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Alzheimer Caregivers: A Study of Associations between Neuropsychiatric Symptoms, Caregiver Coping Strategies, and Quality Of Life

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Pacific University

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Alzheimer Caregivers: A Study of Associations between Neuropsychiatric Symptoms, Caregiver Coping Strategies, and Quality Of Life

Abstract
People with Alzheimer’s Disease (AD) exhibit neuropsychiatric symptoms (NPS) that may negatively impact specific areas of caregiving for care recipients. Additionally, Problem-Focused (PF) and Emotion-Focused (EF) coping strategies have been shown to be differently related to depression in AD caregivers. The present study explored relationships between care recipient NPS, caregiver quality of life (QOL) and caregiver coping strategies. Alzheimer’s caregivers were recruited from support groups and aging and disabilities services offices in the Portland, OR, area. Twenty caregivers completed the Neuropsychiatric Inventory Questionnaire (NPI-Q), Caregiver Quality of Life questionnaire (CGQOL), and Ways of Coping-Revised (WOC-R). Pearson product moment correlations indicated a negative trend between Planful Problem Solving coping strategies and Assistance in Instrumental Activities of Daily Living (IADLS) \( r(18) = -.519 \). A positive trend was found between NPI-Q scores with Assistance in IADLS \( r(18) = .457 \) and Assistance in ADLS \( r(18) = .415 \). Exploratory analyses indicated a negative trend between Escape-Avoidance coping strategies and Role Limitations Due to Caregiving, \( r(18) = -.498, p = .025 \) as well as caregiver Personal Time, \( r(18) = -.520, p = .019 \), Assistance in IADLS, \( r(18) = -.440, p = .052 \) and Assistance in ADLS, \( r(18) = -.466, p = .038 \). Part correlations controlled for several care recipient and caregiver variables. Pearson product moment correlations revealed that relationship to the care recipient, caregiver age, and caregiver ethnicity, and caregiver attendance at support groups affected correlation strengths. Further studies should investigate how caregiver coping strategies mediate the relationship between NPS in people with AD and caregiver QOL.

Degree Type
Thesis

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ALZHEIMER CAREGIVERS: A STUDY OF ASSOCIATIONS BETWEEN NEUROPSYCHIATRIC SYMPTOMS, CAREGIVER COPING STRATEGIES, AND QUALITY OF LIFE

A THESIS
SUBMITTED TO THE FACULTY
OF
SCHOOL OF PROFESSIONAL PSYCHOLOGY
PACIFIC UNIVERSITY
HILLSBORO, OREGON

BY
JULIJA ELIZABETH STELMOKAS

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE
OF
MASTER OF SCIENCE IN CLINICAL PSYCHOLOGY

December 6th, 2010 in which thesis is approved

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[Type text]
Abstract

People with Alzheimer’s Disease (AD) exhibit neuropsychiatric symptoms (NPS) that may negatively impact specific areas of caregiving for care recipients. Additionally, Problem-Focused (PF) and Emotion-Focused (EF) coping strategies have been shown to be differently related to depression in AD caregivers. The present study explored relationships between care recipient NPS, caregiver quality of life (QOL) and caregiver coping strategies. Alzheimer’s caregivers were recruited from support groups and aging and disabilities services offices in the Portland, OR, area. Twenty caregivers completed the Neuropsychiatric Inventory Questionnaire (NPI-Q), Caregiver Quality of Life questionnaire (CGQOL), and Ways of Coping-Revised (WOC-R). Pearson product moment correlations indicated a negative trend between Planful Problem Solving coping strategies and Assistance in Instrumental Activities of Daily Living (IADLS) $r(18) = -.519$. A positive trend was found between NPI-Q scores with Assistance in IADLS $r(18) = .457$ and Assistance in ADLS $r(18) = .415$. Exploratory analyses indicated a negative trend between Escape-Avoidance coping strategies and Role Limitations Due to Caregiving, $r(18) = -.498$, $p = .025$ as well as caregiver Personal Time, $r(18) = -.520$, $p = .019$, Assistance in IADLS, $r(18) = -.440$, $p = .052$ and Assistance in ADLS, $r(18) = -.466$, $p = .038$. Part correlations controlled for several care recipient and caregiver variables. Pearson product moment correlations revealed that relationship to the care recipient, caregiver age, and caregiver ethnicity, and caregiver attendance at support groups affected correlation strengths. Further studies should investigate how caregiver coping strategies mediate the relationship between NPS in people with AD and caregiver QOL.
Acknowledgements

Mom, Dad, Dana, Gina, and other family members and friends, thank you for encouraging and supporting me to this point in my academic career. You have been a consistent source of comfort, patience, and love during several challenging and frustrating times. I have always been driven to succeed and I know that you expect nothing less from me. I would also like to thank the caretakers who welcomed me into their home to share their stories. Finally, Dr. BJ Scott, you have been instrumental in guiding me through this research process. I am so grateful to have you as a mentor to lean on for advice, encouragement, and inspiration. You have provided me the opportunity to grow and learn about myself as a student and as a researcher.
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Alzheimer Caregivers: Associations between Neuropsychiatric Symptoms, Caregiver Coping Strategies, and Quality of Life

Alzheimer’s Disease (AD) is a progressive and debilitating disease involving a deterioration of mental and functional abilities, along with changes in behavior and personality. According to the Alzheimer’s Association (2009), AD was the sixth-leading cause of death across all ages in the United States in 2006. Currently, 5.3 million people in the U.S. have Alzheimer’s Disease, and this number is estimated to reach 7.7 million by 2030. In all, AD accounts for approximately 70 percent of all dementia cases in Americans 71 years of age and older. As the disease progresses, individuals are primarily cared for by family members or by friends and neighbors, who provide an estimated 8.5 billion hours of unpaid care.

