much you agree or disagree with each item, where:
4 = definitely agree,
3 = tends to agree,
2 = tends not to disagree,
1 = definitely disagree,
0 = unsure.

definitely agree

please circle answer

25. One should seek God's guidance when making important decisions.  
   4 3 2 1 0
<table>
<thead>
<tr>
<th>Scale Code</th>
<th>Description</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>definitely agree</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>tends to agree</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>tends not to disagree</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>definitely disagree</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>unsure</td>
<td></td>
</tr>
</tbody>
</table>

**26.** Although I believe in my religion, I feel there are many more important things in life.

**27.** It doesn't matter so much what I believe as long as I lead a moral life.

**28.** What is your religious preference?

- Catholic
- Jewish
- Protestant
- None
- Other, please specify: _______________________

**29.** Would you say your religious practices or beliefs have changed since taking on your caregiving responsibilities?

- Yes
- No

If yes, please explain in what way.

________________________________________________________________________

________________________________________________________________________
Functional Dementia Scale

James T. Moore, MD, James Bobula, PhD, Timothy Short, and Matthew Mischel

Respond to each of the following as to how often the individual you care for exhibits the symptom listed. Circle one rating for each item, where:

1 = none or little of the time;
2 = some of the time;
3 = a good part of the time;
4 = most or all of the time.

The individual I care for or manage:  

<table>
<thead>
<tr>
<th>None/Little</th>
<th>Most/All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>please circle answer</td>
</tr>
</tbody>
</table>

1. Has difficulty completing simple tasks on own eg, dressing, bathing, doing arithmetic.  
2. Spends time either sitting or in apparently purposeless activity.  
3. Wanders at night or needs to be restrained to prevent wandering.  
4. Hears things that are not there.  
5. Requires supervision or assistance in eating.  
7. Appearance is disorderly if left to own devices.  
8. Moans.  
9. Cannot control bowel function.  
10. Threatens to harm others.  
11. Cannot control bowel function.  
12. Needs to be watched so doesn’t injure self, eg., by careless smoking, leaving the stove on falling.
1 = none or little of the time;  
2 = some of the time;  
3 = a good part of the time;  
4 = most or all of the time.

The individual I care for or manage:

<table>
<thead>
<tr>
<th>None/</th>
<th>Most/</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little</td>
<td>All</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

please circle answer

13. Destructive of materials around him, 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 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, doesn't know where he 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. 1 2 3 4
Place an "X" or fill in the blank to indicate the correct response to each of the following questions:

1. What was your age at your last birthday?
   ___ years

2. You are
   ________ Female
   ________ Male

3. What is your race?
   ______ Caucasian
   ______ Black
   ______ Asian
   ______ Hispanic
   ______ Pacific Islander
   ______ Other, please specify___________

4. What is your marital status?
   ______ Married
   ______ Divorced
   ______ Widowed
   ______ Never married

5. What is the highest level of education that you have completed?
   ______ Grade School
   ______ High School
   ______ Some College
   ______ College Degree
   ______ Graduate Degree

6. The person for whom I provide care or manage, is my:
   ______ spouse
   ______ son
   ______ mother
   ______ daughter
   ______ father
   ______ uncle
   ______ grandparent
   ______ aunt
   ______ friend
   ______ mother-in-law
   ______ sibling
   ______ father-in-law
   ______ other, please specify___________
7. Are you presently employed at least 30 hours per week outside of your caregiving role?
   ______ Yes
   ______ No

7a. If no, are you:
   ______ working part-time
   ______ retired
   ______ unemployed
   ______ disabled
   ______ other, please specify______________

8. Has the person you are caring for been diagnosed specifically with Dementia of the Alzheimer's Disease Type?
   ______ Yes
   ______ No

9. Where does the affected individual you care for or manage reside?
   ______ in your home
   ______ with another relative
   ______ in an institution
   ______ other, please specify______________

10. How long have you been a family caregiver?
    ______ months
        ______ years

11. Overall, how long have you attended support group meetings?
    ______ months
        ______ years
        ______ this is my first meeting

12. How often do you attend these meetings?
    ______ monthly
        ______ every other month
        ______ every 3 or 4 months
        ______ rarely
Appendix G

Research Participant Questionnaire
The Ohio State University

ALZHEIMER'S
ASSOCIATION
Someone to Stand By You.

Caregiver Questionnaire

School of HPER
Department Health Education
THOSE QUESTIONS ARE ABOUT HOW YOU FEEL, AND HOW THINGS
HAVE BEEN WITH YOU MOSTLY WITHIN THE LAST MONTH.
FOR EACH QUESTION, PLEASE CIRCLE A NUMBER FOR THE ONE
ANSWER THAT COMES CLOSEST TO THE WAY YOU HAVE BEEN
FEELING.

