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“I Don’t Have Time to Sit and Talk with Them”: Hospitalists’ Perspectives on Palliative Care Consultation for Patients with Dementia

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Abstract

BACKGROUND/OBJECTIVES: Specialty palliative care for hospitalized patients with dementia is widely recommended and may improve outcomes, yet rates of consultation remain low. We sought to describe hospitalists’ decision-making regarding palliative care consultation for patients with dementia.

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

DESIGN: Descriptive qualitative study.

SETTING: Seven hospitals within a national nonprofit health system.

PARTICIPANTS: Hospitalist physicians.

MEASUREMENTS: Individual semistructured interviews. We used thematic analysis to explore factors that influence hospitalists' decision to consult palliative care for patients with dementia.

RESULTS: A total of 171 hospitalists were eligible to participate, and 28 (16%) were interviewed; 17 (61%) were male, 16 (57%) were white, and 18 (64%) were in practice less than 10 years. Overall, hospitalists' decisions to consult palliative care for patients with dementia were influenced by multiple factors across four themes: patient, family caregiver, hospitalist, and organization. Consultation was typically only considered for patients with advanced disease, particularly those receiving aggressive care or with family communication needs (navigating conflicts around goals of care and improving disease and prognostic understanding). Hospitalists' limited time and, for some, a lack of confidence in palliative care skills were strong drivers of consultation. Palliative care needs notwithstanding, most hospitalists would not request consultation if they perceived families would be resistant to it or had limited availability or involvement in caregiving. Additional barriers to referral at the organization level included a hospital culture that conflated palliative and end-of-life care and busy palliative care teams at some hospitals.

CONCLUSION: Hospitalists described a complex consultation decision process for involving palliative care specialists in the care of patients with dementia. Systematic identification of hospitalized patients with dementia most likely to benefit from palliative care consultation and strategies to overcome modifiable family and organization barriers are needed.

Keywords

palliative care; dementia; qualitative; hospitalists

An estimated 5.8 million Americans currently live with dementia, with dramatic increases expected as the population ages.¹ Dementia is an unrelenting debilitating and life-limiting illness, often marked by burdensome treatments and care transitions in the last year of life.² To help mitigate these undesirable outcomes and improve quality of life, palliative care is widely endorsed as an approach to care at all stages of dementia.³

Although palliative care services are limited in most community and nursing home settings,⁴ hospital-based programs are widely available in the United States.⁵ Thus hospital admission, an unfortunately common experience for patients with dementia,⁶ represents an opportunity to engage palliative care.⁷ Evidence suggests that palliative care consultation may improve end-of-life outcomes and reduce costs in hospitalized patients with advanced dementia.^{8,9} Yet consult rates for hospitalized patients with dementia are low relative to those with other life-limiting illnesses.¹⁰

Prior studies to identify barriers to palliative care for patients with dementia focused on geriatricians and palliative care specialists,^{11–13} but hospitalists are more often the primary clinicians caring for these patients in the hospital setting,¹⁴ and thus they are in the position

to decide about consulting palliative care. Furthermore, the critical role of hospitalists in improving palliative care for seriously ill patients has been increasingly recognized.¹⁵ We conducted a qualitative study to understand hospitalists' decision-making about palliative care consultation for patients with dementia and to describe factors that influence their likelihood of referral.

METHODS

Study Design, Setting, and Participants

This study was conducted within Ascension, a large nonprofit health system in the United States, between January and July 2018. We enrolled hospitalists from seven hospitals (two teaching and five community) across seven states. All study hospitals had an established palliative care program ranging in duration from 5 to 18 years. This study protocol was approved with a waiver of written consent per HHS 45 CFR 46.117(c)(2) by the University of Pennsylvania institutional review board.

Study Procedures

All hospitalists employed at participating hospitals who had a valid e-mail address were invited to participate in a telephone interview about "palliative care services for patients with dementia" and offered a \$50 gift card incentive. Non-responders received a maximum of three weekly e-mail reminders. A trained interviewer (T.L.S.) obtained verbal consent from participants and conducted all interviews using a standardized guide (Supplementary Table S1). Median interview duration was 26 minutes (range = 19–41 minutes). All interviews were audio-recorded, professionally transcribed, and redacted. We collected participants' age, sex, race/ethnicity, and years in practice by self-report.

Data Analysis

We used an iterative process of thematic analysis to synthesize the data, identify patterns, and develop themes across interviews.¹⁶ Specifically, we used a combined deductive and inductive approach, whereby themes in the standardized interview guide were used to structure the initial codebook, and new themes that emerged from the data were incorporated.

