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Front-line hospice staff perceptions of barriers and opportunities to discussing advance care planning with hospice patients and their families

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Abstract

Objectives—To understand the facilitators and barriers to hospice staff engagement of patients and surrogates in advance care planning (ACP) conversations.

Design—Qualitative study conducted with purposive sampling and semi-structured interviews using ATLAS.ti software to assist with template analysis.

Settings and participants—Participants included 51 hospice professionals (31 clinicians, 13 leaders, and 7 quality improvement administrators) from four geographically-distinct non-profit U.S. hospices serving over 2,700 people.

Measures—Interview domains were derived from the implementation science framework of Capability, Opportunity, Motivation, and Behavior (COM-B), with additional questions soliciting recommendations for behavior change. Differences in themes were reconciled by consensus. The facilitator, barrier, and recommendation themes were organized within the COM-B framework.

Results—*Capability* was facilitated by interdisciplinary teamwork and specified clinical staff roles and inhibited by lack of self-perceived skill in engaging in ACP conversations. *Opportunities* for ACP occurred during admission to hospice, acute changes, or deterioration in patient

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condition. *Opportunity-related* environmental barriers included time constraints such as short patient stay in hospice and workload expectations that prevented clinicians from spending more time with patients and families. *Motivation* to discuss ACP was facilitated by the employee's goal of providing personalized, patient-centered care. Implicit assumptions about patients and families' preferences reduced staff's *motivation* to engage in ACP. Hospice staff made recommendations to improve ACP discussions, including training and modeling practice sessions, earlier introduction of ACP concepts by clinicians in pre-hospice settings, and increasing workforce diversity to reflect the patient populations the organizations want to reach and cultural competency.

Conclusions and implications—Even hospice staff can be uncomfortable discussing death and dying. Yet staff were able to identify what worked well. Solutions to increase behavior of ACP engagement included staff training and modeling practice sessions, introducing ACP prior to hospice, and increasing workforce diversity to improve cultural competency.

Brief summary:

The primary contributions of our paper is documenting that barriers and facilitators to ACP engagement exist even in hospice. Our results identify teachable factors that could be implemented in other hospice organizations and further improve hospice ACP.

Keywords

Advance care planning; qualitative research; Health workforce; behavior change; implementation

Advance care planning (ACP) involves more than a completed advance directive or a code status/life-sustaining treatment order. ACP is a process that supports patients in understanding and sharing their personal values, life goals, and preferences regarding future medical care through iterative discussions revisited regularly at any age or stage of life. Given that hospice organizations care for people nearing end-of-life, it may seem reasonable to assume that hospice staff and organizations are experts at ACP conversations and have the essential skills and knowledge to engage effectively in ACP. Yet, little research describes staff perceptions of how ACP conversations actually occur in hospice. Existing literature has examined facilitators and barriers to ACP conversations in the context of admissions to nursing home or hospital, and in the context of serious illness such as heart failure or end-stage liver disease, ^{2–4} but not in hospice itself. We need to understand how ACP conversations occur in hospice in order to ensure goal-concordant care for patients at the end-of-life, and to identify opportunities for improvement.

Improving ACP engagement depends on behavior change. Thus, behavior change interventions are needed to increase and promote best practices. The COM-B model provides an overarching framework to identify facilitators/barriers that could be translated into behavior change interventions. COM-B includes three interacting components, Capability, Opportunity, and Motivation, to understand Behavior. *Capability* represents the individual's psychological or physical capacity (e.g. knowledge or skills) to engage in a behavior. *Opportunities* include factors in the physical and social environment that prompt or make the behavior possible. *Motivation* reflects the way an individual is energized to engage in a specific behavior, including emotional responses, habitual or decision-making

processes, and goals or beliefs. COM-B provides a lens through which to understand facilitators and barriers to engagement in ACP conversations and to identify targets for increasing engagement⁶ (i.e. behavior change).

Therefore, we designed a qualitative study to understand hospice clinician attitudes toward and practices of ACP in order to identify facilitators and barriers to ACP at time of admission to hospice and opportunities for improvement. This study addresses two research questions: How do hospice professionals identify facilitators and barriers to engaging hospice enrollees and families in ACP? What opportunities improve engagement in ACP conversations?

Methods

Design

This qualitative study was designed to address research questions involving staff attitudes and practices of ACP engagement in community-based hospice organizations^{7,8} See Appendix for additional information. Our Institutional Review Board determined the study to be exempt.

Settings and participants

Eligible sites included geographically diverse non-profit community-based hospices affiliated with the Palliative Care Research Cooperative (PCRC). Participants were purposively recruited from the hospice organizations and included hospice employees from various organizational roles and training backgrounds (interdisciplinary clinicians, executive leadership, quality improvement (QI) administrators).⁷

Measures

In-depth, face-to-face interviews were conducted by an experienced qualitative researcher (KH). All participants provided verbal consent. Interview domains drew from the Theory of Domains Framework⁹ and associated COM-B model^{5,10} to understand stakeholder perspectives. Semi-structured interview questions addressed: 1) capability, opportunity, and motivation to facilitate end-of-life care conversations; and 2) professional recommendations about opportunities to improve end-of-life care and conversations (see Appendix for interview framework).

Data analysis

Interviews were professionally transcribed and deidentified. Four authors (AO, NT, KM, KH) read the dataset in its entirety. NT and KM created within-site analytic summaries and AO created cross-site matrices. ¹¹ Data were interrogated using template analysis, a combination of deductive and inductive coding that allows for further adaptation and refinement of theory across different clinical contexts. ^{12,13} KH/NT/KM deductively coded ACP practices and attitudes, while AO/KH deductively coded Capability, Opportunity and Motivation (both 10% double-coded). AO/KH then used inductive (open) coding to identify emerging subcategories within the COM-B framework when the subcategory did not fit the data (e.g. participants discussed physical capabilities of learned skills rather than

physical strength or stamina). Other team members (TA/CR/RS) helped adjudicate coding discrepancies and refined subthemes. Differences were reconciled by discussion.

