

Long-Term-Care Placement and Survival of Persons With Alzheimer's Disease

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Although long-term-care (LTC) placement may shorten the survival of persons with Alzheimer's disease, studies have not examined whether the timing of placement matters. A sample of 258 persons with Alzheimer's disease and their family caregivers was used in a Cox survival model that included care-recipient impairments, caregiver characteristics, and LTC placement as covariates. Placement was associated with shortened survival, but the later the placement, the smaller the impact of placement on survival time. In an elaboration on prior work, the increased risk of death associated with wishfulness–intrapsychic caregiver coping was found to occur independently of LTC placement. This is the first study to link delayed LTC with a reduced risk of death in Alzheimer's disease. Interventions to assist family caregivers in the home are indeed appropriate; nevertheless, these findings may help long-term caregivers accept eventual institutionalization for their care recipients when care at home threatens their own health.

DESPITE extensive research into the etiology of Alzheimer's disease (AD), available treatments provide only limited symptomatic relief, and they are unable to prevent, stop, or cure the disease (National Institute on Aging, 2004). The length of time from onset of AD until death varies greatly, with a reported range from 2 to 18 years and a mean of 7 years (Clark, 2000).

Efforts to understand the variation in survival among persons with AD have focused on the characteristics of the diagnosed person. Older 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) have been found to predict earlier mortality for persons with AD (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). Thus, factors that decrease life expectancy even without dementia (i.e., older age and male gender) and factors associated with the progression of AD (i.e., duration and severity of impairments) are strongly predictive of shortened survival time. However, these factors do not tell the whole story.

Because persons with AD require increasingly more assistance from others with daily living as their disease progresses, variations in the caregiving environment may also have an impact on survival. Several studies have found that in-home caregiving variables matter for life expectancy in AD. Brodaty and colleagues (Brodaty, Gresham, & Luscombe, 1997; Brodaty et al., 1993) found that low caregiver psychological distress and caregiver participation in a training program designed to alleviate caregiver distress and improve caregiver coping skills led to longer survival time of the care recipient 5 and 8 years later. A study by McClendon, Smyth, and Neundorfer (2004) reported that caregiving that emphasized a wishful–intrapsychic coping style was significantly associated with earlier care-recipient death, with several measures of care-recipient impairment controlled. Newcomer and

colleagues (2003) found that being cared for by a daughter predicted longer survival. Although the specific caregiver characteristics that affect care-recipient survival vary, these studies support the link between characteristics of in-home caregiving and survival of persons with dementia.

Many family caregivers eventually decide to place the care recipient in long-term care (LTC). However, several studies indicate that institutionalized persons with dementia experience higher mortality than do similarly impaired persons who receive care at home (Aneshensel, Pearlin, Levy-Storms, & Schuler, 2000; Aneshensel, Pearlin, & Schuler, 1993; Aneshensel et al., 1995; Van Dijk, van de Sande, Dippel, & Habbema, 1992). Aneshensel and associates (2000) found that, when they controlled for health status at entry, institutionalization increases mortality twofold. These investigators examined whether excess mortality among institutionalized persons could be attributed to the placement per se (a social causation interpretation) or to the disproportionate placement of persons with high risk for mortality (a social selection interpretation). Although social selection effects were found, they did not fully account for increased mortality associated with nursing home admission. Therefore, there may have been some social causation (e.g., the effect of the transfer or nursing home conditions). In contrast, Brodaty and colleagues (1993) found that, after they controlled for rate of dementia deterioration, nursing home admission was not significantly related to excess mortality. This finding supports a social selection interpretation, that is, a spurious association between placement and death because persons deteriorating more rapidly were both more likely to be placed in LTC and more likely to die.

If LTC placement increases the risk of death, then caregiver characteristics that have an impact on placement have indirect effects on care-recipient survival through placement. Caregiver characteristics found to be predictive of LTC placement include subjective stress (e.g., role captivity and overload; see Aneshensel et al., 1993, 1995; Gaugler, Kane, Kane, Clay, & Newcomer, 2003; Gaugler et al., 2000; Hébert, Dubois,

Wolfson, Chambers, & Cohen, 2001; Yaffe et al., 2002), instrumental ADLs (Gaugler et al., 2003), recent adoption of the caregiver role (Gaugler, Kane, Kane, Clay, & Newcomer, 2005), poor physical health and low income (Aneshensel et al., 1993, 1995), poor self-rated health (Gaugler et al., 2003), and not of Black or Hispanic ethnicity (Gaugler, Leach, Clay, & Newcomer, 2004; Greene & Ondrich, 1990).