Caring for individuals with AD is very demanding, given the repeated stressors that caregivers face over the course of the illness (Vellone, Piras, Talucci & Cohen, 2007). Compared to caregivers for those without dementia, caring for a person with AD is more stressful and has a greater impact on employment, leisure time, and family conflict and is associated with higher rates of psychological and health problems (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). For example, depression has been shown to be highly prevalent among AD caregivers (Shultz & Williamson, 1991; Covinsky et al., 2003). In a review of individual differences in caregiving demands, Dunkin and Anderson-Hanley (1998) found that several variables including caregiver social support, financial resources, coping abilities, feelings of self-efficacy, and ethnicity are associated with the likelihood of depression, anxiety and health problems.

Early studies of AD caregivers focused mainly on caregiver burden (e.g., Zarit, Reever, Bach-Peterson, 1980). The term caregiver burden (CB) refers to the physical, financial, and emotional costs of providing care for an individual with a chronic condition (George & Gwyther,
Important caregiver variables contributing to differences in CB have included education, income, health status, social support and relationship history between the care recipient and caregiver (Papastavrou, Kalokerinou, Papacosta, Tsangari, and Sourtzi, 2007; Dunkin et al. 1998). Furthermore, the level of CB predicts likelihood of care recipient institutionalization (Cohen et al., 1993; Yaffe et al., 2002). In terms of care recipient variables, behavioral disturbances have been found to be one of the largest factors contributing to caregiver burden and distress (Coen, O’Boyle, Coakley, & Lawlor, 2002; Ford, Goode, Barrett, Harrell, & Haley, 1997). However in general, while much attention has been paid to understanding differences in CB in terms of caregiver characteristics, less research has investigated the effects of care recipient problem behaviors on CB.

**Neuropsychiatric Symptoms**

Many people with AD exhibit neuropsychiatric disturbances, commonly referred to as NPS (NPS; Cummings, 2005). These symptoms include apathy, agitation, anxiety, irritability, dysphoria, aberrant motor behavior, disinhibition, delusions, and hallucinations. NPS have been found to be present in up to 90% of individuals with AD (Teri, Borson, Kiyak, & Yamagishi, 1989; Mega, Cummings, Fiorello, & Gornbein, 1996) and are also present to a lesser extent in individuals with mild cognitive impairment who later develop AD (Teng, Lu, & Cummings, 2007). Overall, NPS persist throughout the disease process in a variable manner (Petry, Cummings, Hill, & Shapira, 1989).

In the several attempts to classify and differentiate NPS, various instruments have been used (Lyketsos, 2007). For example, the Frontal Lobe Personality Scale (FLOPS) has been used to measure apathy, disinhibition, and executive dysfunction (Paulsen et al., 1996). Another instrument used to assess NPS is the Neuropsychiatric Inventory (NPI), developed as an
Most recently, the NPI has been adapted into a caregiver-reported inventory (Kang et al., 2004), allowing for the caregiver to easily report care recipient NPS.

**Patient and Caregiver Characteristics Associated with NPS**

NPS of individuals with AD have been correlated with various caregiver and care recipient characteristics. For example, after adjusting for dementia severity, NPS has been correlated with caregiver burden and depression, as well as several caregiver demographic characteristics (Sink, Covinsky, Barnes, newcomer, & Yaffe, 2006), with higher severity and frequency of symptoms predicting higher CB (Tun, Murman, & Colenda, 2008). In fact, behavioral disturbances are one of the strongest predictors of CB (Davis & Tremont, 2007) and are associated with executive dysfunction and cognitive decline in AD (Tsoi, Baillon, & Lindesay, 2008). Furthermore, NPS has been associated with early nursing home placement, decline in instrumental activities of daily living (IADL), increase in cost of care, and decreased quality of life (QOL) for both care recipients and caregivers (Phillips & Diwan, 2003; Tekin, Fairbanks, O’Connor, Rosenberg & Cummings, 2001; Wolstenholme et al., 2002; Shin, Carter, Masterman, Fairbanks, & Cummings, 2005).

The high prevalence and variability of troublesome behaviors throughout the stages of AD can make it difficult for caregivers to care for and cope with the demands of caregiving (Mega et al., 1996; O’Donnell et al., 1992). Unable to cope with these troublesome behaviors, some caregivers choose to institutionalize their loved one. However, nursing home placement is more expensive than in-home care (Leon, Cheng, & Neumann, 1998) and requires further readjustment for both caregiver and care recipient after institutionalization (Gaugler, Mittelman, Hepburn, & Newcomer, 2009). In contrast, delaying nursing home placement lowers economic
burden and increases care recipients’ subjective wellbeing. Therefore, it is essential to focus on strategies that maintain effective homecare for AD care recipients, in order to improve both care recipient and caregiver QOL while reducing costs (Zhu & Sano, 2006).

Quality of Life

In general, there is no agreed upon definition of QOL. In an initial review of the literature, Vellone et al. (2007) found that most definitions of QOL included factors such as income, housing, physical and health functioning, ability to work, socioeconomic status, social support, self-esteem, stress, subjective burden, and life satisfaction. However, phenomenologically, caregivers conceptualized QOL as serenity, tranquility, psychological wellbeing, freedom, general wellbeing, good health and financial status. Additionally, factors that decrease QOL included a caregiver’s worries about the care recipient’s future and progression of the disease, as well as the caregiver’s conceptualization of the stress involved in caring for a loved one with AD. Therefore, a better definition of QOL as it relates to care recipients and caregivers may involve increased understanding of the relationship between AD and each individual’s subjective wellbeing (James, Xie, & Karlawish, 2005).