Results

Seventy-one staff members were recruited across four sites; 51 agreed to particípate. All sites had free-standing inpatient units, accepted full-code patients, and procedures to document patient/family preferences. Participants were evenly spread across sites, including 31 clinicians (48% nurses, 35% social workers (SW), 6% chaplains, 10% physicians), 13 leaders, and 7 QI administrators. Most participants were female and white; 12% of participants were people of color, 20% were male.⁷

When asked to define ACP, 53% (n=27) of the participants defined ACP narrowly, including only completion of documentation or orders such as advance directives, proxy directive, or code status. The remainder defined ACP broadly as any conversation involving immediate or long-term goals of care (GOC), values, plans, or preferences. GOC conversations are only one aspect of ACP, yet these GOC conversations commonly co-occurred with ACP at hospice admission; many participants conflated the two terms. We have retained use of GOC in their quotes. Quotes included in this manuscript are identified by site, participant number, participant type, and credentials, e.g. s4_p44_clinician_MD. We present a summary of key findings regarding hospice and staff perspectives on facilitators and barriers to engaging patients and families in ACP (Figure 1) related to Capability, Opportunity, and Motivation (Table 1, 2) as well as staff recommendations for improvements to previously-identified barriers (Table 3).

Capability

Capability for ACP engagement was facilitated by the interdisciplinary team and staff roles—Hospice staff noted "the team approach, that getting everybody on the same page at the same time" facilitated ACP engagement (increased capability) through the combination of multiple disciplinary backgrounds and abilities (s4_p44_clinican_MD). If one team member was not able to discuss values, fears, and concerns with the patient/family, another team member (i.e. "patient-whisperer") who felt more comfortable could step in and help: "the SW helps to get the conversation going, and then, ... if it's a really complex issue, we'll have our physician go out"(s2_p29_leader_RN). Inclusion of other team members allowed for well-tailored and compassionate conversations.

Participants discussed how different disciplines contributed in different ways to ACP engagement. Nurses and physicians most commonly discussed code status and the need to complete documents such as Physician Orders for Life-Sustaining Treatment. SWs performed case assessments, "owned the advance directives", and were critical in managing unfinished ACP forms and getting copies uploaded to the electronic medical record (EMR) (s4_p42_leader_MD). Chaplains were essential in assisting with funerary arrangements. For example, one nurse described the interdisciplinary team (IDT) as follows:

"There's many facets of the IDT team. There's nursing, doctor, social work, chaplaincy, volunteers....if it's an advance directive or a GOC question, the doctor

or the nurse is gonna tackle it from one end and the other interdepartmental team members are gonna tackle it from another end ... You can tackle that from many different aspects of the team to get somebody to understand it better." (\$1_p19_clinician_nurse)

Personal discomfort in discussing end-of-life reduced capability for ACP—

At all four sites, clinicians identified obstacles to *capability*, including perceived- and personally-experienced discomfort in discussing death and ACP. Participants attributed discomfort to lack of confidence or skill as *"some clinicians do not understand what advance directives are"* (s3_p9_clinician_SW). As one nurse leader shared, ACP is a skill that requires "experience" and "mindfulness," and that can pose challenges with caseload requirements:

"The barriers for staff is just really having the tools to have the meaningful Deep conversations that come with experience or training. And the willingness to be in the struggle. We can have great clinicians that are very adept technically and are efficient. Do they really engage? Really with presence? ... Our clinicians who are willing to be slower and grieve with people and do the wisdom work aren't so good technically or technologically and their pace is really slow. And then they can't carry the caseload requirements.... What we're asking hospice and palliative care clinicians to do is really nuanced difficult work." (s4_p41_leader_RN)

Opportunity

Activating elements in the physical environment—Participants noted that admission to hospice and unanticipated acute events, such as intercurrent hospitalizations, provided the main *opportunities* to initiate and revisit ACP conversations. On hospice admission, staff in all four sites assessed whether advance directives were available and flagged patients who were full-code, requested "aggressive" interventions, and had conflicting perspectives on ACP preferences with family members: "we usually ask the questions, but if the questions get pushed to the side and the subject change[d], then we put that in our summary" (s1_p19_clinician_nurse). Staff discussed these patients at IDT meetings and revisited ACP at any available opportunity.

Structural reminders, such as the Hospice Item Set questions, facilitated ACP conversations by requiring documentation of assessment of preferences or not. As one nurse leader stated, the structured questions "force people to address things that need to be addressed, so I see it only helping our quality, not hurting us" (s2_p29_leader_RN).

Environmental constraints included time restrictions and patient/family characteristics—Most staff remarked on how time constraints for both patients (e.g. length of time in hospice) and clinicians (e.g. time needed to have meaningful conversations) reduced *opportunities* to engage in ACP. Referrals to hospice close to the time of death shortened the time available for engagement in meaningful ACP conversations making "...it so hard to get all of that information and act on it, when they're on for a very short period of time" (s2_p27_leader_MD).

Workload-related time constraints for clinicians required prioritization of ACP versus seeing other patients with urgent and distressing symptoms. Additional physical and social environmental factors that made ACP conversations difficult for staff included serving young patients, reliance on family members as interpreters, or conflicts between patient and family members regarding treatment preferences "because they wanna talk to their loved one but also want them to have pain control and the two can conflict at times" (s2_p39_clinician_RN).

Motivation

Top motivator for ACP conversations was strong desire for personalized, patient-centered care—One SW summarized the importance of whole person-focused conversations as follows:

"Not only are they the physical and medical GOC, but they're also the emotional/ spiritual, what feeds their soul GOC, and that's important to know. That's the foundation of hospice work: their individualized GOC and making them know that we embrace that and we will follow that." (s3_p9_clinician_SW)

Preconceptions that lowered staff motivations for ACP—Several staff acknowledged that once they were familiar with a patient or families' preference, they revisited ACP less often. A QI administrator commented that problems arose when clinicians lost the *motivation* to read other IDT team members' EMR notes:

"...there were so many issues about people not reading the EMR, just focusing in on entering into that system what they had from this visit and not really referring back to, "Well, yeah, but I know that patient, so this is baseline for them." "Did you look at what the SW wrote yesterday and how—what they said yesterday compared to--?" "No, I know this patient".... "The more you get familiar with your own caseload, the less you look at a chart. I mean it's wrong. It's wrong. It's dangerously wrong, but it is the reality." (\$3_p5_QI_NP)

Challenges for long-time hospice staff adjusting to implementation of and changes in EMR also lowered staff *motivation* for ACP engagement.