Here we report the results of an analysis elaborating on the possible role of LTC placement in the survival of persons with AD. To our knowledge, previous studies have not taken into account the *timing* of institutionalization when examining its impact on survival. Nevertheless, public health policy has stressed the importance of keeping impaired persons at home for as long as possible. The objective has not necessarily been to avoid LTC placement entirely, but to delay placement until it is truly the best alternative, all things considered. This policy assumes not only that there may be financial savings associated with delayed placement, but that it may enhance care-recipient well-being as well. Thus, we examined not only the main effect of LTC placement, as previous studies have done, but also whether the hazard of placement increases or decreases as the time from disease onset increases.

In addition to LTC placement, in our analysis we included several caregiver characteristics identified in the preceding literature review as related to survival, namely, coping styles, psychological distress (i.e., depression), and relationship to care recipient. We also included caregiver characteristics found to affect LTC placement (depression, overload, role captivity, self-rated health, and race) and care-recipient characteristics found to affect survival (age, gender, duration of illness, ADL dependency, cognitive status, and behavioral problems). In addition to prior empirical support for the relevance of these caregiver and care-recipient variables, they are also key components of the stress-process model for dementia caregiving (Pearlin, Mullan, Semple, & Skaff, 1990; also see Aneshensel et al., 1995). Our covariates well represent the major categories of the stress-process model: background-context factors (care-recipient age, gender, race, and relationship to caregiver); primary objective stressors (care-recipient ADL, cognitive status, and problematic behaviors); primary subjective stressors (caregiver overload and role captivity); caregiver resources or moderators (coping styles); and caregiver outcomes (depression and self-rated health).

Elsewhere, we have argued that Kitwood's (1997) concept of person-centered care provides theoretical support for extending the stress-process model to include care-recipient survival as an outcome (McClendon et al., 2004). Person-centered care requires caregivers to be psychologically available to care receivers and accept the care receivers' true state—both deficits and remaining capacities. When a person-centered approach to care is lacking, persons with dementia can be inadvertently treated in a way that results in "excess disability" that will be reflected in accelerated decline and death (Sabat, 1994, 2002). Our finding that more frequent use of wishful-intrapsychic coping (WIC) strategies by caregivers shortened survival time (McClendon et al.) provides a link between coping strategies, considered resources in the stress-process model, and care-recipient survival. By definition, WIC strategies are aimed at removing caregivers psychologically from the actual caregiving situation by daydreaming, fantasizing, hoping for miracles, and

trying to alter caregiver feelings about the situation. Hence, WIC on the part of caregivers may reduce the amount of person-centered care those with dementia receive, and in turn reduce their survival time.

Using longitudinal data from a research registry for persons with AD and their family caregivers, we conducted survival analyses examining the relationships of baseline values and changes (where appropriate) in these predictors to the survival of persons with AD. We also tested and controlled for any changes over time in the effects of these variables.

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 caregiver characteristics that increase care-recipient survival, including the choice to delay or forego LTC placement, are likely to do so because they reflect receipt of better care by, and a higher quality of life for, the care recipient.

METHODS

Participants

The sample consisted of 258 persons with AD who lived at home and their primary family caregivers who entered an Alzheimer's Disease Research Center (ADRC) from November, 1992 through 1998. The diagnosis was based on criteria from the National Institute of Neurological and Communicative Disorders and Stroke/Alzheimer's Disease and Related Disorders Association (McKhann et al., 1984).

The ADRC collected data on the variables used in this analysis at the entry and subsequent annual ADRC visits for as long as possible. This design resulted in a variable number of data points per care recipient-caregiver dyad, depending on how recently the care recipients and caregivers entered the study and how long they participated. The number of data points per dyad ranged from 1 to 10, with a mean of 2.6 per caregiver and 3.9 per care recipient. The intervals between data points also varied, because annual visits were not spaced at exact 12-month intervals and some were missed.

We included only those persons who had complete data on the independent variables used in the analysis. We excluded 18 persons because they were unable to complete the mental-status evaluation. Although the means of the excluded and included cases differed on several variables, the number of excluded cases was such a small percentage (6.5%) of the total that these differences are very unlikely to have biased our results.

