



## Perspectives on advance care planning needs of persons with advanced dementia from their surrogates and clinicians

Sara E. Golden<sup>a,b,\*</sup>, Felipe Rubim<sup>a,b</sup>, Rekha Thammana<sup>c,d</sup>, Natalie Disher<sup>a</sup>, Kelly C. Vranas<sup>a,e</sup>, Joan M. Teno<sup>f</sup>, Seiko Izumi<sup>g</sup>, Hyunjee Kim<sup>h</sup>, Jennifer Tjia<sup>i</sup>, Donald R. Sullivan<sup>a,b</sup>

<sup>a</sup> Center to Improve Veteran Involvement in Care, VA Portland Health Care System (VAPORHCS), Portland, OR, USA

<sup>b</sup> Division of Pulmonary, Allergy, and Critical Care Medicine, Oregon Health & Science University (OHSU), Portland, OR, USA

<sup>c</sup> Geriatrics and Palliative Care, Division of Rehabilitation and Long-Term Care, VAPORHCS, Portland, OR, USA

<sup>d</sup> Department of Hematology and Medical Oncology, OHSU, Portland, OR, USA

<sup>e</sup> Section of Pulmonary and Critical Care Medicine, VAPORHCS, Portland, OR, USA

<sup>f</sup> Health Services, Policy, and Practice, Brown University, Providence, RI, USA

<sup>g</sup> School of Nursing, OHSU, Portland, OR, USA

<sup>h</sup> Division of Emergency Medicine, OHSU, Portland, OR, USA

<sup>i</sup> Department of Population and Quantitative Health Sciences, UMass Chan Medical School, Worcester, MA, USA

### ARTICLE INFO

#### Keywords:

Qualitative  
Long-term care  
Quality of life  
Surrogates  
Caregivers

### ABSTRACT

**Objectives:** This study was designed to understand the experience and needs surrounding advance care planning (ACP) discussions for surrogate decision-makers of persons with advanced dementia (PWAD).

**Methods:** Semi-structured qualitative interviews based on end-of-life communication models with a convenience sample of 17 clinicians, and 15 surrogates of PWAD. We used a hybrid approach of deductive and inductive thematic analysis.

**Results:** Two main themes emerged. 1) Deficits in communication: Often surrogates did not fully comprehend the disease trajectory or medical treatments, like the likelihood of pneumonia and use of mechanical ventilation, nor concepts related to ACP, particularly legal documents and orders such as Do Not Hospitalize, which made decision-making challenging as perceived by clinicians. 2) Decision-making conflicts: Clinicians perceived a disconnect between surrogates' understanding of their loved one's preferences and knowing how or when to operationalize them.

**Conclusions:** Significant gaps in knowledge surrounding disease trajectory and complications, such as pneumonia, and aspects of ACP, exist. These gaps create decision-making challenges for surrogates and clinicians alike.

**Innovation:** This study assessed both clinicians and surrogate decision-makers' perspectives on communication and decision-making concerning care preferences, goals, and ACP. The study findings from a national cohort can inform decision-support interventions for clinicians and surrogate decision-makers of PWAD.

### 1. Introduction

Dementia prevalence is increasing rapidly with about 14 million adults estimated to be diagnosed by 2060 in the US. Advance care planning (ACP) discussions (which according to an expert consensus is a process that supports patients sharing their personal values, life goals, and preferences regarding future medical care...to help ensure that people receive medical care that is consistent with their values, goals and preferences) can promote care aligned with patients' and families' preferences [1]. Persons with advanced dementia often receive non-beneficial end-of-life

(EOL) treatments that do not align with their preferences [2]. This intensive care can increase suffering for patients and their families or any surrogate decision-makers (herein referred to as "surrogates," which may or may not be a family member). Misaligned intensive care substantially increases healthcare costs and >90% of surrogates state that patient comfort is the primary goal in advanced dementia [3-11]. Advance directives (i.e., formal ACP documents) are more common among older adults with certain conditions compared to the overall US population, however, completion rates have not increased appreciably in the past decade [12,13].

\* Corresponding author at: 3710 SW US Veterans Hospital Rd. R&D 66, Portland, OR 97239, USA.

E-mail address: [sara.golden1@va.gov](mailto:sara.golden1@va.gov) (S.E. Golden).

<https://doi.org/10.1016/j.pecinn.2023.100241>

Received 27 September 2023; Received in revised form 15 November 2023; Accepted 2 December 2023

Available online 4 December 2023

2772-6282/Published by Elsevier B.V. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

ACP is particularly germane in advanced dementia, as there have been significant increases in the use of mechanical ventilation in this population at the EOL [14,15]. Use of mechanical ventilation is mostly related to disease progression and the development of eating or swallowing problems, contributing to aspiration pneumonia and hospitalizations for acute respiratory failure [10,16]. Importantly, this increase in mechanical ventilation use in persons with advanced dementia is not associated with a survival benefit [15]. While debate exists regarding the overall utility of ACP implementation (in a narrow sense, not including comprehensive care planning), studies show ACP can improve the quality of EOL care by decreasing intensive [16] or life-sustaining treatments, such as mechanical ventilation, and reducing hospitalizations in accordance with patients' and/or surrogates' preferences [17-20]. Studies incorporating both clinician and surrogate qualitative data on the experience of ACP discussions for PWAD do not exist.

A recent consensus statement identified ACP as a key component of good clinical practice among PWAD [21,22]. However, unique barriers to initiating ACP with PWAD exist. There is a lack of actionable disease-specific prognostic information readily available to surrogates, and a lack of confidence and standardization among clinicians in initiating these discussions, which is exacerbated by a lack of available evidence-based decision support resources for surrogates [23-28]. To address this gap and based on our own findings of increased use of non-beneficial mechanical ventilation among PWAD, we performed a qualitative needs-based analysis among surrogates and clinicians to better understand ACP needs among surrogates of PWAD and their clinicians. This study is part of a larger mixed-methods project to develop resources providing prognostic and outcomes data regarding ventilatory support in the treatment of pneumonia among PWAD.

