Journal of Gerontology: MEDICAL SCIENCES
2008, Vol. 63A, No. 9, 1005–1009

The Relation of Patient Dependence to Home Health Aide Use in Alzheimer's Disease

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Background. Although there has been much research devoted to understanding the predictors of nursing home placement (NHP) in Alzheimer's disease (AD) patients, there is currently a lack of research concerning the predictors of home health care. The objective of this study was to examine whether the Dependence Scale can predict home health aide (HHA) use.

Methods. The sample is drawn from the Predictors Study, a large, multicenter cohort of patients with probable AD, prospectively followed annually for up to 7 years in three university-based AD centers in the United States. Markov analyses ($n = 75$) were used to calculate annual transition probabilities for the ''new onset'' of HHA use (instances where an HHA was absent at the previous visit, but present at the next visit) as a function of HHA presence at the preceding year's visit and dependence level at that preceding year's visit.

Results. The dependence level at the previous year's visit was a significant predictor of HHA use at the next year's visit. Three specific items of the Dependence Scale (needing household chores done for oneself, needing to be watched or kept company when awake, and needing to be escorted when outside) were significant predictors of the presence of an HHA.

Conclusion. The Dependence Scale is a valuable tool for predicting HHA use in AD patients. Obtaining a better understanding of home health care in AD patients may help delay NHP and have a positive impact on the health and well-being of both the caregiver and the patient.

***Key Words*:** Alzheimer's disease—Home health care—Dependence Scale.

ALTHOUGH many families eventually send family members with Alzheimer's disease (AD) to nursing homes, residential care is usually considered more desirable, and an effort is made to try to keep the patient at home for as long as possible (1,2). As the AD patient declines, the primary caregiver may hire a home health aide (HHA) or companion to assist with the custodial and supportive care that AD patients require, including assistance with dressing, toileting, bathing, cooking, and companionship.

Although a substantial amount of research has been devoted to understanding the costs and predictors of nursing home placement (NHP) for AD patients (3–15), there has been very little research devoted to understanding the predictors of home health care. NHP is associated with increased mortality rates, is extremely costly, and may not improve caregiver well-being (9,16–20). Having a greater understanding of when and why AD patients employ an HHA may have an effect on lengthening the time to NHP and will allow professionals to provide better advice about the timing of in-home care to caregivers and patients. This article examines what dependence factors specific to AD predict the hiring of a HHA.

Methods

Sample

The sample used in this study is drawn from the Predictors 2 cohort of 224 patients with probable AD recruited starting in 1998 from three sites: Columbia University Medical Center, Johns Hopkins School of Medicine, and Massachusetts General Hospital. The study was approved by each local institutional review board. The inclusion and exclusion criteria are fully described elsewhere (15,21,22). Briefly, participants met Diagnostic and Statistical Manual of Mental Disorders, Third edition, revised (DSM-III-R) criteria for primary degenerative dementia of the Alzheimer's type and National Institute of Neurological Disorders and Stroke/Alzheimer's Disease and Related Disorder Association for probable AD. Enrollment required a modified Mini-Mental State Examination score of $\geq$30 (equivalent to a score of approximately $\geq$16 on the Folstein Mini-Mental State Examination) (23,24). Exclusion criteria were parkinsonism, stroke, alcoholism, schizophrenia, schizoaffective disorder, and electroconvulsive treatments.

Participants were reassessed semiannually, but because the presence of an HHA was, for the most part, assessed

Table 1. The Dependence Scale*

Item	Question
A	Does the patient need reminders or advice to manage chores, do shopping, cooking, play games, or handle money?
B	Does the patient need help to remember important things such as appointments, recent events, or names of family or friends?
C	Does the patient need frequent (at least once a month) help finding misplaced objects, keeping appointments, or maintaining health or safety (locking doors, taking medication)?
D	Does the patient need household chores done for them?
E	Does the patient need to be watched or kept company when awake?
F	Does the patient need to be escorted when outside?
G	Does the patient need to be accompanied when bathing or eating?
H	Does the patient have to be dressed, washed, and groomed?
I	Does the patient have to be taken to the toilet regularly to avoid incontinence?
J	Does the patient have to be fed?
K	Does the patient need to be turned, moved, or transferred?
L	Does the patient wear a diaper or a catheter?
M	Does the patient need to be tube fed?

Notes: In the analyses used in this article, A and B were recoded to a 0 or 1 scale. Therefore, all answers of ''frequently'' were converted from a score of 2 to a score of 1.