Caregiver Quality of Life

With respect to interventions, QOL instruments have become particularly useful in measuring treatment outcomes (Dijkers, 2003; Logsdon & Albert, 1999). Over the past 25 years, there has been an increase in the development of self-report instruments assessing the caregiving experience, including QOL (Deeken, Taylor, Mangan, Yabroff, & Ingham, 2003). Although there have been few measures that specifically assess a caregiver’s QOL, some have used the Satisfaction With Life Scale in order to measure overall caregiver wellbeing (Brodaty, 2007; Diener, Emmons, Larson, & Griffin, 1985). However, while this 5-item scale assesses general
life satisfaction, it lacks the ability to tap into important areas of wellbeing that may be
associated with caregiver QOL, such as care recipients’ physical condition, mood, memory,
interpersonal relationships, and functional abilities.

In their initial review of the literature, Vickrey et al. (2009) found that studies of
dementia caregiver QOL published in English used broad measures of QOL or related constructs,
such as health, burden, or depression, although one French study utilized a questionnaire
developed especially for dementia caregivers. However, as Vickrey et al. pointed out, this study
neglected to include important areas of caregiver’s QOL. For instance, the questionnaire does
not assess the amount of care the caregiver provides or assistance that he or she receives.
Moreover, the normative standardization group did not include an adequate range of educational
levels and ethnic diversity.

Recently, the development of the Caregiver Quality of Life (CGQOL) questionnaire by
Vickrey et al. (2009) allows for assessment of caregiver’s QOL specifically with respect to
caregiving for loved ones with AD. This self-assessment questionnaire directly assesses
dementia caregiver QOL across ten dimensions, including Assistance in Activities of Daily
Living (ADLS), Assistance in Instrumental Activities of Daily Living (IADLS), Personal Time,
Role Limitations Due to Caregiving, Family Involvement, Demands of Caregiving, Worry,
Caregiver Feelings, Spirituality and Faith, and Benefits of Caregiving. In addition, assessment of
QOL using the CGQOL allows measurement of several important aspects of caregiving that may
differ between ethnically diverse caregivers and care recipients that have not been incorporated
into previous instruments, such as the role of caregiver spirituality, perception of burden, and
satisfaction (Roche, 2009).
Although some perceive caregiving as negative, others have a more positive experience (Talkington-Boyer & Snyder, 1994). Therefore, it is important to understand why some caregivers feel “burnt out” and turn to formal care for their loved ones, while others experience a relatively higher QOL, despite the negative effects of caregiving for someone with AD. For example, the importance of caregiver perceptions of the AD care recipient’s functioning has been found to be a better determinant of caregiver burden than are objective care recipient deficits (Hadjistavropoulos, Taylor, Tuokko, & Beattie, 1994). In this respect, it may be useful to explore the construct of coping and how coping strategies may serve as protective factors in a caregivers’ response to stressors and their self-assessment of QOL.

Coping

Lazarus and Folkman (1984) developed a model of coping that involves cognitive appraisal and is useful for understanding caregiver coping strategies. This model takes into account the individual’s perception of a stressor and how this affects which coping strategy is used (Roche, 2009). In its current development, this coping theory utilizes a complex multidimensional, bi-directional, and process-centered approach. According to a cognitive-relational theory of emotion and coping, there is a transactional process between the person and environment such that cognitive appraisal mediates the coping response (Lazarus & Folkman, 1987). From this perspective, coping is defined as “constantly changing cognitive and behavioral efforts to manage specific internal and/or external demands that are appraised as taxing or exceeding the resources of the person” (Lazarus et al., 1984, p. 141). This involves an individual putting forth effort to manage stressful demands, not necessarily limited to emotional processes or implying mastery of the problems. Tolerating, minimizing, accepting, and denying the problem are additional ways that an individual may cope with current stressors. Based on this
model, the Ways of Coping Questionnaire—Revised has become increasingly popular due to applicability across a variety of stressful situations. Further research using this instrument may increase our understanding of the caregiving process and the ultimate success of intervention strategies on increasing caregiver QOL (Gottlieb & Wolfe, 2002).

**Problem-Focused and Emotion-Focused Coping**

Coping has been viewed as two-dimensional: Problem-focused (PF) coping on one hand, and emotion-focused (EF) coping on the other (Zarit & Zarit, 1986). PF coping involves managing or altering a problem in the environment that is causing distress. In contrast, EF coping attempts to regulate the emotional response to a problem, using avoidance, minimization, or distancing. Early research found that the use of PF or EF coping is subject to change depending on a variety of factors (Folkman & Lazarus, 1980; Wright, Lund, Caserta, & Pratt, 1991). Individuals may differentially use coping strategies across a variety of stressful situations, depending on their primary and secondary appraisal of the situation, as well as their perceptions of satisfactory or unsatisfactory outcomes (Folkman, Lazarus, Gruen, DeLongi, 1986; Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986; Folkman & Lazarus, 1985). For instance, EF coping may be used in situations that are appraised as unchangeable, whereas PF coping may be used more often in encounters that are appraised as changeable (Folkman et al., 1980). Furthermore, gender differences have shown that female caregivers use more EF coping than do male caregivers (Papastavrou et al., 2007).

