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RESEARCH ARTICLE

# Practices, challenges, and opportunities when addressing the palliative care needs of people living with dementia: Specialty memory care provider perspectives

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## Abstract

**Introduction:** Palliative care focuses on reducing suffering and improving quality of life for individuals with serious illness and their families. In an effort to develop palliative care interventions for specialty memory care clinics, this study characterizes memory care providers' perspectives on addressing palliative care needs of people living with dementia (PLWD).

**Methods:** Qualitative interviews with specialty memory care providers were followed by thematic analysis by a multidisciplinary research team.

**Results:** Provider approaches overlap with key domains of palliative care. Approaches unique to dementia include having a detailed understanding of dementia syndromes, behavioral symptoms, and caregiver burden. Challenges were identified related to disease progression, provider-level factors, and systems and cultural issues. Respondents identified training needed to strengthen a palliative care approach.

**Discussion:** There are many strengths of using memory care teams to address palliative care needs of PLWD. However, they may require additional knowledge and training to strengthen their work.

## KEYWORDS

advance care planning, caregiving, dementia, end-of-life, memory care, palliative care, qualitative research

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## 1 | INTRODUCTION

Palliative care focuses on reducing suffering and improving quality of life for individuals with serious illness and their families.<sup>1,2</sup> International consensus recommends offering palliative care for people living with dementia (PLWD)<sup>3,4</sup> and only recently have palliative care frameworks begun incorporating the unique challenges specific to dementia.<sup>5,6</sup> Specialty palliative care is delivered by an interdisciplinary team of specialists in any care setting; it includes symptom and distress management, goals of care clarification, and alignment of care with values and preferences.<sup>7</sup> Meta-analyses indicate specialty palliative care improves quality of life, alleviates symptom burden, promotes advance care planning, and increases patient and caregiver satisfaction.<sup>1,2</sup> It is also associated with cost-effectiveness and cost saving.<sup>8,9</sup> However, many barriers to implementing specialty palliative care exist for dementia in the United States,<sup>10</sup> including insufficient palliative care specialists to meet the demand.<sup>11-13</sup> Recommendations for neuropsychiatric care<sup>3,14-18</sup> and for dementia palliative care<sup>5,19</sup> call for improvements in access to palliative care services regardless of setting. As such, dementia and memory care specialists have the opportunity to play an important role in serving the basic palliative care needs of PLWD and their families.

Providers in specialty memory care clinics, where patients with Alzheimer's disease and related dementias (ADRD) are evaluated and managed, historically receive minimal training in palliative care skills. In support of a broader effort to develop palliative care interventions for specialty memory care clinics, the objective of this study was to characterize memory care providers' perspectives on addressing palliative care needs of PLWD, the challenges they face that are specific to dementia, and the training and content support they feel they would need to more successfully realize this approach.

## 2 | METHODS

### 2.1 | Study design

We conducted a qualitative study<sup>20</sup> with specialty memory care providers at an academic medical center from November 2018 to May 2019. Participants were interviewed about current practices addressing patients' palliative care needs, challenges meeting these needs, and opportunities for integrating palliative care principles into their work. The study was approved by the Institutional Review Board at the University of California, San Francisco.

### 2.2 | Setting and participants

We interviewed 16 health-care providers who cared for PLWD at a specialty tertiary memory care center in a Northern California city. Providers were recruited from a variety of disciplines using purposive sampling, selected to represent a range of disciplines and experience.

### RESEARCH IN CONTEXT

1. **Systematic review:** The authors conducted a literature review using PubMed. We identified and reviewed publications focused on basic and specialty palliative care, patient and caregiver challenges in dementia, and neuropsychiatric care. While the importance of palliative care in dementia has been widely studied, less is known about memory care providers' perspectives on palliative care for people living with dementia and their caregivers.
2. **Interpretation:** Our findings helped us gain an understanding of specialty memory care providers' perspectives on addressing palliative care needs among people with dementia and their families, the challenges they face, and their recommendations for practice improvement.
3. **Future directions:** The article identifies core areas that provide the foundation for a basic palliative care approach within specialty memory care. This approach includes key elements of basic palliative care with an additional focus on understanding dementia diagnostics and syndromes, managing behavioral symptoms, addressing dementia-specific caregiver burden, and identifying billing mechanisms to support a palliative care approach within a specialty memory care setting.

