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Hospice Staff Perspectives on Caring for People with Dementia: A Multisite, Multistakeholder Study

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Abstract

Background: In the United States, 45% of people enrolled in hospice have dementia. We know little about how hospice professionals facilitate preference-aligned end-of-life care for people with dementia (PWD) and their families.

Objective: To examine hospice stakeholders' perspectives on caring for PWD and their families.

Design: Multisite qualitative study using semi-structured interviews with interdisciplinary hospice clinicians, leaders, and administrators. The interdisciplinary team used the constant comparative method to identify, code, and characterize relevant themes.

Setting/participants: Four geographically distinct nonprofit U.S. hospice organizations. Fifty-one hospice employees: 61% clinical staff, 25% executive leaders, and 14% administrators.

Measurements: Interview domains included participants' practices of engaging patients/families in discussions of preferences for end-of-life care and professional opinions of changes over time. Cross-topic probes focused on delivering hospice care to PWD and their proxies/families.

Results: Four themes regarding caring for PWD in hospice. (1) Dementia prevalence in hospice is increasing and some hospices are developing programs to accommodate specific needs. (2) Setting impacts discussions of preferences and care decisions. (3) Caring for PWD on hospice poses unique challenges caused by (i) perceptions that dementia is not terminal, (ii) a lack of advance care planning discussions before hospice admission, and (iii) proxy decision-makers who were inadequately prepared for their role. (4) Hospice regulatory and policy changes disproportionately impact PWD.

Conclusions: Hospice professionals perceive increasing demand for, and multilevel challenges to, caring for PWD. Clinicians "upstream" from hospice may help by engaging patients and proxies in discussions of preferences for end-of-life care and providing anticipatory guidance.

Keywords: advance care planning; decision-making; dementia; geriatrics; hospice; palliative care; qualitative methods

Introduction

ALZHEIMER'S DISEASE and related dementia syndromes are terminal diagnoses.¹ Forty-five percent of hospice enrollees in the United States have dementia as either a primary diagnosis or as a comorbid condition to another terminal illness.² At the end of life, both emergency department and acute care utilization contribute to reduced quality of life

for both people with dementia (PWD) and their caregivers.³⁻⁷ International consensus recommends palliative care and improved end-of-life care for this population.⁸⁻¹¹

Hospice, a model of interdisciplinary palliative care for people with a prognosis of six months or less in the United States, focuses on quality of life and provides a holistic biopsychosocial spiritual approach to advanced illness.¹² Hospice providers engage patients and family members in a

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process of discussing and documenting care goals, values, and preferences to create an “individualized written plan of care” for each enrollee.^{13–15} However, for people entering hospice with a primary diagnosis of dementia (or another serious illness with a secondary diagnosis of dementia), the verbal ability to express preferences is impaired; proxy decision-makers typically make decisions on behalf of people with advanced dementia at end of life.¹⁶

Little is known about hospice clinician and staff perspectives on supporting and providing goal-aligned care for PWD entering hospice. As part of a larger study on hospice professionals’ perspectives on and practices of eliciting preferences for end-of-life care to hospice enrollees, we explored attitudes specific to caring for PWD and their families in hospice. Findings from this study provide context for clinicians referring PWD to hospice and a foundation for future clinical and policy initiatives to improve hospice care for PWD.¹⁷

Methods

Design

We conducted a qualitative, descriptive multisite study¹⁸ of the practices, attitudes, and measurement of the ways in which clinicians elicit goals and values for hospice care, the provision of that care, and changes in these practices over time. Feedback from a community advisory group and methodologic experts within the Palliative Care Research Cooperative (PCRC)¹⁹ informed refinement of the study design and interview guides. The community advisory group consisted of clinical, administrative, and caregiver stakeholders from a local nonparticipating hospice; they provided feedback on the research question and interpretation of preliminary research findings. This study was reviewed by the University of California San Francisco IRB and determined exempt.

