

CHARACTERISTICS AND OUTCOMES OF DEMENTIA RESIDENTS IN AN ASSISTED LIVING FACILITY

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ABSTRACT

Background. Assisted living (AL) is the fastest growing segment of residential long-term care in the US. At least half of the estimated 1 million AL residents have dementia or cognitive impairment, with many AL facilities offering specialized dementia services. Little research has been done on the demographics, outcomes, or clinical variables of this population.

Methods. Participants were a cohort of 144 residents admitted to the AL unit of Copper Ridge, a specialized dementia-care facility. Comparison samples included 737 patients with dementia residing in other locations (home, nursing home, and other assisted living facilities). Selected measures of cognition, behavior, medical health, and function were taken at admission to AL and at 6-month intervals.

Results. When compared with residents of the dementia-specialized AL facility, dementia patients at home were younger, less cognitively impaired, and less likely to exhibit wandering, delusions, or aggression. Residents of a dementia-specialized nursing home had more cognitive impairment, greater medical comorbidity, and were more dependent on caregivers. The 2-year mortality rate in the dementia-specialized AL was 23%, significantly lower than rates reported for nursing homes. Primarily due to increasing care needs, most residents in the specialized AL relocated to a nursing home after a median stay of 10.9 months. Depression, falling, and wandering were significant predictors of this transition.

Conclusion. Dementia-specialized AL facilities occupy a unique position in the long-term care continuum that is distinct from home-care and nursing home facilities. This research is the first step toward understanding the significant dementia population residing in assisted living. Copyright © 2000 John Wiley & Sons, Ltd.

KEY WORDS—Assisted Living; Long-term Care; Dementia; Characteristics; Outcomes; Depression

INTRODUCTION

Assisted living (AL) is a growth industry currently in a stage of transition. Defined as a residence that provides some assistance with activities of daily living while still promoting independence in residents, it is now being heavily marketed in the US as the first step in the continuum of long-term institutional care. In 1997 in the US, there were

over 1 million residents of licensed AL facilities (Assisted Living Federation of America, 1996). While 90% of the 21 000 facilities in the US classified as AL accommodate ten residents or fewer, larger facilities account for almost all of the exponential growth in the US\$ 12–15 billion per year industry (Assisted Living Federation of America, 1996). Many insurers, including Medicaid programs in 35 states (Mollica, 1998), are embracing AL in order to avoid more expensive options such as in-home care and nursing home placement. These facts, as well as the projected doubling in the size of the 85 and older population in the next 30 years (US Bureau of the Census, 1995), point to the importance of understanding

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Contract/grant sponsor: American Federation for Aging Research.

Contract/grant number: LROJ-MH56511.

the dynamics and demographics of the AL population.

The growth and changes in the AL industry will have a disproportionate effect on the care of individuals with dementia. Dementia inflicts severe physical, emotional, and economic tolls on both patient and caregiver. Institutionalization is inevitable for many patients in the later stages of progressive dementia, and consequently dementia is a leading cause of nursing home admission. It is estimated that at least half of AL residents have dementia or another cognitive impairment (US General Accounting Office, 1997). The AL industry has recognized this need and provides dementia-specialized facilities with space for wandering, specially trained staff, support for families, and appropriate activities. Approximately 30% of AL facilities in the US are specialized for dementia care or advertise some sort of dedicated dementia or Alzheimer unit, with growth in this segment expected to outperform the industry as a whole (Mollica, 1998).

An understanding of the clinical characteristics and outcomes of dementia patients in AL is crucial to the planning and implementation of good clinical care for these residents and to the allocation of public resources. However, no such study of dementia patients in AL has been done. Such a study is hampered by the transitory nature of the AL industry. This is especially true in the US where many states are currently developing minimum care guidelines for the industry, in part spearheaded by the influx of large for-profit facilities.

