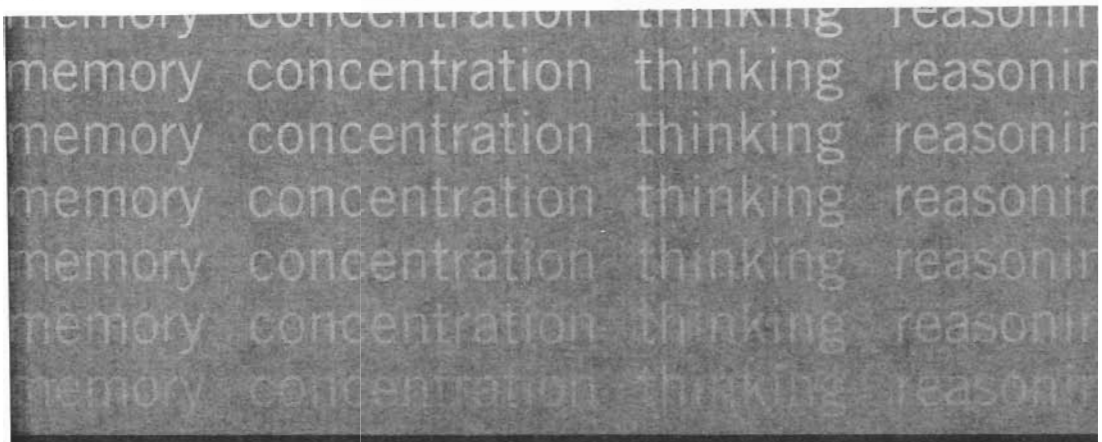

Improving Hospital Care for Persons with Dementia

Nina M. Silverstein
Katie Maslow
Editors

CHAPTER FOUR

The Hospital Experience

Perspectives of Assisted Living Providers

Joan Hyde

Current surveys of assisted living residences report that between 30% and 50% of residents have some levels of cognitive impairment (ALFA, 2000; GAO, 1999; Hawes, Rosen, & Phillips, 1999; Hyde, 1995). One reason people move to assisted living settings is to get personalized oversight and coordination of their care needs, including coordination of care when they need hospitalization. This type of service would seem to be particularly important to those with cognitive impairment.

As cited in other chapters in this volume, individuals with dementia are particularly vulnerable to the problems all patients encounter in hospitals. This chapter reports on a small pilot study of hospitalizations among cognitively impaired residents living in six different assisted living communities. We conclude that assisted living can, if organized appropriately, provide coordination and support for resident transitions to the hospital and back to the assisted living facility, and thereby help reduce some of the problems with this aspect of a resident's hospital experience.

DESCRIPTION OF THE STUDY AND THE STUDY POPULATION

Data were collected from interviews with a convenience sample of six nurses from assisted living residences in two states over a very limited

time period (one month) in late 2003 (Table 4.1). Four of the facilities specialize in dementia care, and two serve a general assisted living population, including some cognitively impaired residents.

Based on this small sample (N = 318 residents with dementia), we found that an average of about 7% of assisted living residents were seen in a hospital emergency room (ER) over a given one-month period, and about 3% were admitted and spent one or more nights in the hospital, whether following an ER visit or as a planned admission. For the traditional assisted living residences in the sample, the staff was unable to break out the data for their cognitively impaired residents, so these numbers are for the mixed population. There is no significant difference in rates of ER use or hospitalizations between these two traditional assisted living residences and the four dementia-specific assisted living units.

Most of the hospitalizations experienced by cognitively impaired assisted living residents are for medical problems unrelated to their dementia. Hospitalizations for the behavioral and psychological symptoms of dementia are typically in a psychiatric hospital or the psychiatric wing of a general hospital. These psychiatric admissions are different in many ways from ER or acute hospital admissions, and their differing issues are outside the purview of this chapter.

Falls, fractures, and stroke were the main reasons reported for ER visits and/or hospitalizations. Table 4.2 illustrates the range and frequency of the conditions that were reported.

TABLE 4.1 Emergency Room Usage and Hospital Admissions (Monthly Averages, by Assisted Living Residence)

Facility code	Number of residents	Number of emergency room trips	ER trips/ number of residents (%)	Number of hospital admissions	Hospital admission (%)
Traditional A	90	8	9	2	2
Traditional B	95	4	4	3	3
SCU C	50	2	4	1	2
SCU D	26	1	4	2	8
SCU E	28	4	14	2	7
SCU F	29	2	7	0	0
Total/Average	318	21	7	10	3

Note: Data were reported by sites based on their last reporting period during the fall of 2003. The precise reporting period varied by site, and a one-month average obtained if the reporting period exceeded one month.