Participants

Sites. Eligible sites were nonprofit community-based organizations providing hospice services affiliated with the PCRC and selected based on geographic diversity. Site refusal rate was 0%: the first four sites recruited agreed to participate. **Individuals:** Eligible hospice employees included executive leaders (i.e., presidents or vice presidents, chief executive, operating or medical officers, directors of nursing), interdisciplinary clinicians (nurses, social workers, chaplains, physicians, nurse practitioners), or quality improvement (QI) administrators. We asked sites to provide contact information for up to 30 eligible hospice staff with a range of clinical and hospice experience. Experience caring for individuals with dementia was not among the recruiting criteria. Two sites scheduled up to 15 potential participants on behalf of the researcher; the researcher scheduled participants at the other two sites. The information communicated to potential respondents and the recruitment approach were consistent across sites. See Supplementary Table S1 for more information.

Data collection

All data were collected during a two-day site visit to each of four hospices between April and September 2016 by the lead author (K.L.H.). All participants gave verbal consent

before participating in a semi-structured interview whose domains included (1) contextual information about the participant and hospice organization; (2) processes and practices of eliciting and documenting preferences for care among hospice enrollees; and (3) professional opinions on eliciting/documenting preferences in the context of the hospice philosophy, including changes in practices over time. Interviews included dementia-specific probes (i.e., “how does advance care planning work with PWD?”). All participants consented to recorded and transcribed interviews except one, for whom we created a transcript-like summary. We coded interviews in ATLAS.ti version 8 (Scientific Software Development GmbH, Berlin, Germany).²⁰

Data analysis

First, relevant data were identified by reviewing the entire dataset and conducting keyword searches of “dementia,” “Alzheimer’s,” or “cognition.” The lead author (K.L.H.) inductively open-coded these data and wrote analytic memos on emergent themes. Guided by the constant comparative method, four co-authors (K.L.H., T.A.A., S.B.G., and R.L.S.) then reviewed and discussed the data and memos. The team affirmed and iteratively refined the themes presented hereunder. Data citations in this article refer to “s,” data collection site number; “p,” participant number; and an indication of participant role or discipline, for example, leader or QI.

Results

Across the four sites, 71 individuals were recommended to the researcher for recruitment; 51 (72%) agreed to participate

TABLE 1. DEMOGRAPHICS OF INDIVIDUAL PARTICIPANTS IN FOUR-SITE QUALITATIVE STUDY, BY CATEGORY

<i>Descriptive characteristics</i>	<i>Percent of participants n = 51</i>
By site	
Site 1—South	24
Site 2—North	25
Site 3—Midwest	27
Site 4—West	24
By stakeholder category	
Clinicians	61
Executive leaders	25
QI administrators	14
By clinical degree	
Nurse (RN)	45
Social work (LCSW, LSW)	24
Chaplain	4
Provider (MD, DO, NP)	16
Other/none	12
By gender	
Female	80
Male	20
By race/ethnicity	
White/non-Latinx	88
People of color and/or Latinx	12

DO, doctors of osteopathic medicine; LCSW, licensed clinical social worker; LSW, licensed social worker; MD, doctor of medicine; NP, nurse practitioner; QI, quality improvement; RN, registered nurse.

(4 declined, 16 did not respond). Of 51 participants, 61% were clinicians (45% nurses, 24% social workers, and 16% physicians and other providers), 25% executive leaders, and 14% QI staff; 80% were women and 88% were non-Latinx white; no one site contributed all data in a single category (Table 1). Participant demographics were similar across sites. Four themes emerged regarding caring for PWD in hospice.

Theme 1: Dementia prevalence in hospice is increasing and some hospices attempt to accommodate dementia-specific needs (Table 2)

Participants at multiple sites noted that the number of PWD receiving hospice care is increasing over time: “It is the fastest growing class of patients that we have. It’s a huge issue” (site 3, participant #8, role: leader). Leaders, clinicians, and administrators across sites referred to this phenomenon. Some hospices sought to accommodate this growing population by modifying their practices and services. For example, one organization created a volunteer-based visiting program for PWD living in facilities, with plans to expand services to home settings. Motivated by new regulations for the training of long-term care staff, this site also chose to provide annual intensive dementia-specific trainings to their entire staff: “The organization committed to training everybody” (s2, p33, QI/RN). A provider at another site mentioned increased use of inpatient units to care for PWD with aspiration pneumonia, whereas a leader there mentioned increased attention to the importance of “structure and routine” in dementia care (s3, p8, leader).

