Nursing Home Admission for African Americans With Alzheimer’s Disease

Susan C. Miller,1 Thomas R. Prohaska,2 and Sylvia E. Furner1

1Division of Epidemiology and Biostatistics, and 2Department of Community Health Sciences, School of Public Health, University of Illinois at Chicago.

Background. For African Americans with Alzheimer’s disease (AD), little is known about the time to, and risk factors for, nursing home admission (NHA). Using Consortium To Establish a Registry for Alzheimer’s Disease (CERAD) data, this study provides information on NHA for African Americans.

Methods. This longitudinal study followed subjects (N=122) for as long as 7 years and used survival analysis methodology and variable values at baseline and at follow-up to identify NHA risk factors. Studied were sociodemographic variables, physical symptom and disease status variables, the Blessed Dementia Rating Scale (including subscores), the Clinical Dementia Rating (CDR), and the Mini-Mental State Examination.

Results. Only 25% of African Americans with AD were estimated to have had a NHA by 3.4 years (confidence interval 2.1, 5.4). Being unmarried resulted in a five times earlier NHA (p<.01), and each unit increase in the CDR resulted in a 74% earlier NHA (p<.01). In the absence of the CDR, limitation in activities of daily living was associated with earlier NHA (p<.05).

Conclusions. Findings suggest that African Americans with AD spend a substantial time in the community prior to NHA, a longer time than observed in similar studies among whites. This raises public health and clinical concern that African Americans with AD may be residing in the community with substantial unmet needs, and that their caregivers have potentially high levels of burden. The independent associations with time to NHA observed here, although few in number, are consistent with other related research.

Nursing home admission rates are high, and stays are long and costly for persons with Alzheimer’s disease (AD) and related disorders (1,2). Still, studies focusing on time to, or risk factors for, nursing home admission (NHA) for these persons are infrequent when compared to the more general nursing home (NH) utilization research. Additionally, no known studies have focused on NHA for African Americans with AD and related disorders.

In survival analysis studies of community-based persons with AD and related disorders (whose access to the health care system for evaluation of dementia symptomatology was proximal to study entry), 5-year cumulative NHA rates ranged from 62.8% (3) to 75% (4), and median times to NHA ranged from 2.5 years (5) to 3.1 years (6). A lack of adequate racial diversity was a limitation of these studies, with all or most of the subjects being non-Latino whites.

Studies focusing on non-Latino whites with AD and related disorders have found patient illness/need variables most consistently associated with NHA. In particular, dementia rating scales have been shown to be independently associated with NHA (5,7), with the Clinical Dementia Rating scale (CDR) the most consistent (3,5-8). Studies also report the Mini-Mental State Exam (MMSE) score (3,6,7) and behavior disturbances and psychiatric symptomatology (9,10) to be important risk factors for NHA. Although limitations in activities of daily living (ADLs) and in instrumental activities of daily living (IADLs) have been associated with increased risk of NHA (6,7,11), these findings are less consistent (9,12). Variables reflecting caregiver burden/need and psychological distress are also important risk factors for NHA (8,9,12).

Contrary to the more general nursing home utilization research, being older and unmarried were independent risk factors for NHA in only a small percentage of the NHA studies on persons with AD and related disorders (5,6,10). The lack of association for being unmarried, however, may be a result of study designs that resulted in rather homogeneous samples [i.e., sampling from groups of patients/caregivers; (9,11)].

In the more general NH literature, research on the effects of race on NHA has consistently shown that being white is an independent predictor of NHA (13–15). In a prospective follow-up study, African Americans, even after adjustment for income, social support, and physical and cognitive impairment, were half as likely as whites to enter a nursing home (16). Furthermore, recent research suggests that formal in-home community care does not fully compensate for the lower NH utilization seen in African Americans (15).

To our knowledge, our study is the first to examine time to, and risk factors for, NHA for African Americans with Alzheimer’s disease. We use survival analysis methodology here to examine time to NHA. In studying risk factors for NHA, we update the variable values with the most recent follow-up information. This methodology results in identification of risk factors most proximal to the event of NHA, which is important in understanding when, in the trajectory of the illness, institutionalization is more likely.

Methods

The Sample Studied

The Consortium To Establish a Registry for Alzheimer’s Disease (CERAD) project enrolled cases between April 1987 and
January 1995. Almost all (99%) of the African American cases were enrolled in 1988 or later. Cases were referred to CERAD research sites (primarily AD research centers) across 14 states, and in 8 of 9 United States census regions. CERAD cases, at study entry, had a diagnosis of probable or possible AD, with minor modifications, according to National Institute of Neurologic and Communicative Disorder and Stroke/Alzheimer’s Disease and Related Disorder Association (NINCDS/ADRDA) guidelines (17). A more in-depth discussion of the CERAD project can be found elsewhere (18).