Although our original question asked only for the identification of patterns seen amongst patients and families who did not want to engage in ACP, we found participants at each site who responded with racialized, ethnic, and religious stereotypes that marked certain groups as "difficult" and reduced clinician *motivation* to engage those families in ACP. Several clinicians generalized that certain groups "do everything till the end." One physician spoke of a "fear of saying the H-word" out of beliefs that it might hasten death, and a nurse asserted that the meaning of the word "hospice" changed in translation to another language. The additional time required to communicate with non-English-speaking patients and families was perceived by several as inconvenient. One leader stated utilizing interpreters "complicated the process" and observed that interpreters were not always available. But these assumptions were also questioned by other participants, such as a SW who described how what she saw and experienced with families was different from what she had been taught to believe.

Behavior-change recommendations

We asked participants for specific recommendations from their organizations and linked these recommendations to previously identified barriers (Table 3).

To facilitate *capability*, staff members at three sites emphasized orientation and training sessions led by specialists or experts to increase "skills" and modelling practice sessions that used role-play to apply skills and increase clinician comfort. One nurse explained: "You learn by watching someone do it really well. So we do a lot of... observing, and then the tables turn, where you're the talker and someone else is observing, and then that person can then debrief after." (s2_p36_clinician_RN)

With regards to *opportunity-related* barriers of time constraints, participants advocated for guidelines or mandates for ACP conversations at any healthcare encounter. They highlighted the importance of engaging clinicians and administrators in pre-hospice locations and not "passing the buck" (s4_p32_clinician_MD).

Clinician *motivation* to engage patients and families in ACP decreased due to preconceptions and assumptions of preferences. In response to barriers related to lack of knowledge of cultural, racial, and ethnic norms and backgrounds, leadership at one site recommended increasing workforce diversity to reflect the patient populations the organization wanted to reach and to cultivate cultural humility. This site utilized community health workers and "culturally-based liaisons" in order to reach communities. Leadership at this site also provided to staff trainings and education "so that we're able to understand what death and dying is to [different] cultures" in order to increase cultural humility, create empathy, and increase understanding of people's life stories as way to increase ACP engagement (s2_p29_leader_RN).

Discussion

In this study, hospice staff identified facilitators and barriers to discussing ACP with patients and families. The presence of multiple team members and variety of clinical roles mitigated clinician discomfort in engaging patients and families in ACP conversations (capability). Activating events such as admission to hospice and major changes in patient condition provided opportunities while patient- and clinician-associated time constraints limited opportunities. Personal commitment to providing patient-centered care was a key motivator. Yet, assumptions about a patient or families' preferences reduced staffs ability and *motivation* to engage patients and families in ACP. This novel study makes explicit the implicit, providing insight into hospice staff perceptions of the structure and content of ACP conversations and the broader factors that facilitate or hinder engagement. It builds on our prior work describing hospice staff perspectives on caring for people with dementia, discussing ethical dilemmas related to caring for people with preferences for full code and aggressive treatments, and measuring ACP quality. 7,8,14 Here, we highlight staff-identified practice elements that facilitated high-quality ACP conversations and goal-aligned care as well as opportunities to improve. These data, coupled with participant recommendations, can provide targets for future interventions aiming to further improve hospice ACP.

Knowing patient and family values is central to the hospice staffs work and aligns with the core mission of hospice. ¹⁵ Yet more than half of the staff in our study defined ACP narrowly as completion of documents and orders, which reflects the wide range of ACP definitions in the field. A Delphi panel of multidisciplinary, international ACP experts only developed a consensus definition of ACP in 2017, which focuses on the iterative process that supports people's understanding and sharing of their personal values, life goals, and preferences. ¹ Our results suggest discrepancies exist within hospice organizations on whether to focus on advance directives versus conversations and more education about the evolving and broadening field of ACP may be needed.

Even in hospice, clinicians expressed discomfort in discussing death and GOC. Behavior change recommendations to increase clinician comfort included trainings to increase "skills" and modelling practice sessions that used role-play to apply these skills. Outside of hospice, similar trainings have been developed around teaching ACP conversations including the Vital Talk curriculum, Education in Palliative and End-Of-Life Care program, and trainings from the End-Of-Life Nursing Education Consortium and Center to Advance Palliative Care. ^{16–19} Clinicians in pre-hospice settings may benefit from behavior change training in ACP engagement in order to increase opportunities for meaningful ACP conversations. ²⁰ Clinician involvement in pre-hospice settings is necessary if we are to address the fact that median hospice enrollment was 18 days in 2018 compared to 6-month enrollment eligibility. ¹⁵

Additional barriers to ACP conversations occurred when clinicians fell back on defaults: (1) assumptions that may not be consistent with evolving patient/caregiver ACP preferences and (2) implicit bias based on racialized or stereotyped assumptions. A handful of participants used stereotypes that mirrored some of the problematic ways in which health inequities have been blamed on socioeconomic, religious, racialized²¹, and cultural groups rather than on structural drivers of disparities.²² This stereotyping is concerning as it compartmentalizes diverse cultural, racial, and ethnic backgrounds and may inhibit trust with diverse groups of patients and families already at increased risk to receive lower quality health care.^{23,24}

A substantial majority (82% in 2018) of hospice patients are white¹⁵, which reflected the race/ethnic characteristics of our staff participants (88% white). Our participants recognized a need to diversify the hospice workforce to better reflect the racial and ethnic makeup of the U.S. and suggested diversity, equity, and inclusion training to confront stereotypes and bias.^{25,26} Explicitly acknowledging the role that racism (institutionalized, internalized, interpersonal²⁷) and other stereotypes about nationality, religion, and income has on the patients' and families' experience over their lifetimes and cultivating cultural competence would improve hospice) care.^{28,29} Acquaviva and colleagues recommend conducting a thorough family and social history that includes questions about cultural beliefs and practices, geographic ancestry, physical environment, and emphasizes the need for inclusive language.^{30,31}

Limitations included recruitment from hospices that were committed to palliative care research (through PCRC) and limited geographic locations. Staff recommendations drawn

from participating practices may be difficult to implement in hospices with fewer resources or may differ from the priorities of for-profit hospices.

