Family caregivers’ reports of hospitalizations and emergency department visits in community-dwelling individuals with dementia

Megan Benner
College of Health Sciences, University of Toledo, Toledo, Ohio, USA

Victoria Steiner
College of Medicine, University of Toledo, Toledo, Ohio, USA

Linda L Pierce
College of Nursing, University of Toledo, Toledo, Ohio, USA

Abstract
Individuals with dementia in the United States have higher rates of hospitalizations and emergency department visits compared to those without. This descriptive study examined the frequency of hospitalizations and emergency department visits among community-dwelling individuals with dementia, reasons for hospitalizations and emergency department visits, and caregivers’ actions to prevent these events. Family caregivers (n = 63) from education/support groups offered through Alzheimer’s Association chapters in western Ohio completed a survey. Twenty-two percent of caregivers reported that their care recipient stayed overnight in the hospital and 30% reported that their care recipient visited the emergency department at least once in the past three months. The most frequent reasons for hospitalization and emergency department visits, such as urinary tract infections and fall-related injuries, were potentially avoidable. Caregivers reported giving medications, seeking healthcare services, and obtaining home care services, as the most frequently used preventive actions. Family caregivers of individuals with dementia should be provided substantive education about preventable hospitalizations and emergency department visits.

Keywords
caregivers, dementia, hospitalization, emergency service/hospital, early intervention (education)
Introduction

There is a correlation between having dementia and increased rates of hospital admissions and emergency department (ED) visits in the United States (Bail et al., 2013; Grober, Sanders, Hall, Ehrlich, & Lipton, 2011; Phelan, Borson, Grothaus, Balch, & Larson, 2012; Weber, Pirraglia, & Kunik, 2011). In a systematic review, Weber et al. (2011) also reported that as the severity of the disease increased, the frequency of hospital and ED visits rose. A visit to the hospital or ED can lead to disorientation, falls, and other problems that complicate medical care, as well as accelerate physical and cognitive decline in individuals with dementia (Phelan et al., 2012). The increased use of EDs and frequent hospitalizations of individuals with dementia also contribute to increased healthcare spending annually among this group (Bail et al., 2013; Hurd, Martorell, Delavande, Mullen, & Langa, 2013). This is especially significant due to the fact that many of the hospitalizations could have been prevented (Lin, Fillit, Cohen, & Neumann, 2013; Phelan et al., 2012).

Literature review

Healthcare costs and utilization

In the United States for 2015, it was expected that individuals with dementia would contribute $153 billion in costs to Medicare and Medicaid, two U.S. health coverage programs, and this number is projected to increase to 1.2 trillion dollars by 2050 (Alzheimer’s Association, 2015; Hurd et al., 2013; Klug, Muus, Volkov, & Halaas, 2012; Segal, 2011). A study by Zhao, Kuo, Weir, Kramer, and Ash (2008) examined healthcare costs and utilization for Medicare beneficiaries with Alzheimer’s disease by comparing demographically matched cohorts to the MEDSTAT MarketScan® Medicare Supplemental and Coordination of Benefits Database (Zhao et al., 2008). They used pharmaceutical and medical claims from the database between 2003 and 2004 to identify cost distributions and reasons for ED visits and hospital admissions by comparing 25,109 individuals with an Alzheimer’s disease diagnosis to 75,327 matched controls. The results of their study found that individuals with dementia had a greater number of comorbidities, as well as higher rates of healthcare utilization including ED visits, hospitalizations, and home health care use compared to the control group (Zhao et al., 2008). Caspi, Silverstein, Porell, and Kwan (2009) also reported that individuals with lower cognitive function levels experienced higher levels of a variety of comorbidities and over-utilized hospital care (Caspi et al., 2009). Several other studies also reveal consistently higher rates of hospitalization and ED visits among community-dwelling individuals with dementia compared to those without the disease (Bail et al., 2013; Grober et al., 2011; Phelan et al., 2012). In a study by Phelan et al. (2012) of 3019 individuals over age 65, 495 individuals developed dementia over 13 years. Of those who developed dementia, 427 (86%) were admitted to the hospital at least once over the course of the study. Additionally, among those with dementia, the average annual hospital admission rate was more than twice that of those without dementia (Phelan et al., 2012). Bail et al. (2013) found that older adults with cognitive impairment account for 87% of ED visits. Grober et al. (2011) found that individuals with dementia had almost a 49 percent higher ED admission rate compared to older adults without dementia.
Reasons for hospitalizations and ED visits