**Coping as a mediator variable.** A number of studies have investigated the association between coping strategies and caregiving variables (Connell, Janevic, & Gallant, 2001). Overall, research has supported the relationship between the uses of PF coping versus EF coping as a mediator in several outcome variables. These have included increase in life satisfaction and
decreased caregiver burden when practical or PF ways of coping are used (McConaghy & Caltabiano, 2005; Papastavrou et al., 2007; Wright et al., 1991). Additionally, the use of PF coping has been associated with decreased depressive and anxiety symptoms in caregivers of those with AD (Batt-Leiba, Hills, Johnson, & Bloch, 1998; Cooper, Katona, Orrell, & Livingston, 2008). To explore these associations further, a study by Mausbach et al. (2006) found that caregivers’ use of escape avoidance mediated the relationship between care recipient problem behaviors and depressive symptoms in caregivers. However, a study by Morano (2003) found that caregiver PF coping did not mediate the effect of problem behaviors on negative psychological outcomes (e.g., caregiver life satisfaction or depression). Still, this study found that EF coping moderated the effects of caregiver depression on caregiver life satisfaction. Given these findings, further research is needed within the area of coping and its effects in caregiving for care recipients with AD.

In a review of cross-sectional and longitudinal research based on Lazarus et al. (1984) stress, appraisal, and coping model, Kneebone & Martin (2003) found that most studies have not incorporated coping measures specific to caregiving or assessed coping with respect to specific caregiver problems. In some studies, there was a general tendency towards problem-solving and acceptance styles of coping, which is likely to be advantageous to caregivers of people with dementia. However, since AD is a progressive disease, different coping strategies may be useful at different points in time. For example, caretakers may adapt to their situations at different rates or stages of the disease, and the use of various coping strategies may be influenced by many factors (Rees, O’Boyle, & MacDonagh, 2001). Therefore, it may be useful to provide clinicians with differential intervention strategies to increase caregiver QOL. Research to date has pointed to the need to gain a better understanding of caregiver coping strategies, such as caregiver’s
response to NPS. Thus, a better understanding of caregiver ways of coping with NPS may help support interventions that potentially prevent early nursing home placement.

In summary, research suggests that AD care recipient NPS negatively impacts caregiver QOL in multiple ways. Therefore, the present study explored relationships between caregiver QOL and ways of coping and care recipient NPS. In order to evaluate the complex relationship between NPS and caregiver QOL, the NPI-Q was used to assess NPS in those with AD, and caregiver QOL was measured using the CGQOL. Because the relationship between these also may be correlated with caregiver strategies for coping, coping strategies as measured by the WOC-R also were analyzed. It was hypothesized that NPS would be correlated with caregiver QOL, with the exception of the Spirituality Faith Scale and Benefits Scale. Additionally, it was hypothesized that PF coping strategies would be correlated with caregiver QOL, again with the exception of the Spirituality Faith Scale and Benefits Scale. Correlations between all other variables were exploratory.

Methods

Participants

Participants for this study included 20 caregivers of persons with AD. Approval for this research project was acquired from the Pacific University Institutional Review Board and the Legacy Hospital Institutional Review Board. Participants were recruited from the Portland, OR, and Vancouver, WA, metro areas. Participants were required to be at least 18 years of age and currently taking care of an individual with Alzheimer’s Disease in a home setting. Caregivers who had a current or previous diagnosis involving psychosis, current substance abuse/dependence diagnosis, or current diagnosis of Major Depressive Disorder were excluded.
from the study during the initial phone screening. Also excluded were professional caretakers who did not have a close relationship with the care recipient.

The age range of participants was between 51 and 70. Gender identification was predominantly female (n = 13), with seven male participants. The majority of participants were Caucasian (n = 17); three identified as African American. Half cared for those with an AD diagnosis received 4 years ago or less; half cared for those with a diagnosis given 5 years ago or longer. More than half had at least some college education. Most caregivers reported caring for a spouse and attending a support group for caregivers. Half had attended a skill-building workshop for AD caregivers. Table 1 provides descriptive information for this sample.

Table 1
Descriptive Statistics for Participant Sample

<table>
<thead>
<tr>
<th>Variable</th>
<th>Total in Sample</th>
<th>Percentage in Sample (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 50</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>51-70</td>
<td>9</td>
<td>45</td>
</tr>
<tr>
<td>Older than 70</td>
<td>11</td>
<td>55</td>
</tr>
<tr>
<td>2. Highest Level of Education Achieved</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than 12 years</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>GED/High school</td>
<td>6</td>
<td>30</td>
</tr>
<tr>
<td>Some College/Bachelor</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>Masters/Doctoral</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>3. Time Since Loved One’s Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0-1 years</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>2-4 years</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>More than 5 years</td>
<td>7</td>
<td>35</td>
</tr>
<tr>
<td>4. Relationship to Person with AD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>16</td>
<td>80</td>
</tr>
<tr>
<td>Child</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>Niece</td>
<td>2</td>
<td>10</td>
</tr>
<tr>
<td>5. Previous Attendance at a Support Group</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>17</td>
<td>85</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>15</td>
</tr>
<tr>
<td>6. Previous Attendance at a Skill-building Workshop</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>50</td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>50</td>
</tr>
</tbody>
</table>
Procedure

Participants were first screened over the telephone to determine if they met inclusion criteria. If the participant met inclusion criteria, the examiner and a research assistant arranged to meet the participant to collect data at the recruitment location or at the caregiver’s home, according to caregiver preference. If the recruitment site was a support group, data was collected before start of the support group. After informed consent was provided, participants completed a demographic questionnaire and the three study questionnaires. Participants were debriefed after testing and thanked for their participation. They were entered into a raffle to win a $50 gift certificate for Fred Meyer stores. Also, all caregivers were given a resource list of support groups and counseling centers within the Portland metro area that specialize in working with those with dementia and their caregivers.

