

Caregiving and Institutionalization of Cognitively Impaired Older People: Utilizing Dynamic Predictors of Change

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Purpose: The purpose of this study was to identify reliable predictors of nursing home entry over a 3-year period in a sample of 3,944 persons with dementia who resided in a home setting at baseline. Strengths of the analysis include a multiregional recruitment strategy, incorporation of salient caregiver characteristics, and a 3-year prospective design that allows for the modeling of change in important variables (e.g., care recipient functional status or caregiving indicators) when time to institutionalization is predicted. **Design and Methods:** Data were derived from the control sample of the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE). A Cox proportional hazards model was used to predict time to institutionalization among individuals with dementia (baseline was enrollment into MADDE). Predictors included care recipient demographics, caregiver demographics, and time-varying measurements of care recipient functional status, caregiving indicators, and service utilization. Indicators of change were also incorporated to capitalize on the prospective data available. **Results:** Although several results were consistent with prior findings, caregiving indicators (i.e., burden and self-rated health) and community-based service use were significant predictors of earlier placement. Change in

caregiver instrumental activities of daily living and care recipient activities of daily living were also related to expedited institutionalization. **Implications:** The findings emphasize the importance of incorporating both care recipient and caregiver function and service use patterns when targeting programs designed to prevent or delay institutionalization for people with dementia.

Key Words: Nursing home placement, Alzheimer's disease, Family caregiving, Dementia

Approximately 4-5% of the older population of the United States resides in a nursing home at any given moment (Strahan, 1997). Many of these nursing home residents suffer from dementia. Because of the public and personal costs associated with the institutionalization of older adults, a number of studies have aimed to identify population-, community-, and individual-level factors that predict or potentially delay nursing home placement (e.g., Branch & Jette, 1982; Cohen et al., 1993; Greenburg & Ginn, 1979; Greene & Ondrich, 1990).

Dementia is a significant predictor of institutionalization (Montgomery & Kosloski, 1994; Pruchno, Michaels, & Potashnik, 1990), though not a sensitive one. Studies that predict nursing home placement among individuals with Alzheimer's disease vary as a result of heterogeneous designs, sample sizes, and model specifications (Fisher & Lieberman, 1999). The main objective of the present study was to address each of these issues by utilizing multiregional, 3-year prospective data drawn from the Medicare Alzheimer's Disease Demonstration Evaluation (MADDE) to predict time to institutionalization for people suffering from dementia (Miller, Newcomer, & Fox, 1999; Newcomer, Spitalny, Fox, & Yordi, 1999).

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Predictors of Institutionalization

The institutionalization process is complex. Multiple variables have been shown to predict nursing home placement in both the general older population and dementia-only samples (Colerick & George, 1986; Dunkin & Anderson-Hanley, 1998; Gaugler et al., 2000; Wolinsky, Callahan, Fitzgerald, & Johnson, 1992). Prior studies have distinguished numerous variables such as advanced age (Branch & Jette, 1982; Greenberg & Ginn, 1979; Pruchno et al., 1990), gender (Greenberg & Ginn, 1979; Hanley, Alecxih, Wiener, & Kennel, 1990; McFall & Miller, 1992), marital status (Hogan, Thierer, Ebley, & Parhad, 1994), socioeconomic status (Branch & Jette, 1982; Colerick & George, 1986; Greenberg & Ginn, 1979), home ownership (Greene & Ondrich, 1990), ethnicity (Salive, Collins, Foley, & George, 1993), and living alone (Wolinsky et al., 1992) as significant predictors of institutionalization among older adults.

Prior studies have also shown that functional status is related to institutionalization. For example, increased dependency in activities of daily living (ADL), poor ratings of subjective health, and severity of cognitive impairment consistently predict nursing home placement (Branch & Jette, 1982; Cohen et al., 1993; Gaugler et al., 2000; Greene & Ondrich, 1990; Wolinsky, Callahan, Fitzgerald, & Johnson, 1993). Among people with dementia, behavior problems such as wandering, agitation, or physical aggression may be potent predictors of institutionalization (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995; Gaugler et al., 2000; Whitlatch, Feinberg, & Stevens, 1999).

As a large body of research emerged to document the role of family members in providing assistance to impaired older adults, several studies incorporated caregiver characteristics when determining time to nursing home placement. Caregiving stressors (such as feelings of exhaustion or being trapped in caregiving responsibilities), depression, or impaired subjective health appear likely to expedite institutionalization (Aneshensel et al., 1995; Colerick & George, 1986; Gaugler et al., 2000; Lieberman & Kramer, 1991; McFall & Miller, 1992; Montgomery & Kosloski, 1994; Whitlatch et al., 1999; Zarit, Todd, & Zarit, 1986). Although some analyses suggest that indicators of caregiver stress are stronger predictors of nursing home placement than older adults' functional status (Dunkin & Anderson-Haley, 1998), other studies have not found empirical support for such conclusions (see Fisher & Lieberman, 1999).