1. How happy, satisfied, or pleased have you been with
your personal life during the past month?
   (circle one)
   Extremely happy, could not have been more
   satisfied ........................................... 1
   Very happy most of the time ....................... 2
   Generally satisfied, pleased ........................ 3
   Sometimes fairly satisfied, sometimes
   fairly unhappy ...................................... 4
   Generally dissatisfied, unhappy ................... 5
   Very dissatisfied, unhappy most of the time ... 6

2. How much of the time have you felt lonely during
the past month?
   (circle one)
   All of the time .................................... 1
   Most of the time .................................. 2
   A good bit of the time ............................. 3
   Some of the time .................................. 4
   A little of the time ............................... 5
   None of the time .................................. 6

3. How often did you become nervous or jumpy when
faced with excitement or unexpected situations during
the past month?
   (circle one)
   Always ............................................. 1
   Very often ........................................ 2
   Fairly often ....................................... 3
   Sometimes ......................................... 4
   Almost never ...................................... 5
   Never ............................................... 6

4. During the past month, how much of the time have
you felt that the future looks hopeful and promising?
   (circle one)
   All of the time .................................... 1
   Most of the time .................................. 2
   A good bit of the time ............................. 3
   Some of the time .................................. 4
   A little of the time ............................... 5
   None of the time .................................. 6
5. How much of the time, during the past month, has your daily life been full of things that were interesting to you?
   (circle one)
   All of the time .................................. 1
   Most of the time .................................. 2
   A good bit of the time ......................... 3
   Some of the time .................................. 4
   A little of the time ............................... 5
   None of the time .................................. 6

6. How much of the time, during the past month, did you feel relaxed and free of tension?
   (circle one)
   All of the time .................................. 1
   Most of the time .................................. 2
   A good bit of the time ......................... 3
   Some of the time .................................. 4
   A little of the time ............................... 5
   None of the time .................................. 6

7. During the past month, how much of the time have you generally enjoyed the things you do?
   (circle one)
   All of the time .................................. 1
   Most of the time .................................. 2
   A good bit of the time ......................... 3
   Some of the time .................................. 4
   A little of the time ............................... 5
   None of the time .................................. 6

8. During the past month, have you had any reason to wonder if you were losing your mind, or losing control over the way you act, talk, think, feel or of your memory?
   (circle one)
   No, not at all .................................... 1
   Maybe a little ..................................... 2
   Yes, but not enough to be concerned or worried about it ......................................... 3
   Yes, and I have been a little concerned ...... 4
   Yes, and I am quite concerned .................. 5
   Yes, and I am very much concerned about it ... 6
9. Did you feel depressed during the past month?
   (circle one)
   Yes, to the point that I did not care about anything for days at a time ................. 1
   Yes, very depressed almost every day .......... 2
   Yes, quite depressed almost every day .......... 3
   Yes, quite depressed several times .......... 4
   Yes, a little depressed now and then .......... 5
   No, never felt depressed at all ................. 6

10. During the past month, how much of the time have you felt loved and wanted?
    (circle one)
    All of the time .................................. 1
    Most of the time .................................. 2
    A good bit of the time .................................. 3
    Some of the time .................................. 4
    A little of the time .................................. 5
    None of the time .................................. 6

11. How much of the time, during the past month, have you been a very nervous person
    (circle one)
    All of the time .................................. 1
    Most of the time .................................. 2
    A good bit of the time .................................. 3
    Some of the time .................................. 4
    A little of the time .................................. 5
    None of the time .................................. 6

12. When you got up in the morning, this past month, about how often did you expect to have an interesting day?
    (circle one)
    Always ............................................... 1
    Very often ............................................ 2
    Fairly often ........................................... 3
    Sometimes .............................................. 4
    Almost never .......................................... 5
    Never .................................................. 6

13. During the past month, how much of the time have you felt tense or "high-strung"?
    (circle one)
    All of the time .................................. 1
    Most of the time .................................. 2
    A good bit of the time .................................. 3
    Some of the time .................................. 4
    A little of the time .................................. 5
    None of the time .................................. 6
14. During the past month, have you been in firm control of your behavior, thoughts, emotions, feelings?
   (circle one)
   Yes, very definitely ......................................... 1
   Yes, for the most part ......................................... 2
   Yes, I guess so ................................................. 3
   No, not too well ............................................... 4
   No, and I am somewhat disturbed ............................. 5
   No, and I am very disturbed ................................ 6

15. During the past month, how often did your hands shake when you tried to do something?
   (circle one)
   Always ............................................................. 1
   Very often ....................................................... 2
   Fairly often ..................................................... 3
   Sometimes ....................................................... 4
   Almost never ................................................... 5
   Never ............................................................. 6