According to Grober et al. (2011), individuals with dementia are also more likely to present to an ED with various other comorbidities. Lin et al. (2013) found similar findings and identified the most common comorbidities as diabetes, hypertension, chronic obstructive pulmonary disease, and heart failure. Rudolph et al. (2010) attempted to identify the specific causes for ED visits for older adults with an increased risk of hospitalization, including individuals with dementia. They refined a short battery of cognitive and physical tests that could be used to better identify the cause for the visits and eliminate or reduce the possibility for a repeat ED visit or hospital admission. Some of the most commonly seen conditions or complications included behavioral issues, urinary tract infections, delirium, pressure ulcers, and fall-related injuries (Rudolph et al., 2010). While some ED visits and hospital admissions are expected as part of the natural course of treatment, others are considered “potentially avoidable” in that they can be prevented by good ambulatory care or early intervention (e.g., preventable complications of diabetes) (Lin et al. 2013).

In a study of 195,024 Medicare beneficiaries, Lin et al. (2013) found that compared with matched non-dementia subjects, dementia beneficiaries had more potentially avoidable hospitalizations for certain uncontrolled comorbidities (such as diabetes and hypertension). The risks of potentially avoidable hospitalizations increased significantly with comorbidity burden. Phelan et al. (2012) reported that individuals with cognitive impairment and dementia have been shown to have a 40% higher probability of hospitalization and 20% higher probability for ED visits due to preventable reasons. They found three specific conditions that can often be treated at home or the doctor’s office, without an overnight hospital stay, accounted for two-thirds of the hospitalizations that might have been prevented. These were bacterial pneumonia, congestive heart failure, and urinary tract infections. Hospital admission rates for these conditions were much higher for those with dementia than for those without it (Phelan et al., 2012; Segal, 2011).

Caregivers’ preventive actions

As the United States develops new healthcare financing and delivery models focusing on the integration and coordination of care (Coleman, Parry, Chalmers, & Min, 2006), it is essential to recognize that for many people with chronic health problems, such as dementia, family caregivers are the primary care coordinators. Currently, more than 15 million Americans provide unpaid care for people with dementia (Alzheimer’s Association, 2015). Phelan et al. (2012) identified that implementing a variety of nursing interventions, including patient and caregiver education, could be a step towards mitigating and reducing these preventable hospitalizations and ED visits among community-dwelling individuals with dementia. According to Rudolph et al. (2010), education about the causes of potentially avoidable hospital conditions, as well as how to identify and treat these conditions, is the number one avenue to lower the incidence of ED visits or hospital admissions in individuals with dementia. Their study, however, focused on individuals with cognitive impairment or dementia who resided in long-term care facilities and as such, not all of their outlined interventions may be applicable to community-dwelling older adults with dementia and their family caregivers.
Although studies have reported the prevalence of potentially avoidable hospital conditions in individuals with dementia (Lin et al., 2013; Phelan et al., 2012) and stated that hospitalizations and ED visits could be prevented by good ambulatory care or early intervention (Lin et al., 2013), the literature is replete with information about whether family caregivers take actions to prevent these events in individuals for whom they provide care. Unpaid, family caregivers are the backbone of long-term care provided to individuals with dementia in the home, but these caregivers are not trained to deal with complex health issues. Several studies have cited that caregivers obtain information about caring for the individual with dementia by seeking advice from family or friends, healthcare professionals, or the Internet (DiZazzo-Miller, Pociask, & Samuel, 2013; Fox & Duggan, 2013; Kernisan, Sudore, & Knight, 2010). Gaugler, Kane, Kane, and Newcomer (2005) reported that of the variety of community-based care options and interventions available (e.g., in-home help, personal care services), only 7% of patients with dementia received any type of community-based service that could potentially prevent institutionalization. The aims of this study are to (1) determine rates of and reasons for hospitalizations and ED visits by persons with dementia as reported by their family caregivers and (2) examine whether the family caregivers took any actions to prevent these healthcare events.

**Methodology**

**Design**

This study employed a descriptive design. Family caregivers of persons with dementia were given a one-time survey about the use of healthcare services for their care recipient and any actions they took to prevent hospitalizations and ED visits.

**Methods of data collection**

With Institutional Review Board approval and permission from the Alzheimer’s Association chapters, the survey was distributed in the spring at various education and support groups sponsored by two chapters located on the western side of the state of Ohio. The purpose of the study was explained to the potential subjects and they were told that their consent was implied by their completion of the survey. If they agreed to participate, they were given the option to complete the survey at that time or to take it home and mail it back. Subjects were provided with an addressed and stamped envelope to facilitate easy return of the survey. Graduate research students who assisted with this study had received human subjects training through the University and were trained by the investigators on the recruitment procedures specific to this study.