The costs and dissatisfaction associated with nursing home placement have resulted in a number of analyses that determine whether community-based long-term care can delay institutionalization. In an early review, Weissert, Cready, and Pawelak (1988) found that few programs delayed institutionalization significantly. National evaluations of case

management for disabled older adults suggested that the referral and arrangement of services provided by case managers do not delay the timing of nursing home placement (Kane, 1986; Miller et al., 1999). The effects of specific community-based programs to delay institutionalization, such as adult day services, also appear equivocal (Gaugler & Zarit, 2001). One reason for the lack of definitive findings may be the inconsistent utilization of these services by older adults or their family caregivers (e.g., Kosloski & Montgomery, 1995).

Research Focus

Although considerable work has been conducted on time to institutionalization, several shortcomings remain in the literature. The samples used in prior research vary greatly; sampling frames range from single communities to national samples. This heterogeneity has made it difficult to pinpoint consistent predictors of placement. In addition, the methodological designs used to study time to institutionalization vary from as short as several months to as long as many years. Fluctuating time frames and the availability of time-varying covariates can affect whether certain indicators predict placement. Many studies use a restricted set of predictors; for example, large-scale analyses of institutionalization often include characteristics of older adults only, ignoring findings from smaller studies that suggest caregiver stressors are potential predictors of placement (e.g., Aneshensel et al., 1995; Colerick & George, 1986; Gaugler et al., 2000; Fisher & Lieberman, 1999). Finally, prior efforts do not consider important changes in care recipient functional status or caregiving indicators leading up to nursing home placement. Many analyses only consider baseline predictors, which offer little insight into the course of events that precipitate institutionalization. Even studies that include time-varying covariates focus primarily on cross-sectional measurements at each wave and fail to model changes in care recipient functional status or caregiving adaptation that elucidate the placement process (Wolinsky et al., 1993).

The goal of this study was to conduct a comprehensive analysis of predictors of institutionalization among people with dementia. Specifically, this analysis extends the findings of prior research and contributes to the literature in the following ways:

1. **Multiregional design and sample:** This study includes 3,944 older adults with dementia and their primary caregivers recruited from home-based settings in eight catchment areas (Rochester, NY; Urbana, IL; Memphis, TN; Portland, OR; Cincinnati, OH; Parkersburg, WV; Minneapolis, MN; and Miami, FL). Although the sample cannot be considered nationally representative of caregivers of individuals with dementia, the

multiregional design makes the findings from this study more generalizable than many past analyses.

2. Consideration of caregiver characteristics: The present study will include important information from both persons with dementia as well as their informal caregivers (e.g., sociodemographic characteristics or stress).
3. Incorporation of change: The present analysis includes up to seven discrete time intervals over a 3-year study period and will take advantage of its prospective design to identify time-varying predictors of placement. Moreover, this study will consider whether changes in care recipient functional status, caregiving stress and depression, and community-based service use predict institutionalization over time.

Methods

MADDE

Funded by the Health Care Financing Administration, MADDE was intended to address policy issues related to the cost, benefits, and effectiveness of expanded community-based services for older adults with dementia and their caregivers. Criteria for enrollment in MADDE were that all older adults had a physician-certified diagnosis of an irreversible dementia, were enrolled or eligible for Parts A and B of the Medicare program, had service needs, and resided in a home-based setting in a MADDE catchment area. A total of eight sites located in different regions of the United States were funded (as just specified). The sites served people with dementia and their families from December 1989 to November 1994. Individuals suffering from dementia (i.e., care recipients) entered the study during a 2-year enrollment period, and their caregivers were administered in-person interviews by trained nurses and social workers at each site for up to 36 months at 6-month intervals in the community, and up to 1 year following nursing home placement (see Miller et al., 1999; Newcomer et al., 1999). "Baseline" in both prior evaluations of MADDE as well as the present study was the enrollment date into MADDE.

MADDE used an experimental research design with care recipients randomly assigned to either a treatment group eligible for the expanded, reimbursable case management services or a control group that received no expanded benefit reimbursement but could purchase available community services at their own expense. Only the MADDE control group was considered for the current analysis because the treatment sample received considerable amounts of community-based services, an aspect of the original evaluation that could have affected predictors of institutionalization (Miller et al., 1999). The control sample included 3,944 care recipients in a home-based setting who received

Table 1. Rates of Institutionalization

Interval (months)	Institutionalized	Censored	Prob. of Inst.
0-6	445	286	.12
7-12	386	283	.13
13-18	293	228	.12
19-24	251	195	.13
25-30	173	113	.11
31-36	142	1149	.08
Total	1690		

Notes: Censored refers to cases that died or were lost to follow-up during the course of the study. In addition, those cases that remained in the analysis for the 3-year duration of the study were considered censored at 36 months. The total given refers to the number of cases institutionalized over 36 months; $n = 1,690$ (42.85%).

a baseline assessment prior to randomization and their "primary" caregivers (i.e., the one person who provided the most assistance to the person suffering from dementia). Almost three quarters of the caregiving sample were women (72.7%). Participant retention was high in the control condition, with only 344 participants lost to follow-up (e.g., the caregiver moved out of the area or refused to participate). Caregivers lost to follow-up reported fewer instrumental ADL (IADL) dependencies for their care recipients at baseline ($p < .05$). In addition, caregivers who reported greater depression at baseline were more likely to exit the study ($p < .05$) than those who were reassessed. Care recipients in the control group had high mortality rates; of 3,944 participants with dementia, 26.7% ($n = 1,053$) died during the 3-year study interval.

