Survival of Persons With Alzheimer’s Disease: Caregiver Coping Matters

McKee J. McClendon, PhD,1 Kathleen A. Smyth, PhD,1 and Marcia M. Neundorfer, PhD2

Purpose: Although persons with Alzheimer’s disease (AD) require increasingly more assistance with activities of daily living as their disease progresses, the caregiving environment has received little attention as a source of predictors of their survival time. We report here on a study to determine whether variation in survival time of persons with AD can be better explained by including caregiver variables such as coping style and depressive symptoms as predictors.

Design and Methods: A sample of 193 persons with AD residing in the community and their family caregivers was used to estimate the parameters of a Cox regression model of survival time that included both caregiver characteristics and care-recipient impairments as covariates.

Results: Caregiver wishfulness–intrapsychic coping was related to shorter care-recipient survival time, but instrumental and acceptance coping and caregiver depressive symptoms were not associated with survival time. Care-recipient impairments (dependency in activities of daily living, low score on the Mini-Mental State Examination, and problematic behaviors) were associated with shorter survival time. Implications: Because this study is the first to report the link between caregiver coping and care-recipient survival, further study to understand the dynamics is required. We discuss several possible mechanisms, including the possibility that caregivers engaging in wishfulness–intrapsychic coping are less psychologically available to the person with dementia. These caregivers may therefore provide less person-centered care that is responsive to the true capacities of the person with dementia, and thus they may inadvertently contribute to excess disability and consequent accelerated decline. Because wishfulness–intrapsychic coping was uncorrelated with instrumental or acceptance coping, our findings suggest that interventions to enhance coping skills among caregivers, which have focused primarily on increasing problem solving and acceptance coping, also may have to include specific attempts to reduce wishfulness–intrapsychic approaches to benefit not only the caregiver but the care recipient as well.

Key Words: Dementia, Depression, Cox regression, Coping, Family caregiving

Despite significant advances over the past decade in understanding the etiology of Alzheimer’s disease (AD), a cure remains elusive (National Institute on Aging, 2000). Currently available treatments provide symptomatic relief to some, but they have no direct impact on the progression of the disease. Furthermore, the length of time from onset of AD until death varies greatly from person to person, with a reported range from 2 to 18 years and a mean length of 7 years (Clark, 2000). The variation may be even greater than studies have reported because many persons with a rapidly progressing illness die before they can be included in studies (Wolfson et al., 2001).

Efforts to understand variation in survival among persons with AD have focused on the characteristics of the diagnosed person. Attributes that have been found to predict earlier mortality for persons with AD include age, male gender, early age of onset, greater cognitive impairment, longer duration of illness, more severe behavioral problems, and greater dependency in activities of daily living (ADLs; Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Brodaty, McGilchrist, Harris, & Peters, 1993; Newcomer, Covinsky, Clay, & Yaffe, 2003; Stern et al., 1997; van Dijk, Dippel, & Habbema, 1991). Because it is widely recognized that persons with AD...
require increasingly more assistance with daily living from others as their disease progresses, it is surprising that few attempts have been made to expand the search for predictors of survival in AD to the caregiving environment. Results from several studies suggest, however, that this may be a fruitful area of research.

Brodaty and colleagues (1993) found that having low caregiver psychological distress and participating in a caregiver training program designed to alleviate caregiver distress and improve caregiver coping skills lead to longer survival time of the care recipient when he or she is assessed 5 years later. An 8-year follow-up of the same participants (Brodaty, Gresham, & Luscombe, 1997) confirmed that care recipients whose caregivers received training tended to live longer than other care recipients in the study. Aneshensel, Pearlman, and Schuler (1993) found an inverse bivariate relationship between caregiver reports of relational deprivation and care-recipient survival. However, when they controlled for care-recipient impairments, the relationship was no longer significant. In a recent study of 12-month mortality for persons with dementia (Newcomer et al., 2003), investigators found that, after they controlled for care-recipient characteristics (age, gender, needing ADL help, prior-year hospitalization, and chronic conditions), one caregiver characteristic (being cared for by a daughter) predicted greater survival. Although the specific characteristics vary (caregiver distress, coping-skills training, relational deprivation, and caregiver relationship to the care recipient), these studies support the link between caregiver characteristics and survival of the care recipient.

Several additional recent studies indirectly support the potential importance of caregiver characteristics for the survival of persons with AD, because they link caregiver characteristics with such outcomes as potential harm to the care recipient, care-recipient function, and behavioral problems, all of which may affect survival. Williamson, Shaffer, and the Family Relationships in Late Life Project (2001) found that caregivers with higher levels of depression were more likely to engage in behaviors that were potentially harmful to care recipients, such as screaming, threatening, withholding food, and handling the person roughly. Gitlin, Corcoran, Winter, Boyce, and Hauck (2001) showed that, compared with controls, caregivers receiving an in-home intervention focused on enhancing caregiver competence and sense of personal control reported fewer behavior problems in care recipients and fewer declines in care recipients’ instrumental activities of daily living (IADLs). Hébert and colleagues (2003) demonstrated the effectiveness of a caregiver intervention focused on improving multiple coping strategies, including problem solving, reframing, and seeking social support. Caregivers receiving the intervention, compared with the control group, exhibited a significantly greater decrease in their negative reactions to behavioral problems, and the frequency of behavioral problems in the care recipient also decreased.

Taken together, these studies highlight the potential importance of caregiver characteristics, particularly coping and depressive symptoms, to survival of the person with AD. They also suggest that an extension of the stress-process model (Aneshensel et al., 1995; Pearlin, Mullan, Semple, & Skaff, 1990) might provide a useful theoretical context in which to examine the relationship between caregiver characteristics and care-recipient survival. The model proposes specific relationships among variables that have the potential to affect care-recipient survival, such as care-recipient cognitive, behavioral, and functional status; caregiver well-being; caregiver coping; and demographic and situational characteristics of the caregiver–care recipient dyad.