*Items A and B are coded as follows: no, 0; occasionally (i.e., at least once a month), 1; frequently (i.e., at least once a week), 2. The other items are coded as follows: no, 0; yes, 1.

annually, all visits during which the participant did not have information on HHA use were excluded. Of the 224 participants in the Predictors 2 cohort, 32 (14%) reported living in an institutional setting (nursing homes, assisted living facilities, retirement homes) during the entire study. These participants were excluded from the analysis sample as were the data from visits during which other participants were living in an institutional setting. There were three participants who did not have any information about HHA presence. To include the maximum number of participant visits and to obtain the most reliable transition probabilities, we required that there be four annual visits at which the presence or absence of an HHA was determined. The first four annual visits for each participant (available for 40% of participants) were used in the Markov analyses. The final study population consisted of 300 observations from 75 participants.

Measures

Presence of HHA.—HHA use was assessed annually by asking a reliable informant: ''In the past 3 months, did an HHA, attendant or any other paid individual look after the subject, excluding adult daycare and respite programs?''

Dependence Scale.—The Dependence Scale (25,26) was used to measure the participant's level of functional dependence. The questionnaire was administered to a reliable informant every 6 months and specifically targets the informant's impression of the amount of assistance required by the participant in everyday tasks. The scale consists of 13 items, representing a range of severity from mild (e.g., ''Does the patient need frequent help finding misplaced objects?'') to moderate (e.g., ''Does the patient need to be watched when awake?'') to severe (e.g., ''Does the patient have to be fed?'') levels of dependency. Table 1 gives the entire Dependence Scale. All items of the Dependence Scale, with the exception of the first two, are coded on a 0 or 1 scale. For the purposes of these analyses, the first two items (originally coded on a 0, 1, or 2 scale) were recoded to a 0 or 1 scale. The total dependence score was calculated as the sum of the items endorsed. This Dependence Scale has been shown to be a useful tool in evaluating levels of need, and hence care required, in AD patients (25,26). Therefore, the elements of this scale were analyzed as predictors of hiring an HHA.

Statistical Analyses

Markov analyses were used to evaluate annual (0.85 ± 0.19 years) transition probabilities of HHA presence (27,28). These analyses investigated the transitional probability of having an HHA as a function of HHA presence at the previous visit and of dependence level at that previous visit. The transition probabilities were calculated only for ''new onset'' of an HHA (instances where an HHA was absent at the previous visit, but present at the next visit).

In the first Markov analysis model, the total dependence score was analyzed in its continuous form. The total dependence score at the preceding year's visit and the presence or absence of an HHA at the preceding year's visit served as independent variables used to determine the transition probabilities.

In the next model, participants were assigned at each visit to one of three ''total dependence score groups,'' corresponding to a total score of 0–3, 4–6, and 7–10 on the Dependence Scale. These groups were created based on the percentage of visits during which these total scores were reported (44%, 41%, and 15%, respectively), and they also roughly correspond to the severity ranges (mild, moderate, and severe) that the dependence score captures. It should be noted that the total dependence score range is 0–13, but that there were no participants in our sample who had total scores > 10 at any visits used in the analyses. The total dependence score group status at the preceding year's visit and the presence or absence of an HHA at the preceding year's visit were the independent variables in this model.

In the last model, we wanted to identify items of the Dependence Scale that were most significant in predicting the presence of an HHA. Therefore, each item of the

Table 2. Demographic and Clinical Characteristics of Patients

Characteristic	Mean or *N*
Men/Women, *N* (%)	37 (49)/38 (51)
Age, y, mean (range) ± *SD*	74.91 (58–89) ± 7.30
Education, y, mean (range) ± *SD*	14.76 (8–20) ± 3.27
White/Black/Other, *N* (%)	69 (92)/5 (7)/1 (1)
Living arrangement, *N* (%)	
Living alone	13 (17)
With spouse or partner	53 (71)
With children	4 (5)
With other family/friends	5 (7)
Type of informant, *N* (%)	
Spouse	50 (67)
Child	16 (21)
Other family member/friend	9 (12)
Informant lives with patient	
Yes/No, *N* (%)	58 (77)/17 (23)
Time informant spends with patient	
Daily/weekly, *N* (%)	62 (83)/13 (17)
HHA present at first visit used in analyses	
Yes/No, *N* (%)	6 (8)/69 (92)
HHA present at any visit used in analyses	
Yes/No, *N* (%)	27 (36)/48 (64)
Modified Mini-Mental State Examination score at first visit used in analyses, mean (range) ± *SD*	42.77 (17–55) ± 6.81
Mini-Mental State Examination score at first visit used in analyses, mean (range) ± *SD*	23.21 (11–30) ± 3.72
Total dependence score at first visit used in analyses, mean (range) ± *SD*	3.32 (0–10) ± 1.79

Note: *SD* = standard deviation; HHA = home health aide.