Nursing Home Stays

MADDE obtained institutionalization dates for stays that the caregiver reported as permanent. Any stays initially paid for by Medicare that ended in death (rather than discharge to the community) were also classified as permanent stays. Nursing home entry dates for short stays (i.e., fewer than 60 days) in which the person with dementia returned to the community were compiled, but these stays have not been counted as permanent nursing home days. Short stays of care recipients that returned to the community were not considered in the analysis under the assumption that these stays were due to an acute, episodic care event as opposed to dementia or some other chronic, long-term care condition (see Miller et al., 1999). Efforts to establish data quality in MADDE and corroborate caregiver reports with demonstration-financed reimbursement claims were successful (Donatoni, 1997). Table 1 documents rates of institutionalization during each 6-month measurement interval. At the conclusion of the 3-year study, approximately 43% ($n = 1,690$) of care recipients experienced a permanent nursing home placement.

Table 2. Descriptive Sample Information (Baseline)

Dummy Variable	<i>n</i>	%
Care recipient demographics		
Site (state)		
FL	564	14.30
IL	484	12.27
OR	447	11.33
MN	679	17.22
NY	518	13.13
OH	446	11.31
TN	487	12.35
WV	319	8.09
Race		
African-American	358	9.07
Hispanic	134	3.40
Other	22	0.56
Caucasian	3430	86.97
Age (years)		
20–64	148	3.75
65–69	319	8.09
70–79	1624	41.18
80–85	973	24.67
85–90	647	16.40
90+	233	5.91
Income (\$)		
<5,000	269	6.82
5,000–9,999	1066	27.03
10,000–19,999	1408	35.70
20,000–29,999	577	14.63
30,000+	449	11.38
Missing	175	4.44
Medicaid status		
Yes	271	6.87
No	3673	93.13
Lives w/ caregiver		
Yes	2769	70.21
No	1175	29.79
Care recipient functional status		
ADL limitations (0–10)		
0–1	812	20.60
2	659	16.71
3	553	14.02
4–5	804	20.39
6–8	655	16.61
9–10 (worst)	460	11.67
Missing	1	0.03
Worsened (≥ 1 activity in 6-month interval)	1683	42.67
IADL limitations (0–8)		
0–3	267	6.77
4–5.5	823	20.87
6–6.5	596	15.12
7–7.5	1073	27.22
8 (worst)	1184	30.02
Missing	1	0.03
Worsened (≥ 1 activity in 6-month interval)	931	23.61
Behavior problems (0–19)		
0–4	540	13.69
4.1–7	844	21.40
7.1–10	1010	25.61
10.1–13	874	22.16
13.1–19 (worst)	671	17.01
Missing	5	0.13
Worsened (≥ 2 pts. in 6-month interval)	1105	28.02

Table 2. (Continued)

Dummy Variable	<i>n</i>	%
MMSE (0–30)		
0 (worst)	359	9.10
1–5	326	8.27
6–10	421	10.67
11–15	641	16.25
16–20	831	21.07
21–25	734	18.61
26–30	394	9.99
Missing	238	6.04
Service utilization		
Chore services (hr)		
None	3167	80.30
Low (1–36)	338	8.57
Medium (37–103)	257	6.52
High (104+)	182	4.62
Increased (48 hr in 6-month interval)	570	14.45
Personal care (hr)		
None	3131	79.39
Low (1–60)	397	10.07
Medium (61–207)	211	5.34
High (208+)	205	5.20
Utilization increased (48 hr in 6-month interval)	851	21.58
Adult day care (days)		
None	3363	85.27
Low (1–30)	277	7.02
Medium (31–77)	162	4.11
High (78+)	142	3.60
Utilization increased (24 days in 6-month interval)	387	9.81
Caregiver needs services		
Yes	3412	86.51
No	361	9.15
Missing	171	4.34
Caregiver demographics		
Rel'ship to client		
Wife	1211	30.70
Husband	621	15.75
Da.	1087	27.56
Da.-in-law	153	3.88
Son	330	8.37
Female rel.	272	6.90
Other	237	6.01
Missing	33	0.83
Age (years)		
<70	2341	59.36
70–74	477	12.09
75–79	469	11.89
80–84	337	8.55
85+	165	4.18
Missing	155	3.93
Income (\$)		
<10,000	334	8.47
10,000–40,000	1024	25.97
40,000+	574	14.55
Missing	2012	51.01
Education		
<high school	789	20.01
High school grad	1190	30.17
Some college	966	24.49

(Table continues on next page)

Table 2. Descriptive Sample Information (Baseline)
(Continued)

