ORIGINAL RESEARCH

New Acute Symptoms in Older Adults with Cognitive Impairment: What Should Family Caregivers Do?

Study findings support targeted interventions that facilitate early recognition and appropriate action.

When older adults with cognitive impairment who are cared for by family caregivers develop new physical or behavioral symptoms, their caregivers face a difficult decision: whether and when to seek professional medical care. Such decisions are hard because cognitively impaired people often have difficulty communicating their symptoms, and most family caregivers lack formal training in assessment. Furthermore, most family caregivers aren't aware that acute illnesses can present differently in this population.[1] Thus they may have trouble discerning whether a change signals the onset of a new acute or subacute illness or is simply indicative of the common day-to-day symptomatic variability seen with cognitive impairment.

The Veterans Health Administration (VHA) provides comprehensive non-institution-based primary care for community-dwelling frail veterans through its home-based primary care (HBPC) program. This program, which is part of the VHA's standard medical benefits package, relies on the use of an interdisciplinary team charged with delivering an alternative to outpatient clinic visits.[2, 3] Like other such programs, it aims to prevent hospitalization and institutionalization in long-term care facilities.[4] Under national guidelines, all veterans are eligible for the HBPC program "if they meet the clinical need for the service and it is available."[3] Enrollment in this program has been shown to decrease both the risk of hospitalization and overall Medicare costs.[5] Patients enrolled in HBPC programs are typically frail, homebound adults ages 65 and older who have multiple chronic conditions and who find it challenging to live in the community.[4] They are therefore an appropriate target population for an investigation.

Study purpose. The purpose of this study was to assess the frequency with which family caregivers of older veterans with cognitive impairment sought prehospital guidance from health care professionals when that resource was available to them, and to describe the characteristics of such events. Specifically, we aimed to identify the presenting symptoms and diagnoses and to describe the guidance provided in order to better understand where there might be opportunities for improvement.

BACKGROUND

Family caregivers play a critical role in maintaining older adults with cognitive impairment in the home setting. Ideally, these caregivers will have access to guidance that allows them to make care decisions in alignment with their loved one's wishes. When family

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ABSTRACT

Background: When older adults with cognitive impairment develop new physical or behavioral symptoms, their family caregivers face a difficult decision: whether and when to seek professional medical care. Most family caregivers lack formal training in assessment and may have difficulty making such decisions. The Veterans Health Administration's home-based primary care (HBPC) program, which is widely available, offers community-dwelling frail veterans and their family caregivers guidance, with the goal of reducing hospitalization and institutionalization in long-term care facilities.

Objective: This study sought to assess the frequency with which family caregivers of cognitively impaired older adults sought prehospital guidance from health care professionals when that resource was available to them, and to describe the characteristics of such events.

Methods: This study used a retrospective chart review of patients who were enrolled in the Orlando Veterans Affairs Medical Center HBPC program for at least one month between October 1, 2013, and September 30, 2014; had a diagnosis indicative of cognitive impairment (Alzheimer's disease, vascular dementia, or mild cognitive impairment); had a dedicated family caregiver; and were not enrolled in hospice care. Data were collected from data collection templates and nurses' narrative notes. Univariate descriptive analyses were conducted regarding the type of staff contacted by family caregivers, the presenting diagnoses, the guidance offered by staff, and the number of unplanned acute care encounters.

Results: Among the 215 patients studied, there were 254 unplanned acute care encounters (including ED visits followed by discharge to home and ED visits resulting in hospital admission). Family caregivers sought guidance from a health care professional 22% of the time before such an encounter. The presenting clinical issues were most often new problems (43%) that included falls, feeding tube problems, fever, new pain, rash or other skin problems, and unexplained edema. Overall, 25% of all unplanned acute care encounters were for reasons considered potentially avoidable. About half of the patients who were subsequently hospitalized had symptoms of delirium, indicating that their illness had significantly advanced before presentation.

Conclusions: It's important for health care professionals to ensure that family caregivers of cognitively impaired older adults can access professional guidance readily when facing decisions about a loved one's care, especially when there is an acute onset of new symptoms. Teaching caregivers how to recognize such symptoms early in order to prevent exacerbations of chronic illness and subsequent hospitalization should be a high priority. Our findings underscore the need to do so, so that caregivers can best use the resources that HBPC programs have (or ought to have) in place, in particular 24/7 guidance and decision assistance.