16. During the past month, how often did you feel that you had nothing to look forward to?
   (circle one)
   Always ............................................................. 1
   Very often ....................................................... 2
   Fairly often ..................................................... 3
   Sometimes ....................................................... 4
   Almost never ................................................... 5
   Never ............................................................. 6

17. How much of the time, during the past month, have you felt calm and peaceful?
   (circle one)
   All of the time ................................................. 1
   Most of the time .............................................. 2
   A good bit of time .............................................. 3
   Some of the time .............................................. 4
   A little of the time .......................................... 5
   None of the time ............................................. 6

18. How much of the time, during the past month, have you felt emotionally stable?
   (circle one)
   All of the time ................................................. 1
   Most of the time .............................................. 2
   A good bit of the time ...................................... 3
   Some of the time ............................................. 4
   A little of the time ......................................... 5
   None of the time ........................................... 6
19. How much of the time, during the past month, have you felt downhearted and blue?  
(circle one)  
All of the time ............... 1  
Most of the time ............... 2  
A good bit of the time ........... 3  
Some of the time ............... 4  
A little of the time .............. 5  
None of the time ............... 6  

20. How often have you felt like crying, during the past month?  
(circle one)  
Always ....................... 1  
Very often .................... 2  
Fairly often .................. 3  
Sometimes .................... 4  
Almost never .................. 5  
Never ......................... 6  

21. During the past month, how often did you feel that others would be better off if you were dead?  
(circle one)  
Always ....................... 1  
Very often .................... 2  
Fairly often .................. 3  
Sometimes .................... 4  
Almost never .................. 5  
Never ......................... 6  

22. How much of the time, during the past month, were you able to relax without difficulty?  
(circle one)  
All of the time .................. 1  
Most of the time ............... 2  
A good bit of the time .......... 3  
Some of the time ............... 4  
A little of the time .............. 5  
None of the time ............... 6  

23. During the past month, how much of the time did you feel that your relationships, loving and being loved, were full and complete?  
(circle one)  
All of the time ............... 1  
Most of the time ............... 2  
A good bit of the time .......... 3  
Some of the time ............... 4  
A little of the time .............. 5  
None of the time ............... 6
24. How often, during the past month, did you feel that nothing turned out for you the way you wanted it to?  
   (circle one)  
   Always ................................................. 1  
   Very often ........................................... 2  
   Fairly often ......................................... 3  
   Sometimes ........................................... 4  
   Almost never .......................................... 5  
   Never .................................................. 6  

25. How much have you been bothered by nervousness, or your "nerves", during the past month?  
   (circle one)  
   Extremely so, to the point where I could not take care of things ............ 1  
   Very much bothered ......................... 2  
   Bothered quite a bit by nerves ............ 3  
   Bothered some, enough to notice ............ 4  
   Bothered just a little by nerves ............ 5  
   Not bothered at all by this .................. 6  

26. During the past month, how much of the time has living been a wonderful adventure for you?  
   (circle one)  
   All of the time ....................................... 1  
   Most of the time ..................................... 2  
   A good bit of the time ............................. 3  
   Some of the time ................................... 4  
   A little of the time ................................. 5  
   None of the time .................................... 6  

27. How often, during the past month, have you felt so down in the dumps that nothing could cheer you up?  
   (circle one)  
   Always ............................................... 1  
   Very often .......................................... 2  
   Fairly often ......................................... 3  
   Sometimes ........................................... 4  
   Almost never ........................................ 5  
   Never ................................................ 6  

28. During the past month, did you ever think about taking your own life?  
   (circle one)  
   Yes, very often ..................................... 1  
   Yes, fairly often .................................... 2  
   Yes, a couple of times ............................ 3  
   Yes, at one time .................................... 4  
   No, never ............................................ 5
29. During the past month, how much of the time have you felt restless, fidgety, or impatient? (circle one)

   All of the time .............................................. 1
   Most of the time ........................................... 2
   A good bit of the time .................................... 3
   Some of the time ........................................... 4
   A little of the time ....................................... 5
   None of the time .......................................... 6

30. During the past month, how much of the time have you been moody or brooded about things? (circle one)

   All of the time .............................................. 1
   Most of the time ........................................... 2
   A good bit of the time .................................... 3
   Some of the time ........................................... 4
   A little of the time ....................................... 5
   None of the time .......................................... 6

31. How much of the time, during the past month, have you felt cheerful, lighthearted? (circle one)

   All of the time .............................................. 1
   Most of the time ........................................... 2
   A good bit of the time .................................... 3
   Some of the time ........................................... 4
   A little of the time ....................................... 5
   None of the time .......................................... 6

32. During the past month, how often did you get rattled, upset, or flustered? (circle one)

   Always ......................................................... 1
   Very often .................................................... 2
   Fairly often .................................................. 3
   Sometimes .................................................... 4
   Almost never ................................................. 5
   Never .......................................................... 6