The first five transcripts were coded jointly by two team members (T.L.S. and S.S.) to develop an initial codebook. Subsequent transcripts were independently coded and jointly reviewed to expand and refine the codebook, with discrepancies adjudicated by a nurse investigator with extensive experience in qualitative research and palliative care (M.E.). After reaching consensus on the final themes, we identified patterns and relationships among them to develop a comprehensive, clinically salient explanatory framework.

Participant recruitment and interviewing occurred concurrently with coding until we reached thematic saturation, defined as the failure to identify new themes from three consecutive interviews,¹⁶ at which point recruitment e-mails ceased. We used several validity and reliability strategies including team-based development of the interview guide and codebook, ongoing review of the transcripts throughout data collection, creation of

detailed memos for each theme, and double coding of a random sample of data with discussion and consensus of final coding. All coding and analyses were conducted using NVivo v.11.

RESULTS

Of 284 hospitalists employed across the study hospitals, 171 (60.2%) had a valid e-mail address and were invited to participate. We reached thematic saturation after 28 (16.4%) interviews. Most participants in this study were younger than 45 years (79%), 61% were male, 57% were white, and 64% had been in practice for less than 10 years (Supplementary Table S2). Overall, hospitalists' decisions clustered within four main themes: patient, family caregiver, hospitalist, and organization (Figure 1). Exemplar quotes about how specific factors influenced hospitalists' likelihood of consulting palliative care are shown in Table 1.

Patient Factors

Hospitalists most often discussed palliative care consultation in the context of advanced dementia, such as those with poor baseline function, recurrent aspiration, or severe symptoms. Among those with advanced disease, receipt of aggressive interventions, including repeated hospitalization, intensive care unit admission, or a prolonged length of stay, were mentioned as prompts to consider palliative care for goals of care conversations. In contrast, if patients were recovering quickly from a reversible cause (e.g., urinary tract infection) and expected to return to their baseline, most hospitalists did not see a role for palliative care. A few hospitalists reflected that engaging palliative care earlier in the disease course might help to avoid potentially unwanted burdensome treatments in the later stages but that they rarely do it.

Family Caregiver Factors

Hospitalists generally acknowledged the family's burden of caregiving and decision-making for a loved one with dementia. When they perceived that necessary medical decision-making was impeded by a family's lack of understanding of the disease trajectory or intra-family disagreement about goals of care, most were inclined to involve palliative care. However, hospitalists reported they were less likely to consult palliative care for patients with limited family presence or involvement in caregiving. Similarly, most were unwilling to consult palliative care if they perceived that families would be resistant to it.

Hospitalist Factors

Many hospitalists opined that there was not enough time to accomplish their daily patient care tasks and also have a presumed lengthy goals of care conversation with families of patients with dementia. Additionally, several hospitalists commented that palliative care specialists had superior skills to navigate the challenging prognostic and goals of care discussions with families. For example, when hospitalists disagreed with a family's preference for aggressive care, they felt palliative care consultation was appropriate to facilitate communication. Even among the few hospitalists who expressed high confidence in their abilities to address the palliative care needs of their patients and families, insufficient time remained a major reason to consult palliative care.

Organization Factors

Hospitalists primarily described their hospital culture of palliative care as focused on end-of-life care, with a few contrasting that they have seen increasing acceptance of earlier palliative care. Relatedly, some hospitalists indicated that their palliative care team often seemed busy, making them more inclined to attempt to address patients' and families' needs on their own when they might otherwise have consulted first. Others commented that their palliative care teams always responded in a timely manner, thereby increasing hospitalists' inclination to request a consult.

Overall, hospitalists' decisions whether to consult palliative care for patients with dementia were typically influenced by a combination of the factors just described. Rarely was the decision based on one dominant factor, except in the case of a family perceived as unreceptive to palliative care. Three exemplar patient cases described by hospitalists and the relevant factors weighed in the consultation decision are shown in Figure 2.

DISCUSSION

Hospitalization in dementia often signifies disease progression and offers an opportunity to engage specialty palliative care.¹⁷ In this multicenter qualitative study, hospitalists described their decision process for and barriers to palliative care consultation for patients with dementia. These findings present clear opportunities to improve palliative care in dementia, and they should be used to inform evidence-based referral criteria to guide hospitalists' decisions and novel care delivery approaches that address modifiable barriers.