Measures

The Ways of Coping Questionnaire-Revised (WOC-R; Folkman & Lazarus, 1988) is a 66-item self-report instrument used to assess strategies that individuals use to cope with stressful life events. Participants were asked to recall a stressful life event within the past week and respond on a four-point Likert-type scale to a series of statements about how they coped with the event. The WOC-R has been used in variety of populations and has acceptable reliability, with a reported Cronbach’s alpha of .86 (Lundqvist & Ahlstrom, 2006). Analysis of the factor structure of the WOC-R (Wineman, Durand, & McCulloch, 1994) yielded eight non-overlapping scale scores measuring the following types of coping strategies: Confrontive Coping, Distancing, Self-Controlling, Seeking Social Support, Accepting Responsibility, Escape-Avoidance (also called EF coping), Planful Problem Solving (also called PF coping), and Positive Reappraisal. The WOC-R has also been found to have good face and construct validity consistent with test
developers’ theoretical predictions (Consulting Psychologists Press, Inc., 1988). The current study utilized the Problem-Focused and Emotion-Focused coping subscale scores from the WOC-R.

The Caregiver Quality of Life Questionnaire (CGQOL; Vickrey et al., 2009) is an 80-item self-report instrument used to assess QOL specific to caregivers for those with Alzheimer’s and related dementias. The CGQOL is relatively new, and preliminary results support adequate reliability, with internal consistency greater than 0.78 for all scales and test re-test coefficients exceeding 0.70 for most scales. As noted above, the CGQOL contains ten non-overlapping scales that measure a caregiver’s level of Assistance in Instrumental Activities of Daily Living (IADLS), Assistance in Activities Of Daily Living (ADLS), Role Limitations Due to Caregiving, Personal Time, Family Involvement, Demands of Caregiving, Worry, Spirituality and Faith, Benefits of Caregiving and Caregiver Feelings. Participants’ scores from each subscale were analyzed in the current study.

The Neuropsychiatric Inventory Questionnaire (NPI-Q; Kaufer et al., 2000) is a 12-item caregiver-completed questionnaire that assesses 12 types of NPS. As noted above, it was adapted from the clinician-reported form of the NPI (Cummings et al., 1994). The NPI-Q was developed and cross-validated with the standard NPI to provide a brief assessment of neuropsychiatric symptomatology in routine clinical practice settings (Kaufer et al., 2000). Respondents first rate the presence, then the severity, then the impact of each NPS. Initial responses to each domain question are "Yes" (present) or "No" (absent). If the response to the domain question is "No," the informant proceeds to the next question. If the response is "Yes," informants then rate both the severity of symptoms present within the last month on a 3-point scale and the associated impact of the symptom on themselves (i.e., Caregiver Distress) on a 5-
point scale. The NPI-Q provides a total score derived from Severity and Distress scores for each symptom type supported.

**Results**

Caregivers reported utilizing higher levels of PF coping strategies compared to EF coping strategies. Additionally, caregivers in this sample reported a low frequency and intensity of NPS, as measured by the NPI-Q, which has a total possible score ranging from 0-80. Scores from the ten scales of the CGQOL are reported in the table below.

Table 2
Descriptive Statistics of NPS, Coping Strategies, and CGQOL Scales

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Planful Problem Solving</td>
<td>8.40</td>
<td>3.60</td>
</tr>
<tr>
<td>2. Escape–Avoidance</td>
<td>2.80</td>
<td>2.00</td>
</tr>
<tr>
<td>3. NPS</td>
<td>26.00</td>
<td>13.66</td>
</tr>
<tr>
<td>4. CGQOL Scales</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Assistance in IADLS</td>
<td>19.00</td>
<td>22.41</td>
</tr>
<tr>
<td>Assistance in ADLS</td>
<td>75.50</td>
<td>29.64</td>
</tr>
<tr>
<td>Role Limitations Due to Caregiving</td>
<td>51.25</td>
<td>28.14</td>
</tr>
<tr>
<td>Personal Time</td>
<td>48.53</td>
<td>20.72</td>
</tr>
<tr>
<td>Family Involvement</td>
<td>58.05</td>
<td>27.50</td>
</tr>
<tr>
<td>Demands of Caregiving</td>
<td>57.85</td>
<td>22.07</td>
</tr>
<tr>
<td>Worry</td>
<td>57.15</td>
<td>13.06</td>
</tr>
<tr>
<td>Spirituality and Faith</td>
<td>74.65</td>
<td>27.01</td>
</tr>
<tr>
<td>Benefits of Caregiving</td>
<td>72.10</td>
<td>20.09</td>
</tr>
<tr>
<td>Caregiver Feelings</td>
<td>33.50</td>
<td>8.05</td>
</tr>
</tbody>
</table>

To analyze the hypothesized relationships between care recipient NPS, caregiver coping strategies and caregiver QOL, Pearson product moment correlations were computed between total scores on the NPI-Q, the Planful Problem Solving scale from the WOC-R, and eight subscales from the CGQOL (all scales except Spirituality and Faith and Benefits, for which exploratory analyses were conducted). Hypotheses related to 16 correlations. Using a Bonferroni correction to control for Type I error across 16 correlations, a \( p \) value of \( \leq .003 \) \((.05/16 = .003)\) was required for statistical significance. Using this correction, the results of correlational
analyses indicated a number of trends but no significant findings. See Table 3 for results of hypothesis testing and exploratory analyses. In follow-up, part correlations were conducted to further examine trends while controlling for several caregiver variables (i.e., gender, ethnicity, level of education, length of time since diagnosis, relationship with care recipient, and attendance at support groups and skill-building workshops).