Theme 2: Discussions of preferences and care decisions for PWD vary based on the care setting (Table 3)

Participants noted an increase in PWD receiving home hospice: “We have a large population now at home either who have care, living with their kids who have paid for private care or are taking care of them themselves” (s2, p27, leader). In these settings, participants reported it can be easier to have in-person discussions but harder to document decisions in forms. Discussions focus on helping caregivers recognize disease progression or seek help: “in the home patients, there probably is more discussion around caregiving and the stresses and strains of being able to do that for however long” (s4, p45, chaplain).

In nursing facilities, participants noted that forms designating proxies and code status are often required to be completed at admission to the facility. Hospice clinicians are more likely to copy those forms than to discuss preferences anew: “[for people] with ACP forms completed because the facility requires it, hospice just has to get copies” (s3, p5, QI/NP). Hospice clinicians noted the difficulty of coordinating care decisions with proxies of PWD in facility settings: “Our interactions with caregivers is much more sporadic in that setting... It’s over the phone, and so that’s going to right away make it more difficult to have these conversations” (s3, p5, QI/NP). At one site, participants observed that their patients living in facilities were more likely to be wards of the state because they had outlived their family members: “We do have lots of patients that do have legal guardians, wards of the state, especially facility patients...because all their family has died and there is no one” (s1, p19, RN). One participant commented that for PWD receiving hospice in assisted living, variability in settings requires tailoring care.

TABLE 2. THEME 1 EXAMPLE QUOTATIONS: DEMENTIA PREVALENCE IN HOSPICE IS INCREASING AND SOME HOSPICES ATTEMPT TO ACCOMMODATE DEMENTIA-SPECIFIC NEEDS

Subthemes	Quotation
The size of the population of hospice enrollees with dementia has increased	<p>“Well, I think there’s a lot more change to come, as hospice primary diagnosis now is dementia” (s1, p24, leader)</p> <p>“When I came [to this hospice], we had a higher percentage of cancer patients than any other diagnosis. I think that we did a lot of work in this area with long-term care facilities. Folks didn’t think of hospice for end-stage dementia patients. Not only has that census grown, we’ve done things like specialized programs around dementia.” (s2, p34, leader RN)</p>
Dementia-specific practices and programs have been created to meet the changes in population	<p>“It’s a huge issue... structure and routine becomes really important. The last thing we want to do is have someone [with dementia] go to the hospital when they don’t need to ... It’s such a conundrum, because memory care isn’t going to work well in a hospital. You are going to put people in a foreign setting. They are going to become agitated and scared. We are going to start using drugs to try and control those things. Their intake is going to go down. Their quality of life is going to go down. Their quantity of life may certainly go down, too. Then we have a real mess when we try and discharge them because now they are sleepless and a bundle of nerves and very difficult to manage.” (s3, p8, leader)</p> <p>“We probably have more dementia patients than we did before. I think we have a lower threshold for inpatient hospice. In the past you’d have the dementia patient who comes in with an aspiration pneumonia, family says no feeding tube, they’re delirious, they’re not really eating or drinking, some symptoms of delirium we would have said they’re not eligible and they’d end up in a nursing home, now we actually do a lot of—let’s bring them to the [redacted - name of inpatient unit] see how they do, we still have a discharge plan, many of them end up dying at [redacted – the inpatient unit]. So I think we see more of that type of patient because before they would have just gone for skilled rehab.” (s2, p32, MD)</p>

Information about the interviewee is presented following each quotation: data collection site (s), participant number (p), and the interviewee’s credentials (e.g., RN, SW) or role in the organization (e.g., leader, QI).
 SW, social worker.

