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Feature Article

Experiences of frequent visits to the emergency department by residents with dementia in assisted living



Tara J. Sharpp, PhD, RN*, Heather M. Young, PhD, RN, FAAN

Betty Irene Moore School of Nursing at UC Davis, 4610 X Street, Suite 4202, Sacramento, CA 95817, USA

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ABSTRACT

Assisted living (AL) is a growing option for housing for older adults with dementia in the United States. Typically, nurses are not employed in AL in California. The purpose of this paper is to describe the health care incidents and experiences of residents and their family members who are transferred from AL to an (emergency department) ED. Data were collected from two dementia-only AL communities in California over a period of six months. In this study, only 32% of ED visits resulted in admission to acute care. Of the 71 residents, eight (11%) were responsible for 47% of the ED visits. Qualitative interviews with 3 employees and 9 family members and focus groups with 11 employee caregivers were conducted to augment the quantitative data. The qualitative theme of frustration and helplessness by family and staff to prevent repeated falling and ED transfers was identified, which complemented the quantitative findings.

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Introduction

Assisted living (AL) is a service-based form of group housing for adults who require meal preparation, housekeeping, and assistance with activities of daily living, such as meals, bathing and dressing, and medication management. In 2010 in the United States (U.S.), there were approximately 31,100 assisted living communities with nearly one million beds.¹ Over half (52%) of residents lived in large facilities, defined as those with 26–100 beds, and 38% of facilities were chain-affiliated.¹

Approximately 17% of AL communities, and 58% of chain-affiliated communities, have special units designed to care for residents with dementia. Nearly 50% of the residents in AL have some form of cognitive impairment.^{2,3} As the U.S. population ages the demand for housing and care of persons with dementia will increase. About five million Americans have a diagnosis of dementia of the Alzheimer's type in the United States currently, and that number is expected to reach 13.8 million in 2050.^{4,5}

AL is now a housing option for people with complex health issues. Approximately 40% of residents need assistance with three or more activities of daily living and about 75% have at least two chronic illnesses.³ About 85% of residents need help with medication administration.⁶ AL communities are not federally

regulated but are licensed by individual states, which vary in their requirements for staffing, supervision, and the presence of a registered nurse (RN) or any professional with gerontological preparation.⁷ Despite the complex needs of the residents, AL communities are not required to employ RNs in California and the training of care staff is consequently minimal, in comparison with that of staff in a nursing home.⁸ In California, direct care staff are required to have 10 h of education initially and 4 h annually, although these requirements will increase in 2016. Specialized dementia units require an additional 6 h of education initially and an additional 8 h annually.^{7,9}

When a resident falls or experiences a change in condition, such as increased confusion, and the community has no on-site RN, assisted living staff must utilize external resources, most often emergency services. This is a costly option. The average cost of a visit to the emergency department (ED) in the U.S. for an older adult who fell in 2005 was \$1086.¹⁰ The total costs for falls for older adults were over \$19 billion in the U.S. in 2000, and with the increase in number of older adults, that costs are expected to rise.¹¹

Transferring from their home environment to the ED can be emotionally burdensome for residents with dementia.¹² Additionally, there are indirect costs of sending a resident with dementia to the ED. Some AL communities send an employee to accompany the resident, resulting in decreased staffing. Policy and regulatory changes with Medicaid and Medicare Services and the Affordable Care Act require organizations to reduce readmissions to ED. Accomplishing this goal requires a deeper understanding of the

* Corresponding author. California State University, Sacramento, School of Nursing, 6000 J Street, Sacramento, CA 95819-6096, USA. Tel.: +1 916 278 1514.

E-mail address: tara.sharpp@csus.edu (T.J. Sharpp).

underlying causes of hospitalization for at risk populations. This paper provides a description of the rate and reasons of health care incidents of residents with dementia and transfers to the ED.

Methods

The purpose of this prospective mixed-methods study was to explore the health care incidents and experiences of residents and their family members who were transferred from AL to an ED. Data were collected over six months in two dementia-only AL communities. The Institutional Review Board at the University of California, Davis approved the study and all consent procedures prior to data collection. A letter describing the research study with a description about how to contact the researcher if they wish to participate was sent by the community administrator to all family members. There were two sources of data: qualitative interviews and audit of facility incident reports. Informed consent was obtained from all staff and family members who were interviewed or were in a focus group. Family members who were interviewed ($n = 9$) all had legal decision-making ability for the residents and provided surrogate informed consent to allow review of their family members' charts. In-depth chart review including medical diagnosis and physician instructions were conducted with those nine residents. For the audit of incident reports, family members were offered an opt-out opportunity. Family members could respond to the administrator's letter and refuse should they not want to participate and allow the investigator access to blinded data on the residents' health care incidents. No family members refused participation, allowing collection of a complete set of both blinded demographic data and de-identified facility incident reports.

