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Do Not Hospitalize Orders for Patients with Advanced Dementia: Health Care Proxies' Perspectives

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Abstract

Objectives—Approximately 5 million patients with advanced dementia reside in nursing homes in the United States. “Do not hospitalize” (DNH) orders can reduce unnecessary hospitalizations for patients at the end of life, but are rarely used. Health care proxies (HCPs) often decide about DNH orders, yet little is known about how well these orders are understood by HCPs or why HCPs may or may not initiate DNH orders

Methods—Semi-structured qualitative interviews were held with HCPs of nursing home residents with advanced dementia at two nursing homes in Western Massachusetts. Interviews were audio-taped and transcribed verbatim. Data were qualitatively analyzed in an iterative process; emergent concepts were conceptually ordered into explanatory categories. Pertinent demographic and clinical information were collected from the Minimum Data Set (MDS) and patient charts.

Results—Sixteen of 31 eligible HCPs were interviewed. Major findings included barriers and facilitators to initiating DNH orders. Barriers included a perceived lack of physician involvement in decision-making and limited understanding of both DNH orders and the resident's prognosis. Facilitators included a HCPs' personal experience in health care, understanding the prognosis of advanced dementia, and a desire to limit resident distress.

Conclusion—The potential barriers and facilitators to HCPs' initiating DNH orders identified in this study suggest that HCPs may benefit from more in-depth discussions with health care providers when making this decision. Interventions to address these barriers may improve the

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capacity of HCPs to make informed decisions about DNH orders that reflect patients' values and wishes.

Keywords

Advanced dementia; do not hospitalize orders; qualitative

INTRODUCTION

In 2000, nearly 5.3 million Americans suffered from Alzheimer's dementia, and this number is expected to rise to 13.2 million by 2050.¹ The intense health care utilization experienced by this population at the end of life² is rarely associated with improved quality of life or better outcomes, and may result in harm.³ Advanced care planning (ACP) is a process of learning about and considering health care decisions ahead of time, and informing others about preferences.⁴ ACP can improve patients' and families' experiences at the end of life.^{4,5} When a patient is no longer able to participate in ACP, a health care proxy (HCP) may serve as a surrogate. Full understanding of the options available is important when making decisions about end of life care.⁶

"Do not hospitalize" (DNH) orders are part of ACP. DNH orders can reduce the likelihood of hospital transfers when transfers are unlikely to increase survival or improve patient quality of life,² yet only 7% of nursing home residents with advanced dementia have DNH orders.⁷ There is regional variation in use of DNH orders as well as an association with urban location, white race, and age over 92.^{3,7} Reasons for the infrequent use of DNH orders and variation in rates remain poorly understood. A randomized controlled trial to increase ACP for patients with advanced dementia found HCPs reluctant to create an advance care plan, but the reasons for this reluctance were unclear.⁸ Because many patients with advanced dementia have a HCP, it is important to understand HCPs' perspectives about DNH orders so that we may begin to understand the factors contributing to their decisions to choose or to forgo DNH orders near the end of life.

This study's objective was to explore how HCPs for nursing home residents with advanced dementia made decisions about DNH orders. Our hypothesis was that factors other than the patient's wishes may contribute to the decision to have or not have a DNH order in place.

METHODS

Design

When there is little empiric data about a phenomenon, such as why few patients have DNH orders and why rates of these orders vary geographically, qualitative inquiry can be an important first step to understanding the phenomenon in question.^{9,10} In this study, we held interviews with key informants⁹, applying qualitative analytic methods^{9,10} to develop explanatory categories for the central research question: how do HCPs make decisions about DNH orders for their family members?

Participants and Setting

The study was conducted at two for-profit nursing homes (387 beds). Neither nursing home had a dementia special care unit. Salaried general internists and geriatricians, as well as independent practitioners, staff the nursing homes. Nurse practitioners and physicians assistants provide most of the daily care. Potentially eligible residents were identified by staff during a routine chart audit. Eligibility included age >65 years, having a HCP related to the resident, being a long-term care resident and having diagnosis of dementia. Nursing

home staff mailed a letter to the HCPs informing them of the study. Eligible HCPs could opt out of being contacted by study staff. The Baystate Medical Center Institutional Review Board approved the study.

Interview guide development

The interview guide (Appendix A) was developed with input from nursing home staff. Questions were designed to elicit responses from HCPs consistent with study goals while allowing for novel themes to emerge. The interview guide contained questions regarding the goals of care for the HCP's family member, experiences with medical decision-making, understanding and attitudes about DNH orders and interpretation of the medical condition of the nursing home resident.