### 2.3 | Data collection

A multidisciplinary team that included experts in the social sciences, neurology, geriatrics, palliative medicine, and health services research iteratively developed and piloted the interview guide (Appendix 2). Interviews were conducted by the lead author, a medical anthropologist. Interview domains included (1) provider perspectives on the needs of PLWD and their families; (2) perspectives on the palliative care needs of PLWD, probing for specific core elements of palliative care practice; (3) current practices addressing palliative care needs; (4) challenges and barriers to addressing palliative care needs; and (5) opportunities to improve dementia palliative care practices. The interviewer asked about relevant clinical cases as examples. The interviewer also probed for specific elements of palliative care, including advance care planning, managing symptom burden, discussing prognosis, providing anticipatory guidance, and caregiver support.<sup>21</sup> After each interview, the interviewer created an analytic case summary summarizing the interview and major themes. All interviews were recorded, transcribed, and entered into ATLAS.ti, a qualitative data analysis software.<sup>22</sup>

### 2.4 | Analysis

We used thematic analysis to analyze the data.<sup>23</sup> The first author developed a preliminary codebook based on a review of analytic case summaries and inductive coding of half of the dataset (Appendix 3). The

**TABLE 1** Provider characteristics

<b>Sex</b>	
Female	6
Male	10
<b>Race/ethnicity</b>	
White	9
Hispanic	2
Asian	3
Other	2
<b>Specialty</b>	
Social work	2
Nursing	2
Neurology	9
Geriatrics psychiatry	1
Neuropsychology	1
<b>Years in practice</b>	
< 5	1
5-10	6
11-20	6
> 20	3
<b>% time in clinic</b>	
< 10%	3
10-20%	7
21-50%	2
> 50%	4

multidisciplinary team then discussed and iteratively refined the codebook, with particular attention to developing deductive codes based on the palliative care literature and National Consensus Project (NCP) domains. Two authors (AB, CR) double-coded 20% of the remaining interviews using the coding scheme and discussed discrepancies in coding until agreement was reached. One author (AB) then coded the remainder of the data. The team reviewed and refined themes and illustrative quotations.

### 3 | RESULTS

Participant characteristics are described in Table 1. Below, we describe (1) provider perspectives on addressing needs of people with dementia that overlap with key domains of palliative care; (2) approaches providers take to address the needs that are unique to people with dementia, (3) challenges these providers face addressing palliative care needs, and (4) training and content support needed to more successfully realize a palliative care approach.

### 3.1 | Memory care providers' perspectives on addressing palliative care needs in dementia

When memory care providers were asked to describe approaches to addressing PLWD and family needs, their answers evinced a high level of overlap with key principles and domains of palliative care. Many participants thought dementia care fundamentally includes a palliative approach, as exemplified in the following two statements:

*I feel like the whole thing is palliative ... so much of it falls back to just the human touch, meaning, like, you have to feel that you're meeting your patients and you're meeting your families, that they have enough trust in you to ask you the questions that they feel they need answered.*

*I think we all need to be agents of palliative care, because this is the nature of the disease we deal with.*

Table 2 summarizes overlap between what memory care providers report they are doing to serve the needs of PLWD and their families and domains of quality palliative care. However, most providers reported that they rarely refer to these practices as "palliative care" with patients.

Memory care providers reported engaging in multiple activities that are aligned with palliative care (Table 3). For example, most providers reported an emphasis on identifying patient and family priorities at the start of visits. One provider noted:

*I'll try to frame my discussion according to who the person is, ... what they tell me they want to get out of the visit, and what are their concerns.*

Providers also reported helping manage family dynamics, particularly around decision making. They engaged in activities that included helping maintain quality of life, symptom management, and emotional support. Participants reported providing anticipatory guidance focused on patient safety, prognosis, and treatment planning. For example, a neurologist discussed a patient who had been seen several times and for whom continued cognitive decline was documented, but no precise diagnosis had been made. Nevertheless, this participant explained,

*So even if I don't have a diagnosis, we know that there's continued cognitive decline.... The most important thing that I think we've done is to help set up her home situation so that even if she continues to decline, she's going to have some support.*

Participants reported engaging in interprofessional care, which most felt was crucial to their work. The interdisciplinary team at this center includes behavioral neurologists, geriatricians, psychiatrists, neuropsychologists, advance practice nurses, and social workers. One provider noted:

**TABLE 2** National Consensus Project palliative care domains and neurology practices identified in this study

NCP palliative care domain <sup>a</sup>	Description of recommendation	Practices reported by providers at the dementia care clinic
Structure and processes of care	Structure of team, interdisciplinary approach, palliative care assessment, palliative care plan, coordination of care and care transitions	Interdisciplinary team, support for care transitions through connections to resources
Physical aspects of care	Physical screening and assessment, treatment, ongoing care	Diagnostics, symptom management, disease course education, some ongoing care or coordinating with patient's other providers
Psychological and psychiatric aspects of care	Psychological screening and assessment, treatment, ongoing care	Neuropsychology assessment, MDs address intersection between neurodegenerative disease and psychiatric symptoms, social work and nursing address specific needs such as connecting to counseling and support
Social aspects of care	Social; family/caregiver	Social work and nursing behavior management clinics, resource and service connections, respite identification for caregivers
Cultural aspects of care	Cultural screening and assessment; communication and language	Some providers discuss cultural background with PLWD, particularly during the diagnostic assessment
Spiritual, religious, and existential aspects of care	Spiritual; legacy/bereavement	Some providers ask PLWD about religion, particularly during the diagnostic assessment
Care at the end of life	Treatment prior to death, during the dying process, and immediately after	Less common to see patients in advanced stages of disease, but some providers maintain contact with families during this stage
Ethical and legal aspects of care	Ethical; financial/legal considerations, screening, and assessments	Social work and nursing provide support around connecting to resources; some providers ask about ACP and medical decision making

<sup>a</sup>[https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines\\_4thED\\_web\\_FINAL.pdf](https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf).