In its current form, the stress-process model treats caregiver well-being as a key outcome variable, influenced by the conditions and experiences of caregiving (Aneshensel et al., 1995). A large literature documents the negative impact of caregiving on caregiver well-being, particularly on mental health. From their review, Schulz, O’Brien, Bookwala, and Fleissner (1995) concluded that nearly all studies report increased levels of depressive symptoms among caregivers. We propose extending the stress-process model by considering survival of the care recipient as an outcome, and caregiver depressive symptoms as an explanatory variable.

The mediating role of effective coping strategies in reducing the negative impact of caregiving on caregiver well-being plays a central role in the stress-process model (Aneshensel et al., 1995; Pearlin et al., 1990). Although Gottlieb and Wolfe (2002) noted that there is no universally accepted typology of coping strategies, and the coping model of Folkman and Lazarus (1991) that differentiates between problem-focused and emotion-focused strategies only loosely guides most coping research, they critically reviewed 17 empirical studies that related the ways of coping used by family caregivers of persons affected by dementia to caregivers’ health and morale. They cited seven studies in which coping characterized by wishfulness and fantasy (emotion-focused strategies) was related to one or more indicators of poor mental health in caregivers (Borden & Berlin, 1990; Lutzky & Knight, 1994; Parks & Pelisuk, 1991; Pruchno & Resch, 1989; Quayhagen & Quayhagen, 1988; Rose, Strauss, Neundorfer, Smyth, & Stuckey, 1997; Williamson & Schulz, 1993). Acceptance coping (a positive emotion-focused strategy) was related to better mental health in three studies (Pruchno & Resch; Rose et al.; Williamson & Schulz) and practical problem-solving or instrumental coping responses were associated with better mental health in four studies (Gottlieb & Gignac, 1996; Haley, Levine, Brown, & Bartolucci, 1987; Pruchno & Resch; Rose...
et al.). For example, Pruchno and Resch found that two emotion-focused coping strategies, intrapsychic (fantasizing) and wishfulness, were associated with greater depression and anxiety among caregivers, whereas a third (acceptance coping) was related to lower depression, higher positive affect, and less negative symptomatology. Problem-focused (instrumental) coping was related to positive affect. In an extended stress-process model, the potential effects of coping on care-recipient survival, both directly (unmediated) and indirectly as mediated by caregiver mental health, can be examined.

The stress-process model (Pearlin et al., 1990) also includes characteristics of the care recipient, called primary stressors, that place demands on the caregiver and predict caregiver well-being. These include care-recipient cognitive status, problemmatic behaviors, and ADL dependencies. These variables also predict care-recipient survival as discussed herein. Care-recipient cognitive status and ADL dependency have, in most studies, been found to be surprisingly weak predictors of caregiver outcomes, including depression (Schulz et al., 1995). Longitudinal studies, however, have shown that high care-recipient ADL dependency increases caregiver depression, particularly if ADL dependency is increasing at a rapid rate (Aneshensel et al., 1995; Neundorfer et al., 2001). Care-recipient problematic behaviors have consistently predicted caregiver depression.

Although the stress-process model focuses on the stressors–outcome relationship and the moderating effects of caregiver resources (Pearlin et al., 1990), the model also recognizes the potential impact of contextual factors on caregiver well-being. Schulz and colleagues (1995) reported that caregivers with poor self-rated health generally have been found to be more depressed than those in better health and that spouses generally were found to be more depressed than other caregivers. Relationship to care recipient may also have important implications for caregiver well-being, as suggested by Montgomery and Kosloski (1994), who found that spouses, as compared with adult children, gave the care recipient more assistance with personal care tasks, spent more hours in caregiving, and had been providing assistance for a longer period of time, all of which might suggest that those cared for by spouses might survive longer than those cared for by adult children. However, as mentioned earlier, Newcomer and colleagues (2003) found that being cared for by a daughter, rather than other kin, predicted longer survival. Finally, race has received increasing attention as potentially affecting multiple aspects of the stress process. For example, Haley and colleagues (1995), in comparing African American and White family caregivers of persons with dementia, found that caregiving was associated with increased depression in White families but not in African American families. Knight, Silverstein, McCallum, and Fox (2000) showed that African Americans' lower appraisal of burden resulted in lower levels of emotional distress, including depression. The effect was counterbalanced by the fact that African American caregivers' greater use of emotion-focused coping (including distancing and escape-avoidance) increased their emotional distress.

Here we report the results of a study that examines whether understanding of variation in the survival of persons with AD can be enhanced by explicitly extending the stress-process model to include care-recipient survival as an outcome and caregiver depressive symptoms and coping as explanatory variables. Our choice of variables and analysis approach draws on the theoretical and empirical literature summarized herein. Using data from a research registry for persons with AD and their family caregivers, we conducted a series of survival analyses examining the relationship of caregiver depressive symptoms and coping to the survival of persons with AD. We controlled for care-recipient characteristics previously found to affect survival (care-recipient age, gender, duration of illness, ADL dependency, cognitive status, and behavioral problems) as well as caregiver self-reported health, race, and relationship to the care recipient, which have been found to affect caregiver depression. We hypothesized that caregiver coping strategies shown to be related to fewer caregiver depressive symptoms, such as problem solving and acceptance coping, would be associated with longer survival time of care recipients, whereas caregiver wishfulness–intrapsychic coping, previously found to be associated with more depressive symptoms, would predict shorter care-recipient survival time. In addition, we expected that fewer caregiver depressive symptoms would be independently related to longer care-recipient survival.

Although our study focuses on care-recipient survival, our interest is not in the extension of life of persons with dementia per se, separate from considerations of their quality of life. We expect that characteristics of the caregiver that increase care-recipient survival are likely to affect survival because caregivers with more effective coping strategies and less depression are able to provide better care.