Keywords: cognitive impairment, family caregivers, older adults

caregivers seek guidance because a loved one has developed new acute symptoms, typically the initial contact is with outpatient nursing or administrative staff, who often advise them to seek care at an ED. But the ED setting exposes the cognitively impaired older adult to a host of potential iatrogenic complications such as adverse drug events, delirium, falls, and pressure ulcers; these in turn can lead to increased morbidity and a greater likelihood of nursing home placement and death.[6-10] In some cases, older adults with cognitive impairment can be more appropriately assessed and treated away from an ED, as evidenced by data cited by the Agency for Healthcare Research and Quality (AHRQ) showing better outcomes at less acute levels of care.[11]

There has been scant research on family caregivers' decisions on behalf of frail loved ones when new acute symptoms arise. That said, there is evidence that in such situations, even in the absence of cognitive impairment, delays in seeking treatment are common and detrimental to the eventual outcomes.[12] A study by Daiello and colleagues, conducted among 16,244 Medicare beneficiaries, found that those with cognitive impairment were at substantially higher risk for hospitalization compared with those without such impairment.[7] In another large study of over 1.2 million Medicare beneficiaries, the presence of dementia was associated with nearly a fourfold increase in the risk of hospitalization.[13] The same study found that dementia was also associated with a twofold increase in the risk of hospitalization for potentially preventable conditions.

In the VHA HBPC program, family caregivers who seek guidance on how to address a clinical problem can interact with a nurse or NP in one of three ways: with non-HBPC providers via the VHA's general 24/7 telephone triage; with HBPC providers through electronic messaging, telephone calls, or home visits; or with outpatient clinic staff on site. (The HBPC providers were available Monday through Friday, 8 AM to 4:30 PM.)

The quality and content of interactions between HBPC staff and family caregivers are important determinants of subsequent actions taken. Encouraging family caregivers to seek HBPC staff guidance early when new symptoms occur can help in achieving more timely intervention. Many family caregivers lack sufficient knowledge about the patient's situation, and interactions with HBPC staff can be critical to optimal decision making. In the context of such interactions, the process of problem recognition involves first becoming aware of new evidence (symptoms), followed by identifying patterns and then labeling the recognized phenomenon.[14] The label might be a nursing diagnosis; a syndrome name, such as delirium; or a nonspecific sense of what's happening, such as "Something's wrong—this is not this person's normal behavior." If a label is unclear or nonspecific, this can result in less effective interventions. Recognition is a pivotal point in decision making. Once recognition and labeling have occurred, the family caregiver, in conjunction with HBPC staff, must decide whether to act and, if action is called for, what that action will be.

Family caregivers sought guidance before taking a loved one to an ED in just 22% of all unplanned acute care encounters.

METHODS

Design and sampling method. This study was a retrospective chart review of patients who met the following inclusion criteria: they were enrolled in the Orlando Veterans Affairs Medical Center (VAMC) HBPC program for at least one month between October 1, 2013, and September 30, 2014; had a diagnosis indicative of cognitive impairment (Alzheimer's disease, vascular dementia, or mild cognitive impairment); and had a dedicated family caregiver. The exclusion criterion was enrollment in hospice care. Data were collected from data collection templates and progress notes. All such notes were reviewed to ensure that our analysis included all relevant documentation. Convenience sampling was used, and all available cases that met these criteria were included.

Measures. Basic demographic information (age, sex, and relationship to family caregiver) was extracted from the VHA's electronic health record (known as the Computerized Patient Record System, or CPRS). Additional information that was extracted included the number of unplanned acute care encounters, the admitting diagnosis, and the content of family caregivers' contact with VHA staff when they sought guidance about potential new acute symptoms. If a patient was hospitalized, the admitting diagnosis was compared with the 11 AHRQ Prevention Quality Indicators (PQIs) associated with potentially avoidable hospitalizations among older adults.[15] These PQIs include three acute illness indicators (dehydration, bacterial pneumonia, and urinary tract infections [UTIs]) and eight chronic disease indicators (four diabetes-related complications, chronic obstructive pulmonary disease [COPD] or asthma, angina, congestive heart failure, and hypertension).

Data collection. Two trained research assistants (including one of us, ES) and the principal investigator (MRS) retrieved the aforementioned data from the VHA's electronic health record and coded it into variables; they also retrieved related text from progress notes in the electronic health record in order to fully understand the events. The research assistants' training included mock data extraction sessions under the direction of the principal investigator until coding and data extraction achieved 80% consistency across both assistants. The principal investigator also reviewed at least 10% of the charts to ensure coding and data extraction consistency.

The study protocol was reviewed and approved by the Orlando VAMC institutional review board

Table 1. Unplanned Acute Care Encounters Among Patients with Cognitive Impairment

No. of Encounters	No. of Patients
0	99
1	57
2	18
3	18
4	12
5 or more	11

before collection began. Data files were saved according to VHA and human subject guidelines.