Abbreviation: ACP, advance care planning; NCP, National Consensus Project for Quality Palliative Care.

*We have the luxury of having a team approach. So, I think that allows me to not feel like I'm carrying the whole burden of dealing with all of these problems that emerge.*

Memory care providers, particularly social workers and nurses, also noted that they spend time coordinating with patients' other providers outside of neurology, making referrals to community services, and helping with care transitions.

Finally, many participants reported recommending or helping with basic advanced care planning. One provider explained,

*I make sure that they have ... POLSTs [physician orders for life-sustaining treatment] or those types of advanced directives completed... [T]he most important thing is that they have conversationa about what they want because I tell them they shouldn't be in a situation where they have to guess what their loved one would have written, and I ask them to think about everything from a feeding tube to intravenous fluid.*

Table 3 summarizes key themes and examples from provider interviews.

## 3.2 | Approaches to addressing palliative care needs that are unique to dementia

In discussing patient and family needs in dementia, some participants described topics that were outside of the traditional domains of palliative care, though were specific to addressing palliative care needs in those with neurological disorders (Table 4).

### 3.2.1 | Detailed understanding of dementia syndromes

Many providers reported an emphasis in neurology on making a correct and specific diagnosis, enabling syndrome-specific disease management. This can provide relief to families who have sought diagnoses in other care settings, and help patients and families plan for the future. One provider stated:

*We distinguish these illnesses because that's how we learn about them, by understanding the protein bases and the distinguishing features and the networks that might be involved in Lewy body versus Alzheimer's versus frontotemporal, right? I mean, that matters to management, it matters to behavior, it matters to a lot of things.*

**TABLE 3** Memory care providers' perspectives on addressing palliative care needs of people with dementia

Domain	Example Quotations
<b>Identifying patient and family priorities</b>	"I think families give you the answer, if you just let them talk and you listen. They'll tell you sort of what's right or wrong for them, and realizing that there isn't a one-size-fits-all, ... although we have certain sense of how things should be, there are some people who can't do it the way we want them to do it."
<b>Managing family dynamics and decision making</b>	"It's hard sometimes to use people's values and the way they've made decisions in this new sort of reality which is dementia. So, people can say 'Oh, our family always makes decisions together, and we really value these sorts of things,' but then dementia is often so different in the type of conflict it brings to families and the types of challenges... There's no one right question that sort of gets it every time. I think it comes up sometimes after multiple conversations. They're getting to know what they can expect from us, and we're getting to know how they operate as a unit."
<b>Interprofessional care</b>	<p>Within neurology interdisciplinary team:                      "Well, the benefit we have at the [specialty center] is that, when we see a patient that ... we feel pretty certain has a neurodegenerative disease, right, and the patient's getting to a stage where help is needed, we—I will rope in support staff, right. So nursing and social work support staff, and in the message ... I will often say something like, 'The family needs more information about future planning,' and that's what will activate the discussions about advanced care planning ... or if it's a stage of thinking of like hospice or palliative care, I will say that too."</p> <p>Coordinating with providers outside of neurology:                      "The oncologist and I had to get on the same page. That turned out to be very, very straightforward once I explained to the oncologist that Lewy body disease was a terminal neurodegenerative disease. It had a really bad trajectory. And that treating him for bladder cancer was going to make his deliria—chronic delirium worse. And so there wasn't a really good way to manage this."</p>
<b>Helping with care transitions</b>	"I think one of the biggest things, and I learned this from patients, was people always ask, 'When will they place someone? When will they know?' ... I ask people to think about what would make ... it untenable at home? Like, what is the thing that would push you over the edge ... Because it's different for every person. Some people wouldn't manage incontinence to save their soul, and for other people it's no big deal to have them incontinent, it's something totally different ... So I think trying to help people, not give them the answer of when it's time to make choices, but helping them to decide what would push them to make a choice."

(Continues)

