LIVING ALONE WITH ALZHEIMER’S DISEASE: CROSS-SECTIONAL AND LONGITUDINAL ANALYSIS IN THE REAL.FR STUDY

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Abstract: The purpose of this study was to examine the characteristics of Alzheimer’s disease (AD) patients living alone and to describe the rate of cognitive and functional impairment after a one-year follow-up. Design and setting: In a prospective longitudinal study conducted by the French network on Alzheimer’s disease (the REAL.FR study), 677 older community-dwelling AD patients were interviewed and completed questionnaires and evaluation scales every 6 months during a one-year follow-up. Measurements: All patients were assessed by trained staff who collected data on neuropsychological status using the Mini Mental State Examination (MMSE), behavioural disturbances with the Neuropsychiatric Inventory (NPI) and nutritional status with the Mini Nutritional Assessment (MNA). Patients were assessed for current mobility and function in activities of daily living (ADL) and instrumental activities of daily living (IADL). Results: At inclusion, 28% of the 677 non-institutionalised individuals with AD lived alone. Those who lived alone were significantly older than those who did not, and among them the percentage of women was significantly higher. Patients living alone were at increased risk of malnutrition and were more likely to have a low income than those living with others. Persons with AD living alone made greater use of health services. Dementia stage evaluated by cognitive impairment (MMSE) and ADL disabilities was similar in both groups. At one-year follow-up, the mortality rate was significantly higher in AD patients living with others. Institutionalisation and hospitalisation rates were similar. Conclusion: These results draw attention to the fact that elderly persons with AD living alone are a subpopulation with specific needs which require the development of targeted interventions. Further investigation of the factors associated with the lower mortality rate in AD patients living alone is necessary, and the results of long-term follow-up in this prospective study should shed light on this question.

Key words: Alzheimer’s disease, dementia, living alone, outcome.

Introduction

There is an increasingly vulnerable group of older people living alone with chronic illness (1, 2), in part because of the constraints of work, finances and location. The number of persons living alone for all age groups increases most rapidly in the oldest age cohort (3). The importance of the fact that the population is ageing is that dementia is more prevalent among this population. There are, of course, many different kinds of dementia, and among them Alzheimer’s disease (AD) has received the most attention.

AD is a chronic progressive illness characterised by loss of memory and other intellectual functions, as well as by personality changes. Affected individuals gradually lose the ability to care for themselves and need increasing levels of supervision and care as the disease progresses. Intuitively, these individuals living alone could be considered a particularly high-risk group for adverse outcomes due to lack of support and supervision. However, little attention has been directed to variability in the course of AD and the extent to which people in various stages of the disease can manage to live alone.

In the present study, we compared the characteristics of 2 groups of community-dwelling AD patients: those who lived alone versus those living with others. We also compared functional and cognitive impairment in these patients after one-year follow-up.

Methods

The study population was recruited during a consultation in one of the 16 centres of the French network on AD (Réseau sur la maladie d’Alzheimer français). All patients met the DSM-IV and NINCDS –ADRDA criteria for AD (4, 5), lived in the community at the time of enrolment and were looked after by an informal caregiver. At inclusion, each patient underwent a full investigation, described in detail elsewhere (6). It included neuropsychological evaluation using the Mini-Mental State Examination (MMSE) (7), evaluation of behavioural disturbances with the Neuropsychiatric Inventory (NPI) (8), and of nutritional status with the Mini Nutritional Assessment (MNA) (9). To assess caregiver burden, Zarit’s Burden Interview was used (10). Patients were assessed for current mobility and function in activities of daily living (ADL) (11) and instrumental activities of daily living (IADL) (12). The IADL scale consists of 8 items: food preparation, housekeeping, grocery shopping, doing laundry, handling
money, using the telephone, taking medications and using public transportation.

In order to investigate evolution of AD, data were examined at 6 months and 12 months with the same methodology. At each visit, patients and caregivers were asked about current function and medical and non-medical care utilisation.