Conclusions and implications

Systemic barriers to ACP still remain in hospice; even hospice staff can be uncomfortable discussing death and dying. Hospice workers identified factors to inform ACP-related behavior change interventions, including interdisciplinary teamwork, training/practice sessions, workforce diversity, and individual commitment to patient-centered care. These practice elements provide targets for intervention, as do identified barriers: lack of training in ACP engagement and implicit bias, lack of diversity among hospice staff, and lack of adequate time to do the "wisdom work" of ACP. Integration of evidence-based training programs, formal diversity, equity and inclusion training with accompanying recruitment of diverse clinicians are appropriate next steps toward ensuring that hospice adequately engages in ACP at the end-of-life.

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Appendix

Appendix

Appendix.

Methodologic orientation and theory	The overarching qualitative, multi-site study ³² was based on a subtle realist epistemology. ^{33,34} The study design is based on the social science case study approach, ^{35,36} appropriate for a study focused on a particular issue or concern (the process of determining and enacting preferences for end-of-life care) in the context of a purposively chosen, clearly identifiable and bounded case used to illustrate the issue (hospice organizations). ³⁷ Within the case study approach, qualitative methods were selected as appropriate for exploratory and descriptive research questions related to processes and 'how' and 'why' questions not previously addressed in the literature. No data previously existed on hospice staff members' perceptions of the practice or measurement of the process of determining and enacting preferences for end-of-life care, making it essential to use a flexible methodology for the formative research.
Interview guide	The interview guide used the Theory of Domains Framework ³⁸ (which is also the basis for the COM-B framework) to investigate hospice staff member attitudes and practices of ACP (as individuals or on behalf of the organization), as well as perception of factors relevant to behavior change. The guide was reviewed and refined in consultation with Palliative Care

	Research Cooperative (PCRC, https://palliativecareresearch.org/) methods experts and a community advisory group which consisted of 7 individuals within a local non-participating hospice who were clinicians, quality improvement administrators, executive leaders, and volunteers who were formerly caregivers. Copies of the interview guide were provided in advance for two study participants upon request (provided below). In conjunction with the interview, participants were asked to share either internal or external documents relevant to the study. Examples of documents included brochures about dementia-specific care available by the front desk; materials carried by clinicians to aid discussions about preferences or advance care planning, such as Respecting Choices or POLST forms; a redacted patient chart printed out; copies of quality improvement projects related to ACP; or copies of quality measure dashboard results.
Qualitative interview guide used for this study	1. Tell me about the discussions you have with referred or newly admitted patient and/or family seeking care from the hospice organization about preferences for care. What are you specifically referring to (e.g. advanced care planning [ACP] vs. goals of care [GOC] conversations? How does the ACP/GOC discussion affect the plan of care? How often do you revisit the conversations about preferences with patients and families? Do you know what is in the ACP documents for all your patients? 2. How often do admissions to hospice already have ACP discussion or forms completed? 3. How do you/members of your organization communicate the results of the ACP/GOC discussion to other team members? How formal or informal is the communication? 4. What are the barriers to full discussions of ACP/GOC? i. Are barriers for patients due to capability, opportunity, or motivation? iii. Barriers for families due to capability, opportunity, or motivation? 5. What patterns do you see among patients and families that do not want to engage in ACP or where conflicts occur around ACP? Due to age or prognosis, symptoms, cognitive impairment, setting of care (home care vs. facility vs. inpatient), type of caregiver (spouse vs. parent vs. child), socioeconomic, race, ethnicity, or culture? 6. What currently works well in your team or organization's practice of asking patients and families about ACP/GOC? 7. What could your team or organization do differently to improve ACP/GOC discussions with patients and families? 8. How does the organization monitor the presence, quality, or frequency of GOC/advance directives [AD] discussions? What are the barriers to monitoring GOC/AD across the patient population (capability, opportunity, motivation)? What could be done differently or better about how your organization measures GOC/AD? 9. Describe what happens when the patient/family preferences do not align with the hospice philosophy?
Field notes	Hand written field notes were made during the interview (recording key details and questions to return to) as well as after the interview (including reflections on what went well or poorly, the interviewer's emotional and physical state that may have influenced data collection, or environmental factors influencing the interview (e.g. interrupting phone call, thunderstorm); additional topics that the participant discussed after the recording was ended; questions to ask other participants or probes to consider adding to the interview guide; and analytic thoughts about new topics, common topics arising within participants at that site or across sites, or comparisons by type of participant or site). All field notes were created in a de-identified way using participant ID keys only. Overarching notes were also created at the beginning and end of each site visit.
Data saturation	Data saturation on broad themes (e.g. process of engaging hospice enrollees in discussion of preferences, documenting preferences, measuring discussions and documentation) was reached at all sites. Saturation by participant type (e.g. leader, clinician, administrator) within or across sites was not attempted.
Description of the coding tree	For the overarching study, deductive primary codes included:

	context of the site (secondary codes: site context, hospice admission process, pre-hospice discussion or documentation of end-of-life care preferences, state policy, changes over time); practice of engaging enrollees/proxies in discussion of end-of-life care preferences (inductive secondary codes: practices generally, good practices, team roles, team communication, training, documentation, materials/forms, and implementing stated preferences); measurement (inductive secondary codes: quality assessment generally, quality measures, quality improvement); attitudes, opinions and beliefs (inductive secondary codes: stakeholder opinion, perception of patient/family perspectives, recommendations, connotations of advance care planning, perceptions of importance of discussion of end-of-life care preferences; tensions between patient, family or clinician preferences) emergent cross-cutting themes (inductive secondary codes: facilitators/barriers, policy-relevant topics, aggressive care or full code; dementia).
Derivation of themes	Primary codes and some secondary codes for the overarching study were deductively derived from the research question and interview guide. The majority of the secondary or tertiary codes inductively derived from the data. This process was repeated with the entire interdisciplinary author team.