**Correlations associated with Hypotheses**

There was a negative trend found between caregivers’ use of Planful Problem Solving scores and Assistance in IADLS, $r(18) = -.519$, $p = .019$, suggesting that increased use of PF strategies may be associated with less assistance with IADL’s. Also, a positive trend was found between NPI-Q scores and Assistance in IADLS $r(18) = .457$, $p = .043$. These results suggest that higher levels of care recipient NPS may be associated with greater assistance with IADL’s. Lastly, a positive trend was found between caregiver Assistance in ADLS and the care recipient’s total NPS $r(18) = .415$, $p = .069$, suggesting that as care recipient NPS increase, there is an increase in caregiver assistance with ADL’s.

**Exploratory Analyses**

Exploratory correlations were calculated between total NPI-Q scores, Escape Avoidant Coping scores, and all scales of the CGQOL, including the Spirituality and Faith and Benefits subscales. A negative trend was found between the use of Escape-Avoidance scores and levels of Assistance in IADLS, $r(18) = -.440$, $p = .052$, suggesting that increased use of EF coping strategies may be associated with lowers levels of caregiver’s assistance with IADL’s. Also, a negative trend was found between Escape-Avoidance scores and levels of Assistance in ADLS, $r(18) = -.466$, $p = .038$, suggesting that increased use of EF coping strategies may be associated with lower levels of caregiver’s assistance with ADL’s. In addition, a negative trend was found
Table 3.

Correlations between hypothesized and exploratory variables among total NPS, Plan Problem Solving Coping, Escape-Avoidance Coping, and scaled scores of CGQOL (n = 20).

<table>
<thead>
<tr>
<th></th>
<th>NPI-Q</th>
<th>PS</th>
<th>EA</th>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
<th>S5</th>
<th>S6</th>
<th>S7</th>
<th>S8</th>
<th>S9</th>
<th>S10</th>
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<tbody>
<tr>
<td>Neuropsychiatric Inventory-Quest. Plan Problem Solving</td>
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<tr>
<td>Plan Problem Solving</td>
<td>-.013</td>
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<tr>
<td>Escape-Avoidance</td>
<td></td>
<td>.004</td>
<td>-.265</td>
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<tr>
<td>S1: Assistance in IADLS</td>
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<td>S2: Assistance in ADLS</td>
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<td>S3: Role Limitations</td>
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<tr>
<td>S4: Personal Time</td>
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<td>S5: Family Interaction</td>
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<tr>
<td>S6: Demands of Caregiving</td>
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<tr>
<td>S7: Worry</td>
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<tr>
<td>S8: Spirituality and Faith</td>
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<tr>
<td>S9: Benefits of Caregiving</td>
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<tr>
<td>S10: Caregiver Feelings</td>
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</tbody>
</table>

* p-value ≤ .05
between the use of Escape-Avoidance scores and Role Limitations Due to Caregiving, \( r(18) = -0.498, p = .025 \), suggesting that caregivers may have more role conflict associated with work or other activities in association with lower levels of EF coping strategies. Lastly, there was a negative trend found between Escape-Avoidance scores and caregiver Personal Time, \( r(18) = -0.520, p = .019 \), suggesting that the use of more EF coping strategies may be associated with less personal time for caregivers.

**Effects of Caregiver Variables**

To examine the effects of control variables on the trend between Planful Problem Solving scores and levels of Assistance in IADLS, part correlations indicated that, when the shared effects of ethnicity were removed, the negative association between variables was strengthened \( (r(17) = -0.586, p = .008) \). Separate Pearson product moment correlations for each ethnic group demonstrated that this trend was stronger for Caucasian individuals. Similarly, when the shared effects of age were removed, this association was strengthened \( (r(17) = -0.598, p = .007) \). Separate correlations for each age category indicated that the trend was strongest for participants who were between the ages of 51 and 70. When the shared effects of relationship to the individual with AD were removed, the trend was attenuated \( (r(17) = -0.544, p = .016) \). Separate correlations for each type of relationship indicated that the trend between Planful Problem Solving and Assistance in IADLS was strongest for spouses. When the shared effects of attending support groups were removed, this association also was attenuated \( (r(17) = -0.483, p = .036) \). See Table 4 for separate correlations using caregiver variables.
Table 4.
Effects of Control Variables on Correlations between Planful Problem Solving and Assistance in IADLS

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pearson Product moment correlations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td></td>
</tr>
<tr>
<td>51-70</td>
<td>-0.803</td>
</tr>
<tr>
<td>Older than 70</td>
<td>-0.308</td>
</tr>
<tr>
<td>2. Ethnicity</td>
<td></td>
</tr>
<tr>
<td>Caucasian</td>
<td>-0.642</td>
</tr>
<tr>
<td>African American</td>
<td>-0.305</td>
</tr>
<tr>
<td>3. Relationship with Person with AD</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>-0.501</td>
</tr>
<tr>
<td>*Other (child, niece)</td>
<td>-0.767</td>
</tr>
<tr>
<td>4. Previous Attendance at Support Group</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>-0.585</td>
</tr>
<tr>
<td>No</td>
<td>0.577</td>
</tr>
</tbody>
</table>

With respect to the trend between scores on the NPI-Q and caregiver Assistance in IADLS, part correlations indicated that, when the shared effects of age were removed, the positive association between variables was strengthened a small amount ($r(17) = .460$, $p = .047$). Separate Pearson product moment correlations demonstrated that this trend was stronger for caretakers older than 70 years of age. When controlling for the relationship with the individual with AD, the association between the NPI-Q total score and caregiver Assistance in IADLS also was strengthened ($r(17) = .480$, $p = .038$). Separate Pearson product moment correlations demonstrated that this trend was strongest for individuals who had a spousal relationship with the care recipient. See Table 5 for separate correlations using caregiver variables.