**TABLE 3** (Continued)

Domain	Example Quotations
<b>Anticipatory guidance</b>	"You know, certainly the things right now that could put her in immediate and imminent harm are, you know, if she has a terrible fall, if she has aspiration, if her mood goes south and she has, you know, suicidal thoughts and decides that it's a good idea to harm herself, and, you know, she's certainly at risk for all of those things and I've been closely watching for all those symptoms and trying to make, you know, everything as safe as possible."
<b>Helping maintain patient and caregiver quality of life</b>	"What I try and tell people is we want to make every day the best that it can be, and so you don't want to spend your time trying to drill her about the date. You don't want to spend your time arguing about the fact that she thinks someone stole her wallet ... So I think the focus on truth isn't everything; sort of the quality of the moment is the most important thing."
<b>Managing symptoms</b>	<p>Support of patient: "Over time, you know, she's had the significant memory changes, visuospatial symptoms, movement changes, changes in being able to feed herself, swallow, do a lot of basic tasks, and, you know, we've added a lot of medications for her symptoms and so, you know, there's needed to be a lot of teaching and guidance on administering those medications, medication side effects, potential benefits of the medications. You know, and the medications for the mood symptoms, because that's been a big part of her management, and then with the, you know, with the movement changes, talking about physical therapy for gait and balance. Talking about ways of minimizing fall risk. Rearranging the home so that there aren't any obstacles that could increase her fall risk. That's been big."</p> <p>Support of caregiver: "I ask this every visit, 'Is there enough care at home? Do you think that there needs to be more?' Or, 'You mentioned that your loved one is getting confused in the middle of the night, sundowning. They're walking around in middle of the night. I know you're getting up in the middle of night and helping, and I know that's disruptive to your sleep and being able to get ready for the next day and work. Do you need someone to be there overnight and redirect your loved one or be there for them?' You know, so certainly assessing the level of care and support at home and seeing if more resources are needed. That's something that I talk about a lot with families."</p>
<b>Making connections to supportive services</b>	"I referred her to community case management, intensive case management, with a Spanish-speaking social worker so they can actually be in the home, and then I coordinate with that social worker, and referred her for more accessible transportation because right now they're taking the bus. It's just really high risk for falls. Also home delivered meals, we were able to, I referred her for home delivered meals to get more meal support and also kind of reduce some of the stress financially for the meals."

(Continues)



**TABLE 3** (Continued)

Domain	Example Quotations
<b>Providing emotional support to patients and caregivers</b>	"You know, we've talked about how long this has gone on and he talks a lot about how, again, how guilty he feels that he couldn't take care of her at home. I mean, he did an amazing job, but there just came a point where he couldn't do it. He worries that he wishes this would end, and he feels really guilty about that."
<b>Advance care planning/end of life planning and discussion</b>	"On the Huntington's Disease team and with the neurologist, they address the end of life ... in the first one or two visits. So they start having those conversations right away ... I think that's really helpful for the patient and the family or the caregiver to be thinking about and really engaging in that conversation, even if we don't make decisions in that first meeting, which rarely we do. So that's really, I think that's a real benefit to them because it kind of helps frame how they want to live and what they want at the end of life, ... and then we can get on with other things to support their quality of life."

As part of their diagnostic process, some participants discussed providing disease specific education—including a description of the science of dementia—as part of their discussions with patients and families. Furthermore, providers noted they are skilled in talking to patients and families about managing changes in cognitive capacity and providing education about available treatment options and opportunities to participate in research.

### 3.2.2 | Emphasis on behavioral symptoms

All providers reported that understanding and addressing behavioral symptoms was a key aspect of the care they provide and should be a priority in dementia palliative care. Providers identified clinic resources they use to address behavioral symptoms. These included a nurse clinic where caregivers can get expert advice on managing behaviors and a behavioral management task force to improve training around behavioral symptoms. One provider noted:

*We do a lot of teaching on behavior management ... we try to teach and sort of say "Even though it sounds like this is sort of a little thing to deal with, this is a really big thing for the caregiver, so we really have to help pay attention to it."*

Another provider explained,

*It can be difficult especially for the caregiver if the patient doesn't have insight, but then it gets difficult for the patient because the caregiver's trying to respond or react ... the patient feels constricted, so they lash out, so the whole family dynamic is very difficult... Impulsivity, aggression, irritability, those can be very difficult behaviors.*

**TABLE 4** Approaches to addressing palliative care needs that are unique to PLWD

Theme	Exemplary Quotations
<b>Detailed understanding of dementia diagnostics and syndromes</b>	"My perception is that in the community a lot of patients jump from doctor to doctor and they never hear a solid hypothesis or impression... But I find it useful when you sit down with a patient and/or the family and say, 'This is what I think it is. It's corticobasal syndrome, and this is the prognosis, and we should prepare for this.'"
<b>Expertise managing behavioral symptoms</b>	"The wife, the caregiver, wasn't getting much support from friends or family, and so she hired a care manager who turned out to be a lifesaver, and that care manager is what allowed her to survive the five, four or five years with her husband becoming mentally incompetent, physically incompetent, and violent. He was a big strong guy, he started to become violent with caregivers. We got him into a home, and I set up regular phone calls with them to try to manage his behavior, atypical antipsychotics, SSRIs, all very difficult to treat. Things would work, but eventually they would stop working, and then we'd have to kind of start fresh again."
<b>Addressing dementia-specific caregiver burden</b>	"A lot of caregivers are burning the candle at both ends for a long time trying to be the primary caregiver and still work full-time and still manage all of their other affairs and, you know, usually I'm the person that says, 'Stop it.' You know, 'You're burning out. I'm seeing that you're burning out. You're talking about burning out during this visit. You need a team around you. You need other people that can step in and help provide care for your loved one, and because if you burn out you're not going to be able to take care of them. You're going to get sick. Your loved one is going to get sick. We don't want that to happen.'" "And so that could mean, you know, being there for the caregiver to talk to or helping the caregiver find a support group or a counselor, helping the person with dementia find some meaningful activities, anything that can kind of help maintain or improve their quality of life for the time they have left is, I think that's kind of like my lens that I see that through in terms of palliative care."