Dementia residents frequently leave the lower level of care provided by AL and seek a higher level of care such as a nursing home. Studies before this recent growth in commercial AL might provide insight into this transition. Such studies investigated the predictors of nursing home admission for dementia patients previously receiving a lower level of care. Dementia severity (as measured by cognitive deficit) has widely been identified as being indicative of nursing home admission (Wilkinson and Graham-White, 1980; Brodaty *et al.*, 1993; Pruchno *et al.*, 1990; Knopman *et al.*, 1988; Haupt and Kurz, 1993; Bergman, 1990; Severson *et al.*, 1994; Morycz, 1985; Colerick and George, 1986; Lieberman and Kramer, 1991), although other studies disagree with this premise (Gilleard, 1984; Gilhooly, 1986). Several studies have implicated functional status, including bowel and bladder incontinence, as a significant predictor of nursing

home admission (Severson *et al.*, 1994; Morycz, 1985; Colerick and George, 1986; Lieberman and Kramer, 1991), while others indicate the significance of extrapyramidal signs such as bradykinesia and rigidity (Lopez *et al.*, 1997; Stern *et al.*, 1997). Behavioral disturbances are often cited by caregivers as significant factors in the decision to institutionalize patients (Ferris *et al.*, 1987). Two studies showed depression in dementia patients to be a predictor of earlier nursing home admission from home (Lyketsos and Rabins, 1994; Steele *et al.*, 1990).

Although significant research has been done on the dementia population in nursing homes and their outcomes over the years, little work has been directed at understanding the AL dementia population. Because of the differences between nursing homes and AL, such as the level and type of care provided, facility design, and marketing strategies, the demographics and clinical characteristics of AL residents are likely different from those of nursing home residents. Since AL is designed to provide assistance with some but not all of the activities of daily living, it is expected that residents will have a level of functional impairment greater than home-care dementia patients and less than residents in a nursing home setting.

The study objectives were the following:

- To describe the clinical characteristics of residents in a dementia-specialized AL facility and compare them to dementia residents at home and in other long-term care facilities.
- To describe the outcomes of residents in dementia-specialized AL, including their duration of residence, discharge location, and mortality.
- To determine what variables are predictors of discharge to a higher level of care.

METHODS

Samples

The primary study population consisted of all admissions to the 60-bed AL unit of Copper Ridge, a facility specializing in the long-term care of patients with dementia, which has been described previously (Lyketsos *et al.*, 1997). All residents of Copper Ridge suffer from dementia. This sample comprised a total of 144 participants. Study inclusion criteria included admission to the AL facility between July 1994 and July 1998 with the intent to seek long-term care and completion of an initial neuropsychiatric evaluation. The facility and

evaluation methods have been described previously (Lyketsos *et al.*, 1997). Three additional samples were studied for comparative purposes. The first was a group of 92 residents admitted to the nursing home unit of Copper Ridge with identical inclusion/exclusion criteria. The other two groups were new cases of dementia seen for outpatient evaluation at the Johns Hopkins Neuropsychiatry and Memory Group between 1995 and 1998. From this population, 682 resided at home while 63 were residents of other AL facilities. Evaluations and data collection methods for these outpatients have been described previously (Lyketsos *et al.*, 1997).

Assessment variables

Initial neuropsychiatric evaluations were performed on all study participants within a month of admission to Copper Ridge. Similar assessments were conducted on the comparison groups upon initial evaluation. With input from the patient, prior caregivers, and physicians, basic demographic and medical history information was collected including education level, family history of dementia, personal psychiatric history, duration of dementing illness, previous care-giving arrangement, and current drug regimen. A positive personal psychiatric history was defined as a psychiatric diagnosis, treatment, or admission. Other assessment instruments included:

- Mini-Mental Status Exams (MMSE) (Folstein *et al.*, 1975);
- Clinical Dementia Rating (CDR) (Hughes *et al.*, 1982);
- Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos *et al.*, 1988);
- Psychogeriatric Dependency Ratings Scale (PGDRS) for assessing levels of physical and cognitive assistance needed (Wilkinson and Graham-White, 1980);
- General Medical Health Rating (GMHR) of comorbid medical disease in dementia patients (Lyketsos *et al.*, 1999);
- DiMascio Scale (DMS) for extrapyramidal signs (DiMascio *et al.*, 1976);
- Behavior Pathology in Alzheimer's Disease Scale (Behave-AD) (Reisberg *et al.*, 1993).