**Methods**

**Sample**

The sample consisted of 193 persons with probable or possible AD and their primary family caregivers who entered an Alzheimer’s disease research center (ADRC) from 1993 through 1997. With the use of the National Institute of Neurological and Communicative Diseases and Stroke/Alzheimer’s Disease and Related Disorders Association (NINCDS/ADRDA) criteria (McKhan et al., 1984), 71.5% of the persons with dementia included in the sample were diagnosed as probable AD and 28.5%
were diagnosed as possible AD. All persons with AD were living in the community at the time they entered the study.

A recommended criterion for survival analysis is that at least 50% of the cases exhibit the endpoint of interest (in this case, death; Singer & Willet, 1991). By restricting cases to those that entered the research registry prior to 1998, we determined that 53.4% were deceased by January 31, 2002, the cutoff date for collecting data on deaths. We used a variety of methods to determine whether or not care recipients had died by the study cutoff date. For approximately 60% of the deaths, the date of death was determined during the ADRC’s standardized procedures for arranging an autopsy following death. For those families that had not agreed to autopsy, family members typically contacted the ADRC Registry Coordinator when their relative died. Otherwise, when the caregiver was contacted for his or her relative’s yearly evaluation, the caregiver informed the caller of the date of death. If we were unable to locate the care recipient or any family member, we searched the online obituaries of the local daily newspaper and the web-based Social Security Death Index to determine if the person had died and to obtain the date of death. A telephone survey of persons previously lost to contact confirmed one additional death. After using all of these sources, we classified persons not known to be deceased as alive at the date of last contact with them. Of the 103 persons with AD who were deceased at the study cutoff date, the mean survival time from date of onset of AD was 8.6 years, with a range from 2 to 28 years.

We included only those persons who had complete data on the independent variables used in the analysis. Fifty-two persons were excluded because they were missing data on at least one variable. Twelve of these were missing a mental status evaluation because they were unable to complete the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). The remaining 40 cases were missing data on one or more of six scales measuring caregiver depressive symptoms, caregiver coping, and care-recipient impairment. In comparison with the 193 cases with no missing data, the 52 care recipients with missing data were not significantly different in age, duration of illness, gender, race, relationship to caregiver, or caregiver health. Furthermore, in comparison with the cases with no missing data, persons among those 52 omitted cases that had valid values on some of these variables were not significantly different in coping strategies, caregiver depressive symptoms, or care-recipient behavioral problems. Only for dependencies in ADLs was there a significant difference: Dependency was greater among the excluded care recipients with valid ADL scores (31 cases) than among those who were included in our analysis. The excluded persons, however, were not significantly different in survival time from those included.

Measures

The measures of the covariates or predictor variables included in the survival analysis are described in the paragraphs that follow, and their means and standard deviations are given in Table 1.

Caregiver Depressive Symptoms.—We assessed these with the Center for Epidemiological Studies—Depression (CES-D) 20-item scale of depressive symptoms (Radloff, 1977). Respondents were asked how often in the past week (less than 1 day, 1–2 days, 3–4 days, and 5–7 days) they had felt the way described in each item (e.g., I felt sad; I could not get going). The possible range is 0 to 60, with a score of 16 or higher indicating risk for clinical depression. Cronbach’s alpha was .90.

Caregiver Coping.—We assessed this with a scale adapted from Kiyak, Montgomery, Borson, and Teri (1985) by Pruchno and Resch (1989). This 16-item measure ask respondents to indicate on a 5-point scale (1 = never to 5 = most of the time) how often they used each approach in the context of caring for their relative. Pruchno and Resch reported that four subscale scores can be derived from this measure: instrumental (5 items, e.g., “Made a plan of action and followed it”); acceptance (4 items, e.g., “Made the best of it”); wishfulness (3 items, e.g., “Wished you could change the way you felt”); and intrapsychic (4 items, e.g., “Had fantasies about how things might turn out”). Factor analysis of our data, however, showed that the wishfulness and intrapsychic items

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>M</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of illness (years)</td>
<td>4.14</td>
<td>2.47</td>
</tr>
<tr>
<td>CR age</td>
<td>72.46</td>
<td>7.91</td>
</tr>
<tr>
<td>CR gender (1 = male, 0 = female)</td>
<td>0.45</td>
<td>0.50</td>
</tr>
<tr>
<td>Race (1 = White, 0 = African American)</td>
<td>0.91</td>
<td>0.29</td>
</tr>
<tr>
<td>ADL</td>
<td>21.06</td>
<td>17.79</td>
</tr>
<tr>
<td>MMSE</td>
<td>17.28</td>
<td>6.50</td>
</tr>
<tr>
<td>BRSD</td>
<td>0.57</td>
<td>0.36</td>
</tr>
<tr>
<td>Spouse caregiver (1 = spouse, 0 = other)</td>
<td>0.75</td>
<td>0.44</td>
</tr>
<tr>
<td>CG self-reported health</td>
<td>3.45</td>
<td>1.06</td>
</tr>
<tr>
<td>Coping</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Instrumental</td>
<td>3.00</td>
<td>0.81</td>
</tr>
<tr>
<td>Acceptance</td>
<td>4.09</td>
<td>0.76</td>
</tr>
<tr>
<td>Wishfulness</td>
<td>2.81</td>
<td>0.82</td>
</tr>
<tr>
<td>CG depression (CES-D)</td>
<td>11.35</td>
<td>9.24</td>
</tr>
</tbody>
</table>

Note: CR = care recipient; CG = caregiver; ADL = activity of daily living; MMSE = Mini-Mental State Examination; BRSD = Behavior Rating Scale for Dementia; CES-D = Center for Epidemiological Studies–Depression Scale.
loaded on a single factor, which led us to create the following three subscales, which are similar to those used by Pruchno, Burant, and Peters (1997): instrumental (5 items, $\alpha = .83$), acceptance (4 items, $\alpha = .79$), and wishfulness–intrapsychic (7 items, $\alpha = .79$).