## 2. Methods

We performed semi-structured interviews from May 2021–August 2022 of surrogate decision-makers of long-term care residents and their clinicians (i.e., physicians, advanced practice providers, social workers, and dementia program managers). Clinicians had to be involved in dementia care and conversations with surrogates, and were all employed in a national, for-profit long-term care chain in the US with dementia care units. The National Director of Clinical Research contacted all long-term facilities around the US on our behalf. Of these, 20 clinicians from

17 facilities in 9 states responded that they would like to participate. The same director also contacted the program director for the dementia care unit in each facility who helped us recruit surrogates. In total, we approached 17 facilities to recruit surrogates for residents in long-term care; two facilities did not want to participate. We successfully recruited surrogates from 7 facilities in 6 states. Surrogates had to self-report as having decision-making responsibility for a resident(s) of a long-term care facility (i.e., nursing home) and be English-speaking. We recruited surrogates through secure electronic referrals from program directors, clinicians, or by surrogates contacting the research team directly via study brochures provided by clinicians. Of note, if surrogates had questions about ACP or their loved one, the study team notified the facility director to follow up. All clinicians and surrogates were consented by phone (IRB #21951).

We used semi-structured interview guides informed by models of EOL communication (e.g., Caring Conversations) and shared decision-making [29] that allowed other questions to emerge. (Fig. 1) Our clinician interview guide focused on: 1) Barriers to ACP initiation and 2) Information that they would find helpful for surrogates to prompt ACP discussions. Our surrogate interview guide focused on two domains: 1) How surrogates make decisions regarding EOL care preferences and 2) What kinds of information they find helpful in making decisions. One social scientist with expertise in health services research (SEG) conducted all interviews via an online platform. Interviews ranged from 20 to 50 min. They were recorded, transcribed verbatim, and verified for accuracy by trained staff.

### 2.1. Analysis

We used a hybrid approach of deductive and inductive thematic analysis to interpret transcripts. SEG used the domains of the interview guide and read the first 10 transcripts for each group of participants (clinicians or surrogates) to create a preliminary codebook. Next, SEG and RT (for clinician data) or SEG and FR (for surrogate data) reviewed a set of 5 transcripts and discussed findings to refine the codebook and come to consensus. SEG and RT or FR then reviewed an additional set of 3 transcripts together to finalize the codebook iteratively and come to an agreement. SEG and FR coded the remainder independently. Findings were discussed among the study team throughout analysis. Matrices of transcript summaries were created to organize qualitative findings and

#### Clinicians

- How well do you think surrogate decision-makers understand their loved one's treatment preferences?
  - Can you tell me a little bit about your experiences in situations where family members make decisions about their loved one's treatment? (Probe: one example where family members did and one example where they did not participate)
- How involved do you think family members want to be in their loved ones' medical treatment decisions? Do you think they should have a say in decisions or do you think they should leave these decisions to their clinicians? Can you describe your feelings or thoughts about this?

#### Surrogates of PWAD

- If you were to consider completing plans for your loved one's future medical care and treatment – what kind of plans would you be interested in learning more about (e.g., do not hospitalize order, advance directive, or living will or something else?) What are your reasons for this choice?
  - What do you think is the best time and place to have discussions about planning with the doctors?
- What kinds of information would you need to complete plans for your loved one's future medical care and treatment?
  - Do you find stories about other similar patients helpful? What are your thoughts about reviewing percentages or numbers when discussing medical care? Is it helpful to hear information about other patients with memory problems when making medical decisions?

Fig. 1. Selected questions from the interview guide.

allow for further thematic analysis across domains and participants. We also utilized an audit trail and memos to track decisions on coding and analysis. We used Atlas.ti 9.0 (Atlas.ti GmbH, Berlin, Germany) to organize and support analysis.

### 3. Results

We interviewed 17 clinicians and 15 surrogates. Most clinicians had been at their current long-term care facility for 5–10 years (53%) and all reported having at least occasional experiences with ACP conversations with residents and surrogates. Surrogates were all family members of residents and 40% had been involved in decision-making for their loved one for 5–10 years (Table 1). We found two main themes with sub-themes as listed below: 1) Deficits in communication about disease trajectory and ACP; and 2) Surrogate and clinician decision-making conflicts. Table 2 includes additional exemplary quotes. Participants were anonymized via a random number and whether they were a clinician (C) or surrogate (S).

**Table 1**  
Self-reported participant characteristics.

	Clinicians (n = 17)	Surrogates (n = 15)
Characteristic	N (%) or Mean (SD)	
Gender		
Female	15 (88%)	12 (80%)
Age, years	54 (10)	66 (11)
Race		
White	14 (82%)	14 (93%)
Asian	2 (12%)	1 (7%)
Black	1 (6%)	-
Ethnicity		
Non-Hispanic	17 (100%)	15 (100%)
Role		N/A
Medical Director	5 (29%)	
Nurse Practitioner	5 (29%)	
Memory Care Manager	5 (29%)	
Social Worker	2 (12%)	
Specialty		N/A
Internal Medicine	2 (12%)	
Geriatrics	3 (18%)	
Not Applicable	12 (71%)	
Relationship to Resident	N/A	
Daughter		10 (67%)
Son		2 (13%)
Spouse		3 (20%)
State where Facility was Located		N/A
Connecticut	4 (24%)	
Delaware	2 (12%)	
Massachusetts	1 (6%)	
Maryland	1 (6%)	
Maine	1 (6%)	
New Hampshire	2 (12%)	
Pennsylvania	5 (29%)	
West Virginia	1 (6%)	
Employment at Facility		N/A
<5 years	4 (24%)	
5–10 years	9 (53%)	
11–15 years	1 (6%)	
> 15 years	3 (18%)	
Time Resident has been at Facility	N/A	
<1 year		5 (31%)
1–3 years		7 (44%)
4–6 years		3 (19%)
> 6 years		1 (6%)
missing		1 (6%)
Time as Surrogate Decision-Maker	N/A	
< 5 years		5 (33%)
5–10 years		6 (40%)
> 10 years		4 (26%)