Rates of specific burdensome events and activities in the 2 weeks before the evaluation, as reported by the caregivers, were also recorded. These included recent incidents of wandering, falls, accidents, aggression, catastrophic reactions,

apathy, crying spells, delusions and hallucinations. While residents of the facility, the study participants were reassessed for clinical purposes every 6 months with the MMSE, CSDD, and PGDRS.

Outcome variables

Outcome analysis was only performed on residents of the Copper Ridge AL facility. The approach to psychiatric treatment, including the evaluation and management of behavioral problems, was not significantly changed during the study period.

In the event of a transfer, information was collected on the location to which the resident was discharged and the reason for discharge. Data on deaths while at Copper Ridge were also collected. For the purpose of this analysis, participants who died within 48 h of discharge from AL (e.g. during an acute medical hospitalization) were considered to have died while still residents of Copper Ridge.

Statistical methods

The study population was compared to patients in other care settings using chi-square tests for categorical variables and one-way analysis-of-variance (ANOVA) for continuous measures, with the Bonferoni correction to account for repeated comparisons. After examining overall outcomes, the analysis focused on the most common resident outcome: discharge to a higher level of care such as a nursing home or hospital. Survival analysis on Kaplan-Meier plots was used to describe time-to-discharge stratified by individual risk factors. Multivariate analysis of survival (Cox proportional hazards model) was then applied to correct for possible confounding relationships between the significant variables. Covariates were entered in a step-wise manner with a threshold significance level of 0.05.

RESULTS

Demographics and clinical characteristics

The mean age of the primary study population was 82 years (SD 7.5) with an average duration of dementia of 5.7 years (SD 3.1). The majority of residents entered the facility from home or an independent-living retirement community, as shown in Fig. 1.

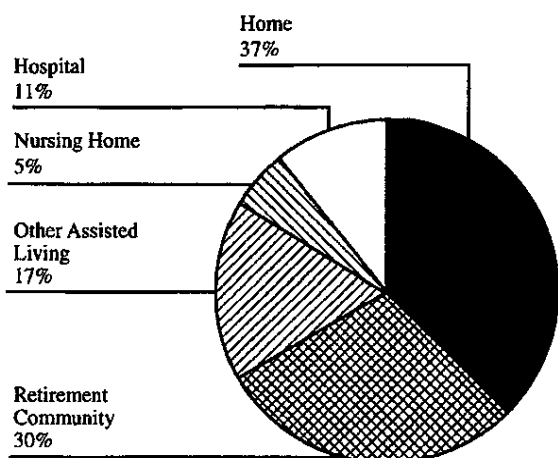


Fig. 1. Location of dementia patient before admission to AL

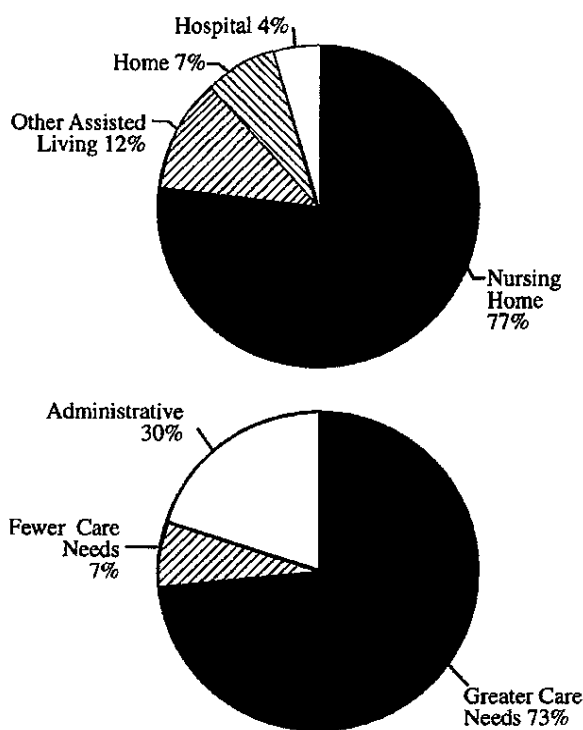


Fig. 2. Location to which the resident was discharged and reason provided for discharge

To examine the characteristics of the dementia-specialized AL population, comparisons were made to three other long-term care samples. The results of the demographic comparison are presented in Table 1. The mean age of the study population was significantly older than were residents either at home or in other AL facilities.

