Mid-Atlantic primary care providers' perception of barriers and facilitators to end-of-life conversation

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Abstract

Background: Among the chronically ill, end-of-life conversations are often delayed until emergently necessary and the quality of those conversations and subsequent decision-making become compromised by critical illness, uncertainty, and anxiety. Many patients receive treatment that they would have declined if they had a better understanding of benefits and risks. Primary care providers are ideal people to facilitate end-of-life conversations, but these conversations rarely occur in the out-patient setting.

Objective: To investigate the self-reported experiences of physicians and advanced practice nurses with conversational barriers and facilitators while leading end-of-life discussions in the primary care setting.

Design: A qualitative descriptive study.

Methods: Six physicians and eight advanced practice nurses participated in singular semi-structured interviews. Results were analyzed using a qualitative descriptive design and content analysis approach to coding.

Results: Reported barriers in descending order included resistance from patients and families, insufficient time, and insufficient understanding of prognosis and associated expectations. Reported facilitators in descending order included established trusting relationship with provider, physical and/or cognitive decline and poor prognosis; and discussion standardization per Medicare guidelines.

Conclusion: Recommendations for improving the end-of-life conversational process in the primary care setting include further research regarding end-of-life conversational facilitators within families, the improvement of patient/family education about hospice/palliative care resources and examining the feasibility of longer appointment allotment.[1]

Keywords: advance care planning, barriers and facilitators, end-of-life conversations, primary care

Introduction

End-of-life conversations are discussions about benefits, risks, and goals of medical treatment at the end-of-life and are a hallmark of informed decision-making. Primary care providers are uniquely positioned to have end-of-life conversations in the out-patient setting due to preestablished rapport and patients' relatively stable health, mentation, and emotion.[2–5] Yet, as many as 80% of outpatients aged 65 years or older deny having engaged in an end-of-life conversation with their primary care providers.[3,6,7] Advance care planning (ACP) is discussion about future medical care within the context of serious illness or incapacitation.[8] Advance care planning is useful throughout the lifespan, becomes increasingly relevant with advancing age and morbidity, and may include the completion of advance directive documents.[8,9] In the United States, advance directive documents include a durable power of

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attorney for health care and a living will.[8] These documents allow for the appointment of a surrogate medical decision-maker and the articulation of preferred medical interventions in the event of future incapacitation.[8] The involvement of primary care providers is associated with earlier ACP.[10]

Upon informed decision-making by patients and/or their families, living wills and/or Physicians Orders for Life Sustaining Treatment (POLST) forms may be completed. However, end-of-life conversations are often delayed until emergently necessary and the quality of those conversations and subsequent decision-making may become compromised by critical illness, uncertainty, and anxiety.[11,12] This can result in treatment decisions that are based on neither sound judgment nor reflective of patients' wishes.[2,13–15] Default medical care is life-saving measures and many patients receive treatment that they would have declined if they had a better understanding of benefits and risks.[15,16] Alternate care includes enrolment in Hospice, a program funded by Medicare that provides personalized, interdisciplinary, comfort-focused care during the last 6 months of life.[17] This qualitative descriptive study investigates the self-reported experiences of physicians and advanced practice registered nurses (APRNs) while leading end-of-life conversations in the primary care setting, a topic that is underrepresented in the literature.[10]

Existing literature considers end-of-life conversational barriers from the points of view of community members and stakeholders, patients, physicians, culture, and theory.[2,18–25] Many studies about ACP focus on disease-specific populations.[26] This study adds to the existing literature by focusing on primary care and examining the patient population through a diagnostically inclusive rather than disease-specific lens, providing a broader perspective. Furthermore, this study uniquely considers the perspectives of both physicians and APRNs, an increasingly utilized group whose experiences are underrepresented in this literature.

Methods
This study utilized a qualitative descriptive design with a content analysis approach to coding, permitting both the qualitative and quantitative analyses of data.[27] Numeric quantification of qualitative data provides visualization of main ideas within the dataset, with interpretation remaining close to the narrative.[28] The reporting of this study conforms to the COnsolidated criteria for REporting Qualitative research (COREQ) guideline.[29,30]

Participants and setting
Individuals were considered for inclusion in the study if they (1) were physicians or APRNs, (2) were currently practicing within a primary care practice, and (3) had conducted end-of-life conversations in the out-patient setting. Convenience sampling was used as the first author had preestablished professional relationships with the providers who served as gatekeepers for both organizations. Primary identification of potential participants was through professional affiliation with a mid-Atlantic Family Practice Residency Program faculty group and with the Delaware Valley Chapter of the Gerontological Advanced Practice Nurses' Association (GAPNA). A gatekeeper within each organization shared a study flier with other members of their organization. Verbiage on the study flier included 'You are invited to participate in a study investigating the experience of the primary care provider while conducting end-of-life conversations in the out-patient setting'. The title of the study and the primary investigator's nursing credentials were also included on the flier. Additionally, physicians and APRNs who were not members of the above groups but had heard about the study through word of mouth, initiated contact with the first author, and met inclusion criteria were also included in the study. Recruitment ended upon reaching data saturation.