33. During the past month, have you been anxious or worried? (circle one)

   Yes, extremely so, to the point of being sick or almost sick .................. 1
   Yes, very much so ........................................... 2
   Yes, quite a bit ............................................. 3
   Yes, some, enough to bother me ................................ 4
   Yes, a little bit ............................................. 5
   No, not at all ............................................... 6
34. During the past month, how much of the time were you a happy person?  
   (circle one)  
   All of the time ........................................ 1  
   Most of the time ...................................... 2  
   A good bit of the time ................................. 3  
   Some of the time ...................................... 4  
   A little of the time .................................. 5  
   None of the time ....................................... 6  

35. How often during the past month did you find yourself having difficulty trying to calm down?  
   (circle one)  
   Always .................................................. 1  
   Very often ............................................. 2  
   Fairly often .......................................... 3  
   Sometimes .............................................. 4  
   Almost never .......................................... 5  
   Never ................................................... 6  

36. During the past month, how much of the time have you been in low or very low spirits?  
   (circle one)  
   All of the time ........................................ 1  
   Most of the time ...................................... 2  
   A good bit of the time ................................. 3  
   Some of the time ...................................... 4  
   A little of the time .................................. 5  
   None of the time ....................................... 6  

37. How often during the past month, have you been waking up feeling fresh and rested?  
   (circle one)  
   Always, every day .................................... 1  
   Almost every day ...................................... 2  
   Most days ............................................. 3  
   Some days, but usually not ........................... 4  
   Hardly ever ........................................... 5  
   Never wake up feeling rested ........................ 6  

38. During the past month, have you been under or felt you were under any strain, stress, or pressure?  
   (circle one)  
   Yes, almost more than I could stand or bear .... 1  
   Yes, quite a bit of pressure .......................... 2  
   Yes, some more than usual ............................ 3  
   Yes, some, but about normal .......................... 4  
   Yes, a little bit ...................................... 5  
   No, not at all ......................................... 6
THIS PART OF THE QUESTIONNAIRE LISTS THINGS THAT CAN BE HASSLES IN DAY-TO-DAY CAREGIVING. FOR EACH ITEM, YOU WILL BE DOING TWO THINGS: 1) INDICATE WHETHER THE EVENT OCCURRED DURING THE PAST WEEK BY CHECKING YES OR NO; AND 2) IF YOU CHECK "NO", GO ON TO THE NEXT ITEM. IF YOU CHECK "YES", INDICATE HOW MUCH OF A HASSLE IT WAS FOR YOU DURING THE PAST WEEK.

YOU WILL FIND THAT DURING THE PAST WEEK, SOME OF THESE HAVE BEEN HASSLES, WHEREAS OTHERS HAVE NOT DEPENDING UPON YOUR PARTICULAR CIRCUMSTANCES. IF AN ITEM APPEARS NOT TO APPLY TO YOUR CIRCUMSTANCES, RESPOND BY CHECKING "NO".

FOR THIS PART OF THE SURVEY, THE CARE-RECIPIENT IS THE FAMILY MEMBER WITH ALZHEIMER'S DISEASE FOR WHOM YOU CARE.

<table>
<thead>
<tr>
<th>EVENT</th>
<th>WAS IT A HASSLE?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Care-recipient criticizing or complaining</td>
<td>yes--&gt; not a hassle</td>
</tr>
<tr>
<td></td>
<td>no</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Care-recipient declining mentally</td>
<td>yes--&gt; not a hassle</td>
</tr>
<tr>
<td></td>
<td>no</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Assisting care-recipient with walking</td>
<td>yes--&gt; not a hassle</td>
</tr>
<tr>
<td></td>
<td>no</td>
</tr>
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<td>4. Extra expenses due to caregiving</td>
<td>yes--&gt; not a hassle</td>
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<td>no</td>
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<tr>
<td>5. Friends not showing understanding about caregiving</td>
<td>yes--&gt; not a hassle</td>
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<td></td>
<td>no</td>
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<td>6. Care-recipient losing things</td>
<td>yes--&gt; not a hassle</td>
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<td>no</td>
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</tbody>
</table>
7. Undesirable changes in care-recipient’s personality
   _yes-->_not a hassle
   ___no  ___somewhat
   ___quite a bit
   ___a great deal

8. Assisting with care-recipient to toileting
   _yes-->_not a hassle
   ___no  ___somewhat
   ___quite a bit
   ___a great deal

9. Transporting care-recipient to doctor/other places
   _yes-->_not a hassle
   ___no  ___somewhat
   ___quite a bit
   ___a great deal

10. Conflicts between care-recipient and family
    _yes-->_not a hassle
    ___no  ___somewhat
    ___quite a bit
    ___a great deal