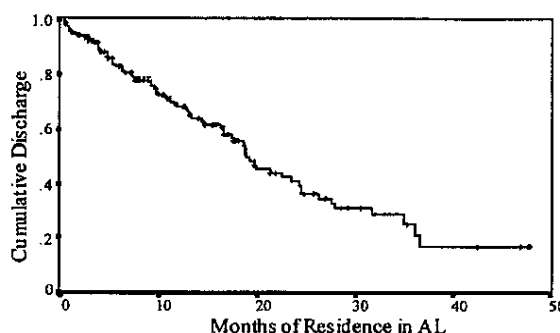


Fig. 3. Time-to-discharge to a higher level of care for dementia patients in AL

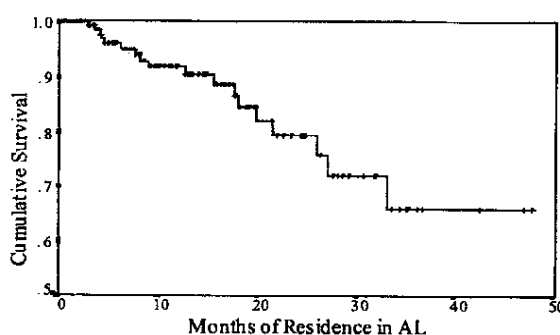


Fig. 4. Time to death for dementia patients in AL

Overall outcomes

After a median observation time of 25 months (range: 0.5–48 months), 12% of the study population died in AL and 48% were discharged. As shown in Fig. 2, the predominant discharge location was a nursing home (77%), although discharges occurred to hospitals, other AL facilities, and back into the resident's home. The primary reason given for discharge was inappropriate level of care, with most residents (73%) needing a higher level of care than was provided in the AL setting. Administrative reasons cited for leaving the facility were financial concerns, a desire to be closer to ones family, and dissatisfaction.

Figure 3 presents a Kaplan–Meyer survival analysis of time-to-discharge to a higher level of care (either hospital or nursing home). The median duration of stay was 10.9 months (SD 10.9). Those moving to the same or a lower level of care were censored on the survival analysis of discharge. Figure 4 presents a survival analysis of time of death, which shows that the median time to death was not reached in this study population.

Table 1. Clinical description of dementia-specialized AL compared to other settings

	Dementia-specialized AL (n = 144)	Dementia patients at home (n = 682)	Dementia patients in other AL facilities (n = 63)	Dementia-specialized nursing home (n = 92)
Age (mean, SD)†	81.6 (7.0)	74.2 (12.4)***	75.8 (14.5)**	78.9 (9.9)
Female (%)	77	66	79	63
Diagnosis				
Poss/pAD (%)	66	56	56	64
VaD/mixed (%)	20	18	19	19
Other (%)	14	26	25	17
Medical comorbidity‡				
None/mild (%)	18	20	18	8****
Mild/moderate (%)	55	58	39	35
Moderate/severe (%)	27	23	43	58
% with personal psychiatric history	43	24***	38	41
% with family history of dementia	58	63	69	55
MMSE (mean SD)	12.0 (5.8)	16.9 (7.6)***	14.9 (15.7)	5.7 (6.4)***
Extrapyramidal signs (mean, SD)†	1.6 (1.9)	n/a	n/a	2.8 (2.6)*
CSDD (mean, SD)§	6.1 (6.1)	6.7 (6.0)	7.7 (6.3)	7.5 (5.1)
PGDRS				
Orientation	3.4	1.6***	2.6	6.1***
Behavior	5.2	4.3	5.5	6.7
Physical	11.1	6.8***	15.5	21.2***
Recent incidents of				
Hallucinations¶ (%)	4	13	8	9
Delusions¶ (%)	42	28	24	26
Aggression¶ (%)	39	16	32	48
Falls (%)	9	10	21	24*
Wandering (%)	50	18***	32*	51
Accidents (%)	1	5	5	7
Out of bed (%)	33	26	23	37
Catastrophic reactions (%)	29	22	27	34
Apathy (%)	24	35	32	33
Crying spells (%)	18	26	26	21