**Sample selection and participants**

A convenience sample of family caregivers was recruited with assistance from the Alzheimer’s Association chapters located in Toledo and Cincinnati, Ohio. Family caregivers were attending education and support-group sessions provided by these chapters which serve residents of 37 counties in Ohio, as well as 14 neighboring counties in the states of Indiana and Kentucky. All caregivers were over 21 years of age and able to read and write English. Potential subjects were fully informed that participation was voluntary and that they were able
to withdraw from the study at any time. Confidentiality and anonymity were protected by not including the subjects’ names on the surveys.

**Measures**

Consenting caregivers were asked to complete a one-time survey that took about 10 minutes. The first part of the survey asked demographic questions about themselves and the person with dementia. The rest of the survey asked about the care recipient’s healthcare service use (e.g., hospitalizations and ED visits) over the past three months. The investigators adapted the self-report healthcare questions used in this survey from the 1999 National Health Interview Survey of the civilian non-institutionalized population residing in the United States (National Center for Health Statistics, 2000). These questions were used previously in the study of web-based support for stroke caregivers (Pierce, Steiner, Khuder, Govoni, & Horn, 2009). The current subjects were also asked if they took any actions to prevent these healthcare events.

**Data analysis**

The caregiver and care recipient demographic information, as well as the data for healthcare service use, were analyzed using descriptive statistics. Data from the open-ended survey questions (e.g., reasons for healthcare service use and actions used to prevent these hospitalizations and ED visits) were reviewed and categorized by the investigators.

**Findings**

**Demographics**

A total of 63 family caregivers of persons with dementia completed the survey. The caregivers were primarily White and had a mean age of 62 years. A bimodal distribution and the mean age of the adult children compared to the mean age of the spouses are not presented due to the small sample size and low frequencies of caregivers in the two groups. At the time of the survey, the majority of the caregivers stated that their health was good to very good. These primarily female caregivers also reported that they had spent an average of 45 months taking care of the individual with dementia. The caregivers on average completed 15 years of education and just over half were unemployed at the time of the survey.

The average age of their care recipients was 80 years old. They were primarily White and the caregivers reported them to be in fair to good health, with approximately 67% having a chronic disease in conjunction with their memory loss. The majority of the care recipients lived independently in their own home or apartment at the time of the survey, and were husbands or mothers of the caregivers. See Table 1 for complete demographic information for the caregivers and care recipients.

**Number of hospitalizations and ED visits**

At the time of the survey, 4 of the 63 caregivers surveyed (6.3%) had a care recipient in the hospital. In the month prior to the survey, seven care recipients (11.1%) spent the night in the hospital. Six caregivers reported that their care recipient had one overnight stay in the hospital, while one caregiver reported that their care recipient had six hospital stays in the prior month. Two months prior to the caregivers completing the survey, three of the
Two care recipients (4.8%) were reported to have stayed overnight in the hospital. Two caregivers reported one hospital stay by their care recipient, while a third caregiver reported that their care recipient had a total of three separate hospital stays two months prior to the survey.

A total of 12 care recipients (19.1%) were reported to have visited the ED in the month prior to the survey; 10 of the caregivers reported that their care recipient made one visit to the ED in the previous month, while one caregiver reported that their care recipient visited twice and another reported their care recipient visited four times. Two months prior to the survey, seven of the care recipients (11.1%) visited the ED. Four caregivers reported one visit, two caregivers reported two visits, and one caregiver reported three separate visits to the ED two months prior to the survey.

