Preventing Burdensome Transitions of Nursing Home Residents with Advanced Dementia: It's More than Advance Directives

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Abstract

Background: Although a palliative approach to care is recommended for people with advanced dementia, many nursing home (NH) residents with dementia experience burdensome interventions such as hospital transfers at the end of life.

Objective: The goal of this study was to examine how decisions to transfer NH residents with advanced dementia are made, from the perspective of NH nurses and physicians.

Methods: A qualitative, descriptive method was used. Purposive sampling was used to recruit 20 healthcare providers from 9 NHs. Data collection included semistructured, open-ended interviews.

Results: Decision making regarding hospital transfer comprised two phases. Phase one, laying the groundwork, was influenced by the ability of the providers to effectively establish trust, foreshadow, and illuminate hazards of hospitalization. Phase two, responding to an acute event, began at the start of an acute event and ended when a decision was made to either treat the resident in the NH or transfer to the hospital. Responding to the acute event was influenced by the ability to care for residents in the NH, the providers' comfort with end-of-life conversations, and surrogates' preferences.

Conclusions: Advance care planning before an acute event is only the first step in a process of decision making. Attention to and support for decision making is needed at the time of each acute event to ensure that goals of care are maintained.

Keywords: decision making; dementia; nursing homes; patient transfer; qualitative research; terminal care

Introduction

DEMENTIA is a leading cause of death in the United States.¹ Although a palliative approach to care is recommended for people with advanced dementia, many nursing home (NH) residents with dementia experience burdensome interventions such as hospital transfers at the end of life.² Hospital transfers can be onerous for people with advanced dementia and costly for the healthcare system.^{3,4} Research suggests that both individual- and facility-level factors are associated with hospital transfers; however, less is known about the actual decision-making process.

The final stage of dementia is characterized by total dependence on others for care, pneumonia, febrile illness, and eating problems.⁵ As the end of life approaches, many ex-

perience dyspnea, pain, agitation, and aspiration, for which palliative care is recommended.^{6,7} Nonetheless, many NH residents with advanced dementia are transferred to hospitals for treatment of acute illness.²

Approximately 25% of NH residents with advanced dementia are hospitalized in the last six months of life.⁸ These transfers are costly for the healthcare system, accounting for 40% of Medicare expenditures for NH residents.³ Hospital transfers can also be burdensome for residents. With limited clinical benefit,⁷ being hospitalized increases the risk of aggressive interventions, such as ICU admissions and feeding tube insertion.^{9,10} They are more likely to experience falls, functional decline, malnutrition and dehydration, superimposed delirium, and death.¹¹ Transfers are not only burdensome for residents, but evidence suggests that they are

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distressing for family members as well.¹² Given that an estimated 59% of hospitalizations are due to conditions that can be effectively treated in the NH, efforts to understand and curb unnecessary hospital transfers are needed.¹³

Several factors associated with hospital transfer have been identified.¹⁴ Resident factors include black race and Hispanic ethnicity,¹⁴ greater age and length of NH stay,⁸ lack of do-not-hospitalize (DNH) orders,¹⁵ and facility-level factors such as staffing¹⁶ and physician presence.¹⁷ Although we know that multiple factors are associated with hospital transfers, less is known about how these factors influence the decision-making process. Therefore, the purpose of this study was to increase an understanding of how decisions are made to transfer NH residents with advanced dementia from the perspective of NH nurses and physicians. A better understanding could lead to strategies to prevent unnecessary transfers.

Methods

A qualitative descriptive method was used.¹⁸ Hebrew Senior Life institutional review board approved the study.

Setting/sample

We recruited nine NHs within 60 miles of Boston with at least 50 beds. We used chart reviews to verify that facilities had residents with dementia, age ≥ 60 , and a Global Deterioration Scale¹⁹ score of 7 indicating advanced dementia. We invited licensed nurses and physicians who worked in these NHs to participate in telephone interviews. Data collection via interviews continued until saturation was reached and no new information was obtained.²⁰

Data collection

After obtaining verbal consent, we collected data by using a semistructured, open-ended interview guide that addressed the influence of: resident factors (overall condition, goals of care, written directives, acute illness), family member factors (role in decision making, preferences), and NH conditions (ability to provide care, programs to reduce hospitalization). Interviews ranged from 30 to 45 minutes and were digitally recorded.