* $p < 0.05$, Bonferroni-adjusted t -test compared to dementia-specialized AL.

** $p < 0.01$, Bonferroni-adjusted t -test compared to dementia-specialized AL.

*** $p < 0.001$, Bonferroni-adjusted t -test compared to dementia-specialized AL.

**** $p < 0.01$, Bonferroni-adjusted chi-squared test compared to dementia-specialized AL.

†As measured by the DiMascio Scale.

‡As measured by the GMHR.

§Mean (SD) where higher values indicate more depressive symptoms.

||Higher value indicates less independence in each category.

¶As measured by clinically significant responses on the Behave-AD scale.

Predictors of discharge to higher level of care

The results of a univariate survival analysis, with discharge to a higher level of care as the outcome of interest, are shown in Table 2. Age, dementia diagnosis, medical comorbidity, presence of

extrapyramidal symptoms (EPS), and gender were not significant predictors of time-to-discharge in the univariate analysis.

In order to address potential confounding of the predictor variables, a multivariate Cox proportional hazards model was estimated to

Table 2. Univariate analysis of time-to-discharge from AL to a high level of care*

Characteristic	Hazard ratio (95% CI)	p-value
Clinical Dementia Rating† CDR ≥ 2	2.2 (1.09–4.4)	0.025
Mini-Mental Status Exam‡ MMSE < 5	2.0 (1.11–3.5)	0.019
Cornell Score for Depression in Dementia‡ CSDD ≥ 7	2.1 (1.14–3.8)	0.015
Behavior Pathology in Alzheimer's Disease Scale†		
Cumulative symptoms§	3.0 (1.62–5.6)	<0.001
Activity disturbances	2.1 (1.10–4.1)	0.021
Aggressive behavior	2.3 (1.27–4.3)	0.005
Diurnal rhythm disturbances	2.5 (1.23–5.0)	0.009
Presence of troubling or dangerous symptoms¶	2.8 (1.40–5.4)	0.002
Recent incidents‡		
Frequent wandering	2.9 (1.57–5.3)	<0.001
Falls	2.6 (1.16–6.0)	0.016

*Univariate log-rank test of the Kaplan–Meyer; factors found to be significant in the univariate log-rank test were entered into a univariate Cox proportional hazard model in order to calculate the hazard ratio.

†Rating done upon admission to the facility.

‡Most recent rating taken during 6-month follow-ups.

§Clinically significant disturbances (total score >5) including nonsignificant subscales of paranoid/delusional, affective disturbances, and anxieties/phobias.

||Trait was considered clinically significant if the subject had a nonzero score on the appropriate subscale of the Behavior Pathology in AD.

¶Global severity rating (of the Behave-AD scale) of all non-mood behaviors based on whether the behaviors are troubling to the caregiver or dangerous to the patient.

Table 3. Multivariate analysis of time-to-discharge from AL to high level of care*

Characteristic	Hazard ratio (95% CI)	p-value
Recent falls†	5.6 (2.04–15.4)	<0.001
Frequent wandering‡	3.1 (1.48–6.6)	0.003
Significant symptoms of depression§	2.28 (1.07–4.9)	0.033

*Cox proportional-hazards model was used to identify significant characteristics from potential variables found to be significant in the univariate analysis.

†Within the past week, as reported by the caregiver.

‡A subjective assessment by the caregiver of 'frequent' falls within the past week.