TABLE 4.2 Conditions Triggering an ER Visit or Hospitalization (in Order of Frequency)

Condition	Approximate % (N = 31)
Falls or fractures (other than hip)	25
Hip fracture	20
Strokes, chest pains, blood pressure changes	20
Pneumonia, urinary tract or other infection	15
Changes in mental status, behaviors	10
Other	10

CONCERNS OF ASSISTED LIVING STAFF ABOUT HOSPITALIZATION

In this brief survey, we heard reports of many of the same kinds of problems described in other chapters of this volume that are likely to occur when any person with dementia goes to the hospital. The following quotation from an assisted living staff person illustrates the frustration:

> "We've had people in the ER for 6, 7, 8 hours, and they don't even do anything . . . at least they should admit them into a room so they have a place to wait. They don't understand what's involved with the process of handling dementia patients and they'll ask the resident questions about medical history, which the patient can't answer. They ask the resident, have you had any surgery? And the resident looks at them like they've got 4 heads."

Some hospital staff, despite being told that the patient has dementia and despite witnessing the patient's inability to respond, nonetheless continue to expect the patient to report both recent and longer term medical and social history, even family members' telephone numbers.

Waiting areas are also problematic. Some ERs have people with dementia waiting on stretchers in busy hallways and fail to provide hydration, assistance with toileting, or other basic needs during long waits. They may not even have briefs available for incontinent patients who are spending many hours in the ER. An assisted living staff member underscores the need to accompany the cognitively impaired elder:

> "We think no older persons should go to the ER by themselves because they will be totally confused and traumatized. If they need help or if they have to go to the bathroom, they don't even know how to tell anybody. And in the ER, people wait hours unless they are having

a heart attack or something like that. For all these reasons, someone needs to accompany them."

Some hospitals have no system for evaluating and monitoring residents who are at risk for wandering out of the building or becoming lost, with no security systems to prevent wandering within or out of the building.

Moreover, many hospital staff members are unfamiliar with the behavioral symptoms of dementia and do not effectively prevent or deal with agitation and other psycho-behavioral symptoms that patients often display under the combined stresses of acute illness and hospitalization. Some ER staff members expect the patient to identify the assisted living staff member who accompanied the patient before they will allow the staff member to stay with the patient.

Residents who spend more than a day or two in the hospital often show signs of having been restrained, such as bed sores and loss of the ability to walk. The failure to order physical therapy or other interventions that would benefit a patient, either while in the hospital or as part of the follow-up plan, simply because the patient has dementia contributes to poorer outcomes following discharge.

CHALLENGES FOR THE ASSISTED LIVING PROVIDER

There are some specific problems that assisted living providers encounter when their residents go to the hospital. For example, families may not understand that assisted living providers must call 911 in an emergency, even when there is a standing Do Not Resuscitate order.

Ambulance companies and the local hospitals have agreements regarding to which hospital the ambulance will take someone. While in a life-threatening emergency it makes sense to take a patient to the nearest hospital, in other cases it would be better to take the patient to the hospital where his or her doctor is on staff or where the assisted living provider has established a good working relationship. Because these individuals live in assisted living residences and cannot speak for themselves, and because the staff cannot always reach a family member quickly enough, assisted living providers may have trouble advocating (and guaranteeing payment for) a transfer to the hospital of choice.

Further, some hospital staff do not understand that assisted living venues have different rules and capabilities from nursing homes, and they therefore assume that they can return a patient to his or her assisted living residence and the patient will get the same services as if he or she were returning to a nursing home.

"We've had people call up and say they're going to discharge someone, and the resident is just not in a condition to come back. The [hospital staff] doesn't understand under what conditions we can accept someone back. They don't know that we can't accept people with catheters – that's happened two times, almost three times. They're also not accommodating when it comes to discharge timings. They wanted to discharge someone at night; they were pushing to discharge this resident at 7 p.m. on Friday, but we wanted them to discharge the resident at a different time because we didn't have a nurse present at that time."

Conversely, the hospital staff may believe that since the patient comes from an assisted living residence, he or she must not have dementia. Or once they realize that the patient has dementia, staff members may assume that the patient cannot return to the assisted living residence and automatically refer the patient to a nursing home.

There is a lack of understanding of what the particular assisted living personnel can or cannot do. For example, in many states (Hyde, 1995), assisted living nurses cannot take orders for medication over the phone, and most assisted living residences cannot manage catheters and IVs. Also, hospital staff members often do not realize that assisted living residences generally do not have a nurse on site 24 hours a day.

Paperwork sent to the hospital, including the original "do not resuscitate" forms, often gets lost or is filed at the hospital, requiring assisted living staff either to retrieve or reestablish the paperwork.