**Table 2**  
Additional exemplary quotes.

Clinician Quote (ID)	Surrogate Quote (ID)
Theme: Deficits in communication about disease trajectory and GOC	
<i>Subtheme: Understanding of Disease</i>	
Dementia is not necessarily talked about as a terminal diagnosis, but it is. Like it will eventually kill the person that has it because their body will stop, their brain will stop functioning and then their body will stop functioning and so I think unfortunately families just don't have education around what dementia is and what it does, and so I think that needs to start early on in the disease process for families. Unfortunately, it doesn't really. (10)	I consider myself a pretty intelligent person and so I took it upon myself to kind of teach myself about doing research, etcetera. To try to figure out what I had facing me going forward. But I can tell you that it's very difficult for a caregiver in a situation like that because... like nobody like sits you down or gives you a school, or like schools you on what to expect or things of that nature, and so basically all what I learned about [dementia] was self-taught. (6)
Some residents or families are very versed in the diagnosis. Some are not. Some have what we would refer to as unrealistic expectations that we deal with frequently. (11)	I think that people should know step-by-step what normally happens [in the disease] so that when it does happen they're not completely in shock or off-kilter about what could happen. (5)
	I would say upon diagnosis, having a realistic "this is what to expect, and one- first, second, third stage," you know, "one, two, three, and when they're hitting four you might see-"I think it would be beneficial... but I would think to have an understanding of what's coming down the pipe, because it's not like any other disease. (3)
<i>Subtheme: Understanding of ACP</i>	
[Families] ask things like can I change my mind? And obviously you can always change your mind, it's not like set in stone it's just sort of... those are the questions I often get, are what does it mean to not send someone to the hospital, so does it mean I'm letting my loved one die, does it mean I'm not taking care of them, does it mean they are going to suffer? (10)	When I think of a Do Not Hospitalize, well, I think it's a Do Not Hospitalize. And my concern is that somebody who has a Do Not Hospitalize, they'll wait before they call me. (10)
After her admission to our facility, her daughter chose to put a feeding tube in her and for almost a year and a half, we battled her pulling the tube out – we'd have to go back to the operating room to have it put back in, aspiration, she had bleeding, and so I don't know if it was so much that she didn't understand as she didn't accept her mother's prognosis and then it was almost the last month before we came together, was able to come together and with the help of hospice- she became amicable to that after the last hospitalization- we were able to focus more on the quality of her life. And the last month she didn't go back to the hospital, and she passed, what I perceived as comfortably in our center, and the daughter at that point I think more understood. (9)	I'm familiar with DNR, but not with "do not hospitalize". (2)
It is a hard conversation to have and some families no matter what just don't get the quality of life. If they do resuscitate them that their quality of life is going to be much worse... it can be very difficult because they don't understand what it is if they do resuscitate and they refuse to have that conversation of 'we really feel like you need to change their code,' and they're like, 'no, keep them alive.' (1)	
[DNR orders] are tough... even I grapple... I have trouble myself with	

(continued on next page)

Table 2 (continued)

Clinician Quote (ID)	Surrogate Quote (ID)
[defining] do not hospitalize, to tell you the truth. (13)	
<i>Subtheme: Preference Discussions</i>	
I think it's a mixed bag. If I had to guess I would say the majority don't really know and that the majority often use their own preferences, you know, just because they don't want to see their loved one go. (14)	We didn't talk about specifics because my mother's not that kind of person... but the one thing she did do was decide how she wanted to end her life. (5)
Our admissions director definitely encourages the family to have [preference discussions] done before they come here and then we can just avoid having that conversation and we just kind of check in so just making sure they are DNI, DNR, DNH, and then it's just checking in. (7)	When [my loved one] was still pretty cognizant we had those discussions and that's when she made those decisions on her own for the living will. I just felt that she would want them carried out when she couldn't make the decisions on her own. (3)
I don't think [families] understand their [loved one's] preferences that well because I don't really believe that the families themselves understand the preferences and what they are and what the possibilities are. (1)	
Maybe 20–30% of families have communicated prior to the dementia diagnosis... Most people are very unprepared as to what their loved one would have wanted if their loved one can't speak to it at the time. (5)	
Theme: Surrogate and clinician decision-making conflicts	
<i>Subtheme: Internal Struggles</i>	
	[the clinicians] said that they had a form and... they went over it with me, and I know a couple times and just in various meetings or whatever they've just reiterated what I've signed and that I haven't changed my mind or anything like that because at some point soon... it was noted that [my loved one] wasn't capable of making his own decisions like that- even now, every now and then they just confirm that that's still my- that that's still in effect and still my wishes. (8)
Like I said, [the biggest barrier to completing DNH orders is] just not really wanting that responsibility. Which is again, I feel like if the doctors could have this conversation with them early on that would really help. (7)	Well the doctor makes all of the decisions that need to be made medically... but as far as medication, they keep me aware of everything, and after I visit I talk with them, or it goes with my approval, or occasionally they had to call me on a few things. Certainly they do what they have to do. (4)
[The daughter] was so close with her mother she had a hard time sort of accepting the fact that she was 95 years old and this is maybe just a part of the gradual decline that we see at 95 years old, but she is comfortable and she's had a good life and to force her to eat or to put in a feeding tube... as much as we want to keep our parents around like maybe that's not the right thing for them. (8)	When [the clinician] called it was all about "well let's- do you want to- let's do a Do Not Hospitalize, let's do that," and I said "mm, well." Because of some of the actions they haven't taken since dad's been there, I don't trust them with a DNH. We'll make that decision. ... We just don't want Do Not Hospitalize to be, you know, something that was perfectly treatable, and they just leave him there at [name of facility]. And honestly, I don't trust them, so I want to know everything. (10)
... I always stress quality of life... I try to urge them to look at the bigger picture, you know if it is pneumonia that we are treating and we are sending the patient out and if they want the patient intubated, etc., all of that, I always educate them and urge them to take a step back and remember that the	

Table 2 (continued)