We computed scale scores as the mean of the items and thus each scale had a possible range of 1 to 5. Acceptance coping was used more frequently ($M = 4.1$) than instrumental and wishfulness–intrapsychic coping, the means of which were about equal ($M = 3.0$ and $M = 2.8$, respectively).

**Cognitive Status.**—We used the MMSE (Folstein et al., 1975) to measure care-recipient cognitive status. This widely used examination was administered directly to the care recipient by ADRC neuropsychology technicians. Scores range from 0 to 30, with lower scores reflecting greater cognitive impairment.

**Activities of Daily Living.**—We measured these with the Cleveland Scale for Activities of Daily Living (CSADL; Patterson et al., 1992), which is administered to the caregiver by a trained examiner. This scale is designed to measure both basic ADLs and IADLs in persons with dementia, across the range of dementia severity. The particular strength of this scale is that it includes higher level tasks, such as initiating, planning, and organizing (e.g., “initiates dressing at appropriate times,” “selects clothing,” “and “prepares bath”), on which persons with early dementia may have deficits. It also includes lower level tasks that are more automatic (e.g., “cleans self” and “feeds self”), on which persons with more severe dementia have deficits. Items are rated 0 (completely independent) to 3 (completely dependent). The possible range for the 35-item scale is 0 to 105. For the scale, $\alpha = .93$.

**Care-Recipient Behavioral Problems.**—We measured these with the Behavior Rating Scale for Dementia (BRSD; Tariot et al., 1995). The BRSD is an informant-based, 45-item structured interview administered to the caregiver by a trained interviewer. The BRSD consists of items tapping a broad range of disturbances such as depressive symptoms, inertia, vegetative symptoms, behavioral dysfunction, irritability, and psychotic symptoms. Behaviors are rated on the frequency of occurrence in the month prior to the interview as measured by a 5-point scale ($0 = never to 4 = 16$ or more days). We calculated a composite score by taking the mean of the items with valid values if there were 6 or fewer items with missing values. Thus, the possible range for the scale is 0 to 4. For the cases with valid data on all 45 items ($n = 58$), $\alpha = .87$.

**Demographic and Contextual Background Characteristics.**—As shown in Table 1, these included three characteristics of the care recipient: gender (45% male), age at baseline ($M = 72.5$ years), and duration of illness at baseline ($M = 4.1$ years). Age at onset of dementia could not be included in the statistical model because that variable equals care-recipient age at baseline minus duration of dementia, and both of these variables were included in the survival equation. Three caregiver characteristics also were included: race (91% White and 9% African American), relationship of caregiver to care recipient (75% spouse), and self-reported health ($M = 3.5$, with $1 = excellent$ to $5 = poor$).

**Statistical Methods**

We conducted survival analyses for time to death of the care recipient by using Cox proportional-hazards regression. We measured time to death from the date of onset of dementia as estimated by the caregiver in the entry interview conducted by an ADRC neurologist. We considered persons who were not known to be deceased at the end date of the survival analysis (January 31, 2002) as censored cases; that is, the length of time to death of these persons was not known. We included censored cases in the survival analysis; we coded them as alive and we calculated their survival time as the time from date of onset until the date of last contact with them.

Under the proportional-hazards assumption of Cox regression, a positive coefficient for a covariate indicates that a unit increase in covariate $X$ causes an increase in the rate of death; this increase is assumed to be the same across all time points in the study period. We tested this proportional-hazards assumption by computing the correlation between the natural log of time and the Schoenfeld residuals of each covariate for those persons who did not survive. A statistically significant correlation between the natural log of time and a Schoenfeld residual indicates a nonproportional hazard for a given covariate. When the correlation is positive, the effect of the covariate increases with time. When the correlation is negative, the effect of the covariate decreases with time. If we find nonproportional effects of covariates, we model them by including an interaction term for each such covariate and time in the Cox regression equation.

**Results**

The Kaplan–Meier survival function (Figure 1) indicates the proportion of persons who were still alive at each point in time. This typical S-shaped curve shows that the proportion of persons who are living decreases at an increasing rate throughout the first 10 or so years. The rate of decrease then slows throughout the remaining time frame. The time at which half the persons had died (the median) is 8.2 years. We carried out proportional-hazards regression by using the following 11 covariates, or...
predictors, of care-recipient survival, all measured at entry into the study: duration of illness, age and gender of the care recipient, extent of dependency in ADLs, cognitive status (MMSE), frequency of behavioral problems (BRSD), spouse or nonspouse caregiver, caregiver race, caregiver self-reported health, three types of caregiver coping, and caregiver depression. The correlations among these variables are given in Table 2. Because the coefficients for ADL and BRSD were not significant in the initial Cox regression, we added squared terms for these variables to the model to check for nonlinear relationships. The results of this regression are shown in Table 3.

**Care-Recipient Characteristics**

The slope for duration of illness at entry into the study was negative and significant. The negative slope indicated that the greater the illness duration prior to baseline, the lower was the hazard of death.