The race of CERAD cases was self-identified. There were initially 151 non-Latino African American cases from 19 CERAD sites to be studied. Twenty-five of the 151 cases (17%) had no follow-up data available after study entry, and thus were excluded from this study (n=126). When compared to those cases remaining in the study, excluded cases had less impairment per the Blessed Dementia Rating Scale (p < .05) and the Blessed ADL subscore (p < .05; variable descriptions follow). No other important differences were evident between the sample of 126 and 151.

For most baseline variables of interest, less than 3% of the cases were missing values. For these variables, cases with missing baseline values were excluded from analyses (n=4, 3%), and the effective sample size became 122. Imputation of missing follow-up variable values will be discussed.

**Independent Variables**

Sociodemographic variables included patient age, gender, education (in years), and marital status. The marital status categories of widowed, separated/divorced, and never married were combined into an unmarried category. Perceived illness/need variables were obtained from a CERAD-modified Blessed Dementia Rating Scale (19). For this scale, the informant provided the information based on the subject’s cognitive ability in the preceding 6 months. Variables derived from scale data included: (a) a continuous variable representing the total Blessed Dementia Rating Scale score (scoring range 0–17); (b) a continuous variable representing the memory and IADLs (scoring range 0–8); and (c) a continuous variable representing the ADLs (scoring range 0–9). For the eight memory and IADL items, the rating scale was 0 for no impairment, 0.5 for some impairment, and 1 for severe impairment. For the ADL sub-score, impairments in eating, dressing, or toileting were rated from 0 (no assistance required) to 3 (total dependence).

Symptom and disease status variables included diastolic and systolic blood pressure readings, depression, and the presence of (and history of at baseline) heart disease, stroke, epilepsy, thyroid problems, Parkinson’s disease, cancer, or other physical condition. A global physical and neurological evaluation (i.e., a clinical assessment of normal or abnormal) was also available at baseline and at follow-up.

The dementia stage was represented via a global score using CDR (20). The CDR stage was based on a clinician’s rating of the categories of memory, orientation, judgment and problem solving, community affairs, home and hobbies, and personal care. Stages range from 0 (no dementia) to 5 (terminal dementia). To study the influence of, and to control for, cognitive impairment a revised MMSE (scoring range 0–30) was used (21).

Because geographic area is believed to influence NHA (22), we controlled for geographic region of residence. Cases resided in eight of nine U.S. census regions. No subjects resided in the Mountain region.

**The Dependent Variable**

The dependent variable is time to NHA. Survival time was counted from the date of entry into the CERAD study to NHA and, as in similar studies (3–7), this time was believed to be proximal to entry into the health care system for evaluation of AD symptomatology. Based on evidence in the literature that NHAs for persons with cognitive impairment are permanent (13), the study endpoint was reached when a subject entered a nursing home for the first time. Right censoring occurred when a patient died or was lost to follow-up. Loss to follow-up occurred when there was no follow-up evaluation, death, or NHA for a 24-month period following date of study entry or last yearly follow-up.

**Analytical Approach**

Using baseline values, descriptive analyses were conducted. The method of Kaplan and Meier (23) was used to generate survival and hazard distribution curves and probabilities.

A Cox Proportional Hazards model using baseline and follow-up variable values (i.e., an updated or time-dependent Cox model) was used for univariate and multivariate analyses. The updated model’s estimation of regression coefficients represents the effect of baseline and of subsequent values (24).

To accomplish the updated modeling, cases were assigned the baseline value upon entry, and the follow-up value for each subsequent year they remained in the community. As recommended by Altman and De Stavola (24), any missing follow-up values were replaced. For continuous variables determined to have strong, consistent linear trends, imputation was performed for a missing follow-up value by averaging, when available, the prior and subsequent year’s values. Only four variables fell into this category—(a) the total Blessed Dementia Rating Scale, its subscores representing (b) memory and IADLs and (c) ADLs, and (d) the MMSE. For all other variables, missing values were replaced by entering the previous variable value.

Continuous variables were tested for linearity. Assessment of the proportionality of the estimated relative risks of the predictor variables over time was performed. This assessment included an examination of log (–log) estimated survival curves, as well as tests for significance of interactions with survival time. The estimated relative risk of the marital status variable was found to be nonproportional over time, the estimated relative risk appearing to change at 3 years. Therefore, to present data for this variable’s effect more accurately and clearly, two marital status variables were included in the univariate and multivariate models; one for the time interval of from-study-entry to 3 years, and the other for the interval of 3 to 8+ years (for those still at risk of NHA at 3 years). The estimated relative risk was proportional within these time periods.