Clinician Quote (ID)	Surrogate Quote (ID)
patient has advanced dementia. Yes, you can treat this bout pneumonia, but are you really going to prolong life? Is this intubation or placing the patient in the ventilator really going to help in any way or is this going to cause more pain and discomfort for someone who is not able express him or herself. So, look at the bigger picture, focus on quality of life and don't just look at the ailment on its own or the problem at hand right now. (16)	
<i>Subtheme: Involvement of Surrogates</i>	
If they're a single person and their mom, they're the only son, there's this one single person involved, they're more yielding to say, 'what would you do? I'm confused. I'm the only son... I don't want to do the wrong thing.' But a lot have family members and even though there's a single power of attorney, the power of attorney rarely feels empowered enough to make the decision on their own. They have to have a meeting with their two sisters or brothers or, you know, the other family members. They have to have like a consensus. And among those family members, there's a range. Some are saying yeah, this is ridiculous to keep her alive or him alive but it's all over the map. So again, it's a complicated process. (10)	I am fortunate enough to have a brother, he and I are two years apart, and he and I discuss all these things about my parents and their care and all that so I guess my saving grace is I'm not completely making decisions on my own. I have somebody supporting me with decisions that I make in their regard. (6)
I think it is 50/50, I think some of 'em really want to [be involved in decisions], some of them will just do what they need to and say 'you deal with it now.' So kind of it goes both way and I've had other people that don't want to deal with it at all and don't even want to talk about it. (11)	There's four of us [children], one's a nurse, one's an oncology nurse navigator, and- um- probably has- we all look to her, like towards the med decisions, and things like that. And we- people get emotional- but so far we hold it together, and we end up agreeing on a course of action. (10)

3.1. Perceived deficits in knowledge about disease trajectory and ACP and how these deficits impacted decision-making and outcomes

Clinicians.

3.1.1. (Mis)Understanding of dementia trajectory

Clinicians reported surrogates often do not seem to understand the disease trajectory in PWAD or concepts surrounding EOL care decisions, making informed decision-making challenging. About half of the clinicians described feeling as if only 50% of surrogates understand the dementia diagnosis. They reported they thought that surrogate understanding depended on how involved surrogates were with the resident (e.g., spouse vs. sibling vs. court-appointed proxy). Some clinicians talked about surrogates having unrealistic expectations about loved ones' prognoses such as thinking loved ones will get better. Other reported that few surrogates understood the dementia disease trajectory as a slow decline in function. For instance, one clinician described, "I find most people really don't understand dementia... they don't understand the progression of it... there's a lot [of] just miseducation or no education surrounding the diagnosis and the natural progression of the disease" (5C). They all agreed that lack of surrogate understanding was a barrier to informed decision-making.

3.1.2. Clinicians desire more surrogate understanding of ACP

Clinicians also perceived a lack of surrogate knowledge about EOL care and ACP concepts, especially terms such as Do Not Hospitalize (DNH). They reported perceived surrogate confusion about the purpose of a DNH order, specifically whether it meant a loved one received no

treatment or never sending a loved one to the hospital. In explaining DNH in particular, one clinician said, “I think there needs to be more focus on all the things you can do besides a tube down your throat... You can give oxygen. You can even give it in a mask form... like that’s the other way to sell it to people is you’re not taking stuff away, you’re just giving lots of other stuff instead” (15C). Indeed, among some surrogates there was a clinician-perceived disconnect between knowing their loved one’s preference and goals, and knowing when and how to operationalize them. One clinician gave an example about explaining to a surrogate about the quality of life (QOL) their loved one would have: “Sometimes you have to be hard and blunt and say, ‘hey, this isn’t about you, this is about your mom. Do you want your mom to be tortured?’ Because you know in a way she is being tortured, having her ribs cracked and everything and she’ll be in pain.” (3C).

Clinicians wanted surrogates to better understand how hard it is on the residents and long-term care facility staff when residents are taken out of the environment in which they are comfortable. More than one clinician mentioned that it could take several days for residents to return to their baseline cognitive and physical function following a hospitalization. For example, “[surrogates] don’t understand... that somebody with dementia may have a Do Not Resuscitate (DNR) order but... you could (still) transport to the hospital. And what that means is somebody with dementia could then be taken off the unit, be taken to the hospital where they don’t know anyone, don’t know what’s going on, the fear and the agitation then, that can ensue” (1C). Some said DNH orders were hard for staff to discuss since they themselves might not fully understand what they meant. Other care options were perceived as being more “black and white” and easier to explain to surrogates (e.g., DNR orders). All clinicians supported creation and use of more surrogate-facing resources to help inform discussions. The majority of clinicians suggested focusing on describing the dementia disease trajectory, defining medical orders and ACP terms, and characterizing what life-sustaining treatments might look like and the potential impact of care on subsequent QOL.

### 3.1.3. Care preference discussions

Further, clinicians estimated about half of surrogates had already talked about care preferences with their loved one prior to the dementia diagnosis and had something in place (e.g., advance directive), while the others had not. When surrogates had not had prior discussions, clinicians expressed this situation made discussions about EOL more difficult. One clinician explained their “best case scenario” as when surrogates “come in with this paperwork already done, it’s already filled out” (7C). That example contrasts with common scenarios clinicians experienced. For instance, one clinician reported, “... for families, it is very complicated to try and make those guesses if they haven’t had those conversations and it is really heart-breaking to watch them struggle with knowing what their loved one would want” (10C). There may also have been a lack of understanding about preferences among surrogates due to the lack of knowledge about ACP and EOL care as discussed above. Difficulties were compounded when there was distance or isolation between surrogates and residents, so surrogates were not able to see the resident and understand what is happening in terms of disease progression. This lack of contact was particularly visible during COVID-19 pandemic lockdowns.