### Table 1. Demographic data for the caregivers and care recipients (n = 63).

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Sub characteristics</th>
<th>Caregiver</th>
<th>Care recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (mean years)</td>
<td>62.3</td>
<td>80.3</td>
<td></td>
</tr>
<tr>
<td>Time providing care (mean months)</td>
<td>44.9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Years of school completed (mean years)</td>
<td>14.7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>10 (15.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>53 (84.1)</td>
<td></td>
</tr>
<tr>
<td>Relationship to caregiver</td>
<td>Husband</td>
<td>16 (25.4)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Wife</td>
<td>9 (14.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mother</td>
<td>20 (31.7)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Father</td>
<td>9 (14.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other relative</td>
<td>5 (7.9)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Friend</td>
<td>4 (6.3)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>American Indian/Alaska Native</td>
<td>1 (1.6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td></td>
<td>Asian/Pacific Islander</td>
<td>2 (3.2)</td>
<td>1 (1.6)</td>
</tr>
<tr>
<td></td>
<td>Black, Non-Hispanic</td>
<td>2 (3.2)</td>
<td>2 (3.2)</td>
</tr>
<tr>
<td></td>
<td>White, Non-Hispanic</td>
<td>58 (92.1)</td>
<td>60 (95.2)</td>
</tr>
<tr>
<td></td>
<td>Hispanic</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Health status</td>
<td>Poor</td>
<td>1 (1.6)</td>
<td>7 (11.1)</td>
</tr>
<tr>
<td></td>
<td>Fair</td>
<td>6 (9.7)</td>
<td>23 (36.5)</td>
</tr>
<tr>
<td></td>
<td>Good</td>
<td>23 (37.1)</td>
<td>23 (36.5)</td>
</tr>
<tr>
<td></td>
<td>Very good</td>
<td>26 (41.9)</td>
<td>7 (11.1)</td>
</tr>
<tr>
<td></td>
<td>Excellent</td>
<td>6 (9.7)</td>
<td>3 (4.8)</td>
</tr>
<tr>
<td>Other chronic conditions</td>
<td>No</td>
<td>21 (33.3)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>42 (66.7)</td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td>Own home or apartment</td>
<td>23 (36.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>With the caregiver</td>
<td>15 (23.8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Assisted living facility</td>
<td>11 (17.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Long-term care</td>
<td>12 (19.0)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>2 (3.2)</td>
<td></td>
</tr>
<tr>
<td>Current employment</td>
<td>None</td>
<td>32 (50.8)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Part time</td>
<td>11 (17.5)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Full time</td>
<td>20 (31.7)</td>
<td></td>
</tr>
</tbody>
</table>
Reasons for hospitalizations and ED visits

The most common reason for hospitalization in the past three months, which was reported by three caregivers, was a fall-related injury. Other caregivers identified abdominal pain/blocked common duct, fluid in the lungs, gall bladder surgery, a mental status change, observation, and urination problems as reasons their care recipient was hospitalized. Among these reasons reported by the caregivers, a fall-related injury, abdominal pain/blocked common duct, and a mental status change are potentially avoidable hospital conditions cited by the Centers for Medicare and Medicaid Services (CMS; Segal, 2011). It is also important to note that some of the caregivers did not provide a reason for the hospitalization and, therefore, no percentages are provided.

The top reasons for ED visits in the past three months, which were each reported by two caregivers, were behavioral issues, a fall-related injury, a heart-related illness, a medication adjustment, and urinary tract infection. Other caregivers included abdominal pain/blocked common duct, an allergic reaction/hand injury, bronchitis, a bleeding ulcer, a car accident, clostridium difficile infection, edema in the leg, an injured knee, and unresponsive as reasons their care recipient visited the ED. Among these reasons for ED visits, behavioral issues, a fall-related injury, a heart-related illness, a medication adjustment, urinary tract infection, abdominal pain/blocked common duct, and clostridium difficile infection are potentially avoidable hospital conditions cited by the CMS (Segal, 2011). Again, note that some of the caregivers did not provide a reason for the ED visit, and therefore, no percentages are provided.

Preventive actions taken by caregivers

The most frequently reported actions by the caregivers that were used to prevent hospitalizations included giving medications, seeking healthcare services, obtaining home care services, and asking friends or family for advice. A complete list of actions can be found in Table 2. Caregivers reported the same actions were also used to try to prevent ED visits, however, obtaining home care services and asking family or friends for advice were reported less frequently (see Table 2). One caregiver also reported an “other action” and stopped a medication to try to prevent an ED visit. Although unexpected, some caregivers answered the questions about preventive actions regardless of whether or not their care recipient was hospitalized or visited the ED.

Discussion

According to U.S. national demographic data, caregivers of individuals over 50 years of age are primarily female; however, the average caregiver (49 years old), as well as the average care recipient (69 years old), is younger than the sample of family caregivers in this study (The National Alliance for Caregiving and AARP, 2012). These caregivers also had a better health status and reported their health as good to very good, compared to the national data which states that caregivers reported their health as poor to fair (The National Alliance for Caregiving and AARP, 2012). More than half of the care recipients had a chronic disease in addition to their dementia, which is consistent with Grober et al.’s (2011) results that individuals with dementia are also more likely to present to an ED with various other comorbidities.
Since this study included a sample that consisted primarily of White caregivers attending support groups facilitated by the Alzheimer’s Association Chapters serving Ohio, Indiana, and Kentucky, the results cannot be generalized to caregivers from other ethnic groups or geographic regions. Additionally, individuals that participate in Alzheimer’s Association support and education groups tend to have a higher socio-economic status, which further reduces the generalizability of the results of this study. The accuracy of the self-report data could also be a limitation of this study since caregivers were asked to think back to a time three months prior to the survey. This could explain missing data for multipart questions.