![Figure 1. Kaplan–Meier survival function.](https://academic.oup.com/gerontologist/article-abstract/44/4/508/564813)

**Table 2. Zero-Order Correlations Among CR and CG Characteristics**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>1</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>
<th>13</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Duration</td>
<td></td>
<td>.07</td>
<td>.04</td>
<td>-.05</td>
<td>.39*</td>
<td>-.33*</td>
<td>.21*</td>
<td>.03</td>
<td>.11</td>
<td>.14</td>
<td>.05</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td>2. CR age</td>
<td>.07</td>
<td>-.04</td>
<td>-.20*</td>
<td>.22*</td>
<td>-.03</td>
<td>.09</td>
<td>-.37*</td>
<td>-.06</td>
<td>.00</td>
<td>.17*</td>
<td>-.09</td>
<td>-.10</td>
<td></td>
</tr>
<tr>
<td>3. CR gender</td>
<td>.04</td>
<td>-.04</td>
<td>.04</td>
<td>.09</td>
<td>.01</td>
<td>.01</td>
<td>.33*</td>
<td>-.16*</td>
<td>-.02</td>
<td>-.01</td>
<td>.18*</td>
<td>.28*</td>
<td></td>
</tr>
<tr>
<td>4. Race</td>
<td>-.05</td>
<td>-.20*</td>
<td>.04</td>
<td>-.07</td>
<td>.02</td>
<td>.04</td>
<td>.30*</td>
<td>.15*</td>
<td>-.04</td>
<td>-.06</td>
<td>.11</td>
<td>.15*</td>
<td></td>
</tr>
<tr>
<td>5. ADL</td>
<td>.39*</td>
<td>.22*</td>
<td>.09</td>
<td>-.07</td>
<td>-.61*</td>
<td>-.22*</td>
<td>-.04</td>
<td>-.13</td>
<td>.10</td>
<td>-.04</td>
<td>.16*</td>
<td>.18*</td>
<td></td>
</tr>
<tr>
<td>6. MMSE</td>
<td>-.33*</td>
<td>-.03</td>
<td>.01</td>
<td>.02</td>
<td>-.61*</td>
<td>-.14</td>
<td>-.02</td>
<td>.12</td>
<td>-.03</td>
<td>.00</td>
<td>-.13</td>
<td>.05</td>
<td></td>
</tr>
<tr>
<td>7. BRSD</td>
<td>.21*</td>
<td>.09</td>
<td>.01</td>
<td>.04</td>
<td>.22*</td>
<td>-.14</td>
<td>.02</td>
<td>-.16*</td>
<td>.03</td>
<td>-.01</td>
<td>.22*</td>
<td>.09</td>
<td></td>
</tr>
<tr>
<td>8. Spouse CG</td>
<td>.01</td>
<td>-.37*</td>
<td>.33*</td>
<td>.30*</td>
<td>-.04</td>
<td>-.02</td>
<td>.02</td>
<td>-.02</td>
<td>.00</td>
<td>.05</td>
<td>.14</td>
<td>.14</td>
<td></td>
</tr>
<tr>
<td>9. CG health</td>
<td>.03</td>
<td>-.06</td>
<td>-.16*</td>
<td>.15*</td>
<td>-.13</td>
<td>.12</td>
<td>-.16*</td>
<td>-.02</td>
<td>.16*</td>
<td>.15*</td>
<td>-.09</td>
<td>-.24*</td>
<td></td>
</tr>
<tr>
<td>10. Instrumental</td>
<td>.11</td>
<td>.00</td>
<td>-.02</td>
<td>-.04</td>
<td>.10</td>
<td>-.03</td>
<td>.03</td>
<td>.00</td>
<td>.16*</td>
<td>.41*</td>
<td>.08</td>
<td>-.20*</td>
<td></td>
</tr>
<tr>
<td>11. Acceptance</td>
<td>.14</td>
<td>.17*</td>
<td>-.01</td>
<td>-.06</td>
<td>-.04</td>
<td>.00</td>
<td>-.01</td>
<td>.05</td>
<td>.15*</td>
<td>.41*</td>
<td>-.09</td>
<td>-.36*</td>
<td></td>
</tr>
<tr>
<td>12. Wishfulness</td>
<td>.05</td>
<td>-.09</td>
<td>.18*</td>
<td>.11</td>
<td>.16*</td>
<td>-.13</td>
<td>.22*</td>
<td>.14</td>
<td>-.09</td>
<td>.08</td>
<td>-.09</td>
<td>.43*</td>
<td></td>
</tr>
<tr>
<td>13. CG (CES-D)</td>
<td>.00</td>
<td>-.10</td>
<td>.28*</td>
<td>.15*</td>
<td>.18*</td>
<td>-.05</td>
<td>.09</td>
<td>.14</td>
<td>-.24*</td>
<td>-.20*</td>
<td>-.36*</td>
<td>.45*</td>
<td></td>
</tr>
</tbody>
</table>

*Note: CR = care recipient; CG = caregiver; ADL = activity of daily living; MMSE = Mini-Mental State Examination; BRSD = Behavior Rating Scale for Dementia; CES-D = Center for Epidemiological Studies–Depression Scale.

*p ≤ .05 (two-tailed test).

**Table 3. Cox Regression of Hazard Rate on Characteristics of CRs and CGs**

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>B</th>
<th>SE</th>
<th>Wald</th>
<th>Sig</th>
<th>Exp(B)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration of illness</td>
<td>-.079</td>
<td>.086</td>
<td>67.854</td>
<td>.000</td>
<td>0.492</td>
</tr>
<tr>
<td>CR age</td>
<td>.018</td>
<td>.017</td>
<td>1.072</td>
<td>.301</td>
<td>1.018</td>
</tr>
<tr>
<td>CR gender</td>
<td>.994</td>
<td>.242</td>
<td>16.871</td>
<td>.000</td>
<td>2.701</td>
</tr>
<tr>
<td>Race</td>
<td>.071</td>
<td>.404</td>
<td>.031</td>
<td>.860</td>
<td>1.074</td>
</tr>
<tr>
<td>ADL</td>
<td>.084</td>
<td>.024</td>
<td>12.544</td>
<td>.000</td>
<td>1.088</td>
</tr>
<tr>
<td>BRSD</td>
<td>-.001</td>
<td>.000</td>
<td>12.512</td>
<td>.000</td>
<td>0.999</td>
</tr>
<tr>
<td>MMSE</td>
<td>-.048</td>
<td>.023</td>
<td>4.363</td>
<td>.037</td>
<td>0.953</td>
</tr>
<tr>
<td>BRSD</td>
<td>2.021</td>
<td>1.060</td>
<td>3.640</td>
<td>.056</td>
<td>7.549</td>
</tr>
<tr>
<td>Spouse caregiver</td>
<td>-.101</td>
<td>.583</td>
<td>3.568</td>
<td>.059</td>
<td>0.333</td>
</tr>
<tr>
<td>CG health</td>
<td>.040</td>
<td>.110</td>
<td>0.135</td>
<td>.713</td>
<td>1.041</td>
</tr>
</tbody>
</table>