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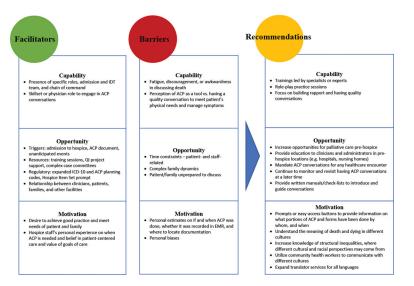


Figure 1. Summary of COM-B model applied to identifying facilitators, barriers, and recommendations to advance care planning discussion with hospice patients and families from front-life staff perspectives

Capability was facilitated by interdisciplinary teamwork and specified clinical staff roles and inhibited by lack of self-perceived skill in engaging in ACP conversations. Hospice staff recommended trainings and modeling practice sessions to improve staff capability for ACP. Opportunities for ACP occurred during admission to hospice, acute changes, or deterioration in patient condition. Opportunity-related environmental barriers included time constraints such as short patient stay in hospice and workload expectations that prevented clinicians from spending more time with patients and families. Hospice staff recommended introducing ACP concepts earlier in pre-hospice settings. Motivation to discuss ACP was facilitated by the employee's goal of providing personalized, patient-centered care. Implicit assumptions about patients and families' preferences reduced staffs motivation to engage in ACP. Hospice staff recommended increasing workforce diversity to reflect the patient populations the organizations want to reach and cultural competency.

Table 1.

Themes and quotes reflecting facilitators on capability, opportunity, and motivations in engaging patients and families in ACP conversations from hospice staff perspectives

Oh et al.

Theme	Illustrative quote or example
CAPABILITY FACILITATOR	
Presence of specific roles and interdisciplinary care and chain of command: admission team, nurse, SW, chaplain, physician	"I think the other part is I wouldn't know how to really elicit well a spiritual care—goals of care. So am I able to delve in and figure that out? No, not as well as a spiritual care counselor can. And the same thing, you know, the social worker isn't going to be able to establish the medical goals of care as well as a nurse or a doctor can." (Site 3, Physician leader, male, [s3_p1_leader_MD)
Physician role or clinicians with unusually good ability or skill to explore fears, discuss values	'Now, do I think that there is a lynchpin person who could open the conversation? The doctor. If the doctor had the hutzpah, if the doctor had the comfort, if the doctor had the farencial incentives to do so that could probably make all of the difference because or unsets, social workers, chaplains, we might be able to get in a side dorn. But the front door of these conversations really is the physician." (Site 4, Nurse leader, female [s4_p4_] Leader_RNI) 'I don't think you need to be a worked with social physician to have these conversations. I've worked with social workers, nurses, chaplains that are just as skilled as I am. I think sometimes you need the MD blessing on it." (Site 2, Physician clinician, male, [s2-p32-clinician-MD])
OPPORTUNITY FACILITATOR	
Triggers – admission to hospice: hospice eligibility determination, required screening and forms prior to admission (lack of advanced directive, full-code status)	"—staring at admissionif a patient comes on and, say they are full code, the social worker really makes a visit very quickly out there with the nurse to start the discussion. We're not force-feeding it but we have to have the discussion with the family. And they say, 'I'm just not ready for that,' then that's fine. We have to respect it, but we do need to revisit it." (Site 2, Nurse leader, female [s2-p29-leader-RN])
Availability of ACP document	"when an individual has advanced directives and you see dissention in family and that you can go back to that document and say."Your mom or your dad gave you the greatest gift when they did these documents so you wouldn't have to carry the burden of making these decisions." And when you frame it that way it kind of changes the whole context of the conversation. They still may not be comfortable, but they realize the greatest gift that they can give to their parent or loved one is honoring those wishes." (Site 3, RN, female [S3_p6_clinician_RN])
Triggers – unanticipated acute events, e.g. infections or falls	"Honestly, though, I think we're more reactive. I think as a society we're more reactive. And I think when people are pushed and busy we're more reactive. And I think when people don't want to deal with it we're just going to say, " we're just going to wait until it comes up. We're going to wait until somebody starts bleeding out and then we have to deal with it." (Site 4, Nurse leader, female [s4_p41_leader_n1])
Resources – training sessions	" as part of the education they get at orientationwe came up with some scenarios, and then we try to use volunteers to act as patients and families. And then we're just showing different people's approaches to having the advanced care planning kind of conversations you can lecture people, but sometimes to have them have the opportunity to see it could they shadow some of us that do it all the time?" (Site 2, Physician leader, female, [s2_p27_leader_MD])
Resources – committees to address complex cases and programs to initiate ACP conversations earlier for certain disease processes	"I'm noticing a lot more of what they call bridge programs. So while they're not hospice patients, they're getting quality care and maybe having some palliative radiation, say, for a tumor that's pressed against the spine and the radiation reduces the tumor size and they have better pain control because of that" (Site 3, RN clinician, [82-p39-clinician-RN])
Regulatory – Expanded ICD-10 codes and ACP planning codes	"You can pretty much ICD-10 anything previously I would not have thought that major depression would have been a terminal diagnosis, we were able to say it actually was. This person had had a traumatic event where their husband had committed suicide in front of them and they had some other traumatic