Data collection

In-person semi-structured interviews were conducted by one research team member (EM). All interviews took place at the study nursing homes in private conference rooms. Interviews were audio-recorded and transcribed by EM. HCPs were compensated \$25 for their time. Demographic and clinical data for the nursing home residents was collected from patient charts and the Minimum Data Set (MDS). The MDS is part of a federally mandated process for clinical assessment of all Medicare and Medicaid nursing home residents. This process includes daily recording of the Brief Interview for Mental Status (BIMS) and scores for Activities of Daily Living (ADLs).^{11, 12}

Data analysis

Two investigators (EM and WC) independently performed open and axial coding on the first ten interview transcripts, using constant comparison to refine the coding process, code selection and emerging concepts.¹⁰ Differences in line coding were resolved through discussion and a provisional codebook was created. The same two investigators then independently recoded the first four interviews; codes and emerging concepts were compared and discrepancies resolved through discussion. A consensus coding strategy was achieved in the fourth independently coded interview (80% agreement). The 12 remaining transcripts were then coded in an iterative process using the consensus codebook (6 were transcripts used in creation of the provisional code book and 6 were coded for the first time); no new codes were added during this phase of coding. Data were further organized and sorted into a cohesive set of concepts and "conceptually ordered"¹⁰ into categories that describe potential barriers and facilitators to HCPs initiating DNH orders.

RESULTS

Participant characteristics

Nursing home staff mailed study invitations to 39 HCPs of residents with dementia. Two individuals opted out and one was excluded because the medical record could not be located. Medical records were then reviewed to determine eligibility. Five residents were excluded because they either had a potentially confounding comorbidity (e.g., Huntington's disease) or had mild dementia. Nine others declined to participate, five could not be reached and one was unavailable due to hospitalization of the nursing home resident. The remaining 16 HCPs were interviewed.

Ten of the nursing home residents had a DNH order in place. All but one DNH order contained a stipulation, such as permission to transfer in the case of an acute injury. None of the residents were enrolled in hospice.

The median age was 92 (range 85-98); 15 were female; 14 were Caucasian and two African-American. One resident had died prior to the interview. The median BIMS score was seven, consistent with severe cognitive impairment. The median ADL score was 20 (IQR 16.5-24.0) on a scale from 0-28, with 28 representing complete functional dependence. HCPs included six women and ten men; three were a niece or nephew and the rest were residents' children.

Barriers and facilitators to initiating DNH orders were the major categorical findings that emerged from the analysis. These findings are described below using headings that indicate the potential for translation to interventions.¹³ Illustrative quotes are provided; additional quotes appear in Table 1.

Barriers to initiating DNH orders

1: Limited understanding of DNH /fear of limited care—HCPs varied in their awareness and understanding of the purpose of DNH orders. Three participants mistakenly thought they had placed DNH orders when they had not. Two could not remember whether or not their family member had a DNH order. Some believed that a DNH order would mean the resident would not be cared for or might suffer if he or she became ill or had an injury and did not go to the hospital.

“They [other HCPs] wouldn't want their loved one hospitalized? Oh my gosh. I can't imagine anybody... in my case [no DNH order] because I would want her taken care of.”

2: Prognostic uncertainty—Participants did not necessarily associate the decline they observed in their family member with progression of their dementia. Some HCPs expressed concern that they might not know when their family member was close to death and they did not want to restrict hospitalizations until they were certain the family member was near the end of life.

“Right now she's not on physical therapy, which they took her off and... said... she reached a plateau. She's not walking... She used to walk. So I would like to get her walking again”

3: Limited contact with physicians—Many HCPs felt that physicians did not have enough of a physical presence in the nursing home and that this limited their ability to make decisions.

“Well hopefully [I'd get information from] doctors but I'll be quite honest with you, I don't think I've talked with any doctors since she's been here.”

4: HCP personal preferences for care—Some HCPs substituted their own preferences for those of the nursing home resident. This was often in the absence of substantial prior discussions about the resident's preferences. When HCPs substituted their own judgment, some felt they should not limit care. In response to being asked how she makes decisions for her family member, one HCP responded:

“Most of the decisions are... natural, they're instinctive... it's almost a “what would I want for myself?”

Facilitators for initiating DNH orders

1: Experience in the health care field—HCPs with experience in the health care field felt that this shaped their understanding of what treatments are available in the nursing home and the disadvantages of hospital transfers.

“I think it makes it easier in a way [to not hospitalize], ‘cause I’ve seen both sides; I see what happens when people pursue [interventions] and go in [to the hospital]. Then I go back to -- it’s her wishes, not my wishes. And she never really wanted to be like this.”