Table 3. Contribution of the Dependence Score to the Probability of Transitioning From Not Having a Home Health Aide to Having a Home Health Aide at the Subsequent Visit

		Transition Probability	OR	(95% CI)	*p* Value
Continuous Model					
1-point increase in total dependence score		0.04	1.45*	(1.17–1.80)	.001
			1.48†	(1.17–1.86)	.001
Group Model					
Total dependence score range	0–3	0.06	N/A	N/A	.020
			N/A	N/A	.026
	4–6	0.17	3.09*	(1.25–7.65)	.015
			3.26†	(1.23–8.69)	.018
	7–10	0.25	4.96*	(1.23–20.03)	.025
			5.19†	(1.21–22.32)	.027
Individual Items Model					
Element of the Dependence Scale	D	0.19	3.04*	(1.32–6.99)	.009
			3.20†	(1.30–7.90)	.012
	E	0.24	3.02*	(1.18–7.73)	.021
			3.09†	(1.11–8.57)	.030
	F	0.24	4.42*	(1.91–10.21)	.001
			4.71†	(1.85–11.97)	.001

Notes: *Unadjusted model.

†Adjusted model that simultaneously controlled for the following variables: age at first visit used in analyses, sex, education in years, and type of informant at previous visit (trichotomized to the following categories: spouse, child, and other).

OR = odds ratio; CI = confidence interval; N/A = not applicable.

Dependence Scale (still coded on a 0 or 1 scale) was studied individually. The presence or absence of a single item of the Dependence Scale at the preceding year's visit and the presence or absence of an HHA at the preceding year's visit served as independent variables.

Initial analyses were unadjusted. In subsequent ones we simultaneously controlled for the following variables: age at first visit used in analyses, sex, education in years, and type of informant at previous visit (a dummy variable trichotomized to the following categories: spouse, child, and other, using spouse as the reference group). In the adjusted analyses only the odds ratios (OR), 95% confidence intervals (CI), and *p* values were reported.

Results

Demographic Characteristics

Demographic and clinical characteristics of the patient sample are summarized in Table 2. There was an almost equal split between men and women. The sample was largely white and well educated. Most participants were living with spouses, and only six had an HHA at the first visit used in the analyses.

The average Mini-Mental State Examination score at the first visit used in the analyses and the average total dependence score indicate that AD patients were in the early stages of the disease. Informants who reported on patient levels of dependency were mostly spouses who lived with and were in daily contact with participants. Although measures of actual caregiving involvement by these informants were not obtained, it would appear that informants were family caregivers with primary responsibility for the welfare of the patients.

Markov Analyses

Table 3 (Continuous Model) reveals that the total dependence score at the previous year's visit was a significant predictor of transitional probabilities at the next year's visit. A transition probability of 0.04 for the presence of an HHA (new onset) with a total dependence score of 1 indicates that 4% of participants who had a total dependence score of 1 at the preceding year's visit (n-1) and who did not have an HHA at the preceding year's visit (n-1), had an HHA at the next year's visit (n). The transition probabilities can be calculated for any total dependence score. For example, a participant with a total dependence score of 5 would have a transition probability of 0.16, indicating that 16% of participants who had that total dependence score at the previous visit and who did not have an HHA at the previous visit had an HHA at the next visit. The transition probabilities increased from 0.03 when the participant had a total dependence score of 0–0.54 when the total dependence score was 10. The adjusted model was also significant.

Table 3 (Group Model) shows that the total dependence score group at the preceding year's visit was a significant predictor of transitional probabilities at the next year's visit. The transition probabilities increased from 0.06 in the first dependence level group to 0.25 in the third dependence

level group. The probability of having an HHA the following year (provided that the participant did not have one at the year before) was 6% for participants with a total dependence score between 0 and 3, 17% for participants with a total dependence score between 4 and 6, and 25% for participants with a total dependence score between 7 and 10. These three total dependence score groups remained significant even in the presence of the other covariates in the adjusted model.

When each item of the scale was examined individually in the Markov analysis, three items showed significant effects on transition probabilities. Table 3 (Individual Items Model) reveals that the presence of items D–F of the Dependence Scale at the previous year's visit were significant predictors of transitional probabilities at the next year's visit. Transitional probabilities for the presence of an HHA (provided that one was not present at the previous year's visit) were 0.19 if the participant needed to have household chores done for him/her at the previous visit, 0.24 if the participant needed to be watched or kept company when awake, and 0.24 if the participant needed to be escorted when outside. These three items had a significant influence on HHA presence over and above the other covariates in the adjusted models.

Discussion

We found that the annual transitional probabilities of the presence of an HHA increased as the total dependence score increased. Caregivers are more likely to hire an HHA as the patient becomes more dependent. HHA use increased substantially when the total dependence score was in the moderate to severe range. The need to have household chores done for oneself, the need to be watched or kept company when awake, and the need to be escorted when outside are the three elements of the Dependence Scale that, individually, were significant predictors of HHA use.