## 3.2. Surrogates

### 3.2.1. Understanding of dementia

Surrogates echoed clinicians saying that many people do not understand a dementia diagnosis, often saying it was conflated with Alzheimer’s disease. The surrogates in our interviews, though, almost all reported being “a little bit more aware of [dementia] than some people are” (5S). However, there was a lack of knowledge reported about typical outcomes or complications, such as feeding or swallowing problems, or even less commonly mentioned, pneumonia. One surrogate

(3S) said, “[I didn’t discuss] pneumonia [with the clinician], not really,” while another (5S) described not discussing pneumonia with their loved one either since “my mother’s not that kind of person... we didn’t talk about specifics.” Many also described not being told about the disease trajectory and doing research on the internet to discover possible outcomes. In terms of decision-making, no surrogates specifically said their lack of disease knowledge impacted their decision-making although they wanted more information about dementia and how EOL care choices might impact the disease and vice-versa for the future.

### 3.2.2. Understanding of EOL care options

Many surrogates requested to learn more information about life-sustaining treatments, like mechanical ventilation and feeding tubes. While they did not explicitly endorse that they did not have knowledge about medical orders or documents, there were several questions to the interviewer about what each term meant, especially the difference between medical orders such as DNH and DNR. To learn more, some surrogates reported they would turn to the internet, family or friends, lawyers, or facility staff. For DNH orders specifically, there were only a handful of surrogates who were familiar with the term, and only two could definitively say whether there was an order in place for their loved one.

Many surrogates expressed a desire to have conversations with facility staff about a DNH order for their loved one after hearing about it from the interviewer. They conveyed feeling like it would be something their loved one would want. For example, one surrogate said after hearing about DNH orders, “I want them to do everything they possibly can at the facility so that [my mother is] not moved, because... she knows the people who are taking care of her, even though she may not remember them from one day to the next, or for from one minute to the next, she’s got a level of comfort there...” (7S). Surrogates agreed that more decision-making support resources would be helpful. One surrogate said, “I think whatever information you can give to the family is going to be helpful. We may not want to hear it, but... I think it’s going to be helpful” (5S). They also agreed that focusing on QOL, and defining ACP terms and what life-sustaining treatments look like would be helpful.

### 3.2.3. Preference discussions

Only one surrogate had not had any discussions about EOL preferences; many times, discussions were initiated by the loved one several years prior to the dementia diagnosis. One said, “My mom asked me before her sickness... to respect [her] wishes. So, I tried to let [the facility] know that she had asked me... I tried to respect that” (11S). All surrogates wanted to respect their loved one’s goals for EOL, and most felt like they know the person so well, they “pretty much know where the person stands on such things” (2S). One surrogate said what many responded saying it is important to make decisions while “respecting my mom’s wish and also taking her well-being at heart” (11S). Some mentioned they were not familiar enough with EOL care options or potential life-sustaining treatments (e.g., mechanical ventilation) to connect those options with their loved ones’ preferences.

## 3.3. Surrogate and clinician decision-making conflicts

### Clinicians.

### 3.3.1. Internal conflicts

Clinicians reported experiencing moral and ethical distress in situations when surrogates elected for receipt of life-sustaining treatments (e.g., mechanical ventilation) despite clinicians’ impressions that such intensive treatment would not benefit the residents. For instance, one clinician said, “I can definitely say I’ve experienced what I feel versus what (the) family feels but for me, it’s not about my decision-making. It’s about that family and what they feel is best for their loved one. So, I take myself out of the equation. But I have a hard time” (2C).

Importantly, all clinicians agreed that the surrogates know the resident best and should be the final decision-maker, as desired.

### 3.3.2. Conflict among surrogates

Family dynamics and involvement also came up frequently in discussing difficulties in decision-making, particularly among surrogates with different levels of agreement between decision-makers. There was a reported effect of family dynamics on communication and decision-making. One clinician described, “it’s like when there’s four kids, each have a different opinion, it starts a war... and the woman just died, but it was a war as to what should be done.” (3C). Some family surrogate decision-makers were very involved with the resident and with each other, but a small number were either minimally involved, avoided decision making, or had internal family disagreement with decision-making and deciding on “what is right.”

## 3.4. Surrogates

### 3.4.1. Internal conflicts

In contrast to clinicians, most surrogates did not report internal or external struggles regarding life-sustaining treatments since they were able to draw on relationships and conversations with their loved ones to identify preferences. An example of “ideal decision-making” came from a daughter who said, “my mom’s had nine strokes, she has vascular dementia, she’s in a nursing home, and she’s got a full code on her chart, so [the nurse] explained to me what full code was... and then let me make that decision [since I know my mom best]” (7S). Overall, surrogates had good experiences with decision-making, such as surrogate 7S who said the staff, “showed me what’s on the MOLST [Medical Orders for Life-Sustaining Treatment] form and on the DNR form what decisions I was making... I think definitely they explained the forms and had both verbal and written information available.” On the other hand, a couple described negative experiences involving poor communication between clinicians and surrogates, ultimately compromising trust. Surrogates described wanting to make the final decision on care, with medical input from the clinicians.

### 3.4.2. Conflict among surrogates

The surrogates interviewed were all very involved in their loved ones’ care and health care decisions. Some did discuss difficulties with other family members, saying things like, “The family involved is the biggest thing... I had two [kids] that, when I first put [my wife] in... the hospital [facility], they were really mad at me. They didn’t talk to me for months. In fact, I have one son that still won’t accept the thing that she’s in the hospital” (1S). Most though, discussed positive experiences with their family members and other decision-makers. All surrogates stressed that they only wanted to do what was best for their loved one and would follow their wishes as closely as possible.

## 4. Discussion and conclusion

### 4.1. Discussion

In this qualitative study among surrogates of residents in long-term care facilities with advanced dementia and clinicians who care for them, we found that often surrogates do not comprehend the trajectory of advanced dementia or potential role for therapies such as mechanical ventilation. Similarly, surrogates had limited understanding of concepts related to ACP like legal documents or medical orders (e.g., DNH orders). As a potential result, clinicians perceived a disconnect between surrogates’ knowledge of their loved one’s preferences and goals, and when to operationalize them based on the disease trajectory (e.g., the development of swallowing/eating problems leading to pneumonia). Clinicians also reported challenges with surrogates’ decision-making when faced with differing opinions with and within surrogate groups. A majority of clinicians and surrogates agreed decision-making

resources are needed to better address ACP needs which may better align residents’ goals and preferences with EOL care and receipt of treatments [6-8]. We plan to try to address this important gap in the second phase of the larger mixed-methods study.