The sample included the 193 cases used in our earlier report on caregiver effects on the survival of persons with AD (McClendon et al., 2004). In addition to including 65 additional cases, this report is based on a cutoff date 1.65 years later, longitudinal data on caregivers and care recipients, and the focal variable LTC placement.

Measures

Date of death.—We determined date of death either through normal operating procedures or by a search of online mortality databases. For 40.5% of the deaths, the date was determined during the ADRC's procedures for arranging an autopsy following death. For those families that had not agreed to

autopsy, family members typically contacted the ADRC when their relative died or informed us of the death when the caregiver was contacted for their relative's yearly evaluation. For care recipients not known to be deceased by these reports, we searched the online obituaries of the Cleveland daily newspaper and the Web-based Social Security Death Index (SSDI) to determine date of death. The online SSDI has excellent specificity (about 99%) and good sensitivity (88%; see Schisterman & Whitcomb, 2004). Because of the less than perfect sensitivity of the SSDI, we relied on family reports of deaths when available. After we used these sources, 67.4% of the care recipients were known to be deceased by the study cutoff date of September 24, 2003.

Survival time.—We calculated survival time as the time in years from onset of disease symptoms to the date of death, or to the date the care recipient was last known to be alive for persons not known to be deceased. Our symptom-onset measure was based on a structured interview in which an ADRC clinician carefully led the caregiver to identify the first symptoms noticed and to pinpoint the month and year they were first observed. This method is used routinely across the federally funded ADRCs. Its validity was supported by Drebing and colleagues, (2004), who found that determining the date of symptom onset by structured interview with the AD caregiver was only slightly, if any, less valid than determining it by using medical records, and that both methods were substantially better than using questionnaires. Interinformant reliability of onset was good (intraclass correlation = .86 for two family members) in a structured interview method that asked about the onset dates of seven types of symptoms (Sano et al., 1995). For 215 dyads in our sample who made estimates of onset date at baseline and 1 year later, there was no significant difference in either the means or the standard deviations, and the test–retest reliability was $r = .86$. The mean survival time of the 174 persons with AD who were deceased by the cutoff date was 8.7 years and ranged from 1.7 to 19.7 years.

LTC facilities.—We considered both nursing homes and assisted living facilities as LTC facilities. The level of care provided in nursing homes and assisted living facilities overlaps considerably (Hawes, 2001). Frytak, Kane, Finch, Kane, and Maude-Griffin (2001) reported no differences in outcome trajectories for ADLs, psychological well-being, and pain and discomfort between types of facility, and Pruchno and Rose (2000) documented that health outcome patterns for residents in assisted living facilities and nursing homes did not differ. Therefore, because in-home caregiving ceases when a care recipient is moved to either type of facility, we considered both to be LTC placement.

We usually determined LTC placement when caregivers were contacted to schedule their next yearly visit. Three additional sources of living arrangement data were the caregiving and demographic questionnaires completed annually by the caregiver and annual telephone interviews with caregivers of persons with dementia who were no longer able to make in-person visits to the ADRC. After the cutoff date, we also attempted to survey by mail and telephone 161 caregivers whose care recipients were not already known to have entered LTC to find out if their care recipients had permanently moved

to LTC before the cutoff date. After the completion of this survey, 165 care recipients (64%) were known to have been placed in LTC (82% in nursing homes, and 18% in assisted living), 57 (22%) were known not to have been placed, and 36 (14%) had an unknown LTC status because we were unable to contact the caregiver. We included a dummy variable in our regression model as a control for missing LTC status (see the Statistical Methods section).

Caregiver depressive symptoms.—We assessed caregiver depressive symptoms with the Center for Epidemiological Studies—Depression (CES-D) 20-item scale of depressive symptoms (Radloff, 1977). The scale, the sum of the 20 items, had a possible range of 0 to 60, with a score of 16 or above indicating risk for clinical depression. Cronbach's index of internal consistency was $\alpha = 0.89$.