Data analysis

Interviews were transcribed and entered in QSR Nvivo (version 11.0). Analysis involved three levels of coding.^{21,22} During first-level coding, two researchers (R.P.L. and J.L.G.) read the interviews line by line, assigned a code to each concept, and found that data grouped into two themes that we labeled phases. In second-level coding, data in each phase were examined to identify processes within each phase. During the third-level coding, the phases and processes were analyzed to identify relationships between and among them. Finally, the overarching phases and processes were compared across transcripts to ensure that they were both representative and inclusive. Trustworthiness of the study was supported by peer debriefing and reflexive dialogue.²³ A record of methodological decisions, logistics, and reflections was maintained.

Findings

Study population

We interviewed 20 providers from 9 NHs. NHs ranged from 50 to 200 beds (mean = 101). Five were for profit, and 4 were not for profit. The U.S. government site for Medicare,²⁴ which rates how well NHs care for residents using 1 to 5 stars (higher stars = better care), indicated that 2 NHs scored 5 stars, 2 NHs scored 4 stars, 1 NH scored 3 stars, and 4 NHs scored 2 stars. Participants included 6 physicians and 14 nurses, with an average age of 50, of whom 16 were women, 19 were white, and 1 nurse was African American.

Qualitative findings

Analysis of the data found that the process of decision making comprised two phases. Phase one, laying the groundwork, took place shortly after admission and consisted of obtaining surrogates' preferences in response to hypothetical acute events. This process was influenced by three processes, that is, the ability of the providers to effectively: (1) establish trust, (2) foreshadow, and (3) illuminate hazards of hospitalization. The goal of laying the groundwork was to "avoid drama" during a real acute event. Phase two, responding to an acute event, began at the start of an acute event and ended when a decision was made to either treat the resident in the NH or transfer to the hospital. The goal of phase two was to ensure that surrogates' preferences were honored and that residents achieved the maximum comfort possible. Responding to the acute event was influenced by three factors: the ability to provide care in the NH, providers' comfort with end-of-life conversations, and surrogates' preferences.

Phase one: Laying the groundwork

According to the participants, laying the groundwork began shortly after admission. It consisted of "blunt discussions" that providers had with surrogates, in either formal family meetings or informal conversations, in which they attempted to ascertain surrogates' preferences for hospitalization in the case of hypothetical acute events. Nurses described laying the groundwork as "laying out a platform," allowing them to "sit with it," and having everything "in place" before the acute situation "comes down."

NH providers were motivated to obtain DNH orders by two complementary forces. The first was their contention that hospitals were not safe places for those with advanced dementia. The second was the general sense that transfers were discouraged by external fiscal pressures. One nurse described her general sense of the NH's attempt to discourage transfers. She referred to "finances" and "whatever is going on in the medical field with how the hospitals are penalized." She said that when a resident is transferred to the hospital, "the facility wants to know why you sent somebody out. How come you did it. Let's chat. Let's look at it." Another participant described a negative experience for a resident in the emergency room:

Her son absolutely wanted her to go [to the hospital] and they [hospital] called us, she had ripped out the IV, she was bleeding everywhere. They couldn't keep her in the bed. They couldn't get near her. She gets that way here, but we know how to handle her and how to go away, come back, keep her safe. They had no idea.

The process of laying the groundwork was influenced by participants' ability to establish trust, foreshadow downward trajectory, and illuminate hazards of hospitalization.

Establishing trust

Providers felt that establishing trust was an essential element to obtaining DNH orders. Surrogates needed to feel safe and confident that their loved ones would be taken care of to the best of the providers' abilities. One nurse described it this way, "if the families are uncomfortable and don't trust the NH then they're going to freak and have to go to the ER." Another said, "they're [surrogates] not comfortable neither are we and neither is the resident."