Abbreviations: PLWD, person living with dementia; SSRIs, selective serotonin reuptake inhibitors.

### 3.2.3 | Managing dementia-specific caregiver burden

All providers recognized the challenges caregivers face. One provider noted,

*I always think about how the family is coping with the stresses of being a caregiver, so I always try to ask the caregivers how they're doing or ask about their mood.*

Participants articulated many ways that they address dementia-specific caregiver burden. These include referring caregivers to sup-

**TABLE 5** Challenges and barriers to addressing palliative care needs of people with dementia

Domain	Challenges and barriers	
	Themes	Exemplary quotations
Disease-specific factors	Slow disease progression with no cure or uncertain diagnosis	"I have four or five patients that haunt me because I don't know their diagnosis. They keep on calling me trying to find out what else I can do to help them, and I don't know what to do, and that's a very big stress, because I don't know what's going on with them. I don't know where to go next."
	Patient loss of cognition and capacity	"I feel like [patients are] vulnerable and so not in control of what's going on. I think it's challenging to not know what they want. It's challenging to be so far down the road that you can't have that conversation with them."
	Reduced access to patient at end stages of the disease	"The sort of patients that we see, when they are at that very advanced stage, at least, we don't see it. At least, you know, as a neurologist, I can tell you I don't get to see those patients. They don't come to clinic. They don't come to research. So, I'm not involved at that level of late stage care."
Provider or practice-specific factors	Emphasis on making a diagnosis	"You become a clinician scientist, then you start to learn, 'Okay, I'm good at all the diagnostics,' but then as you follow the lives of these patients then you start to realize that there's more to this than just diagnosis, of course. Everybody knows that, but another thing is to experience it and to realize that there's so much doctoring involved, you know. Like, just being there listening, talking, educating, and that's a little bit harder to teach. It's teachable, but it's harder."
	Lack of training or standardized protocols for palliative care in dementia	"I think it could probably be more formalized. More streamlined. Sort of an algorithm, a diagnostic, kind of a decision tree for every single patient that comes through.... That would probably make our lives much easier and our patients would get probably better care quicker and more efficiently."
	Challenges communicating about difficult topics (e.g., end of life)	"We haven't talked a lot about end-of-life planning. I think one of the difficulties is that, you know, when she's, of course, still—she's coming to the visits and she's still aware that things are different, that she's not cognitively well, that she's not physically well, and sort of discussion of prognosis and sort of talking about end of life in front of her is—it brings her to tears, quite frankly."
Systems or cultural factors	Concern about disrupting the relationship with the patient and/or family	"I was thinking maybe, like, early, early AD. On the first visit I said this, and then a few weeks later I get a call from his wife asking me, 'What did you tell him?' Like, 'He's been destroyed,' basically. Like, she was upset at me. So that's an example where you go, like, 'Damn, I should not have done that.'"
	Time	"Neurology is slow ... we don't have tests like the heart doctors. If I can get your blood test, then I can tell you you're having a heart attack. We don't have that in dementia, so we rely on this sort of interview that we're doing and putting elements together, so a lot of our time goes to that ... the training that we get in engaging these other resources and the social aspects, I think, they are peripherally touched."
	Structural, cultural, and spiritual competence	"The behavioral aspect puts a lot of emphasis, on the social-cultural background of the patient. What's the socioeconomic status, what is the educational level, what's the cultural background, what's the primary language? You know, those things can be used to make people's lives better, if you engage them correctly. This is what I mean when I say we need to be more structurally competent."
	Stigma	"You also have to fight the big stigma of what palliative care means, so before even recommending [it], there's got to be a little bit of a conversation about what palliative care offers, what it means, kind of destigmatize it saying ... 'I'm not giving you a death sentence by sending you to palliative care.'"

portive services, providing resources and education, and addressing caregiver well-being and quality of life.

### 3.3 | Challenges addressing palliative care needs

Providers were asked to identify challenges to addressing the palliative care needs of PLWD (Table 5). We organized these challenges according to three thematic domains: (1) disease-specific factors, (2) provider-specific factors, and (3) cultural/systems-specific factors.

#### 3.3.1 | Domain 1: Disease-specific challenges

Providers identified specific challenges to addressing palliative care needs in dementia that stem from the patient's loss of cognition or capacity and the progressive nature of the disease. For example, two providers stated,

*Oftentimes our patients just do not have the insight or the cognitive abilities to understand what's happening to them.*



Many also noted the slow disease progression, prognostic uncertainty, variable family acceptance of the disease, and reduced access to care at end stages of the disease as disease-specific challenges to palliative care in dementia.