2: Accurate understanding of prognosis—For many HCPs, prognostic information was vital in considering hospitalization. An understanding of the life-limiting nature of advanced dementia helped them decide to prevent hospital transfers.

“And I’m also a very realistic person...I mean, she’s not gonna live much longer and I wanna make sure that the rest of her days here are not in pain and the quality of her life is okay. I don’t want her lying in a hospital bed for months...She doesn’t want that.”

3: Desire to limit distress associated with hospitalizations—Many of the HCPs who asked for DNH orders did so after experiencing hospitalizations that distressed the nursing home resident. They wanted to prevent future transfers to the hospital to limit this distress.

“She was wandering all over the hospital, she had no idea where she was, they couldn’t find her... She has no clue. She doesn’t understand. This is when she was at a higher functioning...Now it would devastate her.”

4: Prior advance directive discussions—When asked to reflect on their decision-making for their family member, several HCPs asserted that their decisions were based on plans laid out by their family member, either verbally or in writing.

5: Suggestions from physicians—HCPs also discussed how a physician’s recommendation to consider limiting hospitalizations can be helpful. One HCP described it as a catalyst to action.

“A doctor [in the hospital] pulled us aside...she said that...one of the options we should consider is treating her... at the nursing home...I think having a doctor tell us basically reinforced our own thoughts on it and got us into the process of changing the order.”

DISCUSSION

In 2011, the Department of Health and Human Services recommended that care for nursing home residents with advanced dementia be improved by reducing unnecessary hospitalizations in the later stages of the disease.¹⁴ Despite this, and the 1991 Patient Self-Determination Act emphasis on involving nursing home residents and families in advance care planning (ACP),¹⁵ few eligible nursing home residents have DNH orders. In this study, we identified barriers and facilitators to HCPs initiating DNH orders. Barriers included a lack of awareness of prognosis, limited understanding of DNH orders, and limited contact with physicians. These findings suggest that some HCPs may make decisions about DNH orders without full understanding. Other studies have shown that once patients or families fully understand choices at the end of life, they request fewer life-prolonging interventions.⁶

Advanced dementia is a terminal illness, yet is not always recognized and treated as such.¹⁶ Once a nursing home resident with advanced dementia has been admitted to the hospital, 18-month survival is less than 50%. For dementia patients who contract pneumonia, almost 50% die within 6 months,¹⁷ a prognosis similar to Stage IV lung cancer. Uncertainty about prognosis was identified in the current study as a potential barrier to initiating DNH orders.

The converse was also true; HCPs who requested DNH orders had understood the residents' prognosis. A HCP's uncertainty about prognosis can be due to clinical uncertainty, a physician's failure to communicate the prognosis, denial, or a combination of these and other factors.^{18,19} However, prognostic accuracy can be enhanced with predictive tools, such as those developed for other life-limiting illnesses.²⁰ Such a tool might also help HCPs make end-of-life decisions for patients with advanced dementia.

In this study, some HCPs expressed dissatisfaction with the level of physician contact in the nursing home, a finding consistent with previous studies.^{21,22} End-of-life discussions between physicians and families have been shown to reduce care that does not improve quality of life or outcomes.²²⁻²⁵ One HCP in the current study noted that it was a hospital physician's recommendation that prompted her to request a DNH order. Despite the impact physicians can have on end-of-life decisions, they have not generally been the focus of interventions to improve ACP in nursing homes.^{8,26,27} Mandating (and paying for) a yearly physician-HCP discussion addressing prognosis and the goals of care might be one solution. Alternatively, mid-level providers could be taught to provide counseling around DNH orders.

Another important finding was that a HCP's work experience in health care was a facilitator for initiating DNH orders. This is consistent with the findings of Volandes et al; health literacy is a stronger predictor of desire to limit interventions at the end of life than other factors such as race.²⁸ In another Volandes et al study, patients who watched a CPR video as part of end-of-life discussions were less likely to request CPR than those who did not view the video.⁶ This demonstrates the importance of providing information about end-of-life decisions in a way that allows the patient or proxy, regardless of health literacy level, to make a fully informed decision.

This study has limitations. First, we interviewed 16 HCPs from two nursing homes in one geographic setting, limiting generalizability of the results. However, the number interviewed was consistent with the recommended sample size for this type of study²⁹ and no new concepts were identified in the final 6 interviews. Second, the etiology of dementia may affect the disease's trajectory and the type of dementia our nursing home residents had was unavailable in their medical nursing home records. Finally, our sample had little racial/ethnic diversity, also limiting generalizability.