Our findings reinforce barriers to initiating ACP discussions among surrogates of persons with dementia since a lack of knowledge of the dementia disease trajectory and ACP concepts was common [30]. While some surrogates previously participated in ACP, most surrogates lacked knowledge regarding the trajectory in advanced dementia including the link between swallowing/eating problems and the development of pneumonia that can lead to use of low-value or non-beneficial care such as mechanical ventilation. This is significant as infections and eating difficulties are hallmarks of advanced dementia, and 6-month mortality after the development of pneumonia in advanced dementia is almost 50% [10,11,31]. Similarly, a qualitative study of hospice clinicians caring for patients with dementia found that clinicians perceived a lack of knowledge of specific to the disease trajectory and wanted to provide empathy and education [28]. Without an understanding of the disease process, surrogates’ ability to participate in informed EOL care discussions may be limited.

Regarding surrogates understanding of ACP concepts, our sample builds upon previous findings about DNH orders. Similar to a study that was limited to patients in western Massachusetts, we demonstrated that in a sample from a national long-term care network neither surrogates nor some clinicians had adequate knowledge about these orders [29]. This is unfortunate as DNH orders can reduce the likelihood of hospital transfers when transfers are unlikely to increase survival or improve patient QOL [32,33]. ACP efforts more broadly have been ineffective at reducing hospital transfers in long-term care settings, however, perhaps directed educational interventions focused on discussions of available medical orders in long-term care settings may be more promising [27].

Contrasting with clinicians’ perceptions in our study, most surrogates did not report internal nor external struggles regarding decision-making and felt they had a good understanding of their loved ones’ care preferences. Our results suggest there is a possible disconnect between surrogates’ completion of ACP documents or knowing their loved ones’ preferences and goals, and knowing when or how to operationalize or change decisions, as the dementia trajectory was poorly understood [5,10]. Many surrogates were interested in learning more about both the disease trajectory and ACP, but were rarely approached by clinicians in long-term care settings to discuss ACP in the context of disease trajectory. Established clinician-level barriers to ACP discussions include clinical workload, fear of causing stress and anxiety in surrogates, lack of ACP communication skills or ineffective training, and lack of organizational leadership around ACP [30]. The lack of surrogates’ knowledge of the disease trajectory questions their ability to make informed choices about their loved ones’ EOL care. This situation may instead leave them unprepared to make in-the-moment decisions and/or believe they have time to revisit their loved one’s wishes at the very EOL [34-39].

Clinical implications of our findings may include enhanced intake processes at long-term care facilities where clinicians are given time and resources to engage in ACP activities with new residents and/or surrogates. Another potential implication of our findings is demonstrating the need for more institutional support for serious illness communication or primary palliative care training for clinicians across disciplines (e.g., social work, nursing, etc.). High-quality discussions about EOL care and ACP are central components of palliative care which has been shown to improve symptoms and QOL among those with serious illness [40,41]. Finally, having surrogates and clinicians engage in shared decision-making; where both parties meet to exchange information, discuss options (including possible risks and benefits), and make decisions together based on decision-makers’ values and preferences; is critical in health care and may need to be implemented more fully when completing ACP documentation [42].

## 4.2. Innovation

This study is the first to capture perspectives of both clinicians and surrogate decision-makers of PWAD using qualitative interviews concurrently to perform a needs-assessment of ACP decision-making conversation support needs [23]. We utilized both inductive and deductive approaches for analysis and focused on the experience of participants when discussing potentially stressful topics. Our findings demonstrate how a lack of information could lead to potentially non-beneficial or undesired patient outcomes.

While the intrinsic patient- and family- centered value of ACP is straightforward, the literature suggests that ACP may not always have the desired impact on EOL care delivery [17]. In addition, ACP documentation by itself may be insufficient to address EOL decision-making, especially if surrogates do not understand the disease trajectory [17]. Based on surrogates' and clinicians' perspectives, we reasoned additional decision-making resources may help surrogates initiate conversations with clinicians and facility staff regarding EOL care along the continuum of dementia care. As a result of these findings, we are actively developing and testing an information sheet in the next phase of this study. We believe accessible, practical resources are urgently needed that promote discussions of EOL care among surrogates of PWAD in the context of the dementia disease trajectory which may be beneficial in promoting ACP conversations more broadly.

Our study has limitations. First, qualitative studies are influenced by recall bias and our surrogate participants were recalling some events from years prior, which may have impacted responses. Nevertheless, several participants were relaying particularly emotionally charged conversations potentially mitigating some of this bias and not all qualitative data we collected was subject to this bias as participants were asked about current communication challenges [43,44]. Second, almost all surrogates who participated had completed some component of ACP, which suggests that their experiences may be less representative of those who have not engaged in any ACP, likely causing us to underestimate needs in this population. Third, most of our sample identified as non-Hispanic, white, and all surrogates were decision-makers for persons with advanced dementia, which limits generalizability to disadvantaged groups or those with less severe stages of disease. Fourth, multiple roles and disciplines perform ACP conversations at these facilities, and although we included several disciplines, we may not have interviewed all parties. Finally, sampling bias of surrogates likely exists as some clinicians in our study reported about half of all surrogates they encountered had prior decision-making discussions, whereas almost all surrogates we spoke with described already having had some discussions. Surrogates who have not engaged in ACP discussions may experience more barriers that will need to be addressed with an intervention, and future research in this space should try to elicit these individuals' perspectives.

## 5. Conclusion

Neither clinicians nor surrogates were satisfied with the current communication and decision-making support around ACP and EOL care for PWAD in long-term care facilities. Significant gaps in knowledge surrounding disease trajectory and possible complications, such as pneumonia, and aspects of ACP exist. These serious gaps create decision-making challenges for surrogates and clinicians alike. Our findings suggest the potential utility of development of evidence-based decision support resources among PWAD in long-term care facilities to assist clinicians and their surrogates in making informed decisions that are consistent with their preferences and goals of care.