**RESULTS**

Descriptive statistics for sociodemographic characteristics and physical and cognitive functioning are shown in Table 1. There was not a high degree of memory and IADL impairment at baseline, and 67 of the 122 cases (55%) required no ADL assistance at baseline.

During follow-up, 29 cases (23.7%) had a NHA, 26 cases (21.3%) died, 30 (24.6%) cases survived in the community to
Table 1. Characteristics of African American CERAD Cases at Study Entry (N=122)

<table>
<thead>
<tr>
<th>Variables</th>
<th>Mean or Percentage</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at study entry (year)</td>
<td>73.9</td>
<td>7.7</td>
</tr>
<tr>
<td>Gender (female)</td>
<td>72%</td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>57%</td>
<td></td>
</tr>
<tr>
<td>Education (years)</td>
<td>10.4</td>
<td>4.3</td>
</tr>
<tr>
<td>Memory and IADL impairment</td>
<td>4.4</td>
<td>1.7</td>
</tr>
<tr>
<td>ADL impairment*</td>
<td>.88</td>
<td>1.3</td>
</tr>
<tr>
<td>Mini-Mental State Examination</td>
<td>15.4</td>
<td>6.6</td>
</tr>
<tr>
<td>Clinical Dementia Rating 0.5</td>
<td>Uncertain</td>
<td>4%</td>
</tr>
<tr>
<td>I—Mild</td>
<td>46%</td>
<td></td>
</tr>
<tr>
<td>2—Moderate</td>
<td>39%</td>
<td></td>
</tr>
<tr>
<td>3—Severe</td>
<td>11%</td>
<td></td>
</tr>
<tr>
<td>4 &amp; 5—Profound and Terminal</td>
<td>0%</td>
<td></td>
</tr>
</tbody>
</table>

Note: IADL=instrumental activity of daily living; ADL=activity of daily living.
*Impairment per Blessed Dementia Rating Scale subscores.

Table 2. Cumulative Rate of Nursing Home Admission and Other Outcomes

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Percentage of Cases (N = 122)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admitted to nursing home</td>
<td>23.7</td>
</tr>
<tr>
<td>Died prior to nursing home admission</td>
<td>21.3</td>
</tr>
<tr>
<td>Survived in community</td>
<td>24.6</td>
</tr>
<tr>
<td>Lost to follow-up (n = 37)</td>
<td>30.3</td>
</tr>
<tr>
<td>Had at least 1 year follow-up</td>
<td>100.0*</td>
</tr>
<tr>
<td>Had at least 2 years follow-up</td>
<td>67.6</td>
</tr>
<tr>
<td>Had at least 3 years follow-up</td>
<td>32.4</td>
</tr>
<tr>
<td>Had at least 4 years follow-up</td>
<td>10.8</td>
</tr>
</tbody>
</table>

Figure 1. Estimated time to nursing home admission.

Figure 2. Estimated time to nursing home admission by marital status. Adjusted to gender = female and clinical dementia rating = 1.

the end of the study period, and 37 cases (30.3%) were lost to follow-up (Table 2). Table 2 shows the minimum lengths of time that the lost-to-follow-up cases contributed to study findings.

Baseline variable values were comparable between those cases lost and not lost to follow-up. Those who died were more often male ($p = .019$) and, at study entry, were more likely to have a history of heart disease ($p = .013$) and to have higher levels of impairment per the Blessed Dementia Rating Scale ($p = .03$) and the Blessed memory and IADL subscores ($p = .046$).

Table 3 displays those variables found, in univariate survival analysis, to be associated with time to NHA at $p \leq .05$. These variables were then included in beginning multivariate models. As previously discussed, the marital status variable was stratified by two separate time intervals. Whereas in the first 3 study years being unmarried resulted in an over three times shorter time to NHA ($p = .02$), at 3 years and later it was not significantly associated with time to NHA (data not shown). Of interest is that none of the symptom and disease status variables and the global physical or neurological evaluation ratings were significantly associated with time to NHA.

Table 4 displays multivariate analyses using the Cox Proportional Hazards model with updated covariate values. To control for regional heterogeneity, seven of the eight geographic regions were included in this model as fixed effects. Without
this fixed effects model, the relative risk of being unmarried in the first 3 study years was 3.9 [95% CI 1.34, 11.09; (data not shown)] versus 5.2 (95% CI 1.64, 11.23) as shown in Table 4. At 3 years and later, being unmarried was not significantly associated with time to NHA. There was a 74% shorter time to NHA for each unit increase in the CDR (p = .013). Impairment in ADLs was not statistically significant in the multivariate model, but the ADL and CDR variables were highly correlated (.69). Substitution of the ADL variable for the CDR variable in the same multivariate model showed ADL impairment to have a conditional relative risk for each unit increase in impairment of 1.18 [95% CI 1.001, 1.38; (data not shown)]. The MMSE was also highly correlated with the CDR (.74), but was not independently associated with time to NHA (p = .26) when substituted for the CDR. Gender was retained in the multivariate model to control for confounding, the relative risk of being unmarried in the first 3 study years being greater when controlling for gender (5.1 vs 4.2, 95% CI 1.41, 12.5). Interaction terms between marital status and gender and marital status and the CDR were not statistically significant.