Because approximately 75% of AD patients eventually enter nursing homes (29), a significant amount of research has been dedicated to understanding the predictors of NHP (1,3–8,10–14,30,31).

NHP is associated with a variety of both health-related and monetary costs. Placement into nursing homes has been associated with shortened survival (16,17,19,20) and accelerated cognitive decline (32) in patients with AD. Institutionalized patients with dementia experience higher mortality than do similarly impaired patients who remain in the community (16,17,20). Nursing home care is a major expense for AD patients and their families as the cost per year for a private room in a nursing home is about $75,000 (33), and studies (2,34,35) have found that costs are substantially lower for patients living at home than for those living in an institutional setting. Although families may elect to place loved ones in nursing homes to alleviate the physical and emotional burden that increases as the patient's illness progresses, it is not clear that family caregivers' health and well-being improve over time following NHP (9) or that their roles and responsibilities are significantly altered (18).

Understanding at what point AD patients are more likely to get/need an HHA will allow caregivers to be more realistic in assessing how they will continue to provide care for their loved one at home. By establishing dependence markers that predict the hiring of HHAs, clinicians can better advise caregivers about what point additional home care may become necessary. Hiring an HHA represents a vital point in the transition from home care to institutional care. One of the most frequently cited reasons for institutionalization of AD patients is the burden associated with providing 24-hour care (36). Studies have reported, however, that dementia caregivers consistently underuse available formal care resources (37). These low utilization rates are attributed to poor knowledge of the availability of such resources (38). Because most families use institutional care as a last resort, and in-home care is often provided long after it is in the caregiver's best interest (1,39), an HHA may allow AD patients to remain out of long-term care longer and may help caregivers balance their own well-being with that of their loved one. Focusing on how hiring an HHA can alleviate caregiver distress and improve caregiver coping skills may have an impact on the health and well-being of the caregiver and the survival time of the patient (19).

There are several limitations to this study. AD patients in our study were from tertiary care university hospitals and specialized diagnostic treatment centers, were well-educated, and were mainly white. Thus, this is a nonrandom sample of persons affected by AD, and our results may not be generalizable to patients with other ethnicities, patients with lower levels of education, and community-dwelling AD patients. Although we had semiannual data for participants' dependence levels, we had only annual data for HHA use. With semiannual data available for both measures, we may have been able to obtain a more accurate conclusion about the link between the Dependence Scale and HHA use. HHA presence was examined as a dichotomous variable, but it is possible that examining HHA use as a continuous variable would have been more effective.

Confidence in our findings is strengthened by several factors. Participants in this study population received careful diagnosis and clinical follow-up. Clinical diagnosis took place in university hospitals with specific expertise in dementia and AD. The diagnosis of AD has been confirmed in a high proportion (93%) of individuals who have come to postmortem evaluation (14,15). The patients were followed prospectively, which eliminates the potential biases inherent in deriving information from retrospective chart reviews. Our cohort had a high rate of follow-up participation with very little missing data. Evaluations were performed annually, and visits for the first 4 years of enrollment in the study were used. By analyzing the first 4 years of study participation, we were able to study the pivotal time period during which AD patients are most likely to begin needing/using an HHA. Providing multiple assessments of HHA use permits more accurate estimates of transition probabilities. Also, participants were recruited at early stages of the disease and followed for long periods of time. Thus, the analyses are not compressed in time and describe the progression over time.

To our knowledge, this is the first study to investigate how the elements of the Dependence Scale affect HHA use in AD patients and is one of the few investigations into the use of HHAs in AD patients in general. More research concerning the quality of life and health status of caregivers and patients

who have home health care is of critical importance. With more literature devoted to the monetary and emotional impact of home health care on AD patients and caregivers, a more direct analysis between nursing home care and in-home institutional level care can be examined.

ACKNOWLEDGMENTS

The Predictors Study is supported by grants AG07370 (from the National Institute on Aging) and RR0064 (from the National Center for Research Resources).

Author contributions are as follows: Rachel K. Scherer: conception and design, acquisition of data, analysis and interpretation of data, drafting of manuscript, critical revision of manuscript for important intellectual content; Yaakov Stern and Nikolaos Scarmeas : conception and design, acquisition of data, analysis and interpretation of data, critical revision of manuscript for important intellectual content; Jason Brandt, Deborah Blacker, and Marilyn Albert: acquisition of data, critical revision of manuscript for important intellectual content.

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Received August 10, 2007
Accepted December 29, 2007
Decision Editor: Darryl Wieland, PhD, MPH