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Theme	Illustrative quote or example
now reimburse for non-hospice and primary care providers, though may be underutilized and not completely understood	experiences. And so over the course of years, it had debilitated to a point where they were bed bound and like 50 pounds so they were hospice appropriate. It wouldn't have been a traditional diagnosis that we would have used previously." (Site 1, Leader, female [s1_p17_leader])
Regulatory – Hospice Item Set prompt, detailed discussions and improves overall quality	"I use all of what we have to offer [Hospice Item Set measures] in different scenarios. Sometimes, what we have online for symptom management; a great tool. It helps me when I'm under the gun, when there's exacerbation of symptoms, to have a reference to check I definitely think the tools work well." (Site 3, RN clinician, male, [s2-p39-clinician-RN])
Relationships between clinicians and patient/families - staff's ability to assess patient/family readiness and openness and recall patient's wishes	"the son has never wanted to do advanced directives, so after this conversation he made it quite clear to the social worker "These conversations need to stop," but we kept it as a problem because it was still not addressed. So we review it every now and then with not much luck, and then just lately, actually two weeks ago, the doctor did a joint visit with the nurse the son said afterward "I didn't know my mother felt that way." And so a DNR has been signed, and he's actively pursuing filling out advanced directives a year and a half later." (Site 3, SW, female, [S3_p9_clinician_SW])
Relationships with other facilities and processes of sharing forms and warm hand-offs	"it starts on the referral, and it depends on where the referral's coming from. So if they're in the hospital we have a liaison that works in the hospital. and she has a goals of care conversation with them, and it helps kind of determine a lot of those next steps. And so we're fortunate in that that if we are getting a hospice referral that we have someone who can go and have that conversation, and there's also a palliative team that's working there too that can have those conversations, and if needed they can work together for those hand-offs as well." (Site 1, Leader, female [s1_p17_leader])
MOTIVATION FACILITATOR	
Desire to achieve ideal good practices through education for staff, planning, quality improvement cycles	"On any given day I have between five and nine staff members in the field and I really ask for five things first and foremost, obviously determining hospice eligibility, second of all, a good goals of care conversation, third is advance directives, fourth is medications and fifth is DME I'm trying to build a best practices so we are in the midst of that where basically I do a two hour staff meeting once a month and the last 30 minutes has been really talking about our conversation and talking about how we introduce our conversation We also spend a couple of weeks on prep and how we prepare for our cases. So it's going to be about an 8 to 12 month project of really having these great conversations with my staff, building best practices and then it will be something that actually we'll use in on-boarding and everything." (Site 4, RN, male, [84_p40_clinician_RN])
Hospice employee's personal experience where ACP was needed and belief in (i) wanting to see more DNRs at home and (ii) earlier ACP conversations	"I think hospice will always it seems have a vested interest in wanting to see DNRs in homes, and I know that that is a statement that might be a little controversial, because we're not supposed to probably have much of an opinion on that. Our goal is to never sway someone, but I think that we would always hope knowing that this person is going to take a last breath with us that they would not want CPR performed, but again if it is their wish to do so we will honor that wish too." (Site 1, QI administrator, SW, female)
Belief in value of goals of care and patient-centered care	"the care plan in hospice is one of the most brilliantly devised tools ever in healthcare It first exists with the belief that you have a peer professional or an interdisciplinary team of people that are looking at people as a holistic human beingthat care plan should never be cookie cutter. It should truly come from the perspective of what matters most. What is most important to that patient and family and, of course, advance care directives or advance care planning are one of those tools to engage in those sorts of conversations" (Non-clinician leader)
Reflexes in response to family (e.g. letting family guide the goals of care conversations)	"Most people by the time they get to us are, I mean, and I think respectfully, we kind of let them be the guide. You know, I always say, you know, we don't go anywhere we're not invited you know, knowing how to open the door a little bit and then if they don't open a little bit on their side, then I'm not gonna keep trying to open itAnd just kind of being respectful of that." (Site 1, SW clinician, female [s1_p23_clinician_sw])

Table 2.

Themes and quotes reflecting barriers on capability, opportunity, and motivations in engaging patients and families in ACP conversations from hospice staff perspectives

Oh et al.

Theme	Illustrative quote or example
CAPABILITY BARRIER	
Lack of skillset to engage in ACP conversations	"I think barriers for the clinicians here is some of the newer staff, you know, it's a "learned skill" is what I call it, to have that conversation. So think that the newer you are to hospice, the harder it is for you to have it, but it gets easier the lot more you do it. I still think, again, the biggest barriers are people don't want to talk about the fact that everybody's dying." (Site 2, Physician leader, female [s2_p27_leader_MD])
Overall fatigue, discouragement, or awkwardness in discussing death	"It just feels awkward, for one. Like I could think of a social worker trying to do it and feeling like they know this is part of their job so they're trying to do it, but they don't have a lot of skill in being sensitive and going with the flow of the conversation and being able to just approach it in a sensitive way. Like I had gone on an admission visit with a nurse with an infant. And her describing, "Well, that we want a DNR because of the violence involved with the resuscitation process." And she used the word 'violence' several times with a three-day-old baby. There's better ways to describe that." (Site 4, Physician provider, male)
Perception of ACP as a checklist (e.g. Hospice Item Set) vs. having a quality conversation and meeting patient's physical needs and managing symptoms	"You have to have an intuition with that, and I think that my team does, because if you just start talking about advanced directives because it's on a checklist but the family is giving you that sign, "Stop" or "I'm not ready for this," we need to respect that and not keep going, because then you are severing the relationship. You are now causing a trust barrier with that family you may have gotten your advanced directives discussion done, but now maybe they're not quite sure whether or not hospice was the right decision, because, again, the majority of people in this society think that hospice is the death squad and if they don't know anything about hospice and you go and start talking about advanced directives and DNR you've just validated that you're the death squad You need not to make it a checking it off your list but really connecting with that family and finding out that time was important to them and then bringing up the advanced directives and then reading that reaction." (Site 3, SW, female, [83_p9_cthincian_SW])
OPPORTUNITY BARRIER	
Time constraints – patient-related	"they're diagnosed with advanced cancer and it's already widely metastatic, they don't have much time to deal with or even grasp the fact that they have cancer, much less are dying, and they're gonna die by the time they get there. They don't have much time to grieve. And it happens so quickly. And then what ends up happening is we end up, like, addressing all the physical needs and the symptom management, but then that emotional component, they still have to do that work and there's no pill for that. So that can be a big barrier if they don't have much time. The longer they have to cope with and accept, if they do accept that they re, you know, that they have a terminal illness, the better." (Site 4, RN, female, [4_p50_clinician_RN])
Time constraints – staff-related	"A barrier for clinicians is the expected case load expectations, better, faster, cheaper; doing sacred work it just doesn't make any sense. And so, I'm the one that's saying oh this is what the case load needs to be. And do it really great, have a meaningful conversation, do all of your paperwork, make sure you get it all done and do it timely same day. And at some point something's got to give." (Site 4, Nurse leader, female [s4_p41_leader_rn])
Patient and family are unprepared to discuss due to (i) young age, (ii) emotional state, and (iii) lack of appearance of serious illness	"Young parents on both parts, so families of young people, particularly their parents (are not ready to engage in ACP conversations or full discussions). You're not supposed to be caring for your50-year old mom, so that's huge." (Site 4, Physician leader, female [s4, D42 leader_md]) "Or you get the sense that you don't use the word hospice before you come in like (the family) greet you in the driveway, "Don't say hospice and we're not talking adout death and dying." Okay. And then you get the patient and they're like, "Am I dying?" But they can't say it in front of their loved ones." (Site 4, Nurse leader, female [s4, D41_leader_RN]) "So