This relationship appears counterintuitive until one considers that key indicators of dementia severity (ADL, MMSE, and behavioral problems) were held constant in the model. In this context, the negative slope for duration of illness indicated that those who had AD longer, but had the same level of severity as those with a shorter duration, were declining at a slower rate. Thus, those with a slowly progressing illness were predicted to survive longer.

Age of care recipient at entry was not significantly related to survival. Although we might expect older persons to die sooner than younger persons on the basis of age alone, with duration of AD and levels of impairment taken into account, age neither amplified nor ameliorated the risk of death.
Gender was a highly significant predictor of death. The positive slope ($B$) meant that men, coded 1, were more likely to die at any point in time than women, as expected. The exponentiated slope ($e^B$), which indicates the magnitude of that risk, showed that men were 2.7 times more likely to die at any given time point than women.

The regression coefficients for both ADL and ADL$^2$ were significant, indicating a nonlinear relationship between ADL and survival. The positive slope for ADL coupled with the negative slope for ADL$^2$ indicated that, as impairment increased above 0 on the ADL scale, there was an increase in the rate of death. This increase slowed, however, and eventually the rate of death began to decrease at higher values of ADL. Using differential calculus, we determined that above an ADL score of 44.8, there was a decrease in the hazard of death associated with further increases in ADL impairment. In our sample, only 12.4% of care recipients had ADL impairment scores greater than 44.8, and thus the regression equation predicted a negative effect of impairment on death for only a small minority of cases. The relative risk of death indicated by $e^B$ was close to 1 for both ADL and ADL$^2$ (1.088 and 0.999, respectively). Although these odds ratios indicated that the relative risk of death associated with a one-unit increase in ADL was small, this was not surprising because a unit difference on a scale with an observed range of 0 to 101 is a very small difference.

Cognitive status (MMSE) had a significant negative relationship to death. The higher the cognitive status at baseline, the less likely the care recipient was to die at any point in time during the course of the study.

We found no significant linear relationship between behavioral problems (BRSD) and time to death (coefficient not shown). After adding a squared term to the equation, however, we found that BRSD and BRSD$^2$ were both nearly significant ($p = .057$ and $p = .059$, respectively; Table 3). The positive slope for BRSD combined with the negative slope for BRSD$^2$ indicated that as behavioral problems increased above zero, there was at first an increase in the risk of death. At a value of .9 (on a 4-point scale), which was above the mean of .57, the hazard of death began to decline, and it continued to decline throughout the remainder of the range of BRSD. The pattern of this nonlinear effect of behavioral problems was similar to that found for ADLs. The relative risks ($e^B$) associated with BRSD and BRSD$^2$ (7.5 and .33, respectively) were substantially different from 1, which was understandable given that the BRSD scores range from only 0 to 2.4.

**Caregiver Characteristics**

Being cared for by a spouse did not significantly affect survival. Although the sign of the coefficient was negative, suggesting that having a spouse caregiver reduces the risk of death, the coefficient was not even marginally significant. The positive sign of the coefficient for caregiver health suggested that poor caregiver health was associated with earlier death of the care recipient, but the slope was not significant.

Neither instrumental coping nor acceptance coping was significantly related to survival, indicating that these coping strategies neither lengthened nor shortened survival time. Correlations between caregiver depression and instrumental coping ($-0.20$) and acceptance coping ($-0.36$), however, indicated that these two coping strategies were associated with fewer caregiver depressive symptoms, and therefore might have been helpful to the caregiver. Nevertheless, they did not affect the survival time of the care recipient.

In contrast, wishfulness–intrapsychic coping was associated with survival of the person with AD. The significant positive coefficient for this coping strategy indicated that higher levels of wishfulness–intrapsychic coping on the part of caregivers were associated with decreased life expectancy of care recipients. In other words, caregivers who never or rarely engaged in intrapsychic–wishfulness coping at baseline apparently contributed to prolonging the life of the care recipient. This effect is illustrated in Figure 2, which contrasts the survival curves of persons with AD whose caregivers were above average and below average in wishfulness–intrapsychic coping.

The stress-process model suggests that caregiver coping may moderate the effects of stressors on caregiver depression and other outcomes. We tested whether caregiver coping strategies moderated the effects of ADL, behavioral problems, MMSE, and caregiver depression on care-recipient survival by including interaction terms for each of these variables with each of the coping styles, one interaction term at a time. None of the interaction terms were statistically significant.
Although the effect of race was nonsignificant, this might be because race indirectly affects survival through wishfulness–intrapsychic coping; African Americans have been shown to be more likely than Whites to use this style of coping (Knight et al., 2000). However, race was still nonsignificant when wishfulness–intrapsychic coping was removed from the regression equation, indicating that race did not affect survival indirectly through coping.

We also conducted interaction tests to see whether there were any positive or negative effects on survival of caregivers’ use of various coping strategies in combination. To test for these effects, we added three interaction terms to the equation, one for each of the three pairs of coping strategies. None were significant (not shown); nor was a three-way interaction term for the three coping strategies. Thus, we found no evidence of any impact of the caregivers’ use of various combinations of coping strategies on care-recipient survival.

