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

Rachel K. Scherer, 1 Nikolaos Scarmeas, 1 Jason Brandt, 2 Deborah Blacker, 3 Marilyn S. Albert, 2 and Yaakov Stern 1

1Cognitive Neuroscience Division of the Taub Institute for Research in Alzheimer’s Disease and the Aging Brain, the Gertrude H. Sergievsky Center, and the Departments of Neurology and Psychiatry, Columbia University Medical Center, New York, New York.
2Departments of Psychiatry and Behavioral Sciences and Neurology, Johns Hopkins University, Baltimore, Maryland.
3Departments of Psychiatry, Massachusetts General Hospital and Harvard Medical School, Boston.

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 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 ≥ 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
HHA, attendant, or any other paid individual look after the
asking a reliable informant: “In the past 3 months, did an
Measures

The study population consisted of 300 observations from 75
participants. (27,28) These analyses investigated the transitional prob-
ability 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,” corre-
spanding 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

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 de-
pendence. 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 prob-
ability of having an HHA as a function of HHA presence at
the previous visit and of dependence level at that previous
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Note: 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.
Table 2. Demographic and Clinical Characteristics of Patients

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

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

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CORRESPONDENCE

Address correspondence to Yaakov Stern, PhD, Sergievsky Center, 630 West 168th St., P&S Box 16, New York, NY 10032. E-mail: ys111@columbia.edu

REFERENCES


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