Dummy Variable	<i>n</i>	%
College grad	903	22.90
Missing	96	2.43
Duration of care (months)		
0–30	1405	35.62
31–60	533	13.52
61+	506	12.83
Missing	1500	38.03
Caregiving indicators		
Zarit burden (0–28)		
0–6	796	20.18
6.1–10	710	18.00
10.1–14	853	21.63
14.1–18	748	18.97
18.1–28 (worst)	741	18.79
Missing	96	2.43
Worsened (≥ 3 pts. in 6-month interval)	1462	37.07
Depression (0–15)		
0	321	8.14
0.1–2	1022	25.91
2.1–4	887	22.49
4.1–6	668	16.94
6.1–8	420	10.65
8.1–15 (worst)	521	13.21
Missing	105	2.66
Worsened (≥ 2 pts. in 6-month interval)	831	21.07
ADL limit. (0–5)		
0	3236	82.05
0.1–1	404	10.24
1.1–5 (worst)	204	5.17
Missing	100	2.54
Worsened (≥ 1 activity in 6-month interval)	201	5.10
IADL limit. (0–8)		
0	2698	68.41
0.1–1	339	8.60
1.1–2	219	5.55
2.1–8 (worst)	586	14.86
Missing	102	2.58
Worsened (≥ 1 activity in 6-month interval)	524	13.29
Self-rated health		
Excellent	1128	28.60
Good	1804	45.74
Fair	754	19.12
Poor	161	4.07
Missing	97	2.46
Worsened (≥ 1 level in 6-month interval)	150	3.80
Unmet needs (0–18)		
0	1360	34.48
0.1–1	254	6.44
1.1–2.5	509	12.91
2.6–5	530	13.43
5.5+ (worst)	748	18.97
Missing	543	13.77
Worsened (≥ 2 pts. in 6-month interval)	894	22.67

Notes: ADL = activities of daily living; IADL = instrumental ADL; MMSE = Mini-Mental State Examination; Da. = daughter.

Model Specification

Specific variables included in the placement analysis are identified as follows. Table 2 presents descriptive baseline data for the sample. When scales were used, responses were summed.

Care Recipient Demographics.—Care recipient demographic variables included race, age, income, Medicaid status, and living arrangement.

Caregiver Demographics.—Caregiver demographics included caregiver relationship to care recipient, age, income, education, and duration of care.

Care Recipient Functional Status.—Functional status variables were reported at each time point by the primary caregiver and included dependence on personal assistance with ADL tasks (walking, wheeling, transfers from bed or chair, grooming, bathing, dressing, eating, using the toilet, bowel or bladder accidents, and transportation out of walking distance; Katz, Ford, Moskowitz, Jackson, & Jaffee, 1963) and dependence on personal assistance with IADL tasks (meal preparation, shopping, routine housework, managing money, laundry, telephone, medications, and heavy chores or home maintenance; Lawton & Brody, 1969). Responses included 0 = no difficulty, 0.5 = some difficulty, and 1 = maximum difficulty. Behavior problems such as asking repetitive questions, being suspicious or accusative, having trouble recognizing familiar people, engaging in behavior potentially dangerous to self or others, and wandering or getting lost were also assessed on a 19-item measure (Zarit, Orr, & Zarit, 1985; responses are 0 = no and 1 = yes). Case managers administered the 30-item Mini-Mental State Examination (MMSE), which assesses orientation, recall, and ability to name objects (Folstein, Folstein, & McHugh, 1975) at baseline only.

Caregiving Indicators.—Caregiving indicators were included at each time point. Caregiver burden was measured by a 7-item version of the Zarit Burden Scale (Zarit, Reever, & Bach-Peterson, 1980; Zarit et al., 1986; items include “do you feel: stressed between caring for the care recipient and meeting other family responsibilities, stressed between caring for the care recipient and having enough time for yourself, angry around the care recipient, feel tense or anxious due to involvement in caregiving, feel your health has suffered due to caregiving, your social life has suffered, you have lost control of your life since the care recipient’s illness, and burdened in caring for the care recipient”; responses range from 0 = never to 4 = almost always). Caregiver depression was measured by the 15-item Geriatric Depression Scale; responses include 0 = no and 1 = yes (Yesavage, Rink, Rose, & Aday, 1983). Care-

givers' ADL and IADL dependencies as well as a single-item self-rating of health were included. Caregivers' unmet needs with care recipients' ADL and IADL limitations (i.e., not enough help indicated by the caregiver) were also summed.

Service Utilization.—To measure service use, primary caregivers were asked during each assessment interview to identify, from a fixed list of options, the services they had used in the past 6 months and how often they relied on these services. Service use was based on total number of hours or days used during the 6 months prior to each assessment. Some confusion occurred for caregivers who could not distinguish between personal care (e.g., home health aide) and chore (e.g., home maintenance, yard work, and minor repairs) services; however, caregivers could generally identify the number of times such services were used and provide a percentage distribution of these units into applicable service types. When this procedure could not distinguish between types of services, the reported units were distributed equally among the applicable services. Efforts were made in the original MADDE analyses to ensure that services were not double counted.

Three community-based services are included in these analyses (chore, personal care, and adult day care), because these services accounted for 80% of community-based care use in the MADDE samples (Newcomer et al., 1999). Service units were measured in hours for in-home care services and days for adult day care. Comparisons of self-reported service use with demonstration-reimbursed claims in the MADDE analyses found that 93% of the cases could correctly identify that they were or were not receiving a service (e.g., personal care services; Donatoni, 1997). Although the reporting of actual service units was less reliable, no systematic bias was found in such reports. Caregivers were also asked whether or not additional community-based services were needed at each time point.