### 3.3.2 | Domain 2: Provider/Practice-specific challenges

Most participants did not receive training in palliative care, and did not use a standardized approach to addressing palliative care needs. Some providers also reported lack of comfort having difficult conversations, including concern about the emotional reactions they experience or receive after disclosing the diagnosis. These challenges made it difficult to implement key aspects of palliative care. For example, one provider explained the challenge of having these difficult conversations,

*I was thinking maybe, like, early, early AD [as the diagnosis]. On the first visit I said this, and then a few weeks later I get a call from his wife asking me, "What did you tell him?" Like, "He's been destroyed," basically. Like, she was upset at me. So that's an example where you go, like, "Damn, I should not have done that."*

Another provider echoed this discomfort, with a particular focus on his own emotional reaction, explaining,

*I have a brief moment to talk face-to-face and try to provide reassurance, if anything. Right? So when I see distress in either the caregiver or the patient ... I'm saying it's difficult for them, and maybe sometimes it's difficult for me, too, just to start these conversations."*

Furthermore, many participants reported that there is an emphasis among neurologists on identifying a correct diagnosis. Participants reported that correct diagnosis is important for anticipatory guidance, counseling, and symptom management. However, some participants also noted that this emphasis on diagnosis sometimes led to time and scope constraints on other activities with patients and families. However, all providers felt it is important to triage care to the appropriate member of the interdisciplinary team, such as the social worker, or to outside specialists or services to provide families additional support.

*I think we are in a mode of, "Oh, I'm just here to diagnose" ... and then someone else will take care of these things. But, you know, we're physicians. We're supposed to be engaged with these sorts of resources.*

### 3.3.3 | Domain 3: Systems and cultural-specific factors

Providers identified systems and cultural-level factors that challenge their efforts to meet patient and family palliative care needs. These

included lack of time with patients to address all needs, often due to financial pressure to see more patients in less time; the stigma they feel exists around palliative care, making it difficult to raise the topic; and confusion they felt patients and families experience between specialty palliative care and hospice. When responding about whether she could imagine providing palliative care within the specialty memory care clinic, one provider discussed the issue of stigma,

*If we're going to use the term "palliative care," it has to come with the education, otherwise it's going to scare patients and families.*

### 3.4 | Training and content needed to better address palliative care needs

Finally, all providers shared suggestions for training and content that could strengthen their work and make it possible to perform basic palliative care within the specialty memory clinic. For example,

*I think it would be helpful to have, how do you have that first conversation with a patient and the caregiver in clinic that's going to frame it as palliative care from the get-go, so that they understand ... that they can slowly start to accept that there is no cure, that it's going to progress, and that we want to be here with them to support them.*

Training and content recommendations included communication tools, a better understanding of available resources, and protocols for when and how to initiate palliative care discussions, as well as new personnel and billing and systems-level adjustments (Table 6).

## 4 | DISCUSSION

We identified memory care providers' perspectives on addressing palliative care needs of PLWD and their families that overlap with key domains of palliative care, approaches these providers take that are specific to working with PLWD, challenges providers face addressing palliative care needs in this population, and training and content support needed to more successfully realize a palliative care approach.

Palliative care is now considered a core competency for neurologists,<sup>24</sup> yet in a prior study, 20% of adult neurology training programs offer no dedicated training to residents, and 42% of respondents were dissatisfied with current palliative care education.<sup>25</sup> Even so, some successful efforts to improve palliative care for people with dementia have been seen in nursing homes<sup>26-29</sup> and community settings, for example, Palliative Excellence in Alzheimer Care Efforts (PEACE),<sup>30</sup> Resources for Enhancing Alzheimer's Caregiver Health (REACH),<sup>31</sup> Maximizing Independence (MIND) at Home,<sup>32</sup> Aging Brain Care (ABC) Medical Home,<sup>33</sup> Alzheimer's and Dementia Care (ADC) Program,<sup>34</sup> and the Care Ecosystem.<sup>35,36</sup> More work is needed in the outpatient setting.

**TABLE 6** Recommendations for practice improvement in the provision of dementia palliative care

Recommendations for practice improvement	Examples
Personnel	<ul style="list-style-type: none"> <li>• Palliative care trainees in neurology</li> <li>• Team that can monitor symptoms locally when patients live far away</li> <li>• Telehealth opportunities</li> </ul>
Training	<ul style="list-style-type: none"> <li>• Communication               <ul style="list-style-type: none"> <li>○ How to have difficult conversations</li> <li>○ Doctor–doctor communication</li> <li>○ Doctor–patient communication</li> </ul> </li> <li>• Grief counseling</li> <li>• Pharmacology and polypharmacy</li> <li>• Palliative care certification for neurology providers</li> <li>• Cultural competency</li> <li>• Family counseling</li> <li>• Behavioral symptom management</li> <li>• Understanding of what constitutes palliative care</li> <li>• Observational learning—have neurology trainees observe and learn from nurses and social workers</li> </ul>
Protocols	<ul style="list-style-type: none"> <li>• Knowing how/when/who to refer to palliative care</li> <li>• Pamphlet for families (protocol for families/patient–family-facing materials)</li> <li>• Guidelines or checklist for when to initiate goals of care discussions</li> <li>• Incorporate palliative care training and discussion into case conferences</li> </ul>
Systems-level changes	<ul style="list-style-type: none"> <li>• Reimbursements for palliative care-focused appointments in neurology</li> <li>• Infrastructure to facilitate routine home visits</li> <li>• Reducing the stigma around palliative care and hospice</li> </ul>

Specialty memory care providers in our study reported addressing many elements of palliative care within their usual scope of practice. They also described addressing concerns and practices specific to the dementia context—practices that are not within the traditional scope of palliative care. Our data depict a palliative care approach that is tailored to people with dementia and their families. However, given that our study was conducted at a single, well-resourced clinic, the perceptions of palliative care and available resources, such as the interdisciplinary team, may be different than other specialty settings in the community.