Caregiver coping.—We assessed caregiver coping with a scale adapted from Kiyak, Montgomery, Borson, and Teri (1985) by Pruchno and Resch (1989). This 16-item measure asked respondents how often they used each type of coping when they were caring for their relative. Pruchno and Resch reported that four subscales could be derived from this measure: instrumental (e.g., "Made a plan of action and followed it"); acceptance (e.g., "Made the best of it"); wishfulness (e.g., "Wished you could change the way you felt"); and intrapsychic (e.g., "Had fantasies about how things might turn out"). However, Pruchno, Burant, and Peters (1997) and McCleendon and colleagues (2004) found that the wishfulness and intrapsychic items combined into a single factor. We thus used the following three subscales: instrumental (5 items, $\alpha = 0.83$); acceptance (4 items, $\alpha = 0.78$); and wishfulness–intrapsychic (7 items, $\alpha = 0.79$). We computed subscale scores as the mean of the items; these had a possible range of 1 to 5.

Subjective caregiver stress.—We measured subjective caregiver stress by using two scales developed by Pearlin and associates (1990). We measured overload by asking respondents how much they agreed or disagreed with four statements about how caregiving had affected them (e.g., "Because of caring for my relative, I am exhausted when I go to bed at night"). We measured role captivity by using three items that asked caregivers how much each statement described their thoughts about caregiving (e.g., "How much do you feel trapped by your relative's illness?"). We computed subscale scores as the mean of the items; these had a possible range of 1 to 4. Cronbach's index of internal consistency was $\alpha = 0.83$ for overload and $\alpha = 0.85$ for captivity.

Cognitive status.—We measured the cognitive status of the care recipients with the Mini-Mental State Examination (MMSE; Folstein, Folstein, & McHugh, 1975). Scores range from 0 to 30.

Activities of daily living.—We measured ADLs with the 35-item Cleveland Scale for Activities of Daily Living (Patterson et al., 1992), administered to the caregiver, which measures both basic and instrumental ADLs. We calculated scale scores as the mean of the items with valid values, if there were at least 20. The possible range for the scale was 0 to 3; $\alpha = 0.94$.

Table 1. Descriptive Statistics for Care Recipients and Caregivers at Baseline

Variable	<i>M</i>	<i>SD</i>	%
Duration of illness, in years	4.11	2.32	
CR age	73.07	7.82	
CR gender (1 = male; 0 = female)	0.47	0.50	
Race (1 = White; 0 = African American)	0.90	0.30	
ADL	0.64	0.55	
MMSE	17.64	5.60	
BRS-D	0.29	0.10	
Spousal CG (1 = spouse; 0 = other)	0.73	0.44	
Instrumental coping	3.00	0.81	
Acceptance coping	4.06	0.75	
Wishfulness coping	2.83	0.82	
CG overload	2.28	0.48	
CG role captivity	1.96	0.71	
CG depression (CES-D)	12.05	7.90	
LTC (1 = placed; 0 = not known placed)	0.64	0.48	
LTC missing (1 = missing; 0 = not missing)	0.14	0.35	
CG self-reported health			
1 = poor			1.9
2 = fair			20.5
3 = good			32.2
4 = very good			29.1
5 = excellent			16.3

Notes: CR = care recipient; ADL = activity of daily living; MMSE = Mini-Mental State Exam; BRSD = Behavioral Rating Scale–Dementia; CG = caregiver; CES-D = Center for Epidemiologic Studies–Depression scale; LTC = long-term care. LTC data are taken from the cutoff date, not baseline. For the table, *N* = 258.

Behavioral problems.—We measured the behavioral problems of the care recipient with the Behavior Rating Scale for Dementia (BRSD; Tariot et al., 1995), a 45-item instrument administered to the caregiver. It taps depressive symptoms, inertia, vegetative symptoms, behavioral dysfunction, irritability, and psychotic symptoms. We coded each behavior as 1 if it occurred in the prior month and 0 if it not. We calculated a composite score as the mean of all items with valid values; $\alpha = 0.84$.

Demographic characteristics.—The demographic characteristics included care-recipient gender, race, age at baseline, and duration of illness at baseline, plus relationship of caregiver to care recipient (1 = spouse, 0 = child or other) and caregiver self-reported health.

Statistical Methods

We used Cox proportional hazards regression to conduct survival analyses of time to death of the care recipients. We included persons not known to be deceased at the cutoff date (i.e., censored cases) in the analysis, as in all methods of survival analysis (Allison, 1995, p. 5). They are not assumed to be alive at the cutoff date, but they are treated as alive at the date of last contact with them.