Analysis

Months to nursing home placement from baseline MADDE interviews was the dependent variable of interest in this study. In order to effectively identify predictors of time to placement, an event-history analysis was conducted. Event-history analysis (also called survival analysis or hazards modeling) examines whether a particular event occurs (i.e., institutionalization), and, if so, when. A specific type of event-history analysis, a Cox proportional hazards model, was utilized to analyze the probability that caregivers would institutionalize care recipients during the 3-year course of the study (see Singer & Willett, 1991). Like other types of event-history analyses (such as life tables or Kaplan–Meier

analyses), a proportional hazards model corrects for bias in estimates caused by censoring (e.g., a care recipient dies or is lost to follow-up). Additionally, this method can use data from intervals subsequent to baseline, thus allowing for a number of time-varying predictors when time-to-institutionalization data are modeled.

Because of the lack of normal distribution in many of the covariates (e.g., service utilization or depression), potential predictor variables measured at the interval or continuous levels were treated as categorical variables. Quartiles or similar methods were used to partition the variables prior to entry in the Cox proportional hazards model. A missing category was also created for each variable to determine if nonresponse was related to institutionalization for each predictor.

The Cox model included all care recipient demographics, caregiver demographics, and time-varying measurements of care recipient functional status, caregiving indicators, and service utilization. In order to determine the role of change when institutionalization was predicted, dummy variables indicating that care recipients or caregivers either “got worse/changed” or “remained the same/improved” on time-varying measures of interest during their stay in the community were included. These dummy variables specified whether changes on time-varying predictors would trigger placement. Relevant change was defined as a 10% shift (or its equivalent) on a variable (see Table 2).

An initial area of interest in this analysis was to determine whether certain thresholds existed on measures of caregiving indicators and care recipient functional status that would precipitate time to placement. Initially, interaction terms between the change dummy variables and each level of time-varying predictors were created and incorporated into the Cox model. However, none of these interaction terms were found to be significant. Therefore, the final Cox model includes only the main effects of the variables already mentioned and the change dummy variables. Even without interactions, the inclusion of these variables helped to delineate the longitudinal processes that led to institutionalization among care recipients with dementia.

Results

Predictors of time to institutionalization along with parameter estimates, *p* values, and hazard ratios are presented in Table 3. Although all variables presented in Table 2 were included in the Cox model, because of space considerations only those variables that were significant predictors (*p* < .05) are shown, and only their hazard ratios are presented in the text that follows. As already emphasized, significant predictors of time to institutionalization refer to enrollment in MADDE as the

Table 3. Cox Regression Model: Time to Institutionalization

Variable	B	SE	p	Exp (B)
Care recipient demographics				
Site ^a				
FL	-.15	.12	.23	0.86
IL	.53	.11	<.0001	1.69
MN	.66	.10	<.0001	1.93
NY	.38	.11	.0009	1.46
OH	.53	.11	<.001	1.70
TN	.20	.12	.10	1.23
WV	.09	.13	.51	1.09
Gender				
Male	.21	.06	.0007	1.23
Race				
African-American	-.66	.11	<.0001	0.52
Hispanic	-.79	.19	<.0001	0.46
Age (years)				
20-64	-.33	.18	.06	0.72
70-79	.10	.10	.36	1.10
80-84	.08	.11	.50	1.08
85-89	.15	.12	.22	1.16
90+	.38	.15	.01	1.46
Medicaid eligible at any interview	.82	.05	<.0001	2.28
Lives alone	.44	.08	<.0001	1.55
Caregiver demographics				
Age (years)				
70-74	.19	.09	.04	1.21
75-79	.35	.10	.0003	1.43
80-84	.59	.11	<.0001	1.80
85+	.58	.16	.0003	1.78
Caregiver income (\$) ^b				
<10,000	-.56	.13	<.0001	0.57
\$10,000-\$39,999	-.17	.08	.04	0.85
Missing	-.10	.19	.60	0.91
Care recipient functional status				
ADL limit. (TV)				
2	.07	.12	.58	1.07
3	.13	.13	.29	1.14
4-5	.31	.13	.02	1.36
6-8	.31	.14	.02	1.37
9-10 (worst)	.04	.16	.81	1.04
Missing	.90	.78	.25	2.46
Worsened (≥1 activity)	.39	.07	<.0001	1.48
IADL limit. (TV)				
4-5.5	.34	.19	.08	1.40
6-6.5	.53	.21	.01	1.69
7-7.5	.61	.21	.004	1.84
8 (worst)	.66	.22	.003	1.94
Missing	.49	.79	.80	1.04
Worsened (≥1 activity)	.02	.10	.82	1.02
Behavior problems (TV)				
4.1-7	.16	.09	.08	1.18
7.1-10	.28	.09	.002	1.32
10.1-13	.30	.10	.002	1.35
13.1-19 (worst)	.48	.10	<.0001	1.62
Missing	.82	.40	.04	2.27
Worsened (≥2 pts.)	.01	.09	.99	1.00
MMSE				
21-25	.26	.11	.02	1.29
16-20	.37	.11	.0008	1.45
11-15	.54	.12	<.0001	1.72
6-10	.61	.12	<.0001	1.84
1-5	.67	.13	<.0001	1.96
0 (worst)	.19	.15	.22	1.21