#### 4.1 | Integrating palliative care into specialty memory care

Many participants endorsed practices that align with recommendations for neuropalliative care.<sup>3,14–18</sup> Participants also described com-

ponents of “basic palliative care,” where clinicians without specialty training in palliative care provide symptom management and discussion of goals, values, and preferences using skills from palliative care within their existing scope of practice. Furthermore, memory care providers named many challenges to engaging in in-depth or consistent palliative care. Our findings concur with prior work identifying barriers to palliative care for PLWD, including stigma,<sup>37</sup> conflation of specialty palliative care and hospice,<sup>38</sup> lack of palliative care expertise among providers,<sup>39</sup> and difficulty with dementia prognostication.<sup>40</sup> Other studies report that shortage of time and lack of continuity of care also serve as challenges to providing palliative care to PLWD.<sup>41,42</sup>

Some participants worried about how the language of palliative care would be received by patients and caregivers. However, research suggests that when family caregivers of PLWD become better informed about palliative care, they become more open to its use with their relatives.<sup>43</sup> Caregivers in this prior research considered palliative care useful and thought medical providers were the ideal people to provide education about palliative care and also to identify the correct moment for its introduction. Initiating palliative care discussions can be challenging because of unpredictable prognosis in dementia. Many providers in our study endorsed interest in receiving more training in communication and when to initiate palliative care discussions.

Finally, there are many ongoing systems-level adjustments in regards to billing for these types of discussions. For example, the Center for Medicare and Medicaid Services has approved chronic care management and care planning codes, as well as codes to bill for extended time spent with patients, phone calls, and time spent conducting non–face-to-face activities, all of which could enable memory care providers to have more time to address palliative care needs with PLWD. More work is needed to integrate these approaches into existing clinic structures, and train providers on mechanisms for implementation.

#### 4.2 | The importance of in-depth understanding of the disease for addressing palliative care needs, from diagnosis to symptom management

In order to build a palliative care intervention for PLWD, this approach will need to incorporate both traditional palliative care content and content unique to dementia care into training and care provision. Participants felt that working with PLWD requires a nuanced understanding of neurodegenerative diseases and how they manifest in regard to the brain, function, cognition, and medications management. Participants underscored the particular challenge of behavioral symptoms in dementia. Memory care specialists and their teams are well equipped to manage this aspect of dementia palliative care because of their unique in-depth understanding of the syndromes and their specific symptoms. Ideally, a palliative care approach could be initiated upon diagnosis of a dementia syndrome, include advanced care planning, and take into account the unique needs of PLWD.

### 4.3 | The importance of the interdisciplinary team

Participants reported strengths related to the interdisciplinary team-based approach their memory center uses. Members of the interdisciplinary team with different expertise take responsibility for different aspects of a patient's care. This team enables families to connect to dementia-specific resources and support. An awareness of the scope of practice of different team members is important in dementia palliative care. Providers also may provide neuro-education to a patient's other providers.

### 4.4 | The importance of anticipatory guidance, with an emphasis on patient safety and identifying what it means to have quality of life in this disease

Many providers reported engaging in anticipatory guidance, in which providers foreshadow potential challenges and make recommendations for care approaches that incorporate the preferences of patients and families. These practices are in accordance with traditional palliative care frameworks.<sup>44</sup> In our interviews, providers most frequently discussed providing anticipatory guidance around patient safety, such as dementia-specific home safety, driving, financial safety, and identifying referrals to physical or occupational therapy. Furthermore, providers offered guidance around helping to maintain patient quality of life over the disease course.

### 4.5 | Call for additional training and education in palliative care skills

Participants in our study suggested the need for funding for additional dedicated palliative care personnel, training in key aspects of communication, new protocols, and systems-level changes. This aligns with international research on dementia palliative care.<sup>30,45-47</sup>

### 4.6 | Limitations

One key limitation of this work is transferability, given that we did this research within one well-resourced specialty memory center at an academic institution with providers who are involved in both clinical practice and research. The providers' perceptions of palliative care needs, challenges, and resources may be different than those of providers in other settings, such as community neurology, and therefore may not be representative of other memory care neurology practices. More research is needed on these gaps in other types of specialty settings prior to implementing broader recommendations for palliative care practice in specialty memory care settings. Additionally, day-to-day practices in the clinic may deviate from what providers described in these interviews.