A nurse described the evolution of trust:

At the family meeting I said, "at some point you're going to look at this place like your family and you're not going to want your father to go anyplace else. You're going to want these people caring for him." The daughter gave me the biggest eye roll ever. People said that she quoted that in her eulogy [for her father]. She would never have wanted her father to be any place else because we knew him, and we knew how to take care of him, and the aides knew him, and the cat knew him. So if you give us enough time, we'll get it done.

Foreshadowing

Providers also foreshadowed the expected downward trajectory of dementia. They believed that discussing hypothetical acute events that commonly occur in advanced dementia helped prepared surrogates for decision making during real acute events. A physician described it as being "proactive" to "think about things before hand and warn them [surrogates] about future decisions." A nurse explained, "I think it's a lot easier to remind the families that this is a decision that's already in place as opposed to having that decision made in a more acute [situation]."

Illuminating hazards of hospitalization

To illuminate the hazards of hospitalization, providers used three strategies. They emphasized the many risks of hospitalization, including increased confusion, agitation, restraint use, skin breakdown, and infection. If a resident had experience with hospitalization, they drew attention to the negative aspects of that event, and they suggested that hospitalization had little to offer people with advanced dementia. Nurses described these three strategies.

When patients return from the hospital, they are confused number one. Second the patient always has pressure ulcers, always. It's very hard to treat the patient decline if patient returns with pressure ulcer.

You send them this is what's going to happen, they'll be in the emergency room for hours and hours. The staff there are not trained to take care of dementia. They're going to sedate them. They may even restrain them. The person's going to be so confused and so upset and bewildered.

There was nothing that happened at the hospital that helped her bloody nose except she got way more agitated and was all upset and screaming and that family absolutely wrote they never want her to go out to the hospital again.

Providers continued these discussions until a DNH order was achieved. However, unlike other medical orders that

remain in effect until the order is discontinued, the DNH stands only as a symbol of surrogates' preferences in response to hypothetical acute events. Providers did not automatically withhold hospitalization in response to DNH orders. Instead, they transitioned to phase two.

Phase two: Responding to the acute event

When a real acute event took place, armed with an understanding of the surrogates' preference in the event of a hypothetical event, they again queried surrogates to determine how they wanted to handle real acute events. A physician said, "you take a deep breath and you pick up the phone. You have a nice conversation about what's going on. Even if it's total craziness, you try to make sure you have that conversation." Ultimately, whether residents are hospitalized in response to real acute events was influenced by three factors: the ability to care for residents in the NH, providers' comfort with end-of-life conversations, and surrogates' preferences.

Ability to provide care in NH

All participants reported that the ability to manage or palliate acute events was critical to their willingness to keep residents at the NH. Both nurses and physicians reported ready access to medical interventions such as IVs, antibiotics, close monitoring, 24/7 provider coverage (physicians and nurse practitioners with geriatric training), diagnostic equipment, specialized units (acute, rehabilitation, dementia), and emergency pharmacy services as enabling them to care for acutely ill residents at the NH. They also reported their expertise in caring for older adults at the end of life and their access to palliative care as reasons for not wanting to transfer residents with advanced dementia to the hospital. A nurse said, "we're the experts at the nursing home level, taking care of these frail elders with significant cognitive impairment."

NH providers' comfort with end-of-life conversations

Both nurses and physicians spoke about the power they had to influence surrogates' decisions. A physician spoke about his power in terms of being the captain of the ship. He said:

I think the pendulum has swung too much to this patient autonomy realm where it's almost like a Chinese menu where everything's a la carte and you pick your own. But most of the time, families and residents, they don't have the expertise nor the experience to decide what's meaningful and what's appropriate. So I help guide the goals for the care, so they [surrogates] direct the destination, and I am the navigator. I am the medical personnel who will navigate through this medical system to arrive at that destination that they desire. So there are two separate jobs. Their job is not to choose this treatment over that treatment. Their job really is to choose what they want at the end of this treatment, and then I as the professional help to guide treatment towards that.

In contrast, a novice nurse spoke of her discomfort in having this power. She said:

As a new nurse, everything is new, and I want to make sure I do it right and make sure I do what's safe for my patients. I know that I stress out over it. I put this on me and actually with years of experience, down the road, I'll get more comfortable

with decisions I make. It's hard to know that the resident's life is on me.