Contrary to our expectations, caregiver depression was not significantly related to care-recipient survival time. We checked for a nonlinear effect by including a squared term for depression in the regression equation, but it was not significant. Because caregiver depression had a correlation of .45 with wishfulness–intrapsychic coping, we removed wishfulness–intrapsychic coping from the equation to see if depression would then be significant. The regression coefficient for depression, however, was still not significant. Thus, we found no evidence that caregiver depression affects care-recipient survival time.

To check the proportional-hazards assumption (i.e., that the effect is equal or proportional across time) for the covariate effects found, we examined the correlations between time to death (raw time and the natural log of time) and the Schoenfeld residuals for each significant covariate for the 103 deceased care recipients. The only significant correlation was between the residuals for duration and the natural log of time ($r = .22$). This correlation indicated that duration had a nonproportional effect on survival.

As shown in Table 3, longer duration of illness at baseline predicted longer survival when we controlled for indicators of illness progression. The positive correlation between the residual for duration and time suggests that, as time increased, the contribution of longer duration of illness to longer survival diminished. In other words, as time increased, even those with a slowly progressing illness died, as confirmed by the results shown in Table 4. To control for the nonproportional effect of duration, we added an interaction term for the natural log of time and duration to the Cox regression equation (see Table 4). The coefficient for the interaction term was significant and positive (.574). This result was consistent with that for the Schoenfeld residuals. Figure 3 shows a plot of the relationship between time and the effect of duration ($B$). It indicated that the duration coefficient was negative throughout the range of time, but it became less negative as time increased. A comparison of the Cox regression results with and without the interaction term for duration and time (compare Table 4 with Table 3) showed that the coefficients for the other variables in the model were similar.

### Discussion

On the basis of an extension of the stress-process model, we hypothesized that several caregiver
characteristics would contribute to care-recipient survival time independent of care-recipient characteristics known to be associated with survival time. We investigated both linear and nonlinear effects, and we tested whether effects varied in strength over time. Responding to findings from earlier studies, we also checked for the mediating and moderating effects of selected variables. Our results provided partial support for our hypotheses.

Caregiver Characteristics and Care-Recipient Survival

We found, as hypothesized, that care recipients whose caregivers exhibited higher levels of wishfulness–intrapsychic coping at study entry had shorter survival times, when we controlled for care-recipient and other caregiver characteristics. This impact did not vary over time. Contrary to our expectations, however, we did not find instrumental and acceptance coping to be positively related to survival time. Wishfulness–intrapsychic coping was not related to instrumental or acceptance coping (Table 2), which indicates that use of wishfulness did not preclude caregivers from using more effective coping strategies. Although we did not hypothesize specific relationships, we also tested whether various combinations of coping strategies had an impact on survival. None of the interaction terms was significant. It is impossible to say whether our failure to find significant effects for instrumental and acceptance coping are at odds with Brodaty and colleagues’ (1993) finding that an intensive caregiver training intervention increased the survival time of care recipients with dementia. Because their multifaceted program involved much more than training in coping skills—it also consisted of alleviating psychological distress, providing information, reducing isolation, and improving self-care—it is not possible to know which component(s) of the intervention was beneficial to the survival of the care recipients.

The question, then, is this: What are caregivers who engage in wishfulness–intrapsychic coping likely to be doing (or not doing) that makes this type of coping contribute to care-recipient mortality? The theory surrounding person-centered care (Kitwood, 1997) suggests one possible explanation. Person-centered care requires caregivers to be psychologically available to care receivers and accept the care receiver’s true state—both deficits and remaining capacities. It also requires an emphasis on being with the care receiver in his or her world, rather than doing things to or for the care receiver (Kitwood). By definition, wishfulness–intrapsychic coping strategies are aimed at removing caregivers psychologically from the actual caregiving situation by daydreaming, fantasy, hoping for miracles, and trying to alter their feelings about the situation. Hence, wishfulness–intrapsychic coping on the part of caregivers may reduce the amount of person-centered care that these care recipients receive. As Sabat (2002) explained, when a person-centered approach to care is lacking, persons with dementia can be inadvertently treated in a way that is not responsive to their capacity to maintain a personal identity, exhibit positive mental and physical attributes, or take on meaningful social roles. As a result, they may experience “excess disability” (Sabat, 1994) that will be reflected in accelerated decline.

Yet another explanation of the effect of wishfulness–intrapsychic coping may be that caregivers who are using this type of coping may be more likely to relinquish in-home care and place the care recipient in a nursing home. Forty-seven percent of our sample is known to have been placed in a nursing home, which has been found by some investigators to reduce the survival time of persons with AD, independent of the care-recipient’s health (e.g., Aneshensel et al., 1993). The estimation of the effect of nursing home placement on survival, however, is sufficiently methodologically complicated that we believe it is better suited for a separate article. Although the decision to not incorporate institutionalization into this study means that we cannot determine whether the effect of wishfulness–intrapsychic coping is a direct effect, an indirect effect through nursing home placement, or some combination of the two, this omission does not bias the estimated total effect (i.e., direct plus indirect effects) of this coping strategy on survival time because nursing home placement is an intervening variable and thus is not a source of spurious association between coping and survival (McClelland, 1994).

The hypothesis that caregiver depression would predict decreased care-recipient survival, either directly or through its effect on coping, was not
supported. This result appears inconsistent with that of Brodaty and colleagues (1993), who found that shorter survival of dementia patients was related to higher caregiver scores on the General Health Questionnaire, a screening instrument for psychiatric disorders. Perhaps the discrepancy is because the General Health Questionnaire is sensitive to a greater variety of disorders than our measure of depressive symptoms (CES-D). Our results may differ from Williamson and associates (2001), whose research controlled for dementia as a dichotomy (present–absent) and for amount of help provided, whereas we controlled for more powerful and specific predictors of survival (e.g., ADL and cognitive status). Alternatively, our findings may not be consistent with theirs because the potentially harmful behaviors identified as being related to caregiver depression by Williamson and colleagues were not actually harmful in terms of survival. Similar to our findings, Aneshensel and associates (1995) reported no relationship between caregiver psychological distress and care-recipient survival.