Table 5.
Effects of Control Variables on Correlations between NPI-Q and Assistance in IADLS

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pearson Product moment correlations</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Age</td>
<td></td>
</tr>
<tr>
<td>51-70</td>
<td>0.318</td>
</tr>
<tr>
<td>Older than 70</td>
<td>0.627</td>
</tr>
<tr>
<td>2. Relationship with Person with AD</td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>0.519</td>
</tr>
</tbody>
</table>
With respect to the trend between NPI-Q total scores and caregiver Assistance in ADLS, partial correlations indicated that when the shared effects of caregiver variables were removed, no significant differences in the strength of association were present.

**Discussion**

AD caregivers tended to use more Planful Problem Solving coping strategies than Escape-Avoidance coping strategies. Caregivers also tended to rate the care recipient’s overall neuropsychiatric symptoms relatively low in terms of severity and distress. Generally, caregivers reported assisting more with IADL’s and relatively less with ADL’s. Caregivers also reported few negative or bothersome feelings regarding the care recipient. Of note, most caregivers tended to deny spirituality and faith as important factors in their QOL and also did not report much benefit from caregiving.

These results suggest that AD caregiver QOL and ways of coping may be related. After adjusting for multiple comparisons, the first hypothesis that higher NPS would be negatively correlated with caregiver QOL was not supported. However, a positive trend was found between care recipients NPI-Q total scores and caregiver’s Assistance in IADLS ($r = .457$, $p = .043$). In addition, a trend was found between care recipient NPI-Q total scores and Assistance in ADLS ($r = .415$, $p = .069$). A possible explanation for the non-significant correlation is the small sample size used. In addition, research has indicated that NPS are persistent throughout AD, but these symptoms may vary in intensity over the disease process (Ryu, Katona, Rive, Benout, & Livingston, 2005). Given the relatively low NPS reported by caregivers coupled with the small sample size, the results of this study suggest that increased care recipient’s NPS may correlate with caregivers assisting with activities of daily living for loved ones with AD.
The second hypothesis that the use of PF coping strategies would be positively correlated with caregiver QOL was partially supported. Several correlations suggested that different types of coping were related to increased caregiver QOL. Specifically, Planful Problem Solving coping was negatively associated with caregiver Assistance in IADLS. Effect sizes indicated that use of Planful Problem Solving coping strategies, such as using specific problem skills and putting them into action, accounted for approximately 27% of the variance in the amount of assistance that caregivers provided to care recipients. However, after adjusting for multiple comparisons, this association was not significant. Nevertheless, specific PF strategies may be associated with decreases in the amount of assistance that caregivers provide and should be investigated further.

As functional decline progresses with AD severity, so may caregivers increase assistance with IADLS. Research has shown that caregivers are more likely to assist with IADL’s for loved ones with AD compared to other diseases (National Alliance For Caregiving, 2009), and this may correlate with increases in caregiver burden as well as increased care recipient medical care (Zhu et al., 2006).

In terms of exploratory analyses, Escape-Avoidance coping strategies may be related to a number of different aspects of caregiver QOL. Specifically, a trend indicated that caregivers who endorsed more Escape-Avoidance coping strategies were likely to have more problems engaging in their own personal daily activities as a result of being caregiver (i.e., Role Limitations Due to Caregiving) and had less caregiver Personal Time. Effect sizes indicated that variance in the use of Escape-Avoidant coping strategies accounted for approximately 27% of the variance in Role Limitations Due to Caregiving and 25% of the variance in caregiver Personal Time. Caregivers who used more Escape-Avoidance coping strategies endorsed using coping strategies such as wishful thinking, denial, and sleeping or eating more than usual. Such strategies may limit the
amount of engagement in caregiver activities as well as personal time. Of note, negative trends were found between Escape-Avoidance coping strategies and Assistance with IADLS and ADLS. However, Planful Problem Solving coping strategies suggested a positive trend between these CGQOL scales. Thus, use of more PF coping strategies may be related to assisting with IADLS and ADLS and use of EF strategies may be related to less assistance with these activities. These correlations suggest that caregivers who use more PF coping strategies may be assisting with more activities of daily living for their loved ones.

Interestingly, examination of Pearson product moment correlations between CGQOL subscales indicated that Personal Time was correlated with Role Limitations, Demands of Caregiving, and Family Interaction. This suggests that caregiver personal time may overlap with other QOL areas. This finding is consistent with Vickrey et al. (2009) factor analysis of the CGQOL scale in which caregiver Personal Time was related to Assistance in IADLS, Assistance in ADLS, and Role Limitations, as part of a 3 factor solution entitled Tangible Assistance. Thus, a caregiver’s personal time may be a key variable that is highly correlated with other areas of QOL. This finding is not surprising given that respite care tends to increase caregivers’ personal time and positively affect QOL as well (Conlin, Caranasos, & Davidson, 1992; Strang & Haughey, 1999).