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Theme	Illustrative quote or example
	incredibly tired of the whole thing, and they're pretty far along so they don't last long the biggest thing is they haven't been able to accept it, so where there's a still a certain amount of denial." (Site 2, Chaplain, male [s2-p37-clinician-CP)
Complex family dynamics, including conflicting perspectives on ACP and goals of care within families	"they just don't wanna talk about it I can think of one family There's seven children and they're all on a different plane There's a group of 'em that can't accept it But the person that's in charge, so to speak, that's signature's on the most and the do not resuscitate form, is a daughter and she's very much onboard. And the poor guy is just suffering and we're working very hard to overcome that." (Site 2, Chaplain, male [s2-p37-clinician-CP)
Lack of resources to serve diverse communities (e.g. reliance on family as translators)	"This is a pretty diverse area. So, we do haveit's not uncommon pretty much every day in a Hospice Item Set record to read that "Patient's son is translating. Patient speaks only Hungarian. Patient speaks only Arabic. Patient speaks only this or that." We see that almost every single day, but it's not an issue. As you know, hospice, we're required to provide a translator and one's not available." (Site 3, QI administrator, female [83_p3_QI])
MOTIVATION BARRIER	
Personal estimates and perceptions on if when ACP was done, documentation, ability to find goals of care documentation in medical record, and whether it conflicts with existing patient/family preferences	"Patient and family willingness can be a barrier. People are afraid to talk about it, or they otherwise don't want to, or they think the decision's already made. I've had any number of—especially in palitative care—patients tell me, "Well, I already have a living will," implying that, therefore, "We don't need to talk about this, because I've already done that." And, "Okay, your living will, again, doesn't help me right now." So there's some perception that, "Once I've done it, it's done, and I never have to think about it again." (Site 1, MD clinician, female, [s1_p21_clinician_MD])
Lack of comfort in discussing death and in-depth goals of care conversations	"I do think that our staff do back off a little too easily from having conversations, that as soon as there's roadblocks about, "I'm not ready to go there," they accept that as an answer because they hide and my impression is that they often hide behind, "Well, we have to meet families where they are," and don't sometimes have the urgency that they need to when sure, I can meet families wherever they are, but it is clear that we're running out of time here, and we need to press a little bit more because when we don't, we know what's going to happen." (Site 3, QI/Nurse Practitioner clinician, female [83_p3_QL_NP])
Personal biases, including perception of ACP as a tool which conflicts with (i) ability to have a conversation with the patient and family and (ii) staff's own personal ability to focus on patient's physical needs and symptom management (e.g. goals of care is a conversation)	"And that our goals are to respect to their goals and fall in line with that to the best that we can. And certainly it's very common to have people that make decisions that are not in line with our decisions or our preferences in terms of what we feel would be the better outcomeAnd regardless of what you think is the best in their best interest they're going to do it their way. So that's something that we do try to honor. And without a doubt certainly I'm sure that I project and it comes across sometimes that I disagree with their approach. But that s an ongoing learning process." (Site 4, RN, male, [s4_p43_clinician_RN])
Lack of awareness on cultural differences, difficulty engaging with non-English-speaking patients and families, and leaning on cultural stereotypes	"Hispanic families and African American families [are] just not as trusting of the medical community so the discussions are hard, there's frequently this dichotomy of what they want but what it takes to get there they don't like, so "I don't want my mom hurting, but I don't want you giving her pain medicines, because she'll be sleepy. I don't want her to have to go back to the hospital, but I certainly want her a full code, because I want to make sure you do everything," so trying to get them to understand what "do everything" means, what does that mean to you or to the family, but I would say we see that a lot." (Site 4, Physician leader, female [s4_p42_leader_MD])

Oh et al.

Table 3.

Hospice staff recommendations for behavior and intervention functions linked to COM-B model to address previously identified barriers in engaging hospice recipients and families

Barrier Themes	Recommendation for behavior change intervention or policy (definition) – example and quote
Barriers to Capability	Recommendations re: Capability
Lack of skillset to engage in ACP conversations	Training (imparting skills) – trainings led by specialists or experts "we wased our particularly our palliative-care certified physicians on staff are very good at this and using them to train our social workers and gain a level of comfort." (Site 2, Nurse leader, female [82-p34-leader-RN])
Overall fatigue, discouragement, or awkwardness in discussing death	Modelling (providing an example for people to aspire or to imitate) – using practice sessions and role-play "as part of the education they get at orientationwe came up with some scenarios, and then we try to use at orientationwe came up with some scenarios, and then we're just showing different people's approaches to having the advanced care planning kind of conversationsyou can be town ecture people, but sometimes to have them have the opportunity to see itcould they shadow some of us that do it all the time?" (Site 2, Physician leader, female,
Perception of ACP as a checklist (e.g. Hospice Item Set) vs. having a quality conversation and meeting patient's physical needs and managing symptoms	Enablement (increasing means/reducing barriers to increase capability or opportunity) – focus on building rapport and having quality conversations "I actually hink that conversation can help with advance directives. I think it's having a conversation first of all what the goals of care are can help someone to better decide about filling out a form for an advance directive. So yeah, I think it's a more meaningful place to start than just, "Please fill out this form, select if you want to be resuscitated," I don't think that's a very good way to start a conversation or I don't think it's a good way to build rapport or anything like that." (Site 4, SW, female, [84_p48_clinician_SW])
Barriers to Opportunity	Recommendations re: Opportunity
Time constraints – patient-related	Service provision (delivering a service), e.g. palliative care pre- hospice admission that encourages earlier ACP conversations "And I have that in our palliative care, they do a good job too. The social workers on that side, they do, because when our palliative care patients come to us, they've got those [documents]." (Site I, SW clinician, female [s1_p23_clinician_sw])