§Defined by a score of or above 7 on the CSDD.

determine unique predictive characteristics. Only factors found to be significant in the univariate analysis were included as potential variables in the multivariate Cox model. The results of the multivariate analysis of time-to-discharge to a higher level of care are shown in Table 3. Significant predictors of discharge were the presence of clinically significant depressive symptoms, frequent incidents of wandering, and a history of falls. Most significant in predicting a shorter residence time was a positive history of recent

falls, which increased the risk of discharge several fold. Frequent wandering and clinically significant symptoms of depression were also independent predictors of discharge hazard.

DISCUSSION

Assisted living is an intermediate level of care for dementia patients as demonstrated by the clinical descriptors and level of assistance provided to the

residents. As expected, dementia patients cared for in their home were younger, less cognitively impaired, and were less likely to need physical assistance or assistance with orientation. They were also less likely to have a psychiatric history, and they had fewer incidents such as wandering and acts of aggression that were burdensome to the caregiver. Conversely, patients receiving a nursing home level of care in a dementia-specialized nursing home had significantly more cognitive impairment, greater comorbidity, and were more dependent on caregivers. These data support the argument that specialized AL serves residents with an intermediate level of dementia and moderate care needs.

The distribution of many of the clinical variables shows that this dementia specialized AL population is similar to dementia populations in other AL facilities. Differences in wandering incidents between the two samples might be explained by an increased tolerance in the specialized facility for controlled wandering. In addition, there were no significant differences in dementia severity or in comorbid medical conditions of the residents with dementia in the various AL settings. This suggests that the dementia residents of this specialized AL facility are clinically similar to the general AL population, despite the focus on dementia care.

The outcomes of residents of Copper Ridge support the notion that AL is a distinct entity in the continuum of long-term care. Mortality data, although not sufficient to allow detailed analysis, shows 2-year death rates of 23%, which are considerably lower than the approximate 50% rate derived from nursing home survival studies (Hebrt *et al.*, 1995). These data, in conjunction with data on the discharge locations and causes of mortality for the residents, indicate that AL provides a setting that is distinct from nursing homes. This research is the first to include AL in analyses of long-term dementia care.

Measures of behavioral disturbances and wandering/falling were highly correlated with time-to-discharge. Even after controlling for confounding factors in the multivariate analysis, wandering and falling were significant factors, resulting in a three- to five-fold increase in the risk of discharge. This indicates that patient behaviors, either directly or indirectly, are a significant factor in the decision to move a patient to a higher level of care, even in a facility designed to treat and stabilize such problem behaviors in dementia patients.

Symptoms of depression were present in many residents, independent of the type of long-term care they received. In this population, a significant finding was the correlation of depressive symptoms with discharge to a higher level of care. Even after accounting for cofounders in the multivariate analysis, including behavioral pathology and dementia severity, depression was a significant predictor of discharge to a nursing home or hospital, increasing the risk of discharge more than two-fold. The high prevalence of depression in dementia patients, estimated at between 30 and 50% (Lyketsos *et al.*, 1997; Lyketsos and Steele, 1995; Lyketsos and Rabins, 1994) with one estimate as high as 87% (Merriam *et al.*, 1988), makes the influence of depressive symptoms on dementia outcomes clinically pertinent.

Although steps have been taken to ensure that results from this population can be generalized to other dementia-specialized AL facilities, these findings must be recognized as the analysis of only one assisted living facility. This facility is atypical due to its close affiliation with a major teaching hospital. It is notable that the vast majority of residents are Caucasian and were required to demonstrate sufficient financial resources prior to admission. However, this facility is comparable in admission characteristics when compared to the limited industry surveys of the AL population (Mollica, 1998; US General Accounting Office, 1997). Further studies to expound on this initial assessment of dementia-specialized AL facilities should include multi-site sampling and an attempt to include the full range of AL facilities.

Research in AL is appropriate now, especially as evolving state regulations in the US and new market forces demand a better understanding of this unique population. Through this development, the role of AL in dementia care and the future of the estimated half a million patients with dementia in long-term care should be the focus of more clinical investigation.

ACKNOWLEDGEMENTS

Supported by a Hartford Scholar grant from the American Federation for Aging Research and by 1.RO1-MH56511.

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