TABLE 3. THEME 2 EXAMPLE QUOTATIONS: DISCUSSIONS OF PREFERENCES AND CARE DECISIONS FOR PEOPLE WITH DEMENTIA VARY BASED ON THE CARE SETTING

<i>Subthemes</i>	<i>Quotation</i>
Providing in-home hospice requires more discussions with and support of caregivers	<p>“In the home care setting, we get a lot of, ‘Yes, I have a durable power of attorney,’ but we never—it’s hard to get the piece of paper out of people. It’s easier to have the conversation related to, ‘Do you want to be resuscitated?’” (s3, p5, QI/NP)</p> <p>“Because it’s such a prolonged illness, you know someone could be living with advanced dementia for 10 years, or mild dementia that it progresses to advanced, and they’ve still been able to have them home or, and they don’t recognize, ‘Well now you can’t leave them alone, that’s a progression.’” (s2, p31, SW/RN)</p>
Variability in assisted living settings requires tailoring care	<p>“Particularly in assisted living, it’s a unique challenge, ... because they’re all different, they don’t have 24/7 nursing care, some of them do, some of them don’t. And they don’t have medications in the middle of the night. We do a lot of tailoring of care to keep people in their assisted living and those are the hardest ones once we’ve discharged them because they lose that whole blanket that’s kept them safe where they are.” (s1, p23, SW)</p>
Nursing facility-based hospice care focuses more on obtaining copies of existing advance directives than facilitating new conversations about preferences	<p>“I would say more families are not able to have a lot of in-person contact with our staff when their loved one’s in a facility.... We will often see the [ACP] paperwork, get all the paperwork in our charts because the facilities want it” (s3, p5, QI/NP)</p> <p>“We do have lots of patients that do have legal guardians, wards of the state, especially facility patients, mainly facility patients. Because all their family has died and there is no one” (s1, p19, RN)</p>

Information about the interviewee is presented following each quotation: data collection site (s), participant number (p), and the interviewee’s credentials (e.g., RN, SW) or role in the organization (e.g., leader, QI).

Theme 3: Challenges of caring for PWD on hospice (Table 4)

When participants discussed eliciting, documenting, or enacting preferences for care for hospice PWD, most referred to challenges including perceptions from families or non-hospice clinicians that dementia is not terminal, inability to discuss care preferences with PWD, or working with proxy decision-makers.

As one social worker said, “a lot of families did not understand that [dementia] was a terminal illness and that people end up passing because of complications of dementia, and they don’t understand the disease trajectory” (s2, p31, SW). A minority of participants noted that nonhospice clinicians sometimes make recommendations for treatment that also do not seem to acknowledge the terminal nature of the disease (s2, p32, MD).

Many PWD have not engaged in discussions of care preferences before hospice admission. Although some participants reported that discussion of preferences before hospice admission is becoming more common (s2, p27, leader), others echoed this nurse’s observation: “most people we get, who have had an Alzheimer’s diagnosis, have had that diagnosis for many, many years, and yet... they’re coming into hospice relatively unprepared for having discussions about their wishes for end of life” (s1, p25, RN). Because hospice eligibility requires a 6-month prognosis, most people entering hospice with a primary diagnosis of dementia are unable to speak: “most of them, by the time we see them, if they’ve not done it, they can’t do it. By the time they’re on hospice, their dementia is so far advanced” (s2, p27, leader). Participants suggested that clinicians upstream from hospice should start discussions of end-of-life care preferences (s2, p33, QI/RN).

Participants gave many examples of the challenges of working with families and proxy decision-makers of hospice enrollees with dementia. Some reflected the challenges of

working with proxy decision-makers in general. Proxies may be unwilling to make decisions on behalf of the person with dementia: “sometimes you run into the health care proxy who’s like, ‘I can’t sign that, I can’t sign that MOLST ... I feel like I’m signing their death wish’” (s2, p38, RN). Designated proxies may not know or share the person with dementia’s preferences or values (s1, p25, RN), or may disagree with others about care decisions (s2, p38, RN). Participants also discussed the challenge of working with proxies of PWD who choose different treatments than hospice clinicians would recommend: “they don’t want [their parents] to die. So they do more aggressive things than I would do.” (s2, p27, leader). Participants indicated that the uncertain trajectory of dementia syndromes complicate decisions: “sometime(s) you’ll hear people say, ‘Well, they almost died three times and they came back.’ ... So of course, they are going to be a little less willing to talk...or really make decisions about just “comfort care”” (s4, p46, SW). Participants discussed the role of hospice clinicians in educating and coaching proxies and family members through potential care choices for PWD. Topics included reminding proxies of patient preferences or best interests, and teaching and providing guidance about decisions such as administering antibiotics or hospitalizations.