Data analysis. We conducted univariate descriptive analyses regarding the type of staff contacted, the presenting diagnoses, the guidance offered by staff, and the number of unplanned acute care encounters. We calculated the percentage of such encounters that were potentially preventable according to the aforementioned list of 11 AHRQ PQIs.[15]

RESULTS

Sample. Of the 520 patients enrolled in the Orlando VAMC HBPC program during the 12-month study period, 274 had a diagnosis indicative of cognitive impairment. Of these, 59 were excluded because they had been enrolled for less than one month or were receiving hospice care. This left 215 patients for analysis.

Of these 215 patients, the mean age was 82 years (range, 52 to 99 years). Two hundred and nine (97%) were male and six (3%) were female. There were 254 unplanned acute care encounters: these included ED visits after which the patient was discharged to home ("ED-then-home") and ED visits that resulted in subsequent hospital admission ("ED-then-hospital"). The number of such encounters per patient ranged from zero to 10 (see Table 1). Of the 215 family caregivers, 176 (82%) were female and 39 (18%) were male. In terms of the caregiver's relationship to the patient, 85 (40%) were spouses, 88 (41%) were adult children, and 42 (20%) were friends or "other."

Findings. Family caregivers sought guidance from a health care staff person before 56 (22%) of the 254 unplanned acute care encounters. Specifically, guidance was sought before 22 (26%) of the 85 ED-then-home encounters and before 34 (20%) of the 169 ED-then-hospital encounters.

As described by the family caregivers, the presenting clinical issues of the cognitively impaired patients were most often new problems (43%). These included falls, feeding tube problems, fever, new pain, rash or other skin problems, and unexplained edema. Other presenting problems in order of frequency included respiratory symptoms, gastrointestinal symptoms, circulation problems, and altered mental status. (For more details, see Table 2.)

Family caregivers interacted most often with HBPC staff (63%) and less often with VHA telephone triage nurses (27%); the remainder interacted with outpatient clinic staff. Health care staff were most likely to be contacted on Mondays and Fridays, and were least likely to be contacted over the weekend. The most frequent advice given by both HBPC staff and VHA telephone triage nurses was to go to the ED. Of the 49 patients (88%) so advised, 44 (79%) actually did so. Of these 44, 18 (41%) were treated and returned home the same day, and 26 (59%) were admitted to the hospital with an average length of stay of 4.9 days. A total of 17 of the 44 patients who went to the ED were diagnosed with conditions the AHRQ considers potentially preventable. All but one were admitted to acute care; of these 16, eight were exhibiting symptoms of delirium. For more details on the initial interactions, see Table 3.

Of the 254 unplanned acute care encounters, 25% were for reasons the AHRQ considers potentially preventable. More specifically, of the 85 ED-then-home encounters, 8% were considered potentially preventable; and of the 169 ED-then-hospital encounters, 34% were considered potentially preventable. The most common potentially preventable clinical issue was UTI. For more details on the subsequent disposition of cases, see Table 4.

Table 2. Presenting Clinical Problems for Which Family Caregivers Sought Guidance (n = 56)

Presenting Problem	No. (%)
New problem[a]	24 (43)
Respiratory symptoms	14 (25)
Gastrointestinal symptoms	6 (11)
Circulation problems	5 (9)
Altered mental status[b]	4 (7)
Pain	2 (4)
Psychological symptoms[c]	1 (2)

[a] These included falls, feeding tube problems, fever, new pain, rash or other skin problems, and unexplained edema.
[b] This included behavioral changes and symptoms of delirium.
[c] In this case, the patient's chart said "psychotic episode."
Note: Percentages may not sum to 100% because of rounding.

More family caregiver education is warranted on how to access health care staff.

DISCUSSION

Our study of cognitively impaired HBPC patients revealed that when family caregivers sought guidance, they were almost always advised to take the patient to the ED for evaluation. This may indicate either that the symptoms were advanced or that adequate assessments were difficult to conduct by phone. More than one-third (34%) of all 169 unplanned hospital admissions were the result of an illness listed on the AHRQ's PQI list and thus were potentially avoidable. Moreover, in the 56 instances when family caregivers sought guidance first, four patients initially presented with altered mental status, and eight exhibited symptoms of delirium at time of hospital admission. Given that delirium tends to be indicative of advanced illness, this suggests the importance of better educating family caregivers on early recognition.