11. Care-recipient not showing interest in things
    _yes-->_not a hassle
    ___no  ___somewhat
    ___quite a bit
    ___a great deal

12. Bathing care-recipient
    _yes-->_not a hassle
    ___no  ___somewhat
    ___quite a bit
    ___a great deal

13. Family not showing understanding about caregiving
    _yes-->_not a hassle
    ___no  ___somewhat
    ___quite a bit
    ___a great deal

14. Care-recipient yelling, swearing
    _yes-->_not a hassle
    ___no  ___somewhat
    ___quite a bit
    ___a great deal

15. Care-recipient not cooperating
    _yes-->_not a hassle
    ___no  ___somewhat
    ___quite a bit
    ___a great deal
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<tbody>
<tr>
<td>16. Care-recipient forgetfulness</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>17. Assisting care-recipient with exercise/therapy</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>18. Doing care-recipient’s laundry</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>19. Care-recipient leaving tasks uncompleted</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>20. Care-recipient being confused and not making sense</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>21. Lifting or transferring care-recipient</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>22. Not receiving caregiving help from friends</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>23. Care-recipient frowning, scowling</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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<tr>
<td>24. Care-recipient living in the past</td>
<td>yes--⟩</td>
<td>not a hassle</td>
<td>no</td>
<td>somewhat</td>
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</tbody>
</table>
25. Helping care-recipient eat
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

26. Picking up after care-recipient
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

27. Care-recipient verbally inconsiderate, not respecting others' feelings
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

28. Being in care-recipient's presence
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

29. Care-recipient talking about things that aren't real
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

30. Dressing care-recipient
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

31. Not receiving caregiving help from family
   _yes--->_ not a hassle
   _no _ somewhat
   _____ quite a bit
   _____ a great deal

32. Care-recipient asking repetitive questions
    _yes--->_ not a hassle
    _no _ somewhat
    _____ quite a bit
    _____ a great deal

33. Care-recipient not recognizing familiar people
    _yes--->_ not a hassle
    _no _ somewhat
    _____ quite a bit
    _____ a great deal
<p>| | | | | | | | | | | | | | | | | |</p>
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<tbody>
<tr>
<td><strong>34. Giving medications to care-recipient</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>35. Preparing meals for care-recipient</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>36. Care-recipient wandering off</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>37. Care-recipient’s agitation</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>38. Assisting care-recipient with health aids (i.e., dentures, braces)</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>39. Care-recipient requiring day supervision</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>40. Leaving care-recipient with others</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
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<td><strong>41. Care-recipient hiding things</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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<tr>
<td><strong>42. Care-recipient requiring night supervision</strong></td>
<td><em>yes</em>→<em>not a hassle</em></td>
<td><em>no</em></td>
<td><em>somewhat</em></td>
<td><em>quite a bit</em></td>
<td><em>a great deal</em></td>
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USING THE OPEN STATEMENT UNDERLINED BELOW AS A PREFACE, READ EACH OF THE STATEMENTS THAT FOLLOW TO COMPLETE THE SENTENCE. CIRCLE A RESPONSE ON THE RIGHT THAT BEST INDICATES THE EXTENT TO WHICH YOU AGREE THAT THE COMPLETE STATEMENT DESCRIBES YOU, USING THE FOLLOWING SCALE:

5 = STRONGLY AGREE,  
4 = MODERATELY AGREE,  
3 = NEITHER AGREE OR DISAGREE,  
2 = MODERATELY DISAGREE,  
1 = STRONGLY DISAGREE.

WHEN I FACE PROBLEMS OR DIFFICULTIES WITH MY CAREGIVING RESPONSIBILITIES, I RESPOND BY:

<table>
<thead>
<tr>
<th>answer</th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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</thead>
<tbody>
<tr>
<td>1. Sharing my difficulties with relatives</td>
<td>5 4 3 2 1</td>
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<tr>
<td>2. Seeking encouragement and support from friends</td>
<td>5 4 3 2 1</td>
<td></td>
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<tr>
<td>3. Knowing I have the power to solve major problems</td>
<td>5 4 3 2 1</td>
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<tr>
<td>4. Seeking information and advice from persons who have faced the same or similar problems</td>
<td>5 4 3 2 1</td>
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<tr>
<td>5. Seeking advice from relatives</td>
<td>5 4 3 2 1</td>
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<tr>
<td>6. Seeking assistance from community agencies and programs designed to help families in my situation</td>
<td>5 4 3 2 1</td>
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<tr>
<td>7. Knowing that I have the strength to solve my problems</td>
<td>5 4 3 2 1</td>
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<tr>
<td>8. Receiving gifts and favors from neighbors (eg. food, taking in mail, etc.)</td>
<td>5 4 3 2 1</td>
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<tr>
<td>9. Seeking information and advice from the family physician</td>
<td>5 4 3 2 1</td>
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<tr>
<td>10. Asking neighbors for favors and</td>
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### Assistance Scale