Theme 4: Hospice regulatory and policy changes disproportionately impact PWD (Table 5)

Participants at all sites referred to a set of Centers for Medicare and Medicaid Services (CMS) hospice regulatory changes initiated in 2013—which included discontinuing “debility” and “failure to thrive” as eligible diagnoses for hospice admission, clarifying allowable dementia diagnoses, and increasing hospice oversight—and reported that these changes limited their opportunities to care for PWD. As one

TABLE 4. THEME 3 EXAMPLE QUOTATIONS: CHALLENGES OF CARING FOR PEOPLE WITH DEMENTIA ON HOSPICE

<i>Subthemes</i>	<i>Quotation</i>
Lack of recognition of dementia as terminal	“I am sometimes really amazed even our patients in hospice where the doctor sends them to the emergency room.... We just had [a patient], they had an infected toe, probably gangrene but end state dementia and the doctor said, ‘You have to go have an amputation,’ and now the patient’s dying in the hospital, and you’re like, ‘They’re not dying from their toe. We have this reflex of if it’s broken, we have to fix it, rather than we can’t really fix the whole thing.’” (s2, p32, MD).
PWD have not discussed care preferences before hospice admission	“By the time they even admit somebody has a little bit of Alzheimer’s or dementia, the person’s too far gone to even have that conversation, they’re just taking care of crazy old auntie” (s4, p40, RN)
Hospice-eligible, PWD can rarely discuss care preferences	“People ... more so in the home environments, are coming on and they’re so advanced that they’re already semi-conscious. So it’s [discussion of preferences is] not always something that’s able to be done” (s4, p43, RN)
Challenges of working with proxies or caregivers of hospice enrollees with dementia	<p>Unwilling proxy: “I have a patient right now who’s on [hospice] with dementia, and she had a health care proxy designated and the health care proxy didn’t want to be the health care proxy. And she was like, ‘Oh no no no—I’m not doing that.’” (s2, p35, RN)</p> <p>Proxy unaware of preferences: “you do find situations where the person has a healthcare power of attorney, but not an explicit living will. And maybe they never really talked that much to their loved one, who now has this responsibility about what their wishes would be” (s1, p25, RN)</p> <p>Proxy disagreements: “I had another patient that was not at all capable of making her own decisions, but her husband completely was. And that’s who lived with her and took care of her. But their daughter was number one on the health care proxy, and the husband was secondary. And they did not agree on anything, so that was really tricky. You know, like the husband wanted her medicated and he wanted her pain medicated and the daughter didn’t want anything sedating given to her.” (s2, p38, RN)</p> <p>Proxy choosing more aggressive interventions: “You don’t have the situation very often where the person has a written living will, and then the family members still wants to give them antibiotics. But once again, in a situation where they don’t...they don’t have a specific written living will... it’s very hard for a family member to say, ‘No, I don’t want them to get antibiotics.’” (s1, p25, RN)</p>
Hospice clinicians educate and coach proxies about person with dementia’s preferences or best interests regarding treatment decisions	<p>Reminding proxies to consider patient preferences: “the nurses and staff always emphasize, “You have to think about what your mother would want, or your father would want, if this were them. Not that you don’t want them to die, but would they want the feeding tube? Would they want, you know...?”” (s2, p27, leader)</p> <p>Providing guidance: “The patient has dementia and they want to stay on their dementia medications, and we say, ‘You know, there’s really no evidence that that medication has benefited at this point in time,’ and they’re like, ‘But, you know, Dad’s been on it. I’m not willing to stop it... I’m going to pay for it out of pocket.’ ...We have an obligation to give them the information to help them decide if they want to continue that treatment and help them see why it doesn’t make any sense” (s3, p5, QI/NP)</p>

Information about the interviewee is presented following each quotation: data collection site (s), participant number (p), and the interviewee’s credentials (e.g., RN, SW) or role in the organization (e.g., leader, QI). PWD, people with dementia.

participant said about dementia patients earlier in the disease course, “We could have been taking care of a lot more people a lot longer...The people who want you the most are usually family members of dementia patients. And they’re not allowed in” (s4, p41, leader).