Statistical Analysis System software version 6.10 was used for analysis. Frequencies and proportions were calculated for all categorical variables. Means and standard deviations were calculated for all continuous variables. For unadjusted analysis, the chi-square test was used to determine significance for categorical variables. The Wilcoxon rank sum test was used to determine significant differences in distributions of continuous variables. Values of \( P < 0.05 \) were considered as significant. Multiple regression was used to determine the factors independently associated with living alone among the demented subjects.

Results

Nearly 28% of the 677 non-institutionalised individuals with AD lived alone. There were significant differences between those who lived alone and those who did not across a number of variables (Table 1). Persons with AD living alone were significantly older than those who did not, and significantly more women lived alone than men. Patients living alone were at increased risk of malnutrition (39.56% had an MNA < 23.5 versus 29.65% in the group living with others) and were more likely to have limited financial resources (73.14% had an income < 1500 euros monthly versus 38.49% of those living with others; \( P < 0.001 \)). Service utilisation patterns of the 2 groups were compared, and the use of certain services varied by living arrangement. Persons with AD living alone used home health services more frequently. Dementia stage evaluated by cognitive impairment (MMSE) and ADL disabilities was similar in both groups. We found no difference in rate of depression (\( P = 0.901 \)), cardiovascular diseases (\( P = 0.605 \)) or number of intercurrent diseases (\( P = 0.385 \)) between the 2 groups at inclusion.

We analysed the characteristics of 573 patients seen after one year of follow-up (Table 2). The mortality rate was significantly higher in patients with AD living with others (6% versus 1.92%; \( P = 0.044 \)). Institutionalisation and hospitalisation rates were similar. At one year, the average change in cognitive impairment evaluated by MMSE score (follow-up score - initial score/1 year of follow-up) and in dependence evaluated by ADL (follow-up score - initial score/1 year of follow-up) was statistically significant in both groups (\( P < 0.05 \)) and the progression rate was similar.

We used a regression model to determine independent predictors of death. This analysis was carried out in the whole population seen at one year. Living alone decreased the odds of death (OR=0.18; 95% CI=0.04-0.87). Independent predictors of death were male gender (OR=3.56; 95% CI=1.29-9.88), age (OR=1.10; 95% CI=1.01-1.19) and MNA <23.5 (OR=5.55; 95% CI= 2.02-15.29).

Table 1

<table>
<thead>
<tr>
<th>Characteristics of demented subjects</th>
<th>Living alone (n = 186)</th>
<th>Living with others (n = 491)</th>
<th>( p )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in years, mean (SD)</td>
<td>79.4 + 5.9</td>
<td>76.9 + 7.0</td>
<td>&lt; 0.0001</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male (%)</td>
<td>6.46</td>
<td>38.28</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>Home services</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health services (%)</td>
<td>75.55</td>
<td>40.57</td>
<td>0.0217</td>
</tr>
<tr>
<td>Other services (%)</td>
<td>67.23</td>
<td>69.40</td>
<td>&lt;0.0001</td>
</tr>
<tr>
<td>MMSE score (mean + SD)</td>
<td>19.8 + 4.0</td>
<td>20.1 + 4.2</td>
<td></td>
</tr>
<tr>
<td>ADL score (mean + SD)</td>
<td>5.55 + 0.72</td>
<td>5.39 + 0.96</td>
<td></td>
</tr>
<tr>
<td>NPI score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 6 (%)</td>
<td>30.82</td>
<td>47.35</td>
<td></td>
</tr>
<tr>
<td>7-17 (%)</td>
<td>28.10</td>
<td>12.55</td>
<td></td>
</tr>
<tr>
<td>&gt; 17 (%)</td>
<td>41.08</td>
<td>40.15</td>
<td></td>
</tr>
<tr>
<td>MNA score</td>
<td></td>
<td></td>
<td>0.014</td>
</tr>
<tr>
<td>&gt; 23.5 (%)</td>
<td>60.44</td>
<td>70.35</td>
<td></td>
</tr>
<tr>
<td>&lt; 23.5 (%)</td>
<td>39.56</td>
<td>29.65</td>
<td></td>
</tr>
<tr>
<td>Zarit score</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0 – 20 (%)</td>
<td>51.12</td>
<td>49.45</td>
<td></td>
</tr>
<tr>
<td>21 – 40 (%)</td>
<td>34.83</td>
<td>38.13</td>
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<tr>
<td>&gt; 40 (%)</td>
<td>14.05</td>
<td>12.42</td>
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</tbody>
</table>