Table 3. (Continued)

Variable	B	SE	p	Exp (B)
Missing	.46	.14	.001	1.58
Caregiver indicators				
Zarit burden (TV)				
6.1-10	.14	.09	.10	1.16
10.1-14	.14	.09	.12	1.15
14.1-18	.25	.09	.005	1.29
18.1-28 (worst)	.43	.09	<.0001	1.54
Missing	.11	.36	.76	1.12
Worsened (≥3 pts.)	.09	.08	.27	1.09
Caregiver IADL limit. (TV)				
0.1-1	.11	.09	.26	1.11
1.1-2	-.11	.13	.38	0.90
2.1-8 (worst)	.11	.10	.27	1.12
Missing	-.86	.92	.35	0.42
Worsened (≥1 activity)	-.39	.15	.01	0.68
Self-rated health (TV) ^c				
Good	.07	.06	.30	1.07
Fair	.04	.08	.60	1.05
Poor	.37	.13	.004	1.44
Missing	-.51	.56	.36	0.60
Worsened (≥1 level)	-.14	.24	.57	.87
Unmet need (TV)				
0.1-1	-.01	.13	.98	0.99
1.1-2.5	-.07	.09	.47	0.94
2.6-5	.17	.09	.05	1.18
5.5+ (worst)	.01	.08	.92	1.01
Missing	.01	.15	.98	1.01
Worsened (≥2 pts.)	-.03	.11	.75	0.97
Service utilization				
Chore services (TV)				
Low	.30	.09	.0007	1.34
Medium	.04	.10	.71	1.04
High	.19	.12	.12	1.21
Increased (48 hr in ≥6 months)	-.12	.15	.42	0.89
Personal care services (TV)				
Low	.07	.09	.39	1.08
Medium	-.25	.11	.03	0.78
High	-.07	.12	.52	0.93
Increased (48 hr in ≥6 months)	.15	.12	.21	1.17
Adult day care (TV)				
Low	.26	.10	.006	1.30
Medium	.07	.12	.54	1.07
High	.26	.11	.02	1.30
Increased (24 days in ≥6 months)	.02	.14	.91	1.02

Notes: Only domains with significant predictors are presented. ADL = activities of daily living; IADL = instrumental ADL; TV = time-varying predictor; MMSE = Mini-Mental State Examination. Unless noted, the lowest score category for each predictor served as the reference group.

^aOregon was the reference category.

^b\$40,000 and over was the reference category.

^cExcellent was the reference category.

baseline interval, not the start of the caregiving career. However, duration of care was considered in the Cox model to empirically adjust for varying caregiving histories prior to baseline.

Care Recipient Demographics.—Male care re-

recipients were 1.23 times more likely to be institutionalized earlier during the course of the study. Care recipients who were African-American or Hispanic were 0.52 and 0.46 times less likely to experience an early institutionalization, respectively. Also, care recipients over the age of 90 were 1.46 times more likely to be institutionalized sooner. Care recipients who lived alone during the course of the study experienced an earlier nursing home placement (hazard ratio = 1.55). Care recipients who were Medicaid eligible at any interview interval were 2.28 times more likely to experience an earlier move to a nursing home. When compared with those from Oregon, care recipients from Illinois, Minnesota, New York, and Ohio were more likely to enter a nursing home earlier during the 3-year study.

Caregiver Demographics.—Caregivers who were 80 years of age or older institutionalized care recipients sooner, with those in the 80–84 category 1.80 times more likely to place. Caregivers with an annual income under \$10,000 were 0.57 times less likely to expedite institutionalization.

Care Recipient Functional Status (Time Varying).—Care recipients with 6 or more IADL impairments were likely to be institutionalized sooner; those with between 6 and 6.5 IADL impairments were most likely to experience placement (hazard ratio = 1.37). Care recipients with the most frequent behavioral problems were placed earlier (hazard ratio = 1.62). In addition, care recipients with scores of 15 or below on the MMSE experienced earlier nursing home placement; those with scores between 1 and 5 were most likely to be institutionalized sooner during the 3-year study period (1.96 times more likely). One indicator of change was predictive of time to nursing home placement; care recipients who had an increase of one or more ADL limitations were 1.48 times more likely to be institutionalized earlier.

Caregiving Indicators (Time Varying).—Caregivers who reported the highest level of burden (18.1–28 on the Zarit Burden Scale) were 1.54 times more likely to expedite institutionalization of a loved one suffering from dementia. Caregivers who rated their health as poor also institutionalized care recipients sooner (hazard ratio = 1.44). Caregivers who reported 2.6–5 unmet needs with ADL or IADL care demands were 1.18 times more likely to place earlier. One indicator of change was significantly predictive of time to institutionalization; caregivers who had an increase of one or more IADL limitations were 0.68 times less likely to place sooner.

Service Utilization (Time Varying).—“No services used” is the reference category in the Cox model. Care recipients who utilized low levels of in-home chore services were 1.34 times more likely to

be institutionalized earlier, whereas those who used moderate amounts of personal care services were 0.78 times less likely to experience an expedited placement. A curvilinear effect was apparent with adult day service use; care recipients who used low or high amounts of adult day care were 1.30 times more likely to be placed sooner.