Participants described the ways that the policy context, such as organizational payment concerns, shaped the provision of hospice care for PWD. One participant explained: “Because those patients [with dementia] are alive longer, they’re often in a very debilitated state for a very long time, and the cost is more to care for them in hospice than without hospice” (s1, p24, leader). Some described hospice teams as “being more aggressive with discharge planning” because of concerns about their meeting criteria for ongoing hospice eligibility (s4, p45, chaplain). Participants spoke of their discomfort with live discharges and its impact on goal-aligned care for patients and families: “it’s kind of harder to

keep people on hospice longer and I think people are struggling with that. And if you take away hospice, that changes the goals of care conversation just by the nature of who’s going to get called in the middle of the night” (s1, p23, SW). Leaders at multiple sites opined on motivations for prior (s4, p41) and future (s1, p24) hospice policy changes. In discussing policy change, participants referenced its impacts on PWD far more than any other population.

Discussion

In this study, we found that hospice professionals at four participating sites perceived the prevalence of PWD in hospice to be increasing. Some organizations created programs or practices to accommodate these patients. Eliciting preferences for end-of-life care or providing preference-aligned care varied by care setting. Challenges of serving PWD included the timing

TABLE 5. THEME 4 EXAMPLE QUOTATIONS: HOSPICE REGULATORY AND POLICY CHANGES DISPROPORTIONATELY IMPACT PEOPLE WITH DEMENTIA

<i>Subthemes</i>	<i>Quotation</i>
Changes to eligible diagnoses posed challenges to serving PWD	Change in policy, including eligible dementia diagnoses: “A lot of it with the dementia, that we can’t just use dementia. There has to be a specified dementia diagnosis, and now with the changes in the diagnosis, with the ICD-10, the wording is completely different, and now we have to list all the secondary diagnosis as well, and now that hospice is covering those medications that are all related. So it’s very confusing.” (s3, p12, SW) Discontinuation of “failure to thrive” as eligible diagnosis: “Eligibility is scrutinized more. Before, with a patient that doesn’t meet dementia guidelines but is thin as a rail and frail, we could use failure to thrive. But now it’s harder to keep certain patients on service with the loss of that diagnosis” (S2, p30, QI/RN)
Challenges of prognostication	Difficulty prognosticating, discharge alive: “Their trajectory is up and down, up and down. Sometimes patients will stabilize and we do have to discharge them with dementia and hope. We actually have a position that follows live discharge patients, so that we can be there for families when things change” (s2, p34, leader/RN) Difficulty measuring decline to justify continued care: “For Alzheimer’s, dementia, you have scales. I mean, you have things like the MRI and your FAST scale and your PPS. But even those are, in a way, based on somewhat subjective measures. I mean, the categories aren’t entirely precise, like what, in fact, constitutes minimal intake? And that can also be difficult to assess, because sometimes facility staff will tell you, “Oh, yeah, they ate 100 percent today.” But what they’re not telling you is that they’re only giving them a portion that’s like 25 percent of what a normal patient gets, because they know—you know, they know that they’re not going to eat it all.” (s1, p25, RN)
Medicare hospice policy changes have adversely affected the ability to care for PWD	Reduce length of stay and make hospice cost less to Medicare: “And even when we spoke with [CMS oversight representative]. And he’s like, ‘Yeah, you would think that we would be interested in saving all of Medicare money but we’re just interested in the hospice pie. And it can’t keep growing any bigger. And so my job is to keep you from having a long length of stay and having more people in the program. That’s my incentive.’ ... Dr. [name redacted] said that in 2013. That couldn’t have been clearer. It was sad and clear.” (s4, p41, leader) Changes predicted with increase in PWD on hospice: “Well, I think there’s a lot more change to come, as hospice primary diagnosis now is dementia. And so, I think that’s really challenging the whole Medicare trust bond, because those patients are alive longer, they’re often in a very debilitated state for a very long time, and the cost is more to care for them in hospice than without hospice. So, I think we’re going to see a lot more changes coming down the pike” (s1, p24, leader)

Information about the interviewee is presented following each quotation: data collection site (s), participant number (p), and the interviewee’s credentials (e.g., RN, SW) or role in the organization (e.g., leader, QI).