Hospitals and ERs may discharge a patient without notice or without an adequate plan, and with little or no communication between hospital staff and assisted living staff, sometimes occasioned by privacy concerns.

HOW ASSISTED LIVING PROVIDERS CAN HELP REDUCE PROBLEMS FOR RESIDENTS WITH DEMENTIA WHO MUST GO TO THE HOSPITAL

Some assisted living residences surveyed for this study had better experiences than others with their local hospitals. While some of the difference is undoubtedly the result of better systems and training within the hospitals, some assisted living providers have taken steps that have improved residents' hospital experiences and that better serve their residents following the hospitalization:

1. *Accompany a person with dementia to the emergency room.* If a family member is not available to ride in the ambulance or meet the resident in the ER, a staff member should go with the patient and stay

until family arrives. For this strategy to be effective, the staff person must be reasonably fluent in English, knowledgeable about hospital systems, and willing to act as an advocate, which may mean that the staff member should be a nurse or other manager. Typically, assisted living residences that provide this service charge the families for it at a rate that covers the additional staff time. Even when paid for by families, it may be difficult for the assisted living residence to make a staff person available on an unplanned basis. An assisted living staff member describes the importance of accompanying the elder in the ER:

> "When one of our resident[s] goes to the ER, we find that many ER staff members do not understand that the resident has Alzheimer's, and they think they can just talk to him or her in a loud voice. The resident becomes agitated, and sometimes the doctor just leaves the resident there to wait. This situation has happened quite a few times. Now, an aide or a manager accompanies a resident; otherwise, the resident may be left in the ER for hours."

2. *Work with the local ambulance services.* Doing so can ensure that ambulance personnel understand the needs of those they are transporting and that they understand the assisted living provider's systems, as well as the importance of transmitting the paperwork given to them for use at the hospital. This work is ongoing, as illustrated by the following quotation:

> "Our paperwork that we send with the residents either gets lost in the ER or never gets to the ER. The ambulance company blames it on the ER and vice versa. So here we are trying to make their lives easier by giving med sheets, and yet they tend to lose them."

3. *Provide a clear summary of the resident's diagnosis and history.* Further, include a medication record, description of pre-emergency dementia symptoms, and phone numbers for next of kin. Include a copy of insurance information and the health care proxy document if one exists; send this information with the resident in the ambulance. If available, be sure to provide an acceptable copy of the DNR document as well. It takes considerable prior planning to ensure that accurate, up-to-date information is available, even during the night, if someone goes to the hospital on an emergency basis. That information is described by the following quotation:

> "We send a [specific, prearranged nursing home] authorization along with each resident, that should the resident need rehab, he or she will go to that nursing home, and the residence gets med sheet with the diagnosis, medication information, physician's and family's names and numbers, and medical cards. We send two copies, one for hospital and one for ambulance people; yet, invariably, the hospital calls and says 'what meds is this person on' or 'what's the person's contact number.'"

4. *An assisted living nurse should call the ER while the resident is in transit.* The assisted living nurse must talk directly to the intake nurse, giving the intake nurse a medical history of the patient. The nurse should brief the ER on the need to have an assisted living staff member stay with the patient and give the name of the staff member accompanying the resident. Make sure the intake department knows how to reach both the assisted living nursing staff and the family.

5. *Arrange for private-duty aide.* If the resident is admitted to the hospital and is likely to have behavioral issues or need more assistance with activities of daily living (ADLs) than the hospital can provide, staff members should work with the family and the hospital to arrange for a private-duty aide.

6. *Prepare the assisted living staff for the resident's return.* Make sure that assisted living staff members who will be providing assistance know about any new medications or written instructions from the ER.

WORKING WITH HOSPITALS BETWEEN CRISES AROUND RESIDENT TRANSFERS

The intervention that assisted living staff members have found to be most helpful is creating and maintaining relationships with the hospital at times when there is no crisis. This requires:

- Visiting the hospital to understand its systems
- Dropping off materials about the assisted living facility
- Inviting key hospital staff to visit the assisted living residence so they have first-hand understanding of the residents when not in crisis and have an understanding of the assisted living facility
- Providing in-service training to hospital staff on dementia, including strategies for averting and managing wandering, agitation, and other behavioral issues

CONCLUSION

Assisted living staff members have considerable experience with the needs of people with dementia as they move through the hospital system. Staff

members are an effective resource to work with other groups, such as the Alzheimer's Association, to help educate hospital staff about the needs of patients with dementia.

Assisted living residents are fortunate in that they often have both family members and assisted living staff acting as advocates. Consequently, assisted living residents with dementia may fare better than some cognitively impaired elders in the community who may have less support when they need to go to the hospital. Nonetheless, hospitalization continues to be an issue for this subset of the dementia population.

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