Discussion

The large sample of home-based caregivers and care recipients, the multiregional recruitment strategy, the consideration of caregiver characteristics, and the inclusion of change variables provide a more conclusive argument than prior research that attempts to identify factors associated with expedited nursing home placement among persons with dementia. The 3-year analysis emphasizes the wide array of factors that precipitate the timing of placement and reinforces the findings of past research; for example, care recipient demographics such as age, race, Medicaid status, and living alone were all important predictors of time to institutionalization in the present study.

This analysis also builds on the findings of other large-scale studies of nursing home placement by including caregiving characteristics. As smaller studies have noted, caregivers who experience emotional stress and burden are more likely to institutionalize relatives suffering from dementia when compared with caregivers who do not experience these conditions as intensely (Aneshensel et al., 1995; Lieberman & Kramer, 1991; Zarit et al., 1986). The results confirm such findings; caregivers who experienced the highest level of burden during the 3-year study period were 1.5 times more likely to expedite placement of a loved one in a nursing home. Clearly, institutionalization decisions lie heavily with the family member who provides the bulk of assistance at home, and those who have emotional difficulty adapting to care demands will likely seek residential long-term care options for disabled elderly relatives. In addition, caregivers who were older, indicated greater unmet need, and reported poor subjective health were more likely to institutionalize care recipients earlier. As age and impairment of the caregiver increases, the ability to engage in the intensive nature of care provision may become more taxing. Once the physical resources of caregivers decline and community-based support (either informal or formal) is unavailable, the ability to provide 24-hr at-home care erodes and placement becomes a practical option. Caregivers who reported an annual income of \$10,000 or less were not as likely to institutionalize sooner. Caregivers with the lowest income could encounter particularly difficult socioeconomic hurdles when seeking appropriate nursing home care, such as geographic location or quality of available facilities, which limit the family's options to at-home care.

Indicators of dementia severity, such as impaired cognition and behavior problems, were also potent predictors of time to placement throughout the 3-year analysis. Although such results confirm prior findings, a contribution of this study is its use of change variables to further explain the role of care recipient functional status in precipitating the timing of placement. Individuals with dementia who experienced an increase in one or more ADL limitations during the course of the study were likely to be institutionalized sooner. Similar to past research (Wolinsky et al., 1993), those who experience change or decline in health and function while at home may pose greater challenges to caregivers than care recipients who remain stable over time (even while highly dependent on ADL tasks). These more dramatic changes appear to result in an earlier nursing home placement.

Change in caregiving indicators leading up to placement also predicted time to institutionalization. A finding that ran contrary to our initial expectation was that caregivers who reported increased IADL limitations during the study were less likely to expedite the institutionalization of care recipients suffering from dementia. One interpretation is that as the care recipient's status declines during the course of dementia and a primary caregiver becomes more invested in keeping the cognitively impaired relative at home, the primary caregiver no longer has the time to engage in their own instrumental daily tasks, such as shopping, arranging appointments, or managing finances. Thus, caregivers may report they need some or a lot of help with these demands. The finding suggests that shifts that occur in dementia caregiving are dynamic and operate in a more intricate manner than originally hypothesized.

Although past demonstrations have emphasized that community-based services often do not have strong effects on institutionalization, the findings of the current study imply a more complex relationship. For example, care recipients who used moderate levels of personal care services delayed institutionalization, whereas those who used low amounts of chore and adult day services and high amounts of adult day services were more likely to experience an earlier placement. Prior research has emphasized that care recipients who utilize community-based long-term care infrequently are institutionalized sooner, as the "dosage" of service is not sufficient to exert any meaningful impact on care recipient functioning or offer adequate relief to caregiving families (Gaugler & Zarit, 2001; Kosloski & Montgomery, 1995). Other analyses, however, have suggested that for some families community-based support is a stepping stone to institutionalization; caregivers become acclimated to relinquishing responsibilities to formal providers and use these services as a transition to 24-hr skilled nursing care (Zarit, Townsend, Greene, & Leitsch, 1999). The particular services used by these families may be too

little, too late; community-based support is utilized for a short period of time while the nursing home is selected. It appears as though these different processes are at work in the present study. The findings suggest that effective community-based service use is a complex process of utilization whose influence on nursing home placement is dependent on a number of factors, such as timing and family members' preferences, in addition to receiving services.

The availability of nursing home or other long-term care beds can affect institutionalization. Unfortunately, this information was not available at each of the study sites. During close-out interviews conducted at the conclusion of MADDE, case managers asked primary caregivers about possible problems in accessing appropriate care for individuals with dementia during the program's operational years. The question considered various services, among them adult day care, home care, licensed housing, and nursing homes. Access to these services was not described as a particular problem in any community, with the exception of obtaining Medicaid-funded nursing home beds, where waits of 1 month or more would be common. This is not to say that nursing home bed supply did not affect institutionalization rates in the present study; as shown in Table 3, time to institutionalization varied by site, and these differences may have been due to heterogeneity in supply. For example, during the MADDE operational years, Oregon and Florida had low nursing home bed supplies compared with Minnesota, Ohio, and New York. Moreover, licensed housing was uniquely a problem in Illinois because of the absence of such housing in the MADDE service area. Although direct measurements of nursing home supply were not available in the MADDE catchment areas, site may have served as a proxy indicator. Complicating matters was the emergence of assisted living in several of the sites during MADDE's operation, such as Oregon and Florida.