Table 3. Characteristics of Health Care Staff–Family Caregiver Interactions (n = 56)

Variable	No. (%) of Interactions
Type of staff contacted	
HBPC staff (nurse, NP, other)	35 (63)
VHA telephone triage nurse	15 (27)
Clinic provider or nurse	6 (11)
Day of the week	
Saturday or Sunday	5 (9)
Monday	13 (23)
Tuesday	8 (14)
Wednesday	10 (18)
Thursday	7 (13)
Friday	13 (23)
Suggested guidance	
Seek ED care	49 (88)
Patient sought ED care and	44 (79)
• was not given an AHRQ PQI diagnosis	27 (61 of 44)
• was given an AHRQ PQI diagnosis	17 (39 of 44)
• was given an AHRQ PQI diagnosis and was hospitalized	16 (94 of 17)
Suggest intervention at home	3 (5)
Present to clinic	2 (4)
Other	2 (4)
AHRQ PQI Diagnosis in Cases of ED-then-Hospital	**No. (%) of Patients (n = 16)**
Urinary tract infection	6 (38)
Pneumonia	4 (25)
COPD	3 (19)
Heart failure	2 (13)
Hypertension	1 (6)

AHRQ = Agency for Healthcare Research and Quality; COPD = chronic obstructive pulmonary disease; HBPC = home-based primary care; PQI = Prevention Quality Indicator; VHA = Veterans Health Administration.
Note: Percentages may not sum to 100% because of rounding.

Family caregivers sought guidance before taking a loved one to an ED in just 22% of all unplanned acute care encounters. And in only 63% of those encounters did caregivers use the HBPC staff as a resource. In our study, HBPC providers were not on call 24/7; perhaps family caregivers were less likely to call the 24/7 telecare line during nonwork hours because they might have to speak to someone they didn't know, or perhaps they weren't aware of the 24/7 hotline at all. Dening and Hibberd explored the role of community health nurses with family caregivers caring for loved ones with dementia, and reported that many family caregivers don't look ahead or accept help until the need becomes pressing, which can leave them in a bind.[16] Yet a large study by Edes and colleagues found that HBPC patients and caregivers valued being able to call their interdisciplinary teams with questions and concerns; participants felt that this resource helped prevent hospitalization, and described their close relationships with team members as "just like family."[5] Similarly, other studies have found that family caregivers valued being able to talk directly with a nurse or other health care provider.[17-19] It may be that more family caregiver education is warranted on how to access health care staff.

For nonprofessionals, health care decisions can be difficult to make, and even more so when acting on behalf of a loved one. Family caregivers of people with dementia typically have numerous decisions to make, many of which involve significant aspects of health and physical safety.[20] As Stirling and colleagues have noted, decision assistance provides caregivers with access to expert knowledge and helps them evaluate a range of choices for action or inaction, thereby decreasing conflict and indecision.[21] In studies where family caregivers of people with cognitive impairment were offered decision assistance, the caregivers reported feeling more competent in their caregiving skills and viewed the decision assistance as boosting their confidence.[21-23] Moreover, earlier research found that when older adults have decision assistance resources in place or know how to access such resources, they are more apt to use them[24]; it stands to reason that the same would hold true for family caregivers.

Table 4. Unplanned Acute Care Encounters Considered Potentially Preventable, by AHRQ PQI Diagnosis and Case Disposition

AHRQ PQI Diagnosis	ED-then-Home, n (%) (n = 85)	ED-then-Hospital, n (%) (n = 169)	ED-then-Home and ED-then-Hospital, n (%) (N = 254)
Bacterial pneumonia	0 (0)	11 (6.5)	11 (4.3)
COPD	1 (1.2)	9 (5.3)	10 (3.9)
Dehydration	1 (1.2)	6 (3.6)	7 (2.8)
Diabetes complications	1 (1.2)	1 (0.6)	2 (0.8)
Heart failure	2 (2.4)	1 (0.6)	3 (1.2)
Hypertension	1 (1.2)	5 (3)	6 (2.4)
Urinary tract infection	1 (1.2)	24 (14.2)	25 (9.8)
Total	**7 (8.4)**	**57 (33.8)**	**64 (25.2)**

AHRQ = Agency for Healthcare Research and Quality; COPD = chronic obstructive pulmonary disease; PQI = Prevention Quality Indicator.

In a systematic review of outcomes from HBPC programs, Stall and colleagues noted that the more robust programs included such components as multidisciplinary care teams, regular team meetings, and after-hours urgent telephone service.[4] Using staff familiar with all components of the HBPC program during urgent telephone calls may also be crucial to providing timely, targeted support to family caregivers. Indeed, such knowledge should perhaps be a prerequisite, so that staff can offer patients and caregivers more comprehensive guidance.