## Funding

The project described was supported by grant number P30AG064105 from the National Institute on Aging to DRS. It was also supported by

resources from the Center to Improve Veteran Involvement in Care, VA Portland Health Care System, Portland, OR (VAPORHCS).

## Note

The Department of Veterans Affairs did not have a role in the conduct of the study, in the collection, management, analysis, interpretation of data, or in the preparation of the manuscript. The views expressed in this article are those of the authors and do not necessarily represent the views of the Department of Veterans Affairs or the U.S Government.

## Authorship statement

All authors have made substantial contributions to the 1) conception and design, acquisition of data, or analysis and interpretation of data; 2) have contributed to drafting the article for important intellectual content; and 3) have provided final approval of the version to be published. All authors take responsibility for the content of the manuscript.

## Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests:

Donald Sullivan reports financial support was provided by National Institute on Aging.

All authors declare no conflicts of interest with the work presented in this manuscript.

## References

- [1] Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: a consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017;53(5):821–32. e1. <https://doi.org/10.1016/j.jpainsymman.2016.12.331>.
- [2] Gozalo P, Teno JM, Mitchell SL, et al. End-of-life transitions among nursing home residents with cognitive issues. *N Engl J Med* Sep 29 2011;365(13):1212–21. <https://doi.org/10.1056/NEJMs11100347>.
- [3] Brown Medical School Center for Gerontology and Health Care Research. Brown Atlas of Dying. <http://www.chcr.brown.edu/dying/brownatlas.htm>; 25 September, 2023.
- [4] Goodman DC, Esty AR, Fisher ES, Chang CH. Trends and variation in end-of-life care for medicare beneficiaries with severe chronic illness: a report of the Dartmouth atlas project. *The Dartmouth Atlas of Health Care*; 2011.
- [5] Mitchell SL. Clinical practice. Advanced dementia. *N Engl J Med* Jun 25 2015;372(26):2533–40. <https://doi.org/10.1056/NEJMc1412652>.
- [6] Bekelman JE, Halpern SD, Blankart CR, et al. Comparison of site of death, health care utilization, and hospital expenditures for patients dying with cancer in 7 developed countries. *JAMA*. Jan 19 2016;315(3):272–83. <https://doi.org/10.1001/jama.2015.18603>.
- [7] Hogan C, Lunney J, Gabel J, Lynn J. Medicare beneficiaries' costs of care in the last year of life. *Health Aff (Millwood)* Jul-Aug 2001;20(4):188–95. <https://doi.org/10.1377/hlthaff.20.4.188>.
- [8] van der Lee J, Bakker TJ, Duivenvoorden HJ, Droes RM. Multivariate models of subjective caregiver burden in dementia: a systematic review. *Ageing Res Rev* May 2014;15:76–93. <https://doi.org/10.1016/j.arr.2014.03.003>.
- [9] Teno JM, Gozalo PL, Bynum JP, et al. Change in end-of-life care for Medicare beneficiaries: site of death, place of care, and health care transitions in 2000, 2005, and 2009. *JAMA* Feb 6 2013;309(5):470–7. <https://doi.org/10.1001/jama.2012.207624>.
- [10] Mitchell SL, Teno JM, Kiely DK, et al. The clinical course of advanced dementia. *N Engl J Med* Oct 15 2009;361(16):1529–38. <https://doi.org/10.1056/NEJMoa0902234>.
- [11] Mitchell SL. Advanced Dementia. *N Engl J Med* Sep 24 2015;373(13):1276–7. <https://doi.org/10.1056/NEJMc1509349>.
- [12] Yadav KN, Gabler NB, Cooney E, et al. Approximately one in three US adults completes any type of advance directive for end-of-life care. *Health Aff (Millwood)* Jul 1 2017;36(7):1244–51. <https://doi.org/10.1377/hlthaff.2017.0175>.
- [13] Gotanda H, Walling AM, Reuben DB, Lauzon M, Tsugawa Y. Trends in advance care planning and end-of-life care among persons living with dementia requiring surrogate decision-making. *J Am Geriatr Soc* May 2022;70(5):1394–404. <https://doi.org/10.1111/jgs.17680>.
- [14] Sullivan DR, Kim H, Gozalo PL, Bunker J, Teno JM. Trends in noninvasive and invasive mechanical ventilation among Medicare beneficiaries at the end of life. *JAMA Intern Med* Jan 1 2021;181(1):93–102. <https://doi.org/10.1001/jamainternmed.2020.5640>.