Under the proportional hazards assumption, a positive regression coefficient indicates that a unit increase in a covariate is associated with an increase in the risk of death, which is assumed to be the same across all time points. We tested this assumption by computing the correlation between the natural log of time to death and the Schoenfeld residuals of each

covariate for the deceased care recipients. A significant correlation indicated a nonproportional effect, which we modeled by including an interaction between the covariate and time to death in the regression equation.

We used growth curve modeling to compute rates of change for the repeated-measure covariates, an approach that is especially useful when the number of time points of data and the intervals between measurements vary from subject to subject. We used a three-step procedure for estimating the effects of change in covariates. First, we used mixed-effects software (MLwiN) to estimate a rate of change and a baseline value for each repeated-measure covariate, using all data points (1–10) on each covariate. Second, we saved the rates of change and baseline values with significant between-person variance. Third, we entered these rates of change and baseline values into the Cox model as covariates, along with the fixed demographic variables.

We included two dummy variables in the regression equation to represent the LTC data (i.e., we entered LTC—coded 1 for those placed in LTC; and missing data on LTC—coded 1 for those with missing LTC). With both variables in the equation, the coefficient for the first variable contrasts the survival time of those placed in LTC with those *not* placed, and the coefficient for the second variable contrasts the survival of those missing LTC data with those not placed in LTC. We also coded the entered LTC variable as a *time-varying covariate* to capture variance in the timing of placement. At each point prior to a care recipient's placement at which a death occurs, we coded the care recipient as living at home, but at each point after the care recipient is placed that a death occurs, we coded the care recipient as being in LTC. Thus, the care recipients' scores on the LTC variable may change over time from 0 to 1, if and when the care recipients are institutionalized. We also tried coding the other repeated-measure predictors (e.g., caregiver depression, ADL, and MMSE) as time-varying covariates and using them in the regression instead of their baseline values and rates of change. Because the fit of the model with time-varying covariates was not as good as for the model with baseline values and rates of change, we do not report the results for the time-varying covariates.

RESULTS

Table 1 gives the baseline means and standard deviations of the covariates. Of the care recipients, 90% were White, 47% were male, 73% were cared for by their spouse, and 64% were known to be eventually placed in LTC. Care recipients had a mean duration of dementia symptoms of 4 years, a mean age of 73 years, a mean ADL rating of 0.64 on a scale of 0–3, a mean mental status score 17.6 out of a possible 30 points, and a mean of 29% of the problematic behaviors measured on the BRSD scale during the previous month. With respect to the caregivers, most (77.6%) rated their health as good (3) or better on a 5-point scale. On average, they had scores on overload and role captivity that were somewhat below the scale midpoint (2.5), scored 12.0 on the CES-D scale, and used acceptance coping ($M = 4.1$) more frequently than instrumental coping ($M = 3.0$) and WIC ($M = 2.8$).

We found significant between-person variance in the rate of change for all repeated-measure covariates except instrumental

Table 2. Zero-Order Correlations

	Duration	Age	Gender	ADL Base	ADL Rate	BRSD Base	BRSD Rate	MMSE Base	WIC Base	LTC	LTC Missing
Duration	1.000	0.047	0.089	0.316	-0.124	0.124	-0.186	-0.280	-0.007	-0.097	0.049
Age	0.047	1.000	-0.076	0.118	-0.080	0.088	-0.144	-0.034	-0.122	-0.055	-0.014
Gender	0.089	-0.076	1.000	0.019	-0.034	-0.091	0.094	0.045	0.220	-0.033	0.022
ADL base	0.316	0.118	0.019	1.000	0.124	0.281	-0.513	-.648	0.170	0.082	-0.141
ADL rate	-0.124	-0.080	-0.034	0.124	1.000	0.013	-0.170	-0.309	0.070	0.267	-0.106
BRSD base	0.124	0.088	-0.091	0.281	0.013	1.000	-0.672	-0.110	0.216	0.062	-0.034
BRSD rate	-0.186	-0.144	0.094	-0.513	-0.170	-0.672	1.000	0.318	-0.147	-0.164	0.104
MMSE base	-0.280	-0.034	0.045	-0.648	-0.309	-0.110	0.318	1.000	-0.135	-0.078	0.070
WIC base	-0.007	-0.122	0.220	0.170	0.070	0.216	-0.147	-0.135	1.000	0.076	0.014
LTC	-0.097	-0.055	-0.033	0.082	0.267	0.062	-0.164	-0.078	0.076	1.000	-0.536
LTC missing	0.049	-0.014	0.022	-0.141	-0.106	-0.034	0.104	0.070	0.014	-0.536	1.000