Hospitalists identified prognostic understanding, setting care goals, and family communication as the main palliative care needs of patients with dementia. These views align with expert consensus recommendations on optimal palliative care in dementia^{3,18} because serious illness communication can be particularly challenging in this population when patients are unable to participate and express their own preferences. Notably, no hospitalists discussed the emotional and spiritual needs of patients and families; targeted education may be needed for this essential domain of high-quality palliative care.^{18,19}

Hospitalists' limited time was a strong driver of consultation. Confidence, or lack thereof, in serious illness communication skills also impacted the consultation decision. Similar to our findings, a national survey revealed that most hospitalists feel confident in their ability to discuss goals of care or prognosis but less so for improving understanding of disease or resolving conflict.²⁰ However, a recent simulation study suggests that physician's self-assessment of communication skills may not correlate with adherence to best practices in family meetings.²¹ More research is needed to understand the impact of hospitalists' confidence in palliative care skills on the quality of care and patient outcomes.

Consistent with evidence of late palliative care referrals in dementia,²² hospitalists generally only referred patients with advanced disease. Dementia is a debilitating and ultimately terminal disease, and growing evidence suggests that introducing palliative care earlier may reduce burdensome care transitions and acute care utilization.²³ Yet controversy still exists among dementia experts about the appropriateness of early palliative care.²⁴ Furthermore,

existing clinical tools intended to facilitate palliative care referrals in dementia focus only on those with advanced disease.^{7,9} A national study found an increasing trend in intensive care near the end of life among hospitalized patients with dementia²⁵ that is inconsistent with most proxies' preferences.²⁶ Thus empirically defining the optimal time in the course of dementia to engage palliative care specialists is an urgent need.

Even when hospitalists do identify patients with palliative care needs, they confront several challenges to referral. At the organizational level, hospitalists were attuned to the high consult demand of their palliative care teams, so they intentionally rationed consultations. Indeed, palliative care programs across the United States are facing high consult burdens and a severe shortage of specialists to meet the demand.²⁷ With little empirical evidence to guide appropriate use of limited palliative care services in general, or in dementia care specifically, efforts to identify patients systematically who are most likely to benefit from specialty consultation are much needed. Additionally, better role definition for hospitalists and specialists in providing palliative care for patients with dementia would facilitate collaboration and appropriate referrals.¹⁵

Hospitalists also perceived the family as a barrier to referral. Specifically, hospitalists did not feel comfortable consulting palliative care if they sensed the family would be unwilling to have conversations about serious illness. Evidence from other chronic diseases suggests that such hesitancy most often stems from a lack of knowledge about palliative care and thinking that it is synonymous with hospice.^{28,29} Correcting this common misperception requires that nonspecialists understand and are able to describe the distinct roles of palliative and hospice care, yet we found that hospitalists often conflated palliative care with end-of-life care. Perhaps even more concerning, hospitalists were less inclined to consult palliative care if families were not easily accessible. However, patients with less involved or accessible families are particularly vulnerable to receiving unwanted, nonbeneficial care, and they are likely to derive great benefit from expert-facilitated communication and shared decision-making.

Our study findings should be considered in the context of several limitations. First, we do not know if we captured the full range of perspectives; hospitalists with less favorable views of palliative care may have been less likely to participate. Second, we sampled from a single health system, thus potentially limiting the generalizability of the findings. However, participants represented seven hospitals across seven states, with characteristics similar to a national sample of hospitalists.³⁰ Finally, we were unable to explore if or how variation in the volume of patients with dementia that hospitalists care for influenced the consultation decision process.

In conclusion, this study provides an in-depth framework of hospitalists' decision-making regarding palliative care referral for patients with dementia. These findings should inform ongoing and future development of innovative palliative care delivery models to improve patients' quality of care and outcomes. Such efforts will be most effective and acceptable if designed to support these decision processes and attend to key barriers.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Figure 1.

Framework for hospitalists' decision-making regarding palliative care consultation for patients with dementia.

"I have a patient last week who had dementia and was pretty unaware of her situation...she had acute cholecystitis and was not a surgical candidate...and so in that scenario I used palliative care consult for lots of different reasons...help with goals of care...as well as kind of symptom management...helping to set limits...it was really helpful to have a team I think for the family to help with all those complex decision-making." [H10, F]

"...it also depends what time I'm calling them [palliative care], what time they will be able to see the patient...if I'm not really having a lot of pain management issues...if they're not having any kinda like, code status discussion issue, no – they're really not very terminally, they kind of stable-ish – then I would not consult palliative care... basically you would never wanna extend hospital – acute care hospitalization for palliative need." [H20, F]

"I think we have an excellent palliative care team and they're a tremendous resource...and I think that motivates us to get them involved. But then I think the resistance to it comes from a lot of cultures...so they [patient and family] end up being very resistant to not offering treatments...they will be very resistant to even talking about end of life or palliative." [H28, F]

Figure 2.