Page 20

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Barrier Themes	Recommendation for behavior change intervention or policy (definition) – example and quote
Time constraints – staff-related	Education (increasing knowledge or understanding), e.g. provide education to clinicians and administrators in pre-hospice locations such as hospitals and nursing homes. "I would like to see if they could get more presentations in nursing homes and hospitals. That's where we seem to struggle the most with understanding hospitals, they have their own training, probably nursing homes have their own training, but maybe they come from the aspect of how do advanced directives affect a hospice patient or a palliative care patient more so than just in general." (Site 3, Leader, female, [S3_D4_leader]) Guidelines (e.g. creating documents that recommend or mandate practice, includes all changes to service provision), e.g. mandating ACP conversations for any healthcare encounter "I don't think beautiful that want. If something should happen to me, because we just see too many people who don't have a clue, you know, had I hate that, because then I think they end up having a lot of interventions that maybe that patient didn't want. So or just knowing, But, you know, nobody's really talking about that And so I think that, to me, is just the big lack, the big gap in our healthcare right now is folks just not having those conversations." (Site 1, SW clinician, female [s1_p23_clinician_sw])
Patient and family are unprepared to discuss due to (i) young age, (ii) emotional state, and (iii) lack of appearance of serious illness	Communication/marketing (using print, electronic, telephone, or broadcast media), e.g. providing written manuals or check-lists to introduce and guide conversations "[Our company] has a really great manual that we give people at admission, a comfort and caring manual, and then unress use that and the social workers and the chaplains as a way to introduce conversations. It's broken up into a bunch of different chapters there's one on signs and symptoms of you know, the end of life which is really helpful The nurses can say, ""Well, let's look at the manual let's look at the manual let's look to start those conversations early" (Site 2, RN clinician, female, s2-p38-clinician-RN)
Complex family dynamics, including conflicting perspectives on ACP and goals of care within families	Service provision (delivering a service), e.g. IDT continues to monitor and revisits at a later time; hospice organization creates a specific committee to handle tough cases " if I were in a home and I talked with the family and they were adamant that they did not want to discuss the DNR I would typically leave it at that point, because if they're not in an okay place I'm not going to push that with them typically later on it was okay to broach that topic again, with them would keep that top of mind with that patient." (Site I, SW QI, female, [SI_PI5_QI_SW])

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Barrier Themes	Recommendation for behavior change intervention or policy (definition) - example and quote
Lack of resources to serve diverse communities (e.g. reliance on family as translators)	Environmental restructuring (changing the physical or social context), e.g. have the workforce reflect the patient populations one wants to reach we think about that strategically, of how to serve the underserved and get the diversity that we need. We need that in our workforce as well." (Site 2, RN leader, female, [s2_p29_leader_RN]) [s2_p29_leader_RN]) Enablement (increasing means/reducing barriers to increase capability or opportunity), e.g. expand translator services for all languages "there might be a language barrier and if I'm using a translator, I know in the Viennanese community if's a small community, so if I got a translator they probably know that family and it's not necessarily going to stay private. That is been my experience. So families don't always necessarily want to talk about some of those things." (Site 4, SW, female [s4_p51_clinician_SW])
Barriers to Motivation	Recommendations re: Motivation
Personal estimates and perceptions on if and when ACP was done, whether it was documented, ability to find goals of care documentation in medical record, and whether it conflicts with existing patient/family preferences	Environmental restructuring (change the physical or social context), e.g. prompts or easy-access buttons to provide information on what portions of ACP and forms have been done, by whom, and when. "I think that "I think that communication of goals of care across sites and between teams could be better. So there are times when I'm asking patients whatyou know, what's important and what they would like to have done or not done, they'll say, "Well, I just told that to somebody yesterday, don't you ever read"you know, that sort of thing, So, you know, so do people have to kind of print and you need to repeat. So I think, from my standpoint, that could be a little bit better, as far as that communication piece." (Site 3, MD leader, male, [s3_p1_leader_MD])
Lack of comfort in discussing death and in-depth goals of care conversations	Enablement (increasing means/reducing barriers to increase capability or opportunity), e.g. having clinicians "skilled" in having ACP discussion available "there's very skilled clinicians in this company. They make my job easy. They can deescalate folks and maybe they can't turn around their thoughts that day, but they can certainly educate them within the next few days into understanding what's going on." (Site 2, MD leader, female, [82_p34_leader_MD])
Personal biases, including perception of ACP as a tool which conflicts with (i) ability to have a conversation with the patient and family and (ii) staff's own personal ability to focus on patient's physical needs and symptom management (e.g. goals of care is a conversation)	Persuasion (using communication to induce positive or negative feelings or stimulate action) "contrasting the Hollywood approach of you're going to be resuscitated and everything is great versus what things what it actually looks like in practice with somecertainly there are some statistics we can provide about what the fact

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Oh et al.

Barrier Themes	Recommendation for behavior change intervention or policy (definition) – example and quote
	that a lot of people do not come back in the same condition after they've had CPR. And the potential for brain deterioration and so forth." (Site 3, QI/NP clinician, female, [83_p3_QI_NP])
Lack of awareness on cultural differences, difficulty engaging with non-English-speaking patients and families, and leaning on cultural stereotypes	Education (increasing knowledge or understanding), e.g. understand where different cultural and racial perspectives may come from, the meaning of death and dying in inequalities "vising people's stories and to reach clinicians, was extentially use that in the immersion course where we do poetry reading by A frican-Americans, and some of the issues here we reach clinicians, was extently use that in the immersion course where we do poetry reading by A frican-Americans, and some of the lives living people are exprised in the people are pressing to engage them. Because some of the livin clinicians can be luggemental in why people are pursuing, alone of the kind of treatment they be pursuing. And when you have an understanding for where people are coming from, and maybe some of the mistreament and some of the issues around institutional reachs some of the mistreament and some of that such some of that to clinicians. So we created a one-day training, two four-hour blocks for clinicians. And it incorporates a lot of that specifically for African Americans. But we have that every year for new clinicians that are coming on board. So trying to create some of that common that and are coming on board. So trying to create some of that cultural competency, where I thin kome one of the liggest issues come with advance care planning and goals of care." (Site 1, MID leader, formal [81_D24_Leader_MD]) Theadr, fromate [81_D24_Leader_MD]) The communication to induce positive or negative feelings or sfimulate action), e.g. use resources like community health workers to care as we move forward, as our census grows." (Site 2, Nurse leader, female leader, fem