Note: ADL = activity of daily living; BRS-D = Behavioral Rating Scale-Dementia; MMSE = Mini-Mental State Exam; WIC = Wishful-Intrapsychic coping; LTC = long-term care. For the table $N = 258$; $p \leq .05$ for $r > .12$.

and acceptance coping. All covariates showed significant between-person variance in their baseline values. Consequently, in our regression model we included baseline values of all the covariates listed in Table 1 and rates of change in ADLs, MMSE scores, BRSD scores, overload, role captivity, WIC, and CES-D scores.

We carried out regressions with these covariates in three ways: simultaneously, forward stepwise, and backward stepwise. In each case we arrived at the same set of 11 covariates that were significant at $p \leq .05$. We then reestimated the model with only these variables, found that baseline caregiver overload was no longer significant ($p = .077$), and dropped it from the model. We added back care-recipient MMSE scores to explicitly control for impaired cognitive ability, a signature trait of AD. The correlations among these 11 variables are given in Table 2 and the results of the regressions are shown in Table 3.

Care-Recipient Effects on Survival

The negative coefficient for duration of illness at entry into the study (Table 3) indicates that the greater the duration, the lower the hazard of death. This relationship appears to be counterintuitive until one considers that survival time was measured from onset of symptoms, not from time of study entry. Thus, because the person with AD could not die prior to study entry, the longer the duration of the disease prior to entry, the longer the person tended to survive. Although this is an artifactual relationship, we must control for it to get unbiased estimates of the effects of the other covariates. As is the case in the general population, male gender and older age of the care recipient were associated with shorter survival.

The coefficients for the baseline level and the rate of change in both ADL and BRSD scores were positive, indicating that the greater the baseline value and the rate of increase in these impairments, the earlier the death of the care recipient. When we controlled for ADL and BRSD scores, cognitive status was not related to survival.

Caregiving Effects on Survival

WIC was associated with shortened survival. The hazard ratio indicates that a unit increase on the WIC scale (a little more than 1 *SD*), increased the risk of death by 32%.

LTC placement decreased survival time. The risk of death for those placed in LTC was 3.2 times greater than for those who

remained at home. Having missing LTC data was also associated with shortened survival. The risk of death for those with missing LTC information was about 4 times greater than for those who remained at home. Those with missing LTC data were those whom we were not able to contact in our survey to determine LTC status. Perhaps we were unable to make contact because the care recipient was more likely to be deceased and thus the caregiver had moved or was less responsive. The uncertainty about this association, however, does not invalidate the association between LTC placement and death among those with valid LTC data.

Nonproportional Hazards

The Schoenfeld residuals for duration of symptoms, rate of change in ADLs, and LTC placement were significantly correlated with both time and its natural log, but they were stronger for the natural log. To model these nonproportional hazards, we added three interaction terms for $\log(\text{time})$ and the covariate X , that is, $\log(\text{time}) \times X$, to the regression equation. All three interactions were significant (Table 4). The signs of the coefficients indicate that, as time passes, the reduced risk associated with longer duration dissipates and the enhanced risk of death associated with a high rate of increase in ADL dependencies becomes even stronger.

The interaction between LTC and time (Table 4) is negative, which means that the longer LTC placement is delayed, the less

Table 3. Cox Regression With Proportional Hazards

Covariates	<i>B</i>	<i>SE</i>	Wald	<i>p</i>	e^B (Hazard Ratio)
Duration of dementia	-0.412	0.052	63.186	.000	0.663
Age	0.054	0.011	22.206	.000	1.056
Gender	0.778	0.170	21.090	.000	2.178
ADL, base	0.990	0.210	22.145	.000	2.690
ADL, rate	3.722	0.760	24.019	.000	41.365
Behavioral problems, base	3.277	1.091	9.021	.003	26.508
Behavioral problems, rate	31.454	6.502	23.399	.000	$10^{13} \times 4.575$
MMSE, base	-0.001	0.020	0.001	.977	0.999
WIC	0.280	0.127	4.868	.027	1.324
LTC	1.158	0.212	29.764	.000	3.183
LTC missing	1.382	0.272	25.830	.000	3.981

Notes: ADL = activity of daily living; MMSE = Mini-Mental State Exam; WIC = Wishful-Intrapsychic coping; LTC = long-term care.