An experienced nurse echoed the importance of experience in having end-of-life conversations. She said, "I'm used to talking out loud and then with thirty years' experience I know the right things to say now. I think a lot of it is experience. New nurses, fresh off the line want to save everybody."

Surrogates' preferences

Finally, NH providers reported that the most significant influence on decisions to transfer was surrogate preference. As one nurse said, "the family has the final say. It's always the family. The doctor can even try to get them out of it, but if the family says yes, then they go." Nurses and physicians agreed:

Because the family is the healthcare proxy, I understand we have to listen. It's like the voice of the resident and sometimes it's different. The resident is tired, the resident doesn't want to go anywhere, but the family insists and we have to go with the family because the healthcare proxy is activated and we have to listen to the family.

It really all comes down to the family. It's the family. That's really who decides it, whether it's good or bad. It's the family.

Discussion

Our goal was to increase an understanding of hospital decision making for NH residents with advanced dementia. Findings suggest that decision making takes place in two phases. Although several factors influenced both phases, ultimately the preferences of the surrogates dictated where residents were treated. Previous research highlights the importance of engaging in advance care planning and ascertaining goals of care. NH residents who have DNH orders are less likely to experience hospital transfer,² yet DNH orders are rare (6.8%) in this population.¹⁴ At present, efforts to limit hospital transfer are focused on this process and the benefits of programs such as the Physician Orders for Life-Sustaining Treatment (POLST) program.²⁵ Although attention to this phase of decision making is important, this study suggests that advance care planning and DNH orders alone will not ensure that palliative goals of care are attained.

Attention must also be directed at how NH providers respond to an acute event. Indeed, research suggests that nurses can play an unseen role in influencing surrogates' and physicians' preferences for hospital transfer²⁶ and are challenged by unclear expectations, poor communication and collaboration, and lack of resources.^{27,28} This study illustrates the importance of engaging family members in difficult conversations about death at the time of the acute event. Therefore, ensuring that NH providers have skill and time to engage in these conversations is important and supports the benefit of nurse practitioners' and physicians' presence in NHs. In addition, our findings highlight the importance of NH access to diagnostic testing and treatments as a means of reducing hospital transfer. Providers in our study believed that the NH was the best place for residents to be treated, but only if their symptoms could be addressed and palliated. As efforts are underway to prevent transferring residents, equal attention must be paid to the quality of care that residents

receive if they are not transferred. In addition, the paramount role that surrogates play in the decision to transfer is echoed in this study as in others.^{26,29} Additional research is needed to examine how surrogates experience transfer decisions, especially in light of an acute event. Finally, although an attempt was made to purposefully select NH providers from various types of NHs, analysis of the data revealed that all participants agreed that the NH setting was the best environment to care for residents with advanced dementia. National research is needed to understand the vast facility and regional variability in hospital transfers at the end of life.

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References

1. Alzheimer's Association: 2015 Alzheimer's disease facts and figures. *Alzheimers Dement* 2015;11:332–384.
2. Givens JL, Selby K, Goldfeld KS, Mitchell SL: Hospital transfers of nursing home residents with advanced dementia. *J Am Geriatr Soc* 2012;60:905–909.
3. Goldfeld KS, Stevenson DG, Hamel MB, Mitchell SL: Medicare expenditures among nursing home residents with advanced dementia. *Arch Intern Med* 2011;171:824.
4. Goldfeld KS, Hamel MB, Mitchell SL: The cost-effectiveness of the decision to hospitalize nursing home residents with advanced dementia. *J Pain Symptom Manage* 2013;46:640–651.
5. Mitchell SL, Teno JM, Kiely DK, et al.: The clinical course of advanced dementia. *N Engl J Med* 2009;361:1529–1538.
6. Harris D: Forget me not: Palliative care for people with dementia. *Postgrad Med J* 2007;83:362–366.
7. Sampson EL, Ritchie CW, Lai R, et al.: A systematic review of the scientific evidence for the efficacy of a palliative care approach in advanced dementia. *Int Psychogeriatr* 2005;17:31–40.
8. Lamberg JL, Person CJ, Kiely DK, Mitchell SL: Decisions to hospitalize nursing home residents dying with advanced dementia. *J Am Geriatr Soc* 2005;53:1396–1401.
9. Teno JM, Mitchell SL, Skinner J, et al.: Churning: The association between health care transitions and feeding tube insertion for nursing home residents with advanced cognitive impairment. *J Palliat Med* 2009;12:359–362.
10. Fulton AT, Gozalo P, Mitchell SL, et al.: Intensive care utilization among nursing home residents with advanced cognitive and severe functional impairment. *J Palliat Med* 2014;17:313–317.
11. Dewing J, Dijk S: What is the current state of care for older people with dementia in general hospitals? A literature review. *Dementia (London)* 2016;15:106–124.
12. Epstein-Lubow G, Gaudiano B, Darling E, et al.: Differences in depression severity in family caregivers of hospitalized