Note: only significant \( p \) values are given
Discussion

As a result of trends toward nuclear families and fewer children, the proportion of elderly persons living alone has been increasing in recent years. Dementia in persons aged 65 years or over is the most costly disorder in terms of formal services, especially when patients live alone (13).

The present study confirms the relatively high proportion of AD patients living alone in the community. We found that community-dwelling subjects with dementia who lived alone were more likely to be women, which was expected, given their greater longevity and a higher proportion of widows compared to widowers. Many of these patients living alone had low income.

Of the total population believed to have Alzheimer’s disease, 10 to 25% are estimated to be living alone (14, 15). Within a population-based cohort study, Prescpol and colleagues examined characteristics of demented elderly living in the community, with and without caregivers (16). The results showed that approximately one-third of the subjects lived alone. This proportion is similar to that seen in the multicentre Canadian Study of Health and Aging (17). Forty-two percent of subjects whose adult children were their caregivers lived alone. Multivariate analyses revealed that subjects with dementia who were living alone were independently and significantly more likely to be women and to have dementia of shorter duration, lesser severity, and lesser functional impairment than those living with others. In our cohort, we found no association between better cognitive test performance or higher functional ability and living arrangement.

The present study found a significantly higher mortality rate after one year in AD patients living with families. It might be expected that intercurrent diseases would influence the mortality rate, but at inclusion this variable was similar in both groups. Independent predictors of death were male gender, age and MNA < 23.5. Further studies are necessary to address this topic.

In addition to the substantial cognitive, affective, and behavioural deficits affecting people with AD, they are also at risk for problems associated with living alone in later life. These include loneliness, depression and an increased need for community-based or institutional long-term care services. The decision to institutionalise a patient with dementia is complex and is based on patient and caregiver characteristics and the socio-cultural context of both patients and caregivers. In a prospective study at 8 sites in the United States, Yaffe and collaborators showed that living alone is an independent predictor of nursing home placement (18). We plan to examine this finding with a longer follow-up of our cohort.

Selection bias is an issue in many previous dementia studies, including our own. Our volunteers or patients were recruited from specialised service settings. It is possible that family caregivers may have sought help for their demented relatives because they had more difficulty in dealing with the situation. Alternatively, it may have been that the caregivers who were less busy caring for demented elders were those who had the time to participate in these studies. Another bias could be the possibility that centre-based studies cannot really determine the specific problems of demented patients who live alone without caregivers. Also, perhaps informants who did not live with the subject underestimated or under-reported some impairment.

Longitudinal follow-up of this cohort is continuing and will allow the testing of hypotheses regarding long-term outcomes such as survival and hospitalisation or institutionalisation among demented patients, in the context of various living arrangements. Future discussion of which outcomes matter to patients with early-stage Alzheimer disease must address the likelihood that more people will be diagnosed earlier and live alone for some time after diagnosis. Given the increasing numbers of people affected by dementing illness, consideration of effectivenss and generalisable outcomes is more relevant than efficacy of specific treatments tested under tightly controlled experimental conditions. It is important for us to understand this relationship with the aim of developing interventions to improve access, effectiveness, and efficiency of social and health services for older patients.
CROSS-SECTIONAL AND LONGITUDINAL ANALYSIS IN THE REAL.FR STUDY

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