Table 4. Cox Regression With Significant Nonproportional Hazards

Covariates	<i>B</i>	<i>SE</i>	Wald	<i>p</i>	e^B (Hazard Ratio)
Duration of dementia	-1.491	0.351	17.984	.000	0.225
Age	0.054	0.012	21.652	.000	1.055
Gender	0.753	0.172	19.225	.000	2.123
ADL, base	1.015	0.219	21.496	.000	2.758
ADL, rate	-5.058	3.204	2.493	.114	0.006
Behavioral problems, base	3.240	1.114	8.462	.004	25.529
Behavioral problems, rate	29.836	6.748	19.547	.000	$10^{12} \times 9.070$
MMSE, base	-0.004	0.020	0.038	.846	0.996
WIC	0.289	0.128	5.095	.024	1.336
LTC	3.261	0.957	11.620	.001	26.072
LTC missing	1.350	0.274	24.230	.000	3.859
LTC \times log(time)	-1.056	0.447	5.591	.018	0.348
Duration \times log(time)	0.475	0.152	9.722	.002	1.607
ADL rate \times log(time)	4.199	1.562	7.231	.007	66.653

Notes: ADL = activity of daily living; MMSE = Mini-Mental State Exam; WIC = Wishful-Intrapsychic coping; LTC = long-term care.

risky placement becomes. Graphs of the relationship of time with the regression coefficient *B* for LTC and with the relative hazard of LTC (Figure 1) show that, after a care recipient has had AD for 10 years, the increased risk associated with placement is greatly reduced, and that after the recipient has had it 15 years, it is virtually eliminated. The regression coefficients and levels of significance for the other variables in Table 4 are very similar to those in Table 3.

DISCUSSION

Long-Term-Care Placement

Although LTC placement increased the risk of death by about three times on the average, our analysis showed that the risk associated with placement was high early in the duration of illness, but it decreased greatly with time. For example, the hazard ratio, or relative risk of death, for placement at 5 years from symptom onset was 4.8; at 10 years it was 2.3; and by 15

years it was only 1.5. Although other studies have reported the hazardous nature of LTC placement (Aneshensel et al., 1993, 1995, 2000; van Dijk et al., 1992), our study is the first to show the declining risks of death over time associated with placement of persons with AD.

We concur with Aneshensel and colleagues (2000) that social selection factors do not fully account for the association between LTC placement and mortality. A strength of our study is that we controlled for baseline values and rates of change in care-recipient ADL dependency, behavioral problems, and cognitive impairment, well-known predictors of both death (Aneshensel et al., 1995; Brodaty et al., 1993; Newcomer et al., 2003; Stern et al., 1997) and LTC placement (Gaugler et al., 2003; Yaffe et al., 2002). These controls lend support to a social causation interpretation of the placement effect of LTC on mortality, that is, that placement itself increases the risk for death.

The declining mortality risk of placement as time since disease onset increases is also more consistent with a social causation than with a social selection interpretation. If the selection of persons in the poorest health was the primary cause of the association between institutionalization and death, we would expect that effect to be proportional across time, with acute health problems increasing the risk of death by the same amount no matter when in the disease process they occurred. The declining hazard of placement we found, however, suggests that LTC placement could be more disruptive for the care recipient earlier in the course of dementia when awareness is likely to be greater.

A limitation of our data is that we do not have measures of specific comorbidities that might be present at the time of placement or shortly before, and thus might be the basis of both placement and death. For such comorbidities to render our results spurious, however, they would have to be uncorrelated with our measures of care-recipient health (i.e., MMSE, ADL, and BRSD scores), which seems unlikely. A further limitation is that our sample, based on recruits from clinics and volunteers who contacted our center, is probably not representative of