CMS, Centers for Medicare and Medicaid Services; FAST, Functional Assessment Staging Test; ICD, International Classification of Diseases; MRI, magnetic resonance imaging; PPS, Palliative Performance Scale.

of discussing and documenting preferences, perceptions that dementia is not terminal, and working with proxies who may not understand the patient’s prognosis, their wishes, or may be unwilling to make decisions. Hospice regulatory changes have complicated initial and ongoing hospice eligibility for PWD, and live discharge limits available services. Overall, the data suggest that demand for hospice for PWD has increased as regulatory pressures have made it more difficult to serve those needs. To our knowledge, this is one of the first studies to use hospice staff perspectives to elucidate these topics.

CMS hospice regulatory changes from 2013 figured prominently in participant responses.²¹ These changes, including clarifying ICD-9 (International Classification of Diseases, Ninth Revision) diagnoses and discontinuing some eligible principal diagnoses, were intended to improve the accuracy of hospice data, inform payment reform, and facilitate greater oversight of hospice organizations to discourage their prioritizing revenue over patient care—for example, by selectively enrolling people likely to have long lengths of stay with low acuity needs, such as PWD.^{22–24} However, the effect of these policy changes on hospice pa-

tient care is uncertain. PWD on hospice experience higher rates of disenrollment after a stay of 165 days or longer than do people with other serious illnesses, which creates additional care transitions and burdens for family caregivers.^{25–27} Of importance, many of our study participants felt these regulatory changes limited their ability to care for PWD and their caregivers.

Hospice professionals in our study illuminated the ways in which PWD do not adequately prepare for end of life, either by discussing preferences when they still have decisional capacity or by supporting and preparing proxy decision-makers. A recent international systematic review on advance care planning and end-of-life care among PWD and their caregivers found that individuals in these groups often procrastinate advance care planning, perceiving no urgency.²⁷ Indeed, previous research suggests community-dwelling older adults with dementia in the United States are less likely than those without dementia to have engaged in discussions of end-of-life preferences or completed advance directives.²⁸ Some study participants described a desire for clinicians upstream to begin these conversations earlier in the disease course. Although

health care in the United States is a product of the regulatory structure, the issues outlined here of proxy decision-making, the recognition of dementia progression in the hectic context of daily caregiving, and the need for advance care planning earlier in the disease course in this population are relevant issues for PWD around the world. A number of studies are in progress to test mechanisms to engage PWD and/or potential proxy decision-makers in advance care planning discussions.^{29–34} Parallel efforts are needed to support nonhospice clinicians to feel motivated and capable to encourage PWD and their potential proxies to discuss preferences and obtain anticipatory guidance about end-of-life care decisions.^{35–37}

Limitations

The findings from this study emanated from a sample of interdisciplinary hospice staff within a sample of four non-profit hospice organizations. Participants were primarily medically trained hospice clinicians and social workers; research with a wider range of hospice leaders and chaplains, or individuals who specialize in caring for hospice patients with dementia, may yield additional themes. We identified themes related to dementia in the context of a broader conversation about advance care planning. Findings may not be transferable to for-profit hospice organizations,^{38,39} although this should be explored. Aspects of hospice and advance care planning unique to the U.S. health care system, such as Medicare Hospice Benefit regulatory requirements and documentation of preferences in forms in facilities, are not generalizable to other nations.

Nevertheless, this study provides important insights from a broad range of hospice professionals on providing preference-aligned end-of-life care to PWD. Their perspectives reiterate a need for all clinicians to engage PWD in discussions about their values and preferences early in the disease process, and to support families and proxies through the process of making end-of-life care decisions. Hospice professionals also highlight opportunities to improve policy and educate families and clinicians.

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Author Disclosure Statement

The authors have no commercial interests or conflicts of interest, actual or potential, to disclose.

Supplementary Material

Supplementary Table S1

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