Several limitations of this study must be noted. Notwithstanding the sample size and design features, the caregivers and care recipients are not necessarily representative of the entire population. More specific measures of caregiving stress beyond depression and burden may have also provided information on how caregiver adaptation influences the timing of placement (e.g., measures of role captivity, role overload, or work conflict; see Aneshensel et al., 1995). Missing data may have affected the final empirical model; for example, a considerable number of caregivers did not provide complete information on number of years they considered themselves to be care giving. Additional indices of service use may have increased the number of predictors, such as care recipients' overnight hospital use. MADDE did include this information; however, the enrollment process into the MADDE program created a systematic truncation of prior year hospitalization effects in the sample. Individuals could not enroll into

MADDE if they were in a hospital. Thus mortality occurring during or immediately following any such inpatient stays is underrepresented among MADDE participants. Similarly, persons entering hospitals and then dying or entering nursing homes between assessment intervals also created a “survivor” bias among the continuing sample. For these reasons, hospital stays were not included in the analysis. Furthermore, because of the large number of discrete, time-varying predictors considered in the model, some complex relationships between predictors were not analyzed (i.e., interactions). Future research in this area that determines the importance of interactions between key predictors, such as socioeconomic indicators (e.g., Medicaid, income, or race), will offer additional contributions to the study of institutionalization.

This study shapes the overall understanding of how institutionalization occurs for individuals suffering from Alzheimer’s disease and has important clinical and policy implications. Behavior problems and burden were among the strongest predictors of time to institutionalization in the current analysis, and the findings add considerably to research on the dramatic interplay between problematic behavior, caregiver emotional stress, and nursing home placement for older adults with dementia. Clinical interventions that help caregivers manage and deal with the often unpredictable behavior problems that disintegrate the informal care network may prove successful in not only alleviating caregiving burden and exhaustion, but possibly delaying placement as well. Novel psychosocial caregiver interventions evaluated in Minnesota (e.g., Ostwald, Hepburn, Caron, Burns, & Mantell, 1999) and Washington (e.g., Teri & Uomoto, 1991) have demonstrated effectiveness in delaying institutionalization and reducing caregiver stress by helping family members manage and cope with behavior problems through counseling, training, and similar techniques. Although such psychosocial approaches warrant further evaluation across multiple sites, the findings here suggest that interventions that target the consequences of behavior problems may be particularly effective in delaying nursing home placement.

As other studies have noted, the complex array of predictors of nursing home placement have made it difficult to develop targeting mechanisms that identify at-risk older adults for delaying institutionalization. Similarly, defining the need for community-based services is extremely challenging (e.g., Kane et al., 1994; Kemper, Applebaum, & Harrigan, 1987). Many prior efforts at targeting have focused on the older adult at risk. This study suggests that equal attention should be given to the status of caregivers. Future efforts to target at-risk older adults, particularly people with Alzheimer’s disease, for community-based services may enjoy greater success and precision if indices of caregiver stress, burden, and physical well-being are incorporated into

assessment tools. Further development, refinement, and implementation of such approaches could result in more effective targeting practices.

This study also demonstrates that the empirical relationship between community-based service use and time to institutionalization warrants further attention. Whether a caregiver or a person with dementia uses a particular service may not provide adequate information on the effectiveness of a community-based program. In addition, even if estimates of amount of service use are included, more complex associations between utilization and outcomes may exist than simply “more is better.” Empirical work is needed on why caregiving families decide to use community-based support services, reasons for discharge, and whether such programs meet the needs of families and care recipients throughout the caregiving career. Although the state of the art does not allow us to make definitive conclusions, results such as those presented here seem to suggest that the all or nothing approach that guides access to and delivery of some state and federally funded community-based services may not effectively meet the needs of caregiving families. In other words, instead of providing a few caregivers and older adults with a lot of services, a little may go a longer way if appropriately targeted than first realized. Empirical evaluations that carefully consider whether community services are organized and delivered to prevent nursing home placement would significantly advance our understanding of the effectiveness of these programs.

Although the inclusion of change variables only resulted in two significant effects (care recipient ADL change and caregiver IADL change), these predictors add considerably to an understanding of the institutionalization process for individuals with dementia. As in prior work (Wolinsky et al., 1993), the shift to more dynamic modeling of time to institutionalization resulted in the discovery of important effects. A rapid deterioration in care recipient ADL functional status may lead to increased risk for early nursing home placement, as these dramatic changes may make it difficult for caregivers to adjust and offer the necessary amount of home-based assistance the person with dementia needs. Increases in caregiver IADL limitations may reflect shifts in the intensity of support provided by the primary caregiver in response to the progression of a loved one’s cognitive impairment. Future longitudinal research that deals with how shifts in family care occur and what triggers these transitions may offer significant contributions to our understanding of the caregiving career.

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