- individuals with dementia and family caregivers of outpatients with dementia. *Am J Geriatr Psychiatry* 2012;20:815–819.
13. Kruse RL, Mehr DR, Boles KE, et al.: Does hospitalization impact survival after lower respiratory infection in nursing home residents? *Med Care* 2004;42:860.
 14. Gozalo P, Teno JM, Mitchell SL, et al.: End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* 2011;365:1212–1221.
 15. Houttekier D, Vandervoort A, Van den Block L, et al.: Hospitalizations of nursing home residents with dementia in the last month of life: Results from a nationwide survey. *Palliat Med* 2014;28:1110–1117.
 16. Carter MW, Porell FW: Vulnerable populations at risk of potentially avoidable hospitalizations: The case of nursing home residents with alzheimer's disease. *Am J Alzheimers Dis Other Demen* 2005;20:349–358.
 17. Helton MR, Cohen LW, Zimmerman S, et al.: The importance of physician presence in nursing homes for residents with dementia and pneumonia. *J Am Med Dir Assoc* 2011;12:68–73.
 18. Sandelowski M: Focus on research methods. Whatever happened to qualitative description? *Res Nurs Health* 2000;23:334–340.
 19. Reisberg B, Ferris SH, DeLeon MJ, Crook T: The global deterioration scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982;139:1136–1139.
 20. Strauss A, Corbin J: *Basics of Qualitative Research*. Thousand Oaks: Sage, 1998.
 21. Wolcott H: *Transforming Qualitative Data: Description, Analysis, and Interpretation*. Thousand Oaks, CA: Sage, 1994.
 22. Schreiber RS: The “how to” of grounded theory: Avoiding the pitfalls. In: Schreiber RS, Stern PN (eds) *Using Grounded Theory in Nursing*. New York: Springer Publishing Company, 2001.
 23. Lincoln YS, Guba EG: *Naturalistic Inquiry*. Beverly Hill, CA: Sage Publications, 1985.
 24. Medicare.gov: Nursing home compare. www.medicare.gov/nursinghomecompare/search.html? Updated 2017.
 25. Kim H, Ersek M, Bradway C, Hickman SE: Physician orders for Life-Sustaining treatment for nursing home residents with dementia. *J Am Assoc Nurse Pract* 2015;27:606–614.
 26. Lopez RP: Nurses in the middle: Decision making for acutely ill nursing home residents. *J Adv Nurs* 2009;65:1001–1009.
 27. Laging B, Ford R, Bauer M, Nay R: A meta-synthesis of factors influencing nursing home staff decisions to transfer residents to hospital. *J Adv Nurs* 2015;71:2224–2236.
 28. O'Neill B, Parkinson L, Dwyer T, Reid-Searl K: Nursing home nurses' perceptions of emergency transfers from nursing homes to hospital: A review of qualitative studies using systematic methods. *Geriatr Nurs* 2015;36:423–430.
 29. Tappen RM, Worch SM, Elkins D, et al.: Remaining in the nursing home versus transfer to acute care: Resident, family, and staff preferences. *J Gerontol Nurs* 2014;40:48–57.

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