Case examples of hospitalists' decision-making for palliative care consultation in dementia care.

Table 1.
Exemplar Quotes of Influential Factors on Hospitalists' Decision to Consult Palliative Care for Patients with Dementia

	Palliative care consult unlikely	Palliative care consult likely
Patient		
Acute clinical status	<i>[Y]ou see a patient for one time, for a UTI and dementia, you do not think about that [palliative care] in that situation, right? You're thinking about dehydration, UTI and sending the patient back to the nursing home.</i> [H03, M]	<i>Another factor is length of stay. I'm thinking about a patient in particular that's been on our service for 30 days and he keeps declining and things keep getting worse and at that point do we need to kinda step back and consult palliative.</i> [H10, F]
Functional status/ Dementia stage	<i>If they are still able to do their normal basic ADLs [activities of daily living], they are bathing themselves, they are dressing themselves, but they need some help with their finances, I probably would not start to have a palliative care discussion with that patient.</i> [H03, M]	<i>[H] the patient is living at home having severe dementia where they cannot by themselves be able to support themselves, maintain themselves, do daily activities living. I definitely would like palliative care folks to come.</i> [H02, male]
Symptoms	<i>I know of some palliative care physicians who are more focused in controlling the symptoms, and that is not the focus from a referring physician, as far as I'm concerned.</i> [H11, F]	<i>[P]alliative care can be particularly helpful for patients with dementia from a medication management perspective in patients with dementia who, obviously, have bouts of depression delirium issues with pain control that can be sometimes difficult to ascertain.</i> [H08, M]
Family caregivers		
Need for information and support	<i>[P]atient who [has] home support, a caregiver who is not exhausting themselves to that extent that they cannot function or they do not have to be all the time with a patient, that is okay as long as they have follow-up with primary care physician.</i> [H17, M]	<i>That might maybe lower the threshold a little bit if there was a setting where I did not feel they were receiving adequate—or the requirements of care for the patient seem too much for their caretaker and maybe an alternative situation would be required. I think sometimes it might be reasonable to also bring palliative care on board for that.</i> [H13, M]
Receptiveness to palliative care	<i>[H] the family is just completely not open to that idea. If mentioning palliative care makes them think we are talking about death or hospice and if they are not quite ready or open to that, then I would not bring palliative care in until family or patient felt it was appropriate.</i> [H21, F]	<i>So if the family is agreeable, the earlier the better. It only helps to get more patients that palliative care involved earlier.</i> [H23, M]
Understanding of dementia trajectory	<i>If I have family members who are already on board with it, they understand their family member's poor prognosis. I usually do not call it a palliative care consult because it's easier. I do not have a barrier to go through that step.</i> [H24, F]	<i>[W]ith dementia. I find that there's a lot of times the patient—the family just does not really—they are not really getting it it's not sinking in that the situation is as dire as it is. And that's something that usually prompts me [to consult palliative care].</i> [H05, M]
Goals of care among caregivers	<i>[H] everything is going well and the family is comfortable with how things have been going, I would not necessarily get a palliative care consult in that patient.</i> [H14, M]	<i>[S]ometimes you have some children that want to go—want to do everything and you have some kids that do not, and you are having to kind of mediate sometimes the disagreement.</i> [H04, F]
Level of involvement	<i>I'm gonna use palliative care when the family is benefiting from bedside conversations, and they get the benefit from our interaction.</i>	<i>Recently—my dementia patients were the ones who were transfer from nursing home for their behavioral disturbances. And family wasn't really that much</i>

	Palliative care consult unlikely	Palliative care consult likely
Hospitalist		
Confidence in primary palliative care skills	[H15, M] [H20, F] [H06, M]	<i>[H20, F]</i> <i>[H06, M]</i>
Perceptions of palliative care	[H13, M] [H07, M]	<i>[H07, M]</i>
Goals of care among caregiver-hospitalist	[H17, M] [H14, M]	<i>[H09, F]</i>
Time	[H15, M]	<i>[H02, M]</i>
Organization		
Palliative care team workload	[H14, M]	<i>[H24, F]</i>
Culture of palliative care	[H22, M]	<i>[H14, M]</i>