## 5 | CONCLUSION

There are many strengths of using the expertise of specialty memory care teams to address palliative care needs of PLWD. These strengths include their in-depth understanding of the disease, its symptoms, and the burdens caregivers face, as well as the team-based approach that is already used, which maps onto aspects of the structure of specialty palliative care teams. However, clinical teams may require additional knowledge and new approaches to training to address specific challenges to meeting all of the palliative care needs of PLWD. These findings will inform the development of a basic palliative care intervention in a specialty neurology memory clinic. They also lay the groundwork for additional research to better understand what constitutes high-quality palliative care for people living with dementia.

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## APPENDIX 1.: CO-INVESTIGATORS (DEMENTIA PALLIATIVE CARE WRITING GROUP MEMBERS)

Name	Location	Role	Contribution
Tala Al-Rousan, MD	University of California, San Diego; Senior Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute	Dementia Palliative Care Writing Group Member	Participated in data analysis
Nicole Boyd	University of California, San Francisco	Research Coordinator, Dementia Palliative Care Writing Group Member	Coordinated recruitment, participated in data analysis
Shamiel McFarlane, MD	Senior Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute	Dementia Palliative Care Writing Group Member	Participated in data analysis
Brenda Perez-Cerpa, MD	Senior Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute	Dementia Palliative Care Writing Group Member	Participated in data analysis
Maritza Pintado Caipa, MD	Senior Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute	Dementia Palliative Care Writing Group Member	Participated in data analysis
Talita D. Rosa, MD	University of Louisville; Senior Atlantic Fellow for Equity in Brain Health at the Global Brain Health Institute	Dementia Palliative Care Writing Group Member	Participated in data analysis

## APPENDIX 2.: INTERVIEW GUIDE

### PROVIDER Interview Guide

#### 1. Provider background

What is your **clinical training**? What are your areas of **specialization**?

What is your **current role** at [specialty clinic]? How many years have you been in this role?

#### 2. Provider understanding of patient and family needs

- Think about a recent patient you saw with dementia in your practice. What did you perceive to be the most significant needs of this patient and his or her family?
- Think about a recent patient with dementia who was near the end of life. What did you perceive to be the most significant needs of this patient and his or her family?

Next I'd like to talk with you specifically about palliative care, which is an approach to care that seeks to provide holistic approaches to reduce suffering associated with a serious illness. It also tries to optimize person/caregiver-centered care by understanding what is important to the patient and caregiver and providing support and anticipatory guidance.

Typical activities of palliative care can include *advanced care planning; managing symptom burden; discussing prognosis; providing guidance about what to expect with disease progression; and providing caregiver support*.

We are particularly interested to talk with you about how what you do may relate to these activities.

#### 3. Current practices, supports & barriers relevant to Palliative Care

- What are some activities you do with or for your patients that you feel are aligned with palliative care approaches? Please share some specific examples.
  - What is going well with these activities?
  - What is challenging or going poorly?
  - What helps you to do this work?
- Are there patient or family needs that you feel you're not addressing? Please share some specific examples.
  - What is getting in the way of your addressing these needs?
  - Are there other clinicians who meet these needs (e.g., SW/RN)?
- What challenges do you personally experience in the care of these patients?
- What do you think could be done better by you or others?
- What would be the most helpful to you personally in caring for these patients and their caregivers?

#### 4. Provider needs to do additional Palliative Care-type support

- What additional content knowledge or skills would you need to incorporate more palliative care approaches into your practice?
- Have you ever referred a patient of yours to specialty palliative care? Why or why not?
  - If yes, please briefly describe the experience

Is there anything else relevant to this that we have not discussed? That you think we should know?



## APPENDIX 3.: CODING STRUCTURE

Code Name	Definition
<b>Provider background</b>	Quotes that pertain to provider background, training, or experience.
<b>Current practices</b>	Quotes that pertain to current practices providers engage in to understand or address the needs of patients and their families. Subcodes:
a. <b>Aligned with palliative care domains</b>	a. code practices identified that are aligned with literature-identified palliative care domains
b. <b>Neurology-specific</b>	b. code practices that are unique to neurology settings
<b>Challenges</b>	Quotes that pertain to challenges addressing patient and family palliative care needs based on the definition of palliative care provided. Include: challenges, hardships, sources of discomfort, ethical struggles, difficulties, concerns, or frustrations. Subcodes: tag challenges as they pertain to:
a. <b>Patient and family</b>	a. patient or family challenges
b. <b>Provider</b>	b. provider-level challenges
c. <b>Systems</b>	c. systems-level challenges
<b>Supports</b>	Quotes that pertain to areas providers identify that currently help or support their work addressing the palliative care needs of patients and their families.
<b>Provider Needs</b>	Quotes that pertain to areas providers identify that would help them to better address their patients' palliative care needs (met or unmet); desire for more information, support, or education; wishes; or any content areas that they identify would be useful for improving care or developing a palliative care intervention.
<b>Perspectives on palliative care</b>	Quotes that pertain to provider perspectives on or attitudes about palliative care, including discussions of prior experience, reflections, critiques, or support.
<b>Good quote</b>	Quotes that are well-said and representative of a given theme.