Contrary to our expectations, we did not find that being cared for by a spouse, as opposed to another relative, resulted in increased survival time. This finding suggests that the greater quantity of assistance provided by spouse caregivers in comparison with adult-child caregivers, reported by Montgomery and Kosloski (1994), is not sufficient in and of itself to increase the survival time of persons with AD.

If our findings are validated by additional research, they may suggest the need to reexamine the prevailing approach to caregiving interventions that focuses on improving caregiver coping. Interventions to strengthen caregiver coping skills have been widely recommended as a key element in enhancing caregiver well-being and enhancing capacity to maintain the caregiving role (Cotter, Stevens, Vance, & Burgio, 2000). To date, these interventions have focused primarily on increasing problem solving and acceptance coping among caregivers (e.g., Bourgeois, Schulz, Burgio, & Beach, 2002; Cummings, Long, Peterson-Hazen, & Harrison, 1998; Gallagher-Thompson et al., 2000; Ostwald, Hepburn, Caron, Burns, & Mantell, 1999; Roberts et al., 1999). Although these interventions may be helpful to caregivers (Cummings et al., 1998; Roberts et al., 1999), our findings suggest that interventions to enhance coping skills also may have to include specific attempts to reduce wishfulness–intrapsychic approaches. Wishfulness–intrapsychic coping was uncorrelated with instrumental or acceptance coping in our sample. This suggests that increasing caregivers’ use of instrumental or acceptance coping strategies will not in itself reduce the use of wishfulness–intrapsychic strategies. The recent work of Powers, Gallagher-Thompson, and Kraemer (2002) documenting the stability of caregiver coping strategies over time underscores the importance of addressing the potentially deleterious effects of wishfulness–intrapsychic coping on care recipients early in the course of the illness.

Care-Recipient Characteristics and Care-Recipient Survival

As expected, care-recipient characteristics at entry that predicted survival were higher dependence in ADL, lower cognitive status, and increased frequency of behavioral problems. However, ADL and behavioral problems had a nonlinear effect on survival; for a minority of long-term survivors, high ADL impairment and more frequent behavioral problems were associated with increased survival time. This minority may represent those hardy long-term survivors with AD who continue to live despite high levels of dependency. For the great majority of cases, however, increases in ADL impairment and problematic behaviors were associated with an increased risk of death. Men died sooner than women, as expected.

Longer duration of dementia at entry to the study was related to longer survival. Because indicators of disease progression were controlled for, including ADL, cognitive status, and behavioral problems, this surprising finding may indicate that those who entered with a longer duration of dementia had a more slowly progressing illness. However, this effect was nonproportional, indicating that the beneficial effect of duration of illness at entry waned over time.

Age was not a predictor of survival. Although older age at entry would be expected to increase the hazard of death, given that younger age of onset is often associated with rapidly progressing illness, this may blunt the effect of age alone on death.

Limitations

We used only baseline measures of caregiver characteristics, which precluded examining how changes in coping and depression might affect care-recipient survival. A recent study, however, showed that coping and depression in Alzheimer’s caregivers were largely stable at four times of testing over a 2-year period (Powers et al., 2002). This finding is important for the current study because it suggests that baseline measures of caregiver coping may reflect enduring caregiver characteristics with ongoing implications for care recipient survival.

Our analysis was limited by the variables available to us in our ADRC registry database. As a result, we were unable to examine the impact of some variables (e.g., caregiver personality characteristics, other medical illnesses of the care recipient, and care-recipient recent hospitalizations) that might be related to care-recipient survival. During the time of this study (1993–1997), the ADRC Registry from
which our sample was drawn enrolled persons with a diagnosis of probable or possible Alzheimer’s disease, with mild to moderate severity, who were residing in the community, were medically stable enough to participate in future research studies, and had no comorbidities that potentially could confound the impact of AD. Individuals with imminent nursing home placement, high mortality risk, a history of strokes, hypertension, insulin-dependent diabetes, cancer, alcoholism, and head injury, or who were taking steroids, were excluded. Some of these exclusion criteria were relaxed in 1997, but this change would have had little effect, if any, on the characteristics of this sample. It is therefore unlikely that any comorbidities present at entry to the study would have influenced survival independent of our measures of age, ADLs, cognitive status, and duration of dementia.

In spite of its limitations, our study helps us to evaluate an extended stress-process model that includes survival of the care recipient as an outcome. Our findings indicate that there is not a one-to-one correspondence between caregiver practices that are helpful to the caregiver and those that are helpful for the survival of the care recipient. Whereas instrumental and acceptance coping have been found to improve caregiver mental health, including the reduction of depressive symptomatology, we did not find any effect of these coping styles and of caregiver depression itself on the survival time of care recipients. In contrast, avoidance coping styles, such as wishfulness—intrapsychic coping, which are associated with poorer caregiver mental health, were also related to shorter survival of the care recipients. Thus, we cannot assume that processes and outcomes that are beneficial to caregivers will also be so for their care receivers’ survival. Our work also suggests a possible theoretical foundation for this extended model based on the work of Kitwood (1997). Wishfulness—intrapsychic coping strategies may interfere with the provision of person-centered care and thus contribute to excess disability in the care recipient. If additional studies guided by this extended model validate our findings, they may pave the way for the development of new caregiving interventions that support both caregivers and care recipients.

References


Williamson, G. M., & Shaffer, D. R., The Family Relationships in Late Life Project. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: How we were then, how we are now. *Psychology and Aging, 16*, 217–226.


Received January 31, 2003
Accepted August 29, 2003
Decision Editor: Bob Knight, PhD (Guest Editor)