DISCUSSION

Time To Nursing Home Admission

Twenty-five percent of the African Americans with AD studied here were estimated to have been admitted to nursing homes by 3.4 years after study entry (95% CI 2.1, 5.4). Similar studies among whites with AD estimate that 50% have been admitted by this time (5,6). Although this comparison suggests that African Americans are residing in the community for longer periods of time than whites with AD and related disorders, a comparative study across these race groups is needed to conclude whether real differences exist.

Risk Factors for Nursing Home Admission

As in other studies (5,6), being unmarried was associated with a shorter time to NHA, a five times faster NHA in the first 3 study years. After the first 3 study years, however, this variable’s importance diminished, possibly due to the small number of cases remaining in the study at 3 years (n=43) and the small number of NHA after 3 years (n=7). The independent association seen here between a more advanced dementia stage, per the CDR, and a shorter time to NHA is comparable to findings in similar AD studies focusing on whites (3,6,13). This finding supports the utility of the CDR in predicting NHA across race groups. The MMSE was not independently associated with time to NHA. Although this finding is not consistent with other NH utilization studies on persons with AD (3,6,8), it is consistent with work by Salive and associates (16), who found the Short Portable Mental Status Questionnaire predictive of NHA for whites but not for African Americans. ADL impairment was independently associated with a shorter time to NHA (p=.05) when substituted for the CDR in the final multivariate model. This finding provides support for the importance of ADL impairment as a predictor of NHA for African Americans with AD, especially in the absence of the CDR.

Limitations

As in most of the studies of NHA for persons with AD and related disorders, the African Americans studied here were referrals. Therefore, generalization of study findings is most likely affected by referral bias. For whites, referral bias has resulted in subjects being less frequently women, more highly educated, more commonly white-collar workers, more frequently married, more likely not to live alone, and less frequently institutionalized than AD incident cases (25). Also, because of CERAD screening criteria, persons in this study, at study entry, had no serious physical illness, lower levels of cognitive impairment /dementia, and had an informant available. Because of these factors, findings presented here are likely not generalizable to the population of African Americans with AD residing in the community. The CERAD data, however, represent some of the best data now available on persons with probable or possible AD, and our findings provide an important first glimpse of NHA for non-Latino African Americans. Differential lost to follow-up may have influenced the results seen here. Cases lost to follow-up prior to attainment of any...
follow-up information had less impairment (per Blessed Dementia Rating Scale) than those cases remaining in the study. This may have resulted in earlier NHA than would have been otherwise observed.

Even considering the above limitations, our study findings appear valid in that they are consistent with previous related research. By using survival analysis methodology, we were able to utilize available time and variable information even for those persons who died or were lost to follow-up. Additionally, for those cases with any follow-up information, there were no significant differences between cases lost and not lost to follow-up.

Conclusion

Our findings suggest that African Americans with AD spend a substantial period of time in the community prior to NHA, and this time is much longer for married persons. In addition to marital status, this study documents the importance of the CDR in predicting time to NHA for African Americans with AD and of ADL impairment in the absence of the CDR.

To gain a broader, more definitive understanding of the time to, and risk factors for, NHA for individuals with AD across racial/ethnic groups, comparative longitudinal research designs using expanded multivariate models (with community-level and caregiver-related variables) and probability sampling of a community-based cohort are needed. While a more definitive understanding is needed, findings here do raise a public health and clinical concern that African Americans with AD may be residing in the community with substantial unmet needs, and their caregivers may have potentially high levels of burden. Clinicians are advised to consider this possibility when caring for, and when counseling, these persons and their families on care alternatives.

Acknowledgments

This study was supported by an Alzheimer’s Association Pilot Project Grant and by NIA Training Grant AG-00231.

The authors thank Dr. Albert Heyman, the CERAD principal investigator, for his input and support of this study, and Dr. Gerda Fillenbaum for her assistance and support. We also thank the CERAD staff who provided assistance, especially Mary Strickland and Duane Beekly.

A related paper examining nursing home admission for nonwhites (i.e., African Americans and Hispanics) was presented at the 1997 Annual Meeting of the American Geriatrics Society.

Address correspondence to Dr. Susan C. Miller, Center for Gerontology and Health Care Research, Brown University, Box G-H3, Providence, RI 02912. E-mail: Susan_Miller@Brown.edu

References


Received June 18, 1998
Accepted September 10, 1998