- [15] Teno JM, Gozalo P, Trivedi AN, et al. Site of death, place of care, and health care transitions among US Medicare beneficiaries, 2000-2015. *JAMA*. Jul 17 2018;320(3):264–71. <https://doi.org/10.1001/jama.2018.8981>.
- [16] Manabe T, Fujikura Y, Mizukami K, Akatsu H, Kudo K. Pneumonia-associated death in patients with dementia: a systematic review and meta-analysis. *PLoS One* 2019; 14(3):e0213825. <https://doi.org/10.1371/journal.pone.0213825>.
- [17] Morrison RS, Meier DE, Arnold RM. What's wrong with advance care planning? *JAMA* Oct 26 2021;326(16):1575–6. <https://doi.org/10.1001/jama.2021.16430>.
- [18] Brinkman-Stoppelenburg A, Rietjens JA, van der Heide A. The effects of advance care planning on end-of-life care: a systematic review. *Palliat Med* Sep 2014;28(8): 1000–25. <https://doi.org/10.1177/0269216314526272>.
- [19] Ashana DC, Chen X, Agiro A, et al. Advance care planning claims and health care utilization among seriously ill patients near the end of life. *JAMA Netw Open* Nov 1 2019;2(11):e1914471. <https://doi.org/10.1001/jamanetworkopen.2019.14471>.
- [20] Vranas KC, Plinke W, Bourne D, et al. The influence of POLST on treatment intensity at the end of life: a systematic review. *J Am Geriatr Soc* Dec 2021;69(12): 3661–74. <https://doi.org/10.1111/jgs.17447>.
- [21] Prince M, Comas-Herrera A, Knapp M, Guerchet M, Karagiannidou M. *World alzheimerreport 2016: Improving healthcare for people living with dementia coverage, quality and costs now and in the future*. 2016.
- [22] Institute of Medicine (U.S.). *Committee on approaching death: addressing key end-of-life issues*. In: *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. xxv. The National Academies Press; 2015. p. 612.
- [23] Tjia J, D'Arcangelo N, Carlston D, et al. US clinicians' perspectives on advance care planning for persons with dementia: a qualitative study. *J Am Geriatr Soc* Dec 22 2022. <https://doi.org/10.1111/jgs.18197>.
- [24] Dening KH, Jones L, Sampson EL. Advance care planning for people with dementia: a review. *Int Psychogeriatr* Dec 2011;23(10):1535–51. <https://doi.org/10.1017/S1041610211001608>.
- [25] Morrison S. Advance directives/care planning: clear, simple, and wrong. *J Palliat Med* Jul 2020;23(7):878–9. <https://doi.org/10.1089/jpm.2020.0272>.
- [26] Caron C, Griffith J, Arcand M. Decision making at the end of life in dementia: how family caregivers perceive their interactions with health care providers in long-term-care settings. *J Appl Gerontol* 2005;24(3):231–47.
- [27] Mitchell SL, Volandes AE, Gutman R, et al. Advance care planning video intervention among long-stay nursing home residents: a pragmatic cluster randomized clinical trial. *JAMA Intern Med* Aug 1 2020;180(8):1070–8. <https://doi.org/10.1001/jamainternmed.2020.2366>.
- [28] McDarby M, Russell D, King L, Kozlov E, Luth EA. Knowledge gaps in end-of-life family caregiving for persons living with dementia: a study of hospice clinician perspectives. *Am J Hosp Palliat Care* May 2023. <https://doi.org/10.1177/10499091231176298>.
- [29] Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med* Mar 2012;366(9):780–1. <https://doi.org/10.1056/NEJMp1109283>.
- [30] Phenwan T, Sixsmith J, McSwiggan L, Buchanan D. A narrative review of facilitating and inhibiting factors in advance care planning initiation in people with dementia. *Eur Geriatr Med* Jun 2020;11(3):353–68. <https://doi.org/10.1007/s41999-020-00314-1>.
- [31] Volicser L. Management of severe Alzheimer's disease and end-of-life issues. *Clin Geriatr Med* May 2001;17(2):377–91. [https://doi.org/10.1016/s0749-0690\(05\)70074-4](https://doi.org/10.1016/s0749-0690(05)70074-4).
- [32] Mann E, Goff SL, Colon-Cartagena W, Bellantonio S, Rothberg MB. Do-not-hospitalize orders for individuals with advanced dementia: healthcare proxies' perspectives. *J Am Geriatr Soc* Sep 2013;61(9):1568–73. <https://doi.org/10.1111/jgs.12406>.
- [33] Givens JL, Selby K, Goldfeld KS, Mitchell SL. Hospital transfers of nursing home residents with advanced dementia. *J Am Geriatr Soc* May 2012;60(5):905–9. <https://doi.org/10.1111/j.1532-5415.2012.03919.x>.
- [34] McMahan RD, Tellez I, Sudore RL. Deconstructing the complexities of advance care planning outcomes: what do we know and where do we go? A scoping review. *J Am Geriatr Soc* Jan 2021;69(1):234–44. <https://doi.org/10.1111/jgs.16801>.
- [35] Bakke BM, Feuz MA, McMahan RD, et al. Surrogate decision makers need better preparation for their role: advice from experienced surrogates. *J Palliat Med* Jun 2022;25(6):857–63. <https://doi.org/10.1089/jpm.2021.0283>.
- [36] Bernard C, Tan A, Slaven M, Elston D, Heyland DK, Howard M. Exploring patient-reported barriers to advance care planning in family practice. *BMC Fam Pract* May 25 2020;21(1):94. <https://doi.org/10.1186/s12875-020-01167-0>.
- [37] Krawczyk M, Gallagher R. Communicating prognostic uncertainty in potential end-of-life contexts: experiences of family members. *BMC Palliat Care* Jul 12 2016;15: 59. <https://doi.org/10.1186/s12904-016-0133-4>.
- [38] Heyland DK, Barwich D, Pichora D, et al. Failure to engage hospitalized elderly patients and their families in advance care planning. *JAMA Intern Med* May 2013; 173(9):778–87. <https://doi.org/10.1001/jamainternmed.2013.180>.
- [39] Rosa WE, Izumi S, Sullivan DR, et al. Advance care planning in serious illness: a narrative review. *J Pain Symptom Manage* Jan 2023;65(1):e63–78. <https://doi.org/10.1016/j.jpainsymman.2022.08.012>.
- [40] ACP Decisions. *The Crucial Role of Primary Palliative Care in Healthcare*. Nous Foundation. [https://doi.org/10.1007/s13311-021-01171-x](https://www.acpdecisions.org/the-crucial-role-of-primary-palliative-care-in-healthcare/#:~:text=Specialty%20palliative%20care%20that%20occurs,patients%20living%20with%20serious%20illness; November 15, 2023</a>.</p>
<p>[41] Weisbrod N. Primary palliative care in Dementia. <i>Neurotherapeutics</i>. Jan 2022;19(1):143–51. <a href=).
- [42] Elwyn G, Frosch D, Thomson R, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* Oct 2012;27(10):1361–7. <https://doi.org/10.1007/s11606-012-2077-6>.
- [43] MacKay DG, Shafto M, Taylor JK, Marian DE, Abrams L, Dyer JR. Relations between emotion, memory, and attention: evidence from taboo stroop, lexical decision, and immediate memory tasks. *Mem Cognit* Apr 2004;32(3):474–88. <https://doi.org/10.3758/bf03195840>.
- [44] Johnston E, Olson L. *The feeling brain: The biology and psychology of emotions*. WW Norton & Company; 2015.