Quantitative data collection

Data from demographic characteristics of residents and incident reports were collected to describe the rate and reasons for reported health care incidents and details related to ED transfer decisions. The AL administrators provided blinded demographic data (age, race, ethnicity, and gender) and data fields from incident reports monthly, for a period of six months with personal and identifying information removed. An inclusion criterion was residence in the community for the entire study period of 6 months. The incident reports contained the data for the health care incidents and transfers analyzed in this paper. Any time a resident experienced a fall, change in condition, medication error, or aggressive behavior which required a PRN (as needed) medication, a staff member was expected to complete an incident report. The incident reports contained information regarding the event including the date and time, actions taken by the employees, and disposition of the resident after the incident.

Semi-structured interviews were completed with nine family members in a private setting that the participants chose. The interviews each lasted approximately 75 min and were recorded and transcribed verbatim, with all identifiers removed. Questions included, 'Does your family member have any health care needs?' 'Has your mother/father/spouse ever had a fall or an acute illness, such as the flu or an infection?' and 'Has your mother/father/spouse ever needed to go to the hospital or be seen by paramedics?' The prepared questions served as a guide; as the participants' answers varied, the qualitative interview questions changed.¹³ Formal, semi-structured interviews were also completed with three assisted living supervisors, including one licensed vocational nurse (LVN), who began work in one community during the fifth month of data collection. Two focus groups, one in each community, were conducted with a total of 11 employees in the sixth month of data collection. Questions included, 'Will you please tell me about a

typical day of work here?' 'Please describe a typical resident who lives here.' 'What happens if a resident has an acute illness or accident?' 'What happens if a resident needs to be taken to the hospital or needs the paramedics?' The employees who participated in the focus groups were nine caregivers and two medication technicians.

Quantitative data analysis

Methods for quantitative analysis included descriptive statistics of participants, (residents, family members, and employees). The staff were required to complete an incident report for each event, such as a fall or change in condition. Incident report data were collected over six months and analyzed with descriptive statistics and frequencies. Additionally the demographic characteristics of the residents in the two communities were compared using independent *t*-tests for continuous variables and chi-square for categorical variables at 2-sided significance of 95% (Table 3).

Qualitative data analysis

Descriptive thematic analysis was utilized to uncover themes regarding the experience of health care incidents and ED transfers for residents with dementia.^{14,15} The qualitative data were transcribed verbatim and organized using Atlas Ti software. First, the data were coded using open and in-vivo coding to categorize and provide meaning of the texts using spoken words by the participants when possible.¹⁶ Next, the codes were expanded into themes that answered the research question by creating integrative and theoretical memos.¹⁷ Cyclical data collection and analysis continued until data saturation was reached, or the point where no new themes emerged from the data.

Data triangulation methods

Method and respondent triangulation were used to establish the trustworthiness of the data. Method triangulation is used to establish credibility by matching codes from one source of data collection to another.¹⁸ For instance, when the family member of a resident reported a high number of recent falls, a review of the chart and incident reports revealed that the resident had fallen 14 times in six months. Studies that investigate a phenomenon both quantitatively and qualitatively are currently referred to as mixed-methods studies; the classical term in this case is methodological triangulation,¹⁹ which yields both measurement and explanation. Respondent triangulation was used to check themes that emerged from the opinions of some participants with those of other participants.²⁰ Two focus groups, one in each community with a total of 11 caregivers, were conducted at the end of the six months of data collection to verify themes that emerged with participants. The focus groups lasted 2 h each and covered topics such as assessing residents for changes in condition, making the decision to call 911, and talking with family members about health conditions.

Setting

The setting was two specialized dementia units of large, chain-affiliated assisted living communities in Northern California. The facilities were purposively chosen as they were part of a national chain and had dementia-specific communities. Both communities were in ethnically diverse, suburban cities and could care for a maximum of 35 (community A) and 50 (community B) residents with dementia.

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