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<tr>
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<tr>
<td>5</td>
<td>STRONGLY AGREE,</td>
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<td>3</td>
<td>NEITHER AGREE OR DISAGREE,</td>
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<td>2</td>
<td>MODERATELY DISAGREE,</td>
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<td>1</td>
<td>STRONGLY DISAGREE.</td>
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**WHEN I FACE PROBLEMS OR DIFFICULTIES WITH MY CAREGIVING RESPONSIBILITIES, I RESPOND BY:**

<table>
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<tr>
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<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>11. Facing the problems &quot;head-on&quot; and trying to get solution right away</td>
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<td>4</td>
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<tr>
<td>12. Watching television</td>
<td>5</td>
<td>4</td>
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<tr>
<td>13. Showing that I am strong</td>
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<tr>
<td>14. Attending church services</td>
<td>5</td>
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<tr>
<td>15. Accepting stressful events as a fact of life</td>
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<tr>
<td>16. Sharing concerns with close friends</td>
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<tr>
<td>17. Knowing luck plays a big part in how well I am able to solve caregiving problems</td>
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<tr>
<td>18. Exercising with friends to stay fit and reduce tension</td>
<td>5</td>
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<tr>
<td>19. Accepting that difficulties occur unexpectedly</td>
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<tr>
<td>20. Doing things with relatives (get-togethers, dinners, etc.)</td>
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<tr>
<td>21. Seeking professional counseling and help for caregiving difficulties</td>
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<tr>
<td>22. Believing I can handle my own problems</td>
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Please circle answer.
23. Participating in church activities 5 4 3 2 1

5 = STRONGLY AGREE,
4 = MODERATELY AGREE,
3 = NEITHER AGREE OR DISAGREE,
2 = MODERATELY DISAGREE,
1 = STRONGLY DISAGREE.

WHEN I FACE PROBLEMS OR DIFFICULTIES WITH MY CAREGIVING RESPONSIBILITIES, I RESPOND BY:

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
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<tbody>
<tr>
<td>24. Defining the caregiving problem in a more positive way so that I do not become too discouraged</td>
<td>5 4 3 2 1</td>
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<tr>
<td>25. Asking relatives how they feel about the problems I face</td>
<td>5 4 3 2 1</td>
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<tr>
<td>26. Feeling that no matter what I do to prepare, I will have difficulty handling problems</td>
<td>5 4 3 2 1</td>
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<tr>
<td>27. Seeking advice from a minister</td>
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<tr>
<td>28. Believing if I wait long enough, the problem will go away</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>29. Sharing problems with neighbors</td>
<td>5 4 3 2 1</td>
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</tr>
<tr>
<td>30. Having faith in God</td>
<td>5 4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>

THERE ARE NO RIGHT OR WRONG ANSWERS. FOR THE FOLLOWING ITEMS, CHECK THE ANSWER THAT BEST DESCRIBES YOUR FEELINGS.

1. Which of the following statements comes closest to expressing what you believe about God?

_____ I know God really exists, and I have no doubts about it.
_____ While I have doubts, I feel that I do believe in God.
_____ I don’t believe in a personal God, but I do believe in a higher power of some kind.
_____ I don’t know whether there is a God or not, and don’t believe there is any way to find
I don’t believe in God.

CHECK THE APPROPRIATE RESPONSE THAT DESCRIBES THE FREQUENCY WITH WHICH YOU PARTICIPATE IN EACH OF THE FOLLOWING ACTIVITIES:

2. How often do you attend church services?

_____ Several times a week
_____ About once a week
_____ Several times a month
_____ Several times a year
_____ Seldom
_____ Never

3. How often do you participate in other religious group-related activities? (Bible study groups, prayer groups, adult Sunday school classes)

_____ About once a week
_____ Several times a week
_____ Several times a month
_____ Several times a year
_____ Seldom
_____ Never

4. How often do you pray privately?

_____ More than twice a day
_____ Twice a day
_____ Once a day
_____ Several times a week
_____ Only occasionally
_____ Not at all

5. How often do you read the bible or other religious literature (magazines, papers, books) at home?

_____ Several times a day
_____ Daily
_____ Several times a week
_____ Several times a month
_____ Only occasionally
_____ Not at all

6. How often do you watch religious television programs or listen to religious radio programs?

_____ Several times a day
_____ Daily
_____ Several times a week
Several times a month
Only occasionally
Not at all

THE NEXT SECTION OF THE QUESTIONNAIRE ASKS HOW MUCH YOU AGREE OR DISAGREE WITH EACH ITEM. CIRCLE THE RESPONSE ON THE RIGHT THAT BEST DESCRIBES YOUR FEELINGS FOR EACH ITEM, WHERE:

6 = STRONGLY AGREE
5 = MODERATELY AGREE
4 = SLIGHTLY AGREE
3 = SLIGHTLY DISAGREE
2 = MODERATELY DISAGREE
1 = STRONGLY DISAGREE

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>please circle answer</td>
<td></td>
</tr>
</tbody>
</table>

7. I experience God’s love and care for me in my relationship with Him.
   6 5 4 3 2 1

8. I believe that God is impersonal and not interested in my daily situations.
   6 5 4 3 2 1

9. I have a personally meaningful relationship with God.
   6 5 4 3 2 1

10. While dealing with difficult times in my life, I don’t get much personal strength and support from God.
    6 5 4 3 2 1

11. My relationship with God helps me not to feel lonely.
    6 5 4 3 2 1

12. Private prayer is important in my life.
    6 5 4 3 2 1

13. I do not experience God’s intervention in my life in any concrete or personal way.
    6 5 4 3 2 1
14. God has revealed things to me about my life, other people, Himself, or His Divine Plan.
6 = Strongly Agree
5 = Moderately Agree
4 = Slightly Agree
3 = Slightly Disagree
2 = Moderately Disagree
1 = Strongly Disagree

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>please circle answer</td>
<td></td>
</tr>
</tbody>
</table>

15. Prayer does not help me to cope with difficulties and stress in my life.

16. I feel most fulfilled when I am in close communion with God.

RESPOND TO THE FOLLOWING STATEMENTS BY CIRCLING THE RESPONSE THAT BEST DESCRIBES HOW YOU FEEL, WHERE:

4 = DEFINITELY TRUE OF ME,
3 = TENDS TO BE TRUE,
2 = TENDS NOT TO BE TRUE,
1 = DEFINITELY NOT TRUE OF ME,
0 = UNSURE.

<table>
<thead>
<tr>
<th>definitely true</th>
<th>unsure</th>
</tr>
</thead>
<tbody>
<tr>
<td>please circle</td>
<td></td>
</tr>
</tbody>
</table>

17. My faith involves all of my life. 4 3 2 1 0

18. Although I am a religious person, I refuse to let religious considerations influence my everyday affairs.

19. In my life I experience the presence of the Divine. 4 3 2 1 0

20. Nothing is as important to me as serving God as best I know how. 4 3 2 1 0

21. My faith sometimes restricts my 4 3 2 1 0
4 = definitely true of me,  
3 = tends to be true,  
2 = tends not to be true,  
1 = definitely not true of me,  
0 = unsure.

   definitely    unsure
   true
   please circle

answer

22. My religious beliefs are what 4 3 2 1 0
really lie behind my whole
approach to life.

23. I try hard to carry my religion
over into all of my other dealings
in life. 4 3 2 1 0

24. My religious faith is the most
important influence in my life. 4 3 2 1 0

THE FOLLOWING SECTION ASKS HOW MUCH YOU AGREE OR DISAGREE WITH EACH ITEM, WHERE:

4 = DEFINITELY AGREE,
3 = TEND TO AGREE,
2 = TEND DISAGREE,
1 = DEFINITELY DISAGREE,
0 = UNSURE.

   definitely    unsure
   agree
   please circle

answer

25. One should seek God's guidance
when making important decisions. 4 3 2 1 0

26. Although I believe in my religion,
I feel there are many more
important things in life. 4 3 2 1 0

27. It doesn't matter so much what I
believe as long as I lead a moral
life. 4 3 2 1 0
28. What is your religious preference?

_____ Catholic
_____ Jewish
_____ Protestant
_____ None
_____ Other, please specify: _______________________

29. Would you say your religious practices or beliefs have changed since taking on your caregiving responsibilities?

_____ Yes
_____ No

If yes, please explain in what way.________________________

RESPOND TO EACH OF THE FOLLOWING AS TO HOW OFTEN THE INDIVIDUAL YOU CARE FOR EXHIBITS THE SYMPTOM LISTED BELOW. IF YOU FEEL THAT AN ITEM DOES NOT APPLY TO YOUR CARE-RECIPIENT, RESPOND BY CIRCLING "1". CIRCLE ONE RATING FOR EACH ITEM, WHERE:

4 = MOST OR ALL OF THE TIME;
3 = A GOOD PART OF THE TIME;
2 = SOME OF THE TIME;
1 = NONE OR LITTLE OF THE TIME.