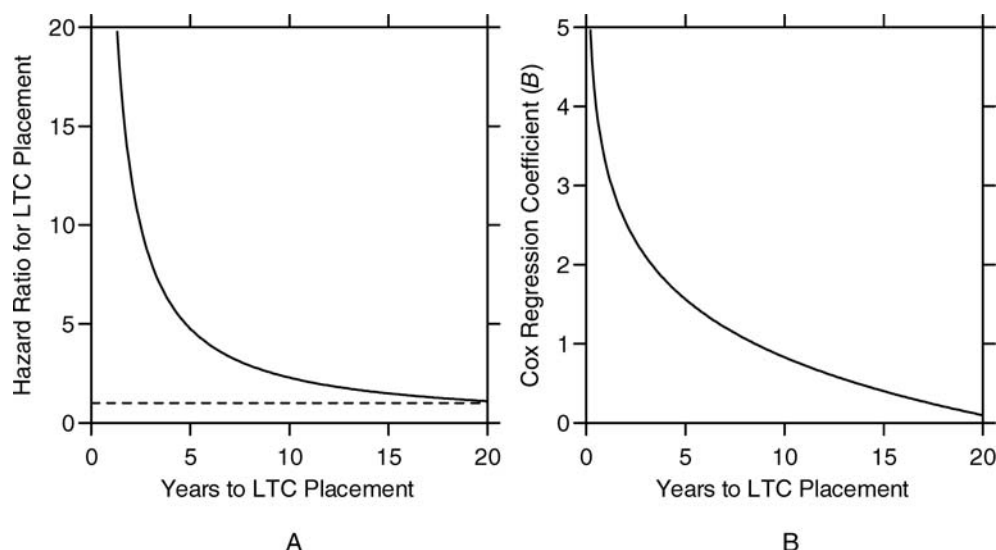


Figure 1. Risk of death as a result of long-term-care (LTC) placement.

caregivers or persons with AD. Our sample is also not large ($n = 258$), although it is sufficiently so for us to have found significant effects for LTC and WIC.

Wishful-Intrapsychic Coping

The relationship between a WIC style and shortened survival time, previously reported by us (McClendon et al., 2004), is also found in this sample with 65 additional cases, a longer follow-up time, and controls for additional covariates. Using additional types of covariates, we are able to refine our interpretation of the nature of this effect. We previously theorized that caregivers using this style would be more likely to place their care recipients in LTC, which might shorten life expectancy. We have now demonstrated that the association of WIC with shorter survival exists independently of institutionalization. The impact of WIC is a direct effect, not one that is mediated by placement.

We have also shown in this study that baseline WIC, not the rate of change in such coping, impacts survival. Although we found that caregivers varied significantly in the rate of change in this style of coping, it was the use of WIC relatively early in the caregiving career that was associated with reduced care-recipient survival. This indicates that this caregiver characteristic exerts an early effect on the person with dementia that is not affected by subsequent changes in caregiver coping style. In our original report of the WIC effect (McClendon et al., 2004), we suggested that it might be a product of a neurotic personality trait, which is consistent with the finding of Hooker, Frazier, and Monahan (1994) that emotion-focused coping was closely related to neuroticism. We have now shown, however, that this coping style is not traitlike because it changes significantly. Furthermore, preliminary results from a smaller sample of caregivers with personality measures that overlapped with the present sample showed that WIC was still significantly related to care-recipient survival when five dimensions of personality were controlled for (McClendon, Smyth, & Neundorfer, 2005).

We think it is important that even with other potentially important caregiver characteristics in the model, such as subjective stress and depressive symptoms, WIC is independently associated with survival. Thus, it does not appear to be the caregiver experience of stress but how the caregiver deals with the stress that is important for care-recipient survival.

Implications for Interventions

Our finding that the increased risk of death associated with LTC placement diminishes as the time from dementia symptom onset increases supports interventions and policies designed to help keep persons with dementia in their homes for as long as possible. The fact that newer caregivers are more likely to institutionalize the person with dementia (Gaugler et al., 2005) is congruent with such policies. However, extending the length of in-home caregiving is associated with diminishing returns. At some point, care recipients can be placed with little or no increased risk of death. Practitioners have long struggled with how to convince family caregivers that LTC is appropriate when they are no longer able to handle in-home caregiving without suffering mental and physical health consequences. Our findings may be helpful in reducing the feelings of guilt that many caregivers experience when terminating in-home care.

Our finding that the shortened life expectancy associated with WIC is due to the baseline use of this coping strategy and not its change also has implications for interventions. Caregiving has been called “the unexpected career” (Aneshensel et al., 1995), implying that most family members are not prepared for their caregiving roles. Our findings suggest that interventions to enhance caregiver coping should be offered early in the caregiving career, rather than waiting until caregivers reach out for assistance when they become overwhelmed with the burdens of care.

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