As the U.S. population ages, increasing numbers of HCPs for patients with advanced dementia will face the decision of whether or not to seek care in hospitals at the end of life. Our study suggests that some HCPs may be making decisions about DNH orders without a full understanding of several important pieces of information: the prognosis associated with advanced dementia, what a DNH order means, and the risks and benefits of hospitalization near the end of life. Quantitative studies are indicated to estimate how frequently HCPs make decisions about DNH orders and whether they have adequate understanding of the choices.

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Table 1**Barriers and facilitators to initiating DNH orders and additional reflections**

Barriers to initiating DNH orders
<p><i>Limited understanding of DNH orders/ fear of limited care</i></p> <p>"I could not imagine my mother falling and breaking her hip and not going to the hospital... Because I think that would be very painful for her. And [it] would be cruel. And someone could say well what's the difference between having pneumonia and not going to the hospital and breaking an arm and not going to a hospital. And I don't know that I can answer that except in my mind there is a difference..."</p> <p>"If she'd had a massive stroke while here and I was confronted with "we can take her to the hospital and probably do something"... that would be a tough call. Not so much if they're not suffering, if they're in a coma, but if they're suffering that's when it gets tough."</p> <p>"See I think part of the thing is, you get the form and they ask you well do you want to do this, do you want to do that, they're reading it to you. And you don't know what that means... I actually think that before they have family members fill out that form, that somebody should actually ... sit down and explain to you every little thing on the form instead of well do you want to do this, do you want to do that. They're doing it in a rush ... and you don't know half the time what you're signing. Or what sounds really good one month six months later doesn't sound so good anymore."</p>
<p><i>Prognostic uncertainty</i></p> <p>"If it was anything crucial where it looked like he was passing, no, I would not send him to the hospital. I would prefer that he goes here which is the second alternative to his own home, than being in the hospital setting. But it's... how do you know?"</p> <p>"So I know she's happy...[actually] she's not happy, [but] she's happy in the sense that she's not got really critical [yet]...[If she were] sick, sick ... she'd be on hospice or something and I don't think she's got to that point."</p>
<p><i>Limited contact with physicians</i></p> <p>"Well hopefully [I'd get information from] doctors but I'll be quite honest with you, I don't think I've talked with any doctors since she's been here."</p> <p>"I think doctors don't really advise you all that much any more. It's kinda out of their hands. You know, way back when they used to kind of say you should do this, you should do that. It's kind of up to the families now."</p> <p>"I find the nurses talk to the patients; the doctors don't and they shy away from the thing."</p>
<p><i>HCP personal preferences for care</i></p> <p>"I try to think how I would feel and have my mother treated the same way."</p>
Facilitators for initiating DNH orders
<p><i>Experience in the health care field</i></p> <p>"Now, do some people think the hospital's the cure? You know, I think I have a different perspective because I am a nurse, and I've seen the hospitalization where I keep shaking my head going, "well, why couldn't they have done this at the nursing home?" You know, so, no, I wouldn't want to see her at the hospital."</p> <p>"I think it makes it easier in a way [to not want family member hospitalized] , 'cause I've seen both sides; I see what happens when people pursue [interventions] and go in [to the hospital]. Then I go back to -- it's her wishes, not my wishes. And she never really wanted to be like this."</p>
<p><i>Accurate understanding of prognosis</i></p> <p>"He's getting up there. He's going to be 93. But if it looks like whatever he's got and everything is starting to fail, absolutely not, he stays here. And hopefully they know the difference."</p> <p>"I would want to talk to a doctor ... and see what the prognosis would be at her age and her health which is poor ... I definitely would want to talk to somebody before making that decision."</p>
<p><i>Desire to limit distress associated with hospitalizations</i></p> <p>"We found after a few visits to the hospital that the stress level that my mother was under in the ambulance ride over and in the emergency room... her blood pressure would become elevated and it seemed to be more of a hassle on her end to go out to a hospital than stay here."</p>
<p><i>Prior advance directive discussions</i></p> <p>"They've spelled everything outright in their health care proxy. And that is what we have used as our kind of a bible for our decisions"</p> <p>"We had talked to her when she was in her mid-80s and very much alive and vibrant and discussed what she wanted when this situation arose, and she was very clear that when it's time it's time. And she was anxious to sign a DNR and she didn't want to be kept alive and she wanted to die peacefully and comfortably. She was very much a part of the decision process and we just fulfilled those wishes for her"</p> <p>"I became a little bit more calm with the decision as time went on and I think we just have such a relationship with our mom knowing what she wanted ahead of time. She's a very pragmatic woman. She used to say to us, she said, "You know the problem with growing old? You just live too long". She knew that one day she would come along to the point where the quality of life would just not be there. And I think she's... I think she's probably reached that now."</p>