In our study, UTIs, COPD, and pneumonia were the most common AHRQ PQI diagnoses. Educating family caregivers on the prevention of recurrent exacerbations of chronic illness and the early recognition of symptoms must be a high priority. Such education should include what actions the caregiver should take when new symptoms arise, so that the patient can be treated as early in the illness trajectory as possible. There is evidence that teaching patients to recognize symptom patterns and to know when and how to intervene in order to avoid or minimize illness exacerbation is effective.[25, 26] It stands to reason that educating family caregivers in this way would also be effective.

Of the 56 instances in which caregivers sought guidance, four (7%) concerned patients with symptoms of altered mental status. Similar results were reported by Han and colleagues, whose study aimed to determine the diagnostic performance of "altered mental status" as the chief complaint in detecting delirium in older ED patients.[27] They found that altered mental status was the chief complaint of 5.7% of the study population. Although the absence of altered mental status did not significantly decrease the likelihood that delirium was present, its presence strongly increased that likelihood. In our study, of the 16 patients who presented to the ED and were given an AHRQ diagnosis and admitted to acute care, eight (50%) exhibited symptoms of delirium.

Early symptom recognition makes it more likely that the patient can be treated in place and trips to the ED can be avoided.

Limitations. Since the study population was limited to one HBPC program, the findings must be viewed with caution. Also, this was a retrospective chart review, not a prospective study, which could have yielded additional information through patient and caregiver interviews. Lastly, the study population was limited to older adults with cognitive impairment; it may be more difficult to help caregivers determine a course of action for patients who face other physical and mental health care issues. For example, combat veterans have high prevalences of chronic pain, traumatic brain injury, posttraumatic stress disorder, depression, substance abuse, divorce, and homelessness.[28]

Implications for practice and research. Practice implications include

- teaching family caregivers how to identify signs and symptoms of preventable illnesses that often develop in frail older adults, including congestive heart failure, COPD exacerbations, pneumonia, and UTIs.
- teaching family caregivers what actions to take when such symptoms arise, before the illness advances to the point where the patient requires hospitalization.
- providing specific education on recognizing delirium symptoms and treating this as a medical emergency.
- developing a multipronged approach to teaching family caregivers exactly how and when to contact their health care professionals, so that potential problems can be addressed earlier in the illness trajectory.

To that end, future research efforts should be aimed at identifying and addressing barriers that prevent family caregivers from contacting health care professionals for guidance before seeking ED or hospital care. Educational interventions for family caregivers that will help them to recognize subtle changes in symptomatology earlier in the illness trajectory also need to be developed and implemented. If caregivers have a clear understanding and awareness of their loved ones' existing symptoms, they'll be better prepared to recognize changes and new symptoms. Early recognition makes it more likely that the patient can be treated in place and trips to the ED can be avoided. Similarly, health care professionals working in HBPC and similar services should have access to patients' illness profiles. Outcomes will improve when prodromes are documented and made accessible to on-call staff.

Emerging technologies offer greater flexibility in communications between health care professionals and family caregivers. As Sugihara and colleagues report, telecare networks in Japan may involve professionals from the fields of caregiving, nursing, and medicine.[29] In Sweden, Lundberg and colleagues introduced an integrated Internet–videophone system that offers both information and social support to family caregivers.[30] In the United States, Tinetti and colleagues have proposed a model of care for older adults with multiple chronic conditions (and which is applicable to those with dementia): patient priority–directed care.[31] One of its guiding principles is to provide anticipatory guidance by having clinicians prepare patients and their family caregivers "for anticipated events, trajectories, and situational crises." This facilitates more informed decision making regardless of whether a situation is acute or chronic. And the Centers for Medicare and Medicaid Services is currently testing an innovative program, Independence at Home Demonstration, that builds on existing benefits by providing chronically ill patients with comprehensive primary care services in the home setting.[32]

Improving communication between family caregivers and health care professionals—whether face-to-face, by telephone, or via emerging technologies—will improve the effectiveness of HBPC and similar programs in serving patients with cognitive impairment.

CONCLUSION

It's important for health care professionals to ensure that family caregivers of cognitively impaired older adults can access professional guidance readily when facing decisions about a loved one's care, especially when there is an acute onset of new symptoms. Teaching caregivers how to recognize such symptoms early in order to prevent exacerbations of chronic illness and subsequent hospitalization should be a high priority. Our findings underscore the need to do so, so that caregivers can best use the resources that HBPC programs have (or ought to have) in place, in particular 24/7 guidance and decision assistance. ▼

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