THE INDIVIDUAL I CARE FOR OR MANAGE:

<table>
<thead>
<tr>
<th>Most/All</th>
<th>None/Little</th>
</tr>
</thead>
<tbody>
<tr>
<td>4 3 2 1</td>
<td>please circle answer</td>
</tr>
</tbody>
</table>

1. Has difficulty completing simple tasks on own eg, dressing, bathing, doing arithmetic. 4 3 2 1

2. Spends time either sitting or in apparently purposeless activity. 4 3 2 1

3. Wanders at night or needs to be restrained to prevent wandering. 4 3 2 1

4. Hears things that are not there. 4 3 2 1

5. Requires supervision or assistance in eating. 4 3 2 1

6. Loses things. 4 3 2 1
4 = MOST OR ALL OF THE TIME;  
3 = A GOOD PART OF THE TIME;  
2 = SOME OF THE TIME;  
1 = NONE OR LITTLE OF THE TIME.

<table>
<thead>
<tr>
<th>The Individual I Care For Or Manage:</th>
<th>Most/All</th>
<th>None/Little</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. Moans.</td>
<td>4</td>
<td>3 2 1</td>
</tr>
<tr>
<td>8. Appearance is disorderly if left to own devices.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>9. Cannot control bowel function.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>10. Threatens to harm others.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>11. Cannot control bladder function.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>12. Needs to be watched so doesn’t injure self, eg, by careless smoking, leaving the stove on, falling.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>13. Destructive of materials around him, eg, breaks furniture, throws food trays, tears up magazines.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>14. Shouts or yells.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>15. Accuses others of doing him bodily harm or stealing his possessions when you are sure the accusations are not true.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>16. Is unaware of limitations imposed by illness.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>17. Becomes confused, doesn’t know where he/she is.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>18. Has trouble remembering.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>19. Has sudden changes of mood, eg, gets upset, angered, or cries easily.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
<tr>
<td>20. If left alone, wanders aimlessly during the day or needs to be restrained to prevent wandering.</td>
<td>4 3 2 1</td>
<td></td>
</tr>
</tbody>
</table>
CHECK OR FILL IN THE BLANK TO INDICATE YOUR RESPONSE TO EACH OF THE FOLLOWING QUESTIONS:

1. What was your age at your last birthday?
   ___ years

2. You are
   ____ Female
   ____ Male

3. What is your race?
   ____ Caucasian
   ____ Black
   ____ Asian
   ____ Hispanic
   ____ Pacific Islander
   ____ Other, please specify________________

4. What is your marital status?
   ____ Married
   ____ Divorced
   ____ Widowed
   ____ Never married

5. What is the highest level of education that you have completed?
   ____ Grade School
   ____ High School
   ____ Some College
   ____ College Degree
   ____ Graduate Degree

6. The person or persons for whom I provide care or manage, is/are my:

   ____ spouse
   ____ son
   ____ mother
   ____ daughter
   ____ father
   ____ uncle
   ____ grandparent
   ____ aunt
   ____ friend
   ____ mother-in-law
   ____ sibling
   ____ father-in-law
   ____ other, please specify________________
7. Are you presently employed at least 30 hours per week outside of your caregiving role?

______Yes
______No, working part-time (less than 30 hours)
______No, retired
______No, unemployed
______No, disabled
______Other, please specify_________________

8. Has the person with dementia that you are caring for been diagnosed specifically with Alzheimer's Disease?

______Yes
______No

9. Where does the affected individual you care for or manage reside?

______in your home
______in his/her own home
______with another relative
______in an institution (ex. nursing home)
______other, please specify_________________

10. How many years have you been a family caregiver?

______years
OPTIONAL: Is there anything you would like to share regarding the stress or your coping with your personal caregiving experience which you feel was not already identified by the preceding survey? Use the space below to write further comment.
APPENDIX H

Verbal Address
Verbal Address given at each Support Group Meeting

I am conducting a study of caregivers for individuals with Alzheimer’s Disease. This study will involve your completion of a 20-30 minute written survey, for which all responses will be anonymous.

Specifically, I am interested in the characteristics and coping mechanisms of family caregivers for Alzheimer’s Disease affected individuals (community dwelling [homebound] or those in institutions). A family caregiver is the family member (or significant other whose relationship is considered "family") who is involved and responsible for providing or coordinating the resources required by the AD affected individual, and is not receiving financial reimbursement for these caregiving activities.

If you are a family caregiver, as described above, and are willing to participate in this study, please take one questionnaire packet, complete the enclosed questionnaire and return it in the pre-addressed, pre-stamped envelope. Your completion of the questionnaire indicates your willingness to participate in this caregiver study. It is further requested that you try to complete this questionnaire within two weeks. Study findings will be published in your Chapter’s newsletter at the completion of the study.

Your participation or non-participation in this study will in no way effect your status as a member in this support group. Your ultimate participation in this study will remain confidential, known only to your support group leader.

Thank you for your consideration. Your participation in this study is greatly appreciated.
LIST OF REFERENCES


Brook, R.H. and Ware, J.E. (1979). Supplement to Medical Care, 17(7), 1-55.