Rates of hospitalization and ED visits were lower in this study as compared to previous studies. Phelan et al. (2012) found that 86% of their subjects with dementia were admitted to the hospital at least once over the course of the 13-year study. In the current, although much shorter, study about 22% of individuals with dementia were hospitalized in the three-month period. Zhao et al. (2008) reported rates of hospitalization at 30% and ED visits at 41% over a one-year span. The current study found that only 30% of individuals with dementia used the ED during a three-month period.

The most frequent reason for hospitalizations reported by the caregivers in this study, fall-related injury, is on the CMS list of potentially avoidable hospital conditions (Segal, 2011). Two other reasons given for hospitalizations, abdominal pain and mental status change, are also on the CMS list. Similarly, the top reasons for ED visits reported in this study also coincide with potentially avoidable hospital conditions and include behavioral issues, fall-related injury, heart-related illness, medication adjustment, and urinary tract infection (Segal, 2011). These results are consistent with reasons described by Rudolph et al. (2010) and, as Lin et al. (2013) and Phelan et al. (2012) found, indicate that many of the reasons individuals with dementia are hospitalized or go to an ED are preventable.

This study also identified actions that caregivers had taken to prevent hospitalizations and ED visits in their care recipients, including seeking healthcare services, obtaining home care services, and asking advice from friends or family. In their systematic review, Weber et al.
(2011) found that caregivers sought out medical services, such as physician visits, and community services, such as home health, to aid them in providing care to ambulatory individuals with dementia living in the community, although they did not state that these were preventive actions. They also reported, however, that less than half of the caregivers were utilizing home health care for their care recipient. Individuals with dementia frequently use the full range of medical services, but community resources are used less frequently. The results of the study by Gaugler et al. (2005) were similar and indicated low rates of utilization of community services. Additionally, they found a relationship between utilization of community services and delay of institutionalization (Gaugler et al., 2005). Mittleman, Haley, Clay, and Roth (2006) also identified a delay in institutionalization of care recipients whose caregivers sought support (Mittleman et al., 2006). More recent studies have found that caregivers often seek advice from friends or family members, as well as healthcare professionals about their care recipients’ health (DiZazzo-Miller et al., 2013; Fox & Duggan, 2013; Kernisan et al., 2010). DiZazzo-Miller et al. (2013) identified an increased use of the Internet as a resource for caregivers as the disease progressed in their care recipient.

**Conclusion**

This study confirmed the occurrence of potentially avoidable hospital conditions in persons with dementia that have been previously identified in the research literature (Lin et al., 2013; Phelan et al., 2012). Knowledge of preventable conditions that are likely to lead to hospitalization and ED visits is important for family members, caregivers, and healthcare providers, who can work together to help prevent them from getting worse. Since family and unpaid caregivers provide the vast majority of long-term care for people with dementia, providing training to them on proactive, early management of these conditions and regular monitoring is especially critical. Although many caregivers in this study stated that they performed actions to try to prevent hospitalizations and ED visits, providing family caregivers with substantive education could help decrease unnecessary hospitalizations and ED visits of their care recipients. This education has the potential to promote the health and well being of older individuals with dementia and their family caregivers, as well as reduce the national costs associated with Alzheimer’s disease and related dementias.

**Declaration of Conflicting Interests**

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

**Funding**

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This research was support by a grant from the Center for Community Based Care, Ohio Council for Home Care.

**References**


**Author Biographies**

**Megan Benner, MPH**, is a doctoral student in Health Education at the University of Toledo. Her research interests include caregiving, nursing home care quality, and nursing assistant retention and turnover.

**Victoria Steiner, PhD**, is an associate professor in Public Health at the University of Toledo in Toledo, Ohio. She is also the assistant director of the Center for Successful Aging. Her current research interests focus on how individuals cope with the challenges they encounter in their lives as they age, including functional decline, chronic illnesses such as Alzheimer’s disease and stroke, and caregiving.

**Linda Pierce, PhD, RN, CNS, CRRN, FAHA, FAAN**, is a professor of nursing at the University of Toledo in Toledo, Ohio. She is a Fellow of the American Heart Association and the American Academy of Nursing and also Associate Editor for the Rehabilitation Nursing journal. Her research interests are caring, family caregivers of persons with stroke and dementia, and web-based education and support interventions.