Taken together, these results suggest that different types of coping strategies may differentially affect specific areas of a caregiver’s QOL. The current study suggests that Assistance with IADLS, ADLS, and Role Limitations Due to Caregiving as well as caregiver Personal Time may be the most affected areas in caregiver QOL for those caring for loved ones with AD. Furthermore, different caregiver coping strategies may be negatively or positively related to specific areas of caregiver QOL. These results are not surprising given that past
research (e.g., Folkman et al., 1980; Folkman et al., 1985) has shown that both EF and PF coping strategies are utilized across various stressful situations and that use of these coping strategies tends to be variable depending on circumstances. It may be that caregivers appraise assistance with care recipient IADLS as changeable, and utilization of Planful Problem Solving strategies is elected due to being most adaptable to this specific stressful situation. On the other hand, caregivers may feel that the caregiver role in the present situation is uncontrollable. Therefore, caregivers may use Escape-Avoidance coping strategies to adapt. Although the CGQOL does not yield a total score that provides a general index of caregiver QOL, the current study highlights how certain coping strategies (i.e., EF and PF) may be used more often by AD caregivers and differentially impact quality of life domains. The trend for Planful Problem Solving coping scores to be negatively correlated with Assistance in IADLS was strengthened for caregivers 51 to 70 years of age who identified as Caucasian and had a spousal relationship with the individual with AD. These results indicate that relatively younger individuals with a spousal relationship to the care recipient may utilize more Plan Problem Solving coping strategies and also spend decreased amounts of time assisting with IADLs. In terms of ethnicity endorsement, three individuals identified as African American and 17 identified as Caucasian. Therefore, results should be interpreted with caution, given the restricted range in caregivers from diverse backgrounds. This is especially of interest because qualitatively, African American women who were caring for their spouses seemed to rely more on spirituality or faith as a primary coping strategy. Therefore, future research should investigate the influence of religion or spirituality for caregivers from diverse backgrounds. Lastly, the relationship between Plan Problem Solving coping strategies and Assistance in IADLS was not significant for individuals who endorsed attending a support group. This non-significant correlation may reflect that caregivers who attend
support groups also experience or report greater difficulties with caregiving. Alternately, some caregivers may use other problem solving strategies that do not include support group attendance as a means of support in caring for a loved one with AD. Another possible interpretation is that attendance at support groups may not provide specific caregiver education regarding strategies to help with care recipient assistance with IADLs.

**Limitations**

Several limitations are evident in this study. First, AD status was assessed by caregiver report and not validated with clinical information that would more reliably separate Alzheimer-type dementia from other dementias in which NPS may not be as prominent. In addition, administration of a dementia rating scale, such as the Mattis Dementia Rating Scale—2nd Edition (DRS-2), would have provided an objective diagnosis of severity of AD in the care recipient. Also, recruitment was primarily conducted at support groups. In some cases, support groups may educate caregivers about strategies that serve to increase satisfaction with life and QOL. Therefore, recruitment of individuals primarily from support groups may lead to range restriction, since individuals attending support groups may have a better understanding of the demands of caregiving, caregiver feelings, and family interaction difficulties than those who do not attend support groups. In addition, the small sample size limits the generalizability of these results. Also, the sample was primarily comprised of caregivers who identified as Caucasian. As a result, racial or cultural differences in coping strategies and variables associated with caregiver QOL may not have been detected in the present study. With respect to the CQGOL, although this questionnaire has been found to have adequate psychometric properties when used with the normative sample with which it was developed, it is a new measure that was used for the first time in the community and further investigations in other studies are needed. Finally, it should
be noted that some studies have shown differences in the level of caregiving provided by primary and secondary caregivers (Gaugler, Mendiondo, Smith, & Schmitt, 2003). In the current study, caregivers reported varying degrees of support in the form of paid caregiving help, respite care, and amount of hours spent caregiving, which were not analyzed in this study. For example, caregivers had a range of respite care for the care recipient, including paid caregivers residing in their home. These variables may affect accurate reporting of the care recipient’s NPS and also reflect the result of increased help with respect to caregiver QOL and coping strategies. Although most care recipients resided in the caregiver’s home, two individuals with AD were living in an adult foster home, with significant caregiving also provided by the family member. Specifically, these caregivers were included in the study because they engaged in caregiver activities and behaviors similar to caregivers of care recipients who were currently residing in their home. Such similarities included visiting their care recipients on a daily basis and assisting with IADL’s and ADL’s. In addition, they reported similar levels of role limitations, family interactions, and feelings regarding caregiving. Therefore, this study highlights the need for a clear definition of community dwelling adults and how to best measure a caregiver’s level of involvement for an individual with AD.

**Future Directions**

The results of the current study indicate a number of future directions to better understand the interaction between patient NPS, caregiver coping strategies, and caregiver QOL. First, a larger sample size is required to adequately measure the effects of these variables and confidently generalize results to AD caregivers. Secondly, the current study lacked representative racial diversity in its sample. Future studies should recruit racially diverse caregivers to examine potential cultural or racial differences across caregivers from diverse
backgrounds. It also is suggested that future studies examine how specific NPS and caregiver QOL may be mediated by different coping strategies using more sophisticated statistical analyses with respect to the relationship between variables, such as structural equation modeling. In addition, recent research on AD caregivers’ coping strategies has indicated that use of PF coping is related to slower cognitive decline in the caregiver (Tschantz et al., 2010). Therefore, future research might investigate the relationship between caregiver coping strategies, cognitive abilities, and QOL.
References