Potential participants contacted the first author *via* email and interviews were either conducted electronically *via* FaceTime or in person. In-person interviews occurred privately within providers' offices during work hours or after hours at the University of Delaware. Confidentiality was maintained through de-identification of interview transcripts and storage of study materials on a password protected computer.

Data collection
A semi-structured approximately 30-min qualitative interview was conducted between 11 May 2017 and 24 May 2019 with each participant by the first author, a PhD in nursing science student. Interview questions were provided to

participants beforehand and included: (1) As a primary care provider, how would you describe your experiences with having end-of-life conversations in an out-patient setting? Are there any experiences that have particularly resonated with you? (2) Under what circumstances would you initiate an end-of-life or goal-setting conversation with your outpatients? How do you initiate the conversation? (3) Under what circumstances would you not initiate an end-of-life or goal-setting conversation with a patient who has multiple, potentially life-limiting co-morbidities? (4) In your experience, what factors do you think have facilitated the occurrence of end-of-life conversations? How and why? (5) In your experience, what factors do you think have hindered the occurrence of end-of-life conversations? How and why? Afterwards, participants were asked if there was anything else that they would like to add. Interview questions were reflective of knowledge of the literature, identification of existing gaps, and agreed upon by both authors. The interviews occurred in two phases. Piloting of the interview guide occurred while interviewing four physicians during the first phase of the study.

Interviews were audio-recorded with field notes taken *in situ*. Audio-recordings were transcribed verbatim *via* a professional transcription service. Transcription accuracy was confirmed by the first author. In addition to the interviews, participants completed a seven-question demographic questionnaire. Confidentiality was maintained through the de-identification of the participants and their affiliate institutions.

Data analysis

Data collection and analysis occurred concurrently, and no changes were made to the interview guide during this process. Results were analyzed using a qualitative descriptive design and content analysis approach to coding, permitting both the qualitative and quantitative analyses of data.[27] Numeric quantification of qualitative data provides visualization of main ideas within the data set, with interpretation remaining close to the narrative.[28,31]

Through multiple instances of careful reading, researchers independently examined the professionally transcribed interviews, recording impressions of the content, identifying emerging ideas within the content, and labeling them with code names.[27] Researchers then collectively discussed

recurrent codes, systematically grouping them by similarity and then inductively expanding them into broader themes.[32] Data were re-coded per affiliation with the identified themes and thematic amendments were made when necessitated by the emerging data. Examples of thematic amendments include an initial barrier of 'inadequate patient/family health literacy' becoming better understood as 'insufficient understanding of prognosis and associated expectations'. Additionally, initial facilitators of 'poor prognosis/ personal relevancy' and 'decline of physical and/ or cognitive wellbeing' became better understood as 'physical and/or cognitive decline and poor prognosis'. Excel spreadsheets were constructed to quantify and compare categorical occurrences. Reliability was strengthened by having two researchers code the interview data. Credibility was strengthened by prolonged engagement and persistent observation as interviews continued until data saturation was achieved.[33] Credibility was further strengthened by peer debriefing, as coding and thematic consensus was reached with the second author, an expert in qualitative research.[33] Reflexivity was through narrative autobiography and related discussion between the research team.[34]

Results

Of 14 participants ($n = 14$), 4 physicians were recruited from among the six-member Family Practice Residency Program faculty group; 5 APRNs were recruited from the approximately 1050 members of GAPNA; 2 physicians and 3 APRNs were recruited *via* word of mouth. Six participants were physicians (42.86%) and eight participants were APRNs (57.14%). Please see Table 1 for demographic data in detail.

Barriers reported in the interviews

Reported barriers in descending order included resistance from patients and families, insufficient time, and insufficient understanding of prognosis and associated expectations (Table 2).

Resistance from patients and families. Resistance from patients and families was the most frequently ($n = 10$) reported hinderance to conducting end-of-life conversations in the primary care setting. Operationally, resistance is 'a force that acts to stop the progress of [end-of-life conversation] or make it slower'.[35] Words used by the participants to describe resistance included aversion,

Table 1. Participant demographics (*N* = 14).

Characteristics	Total sample (*n* = 14)	Physicians (*n* = 6)	Advance practice nurses (*n* = 8)
	n	*n*	*n*
Gender			
Male	6	5	1
Female	8	1	7
Race			
Caucasian	12	6	6
African American	2	0	2
Religion			
Catholic	7	3	4
Protestant	4	0	4
Jewish	2	2	0
Humanist	1	1	0
Age			
30–39	1	0	1
40–49	3	2	1
50–59	6	3	3
60–69	4	1	3
Years of experience			
1–4 years	2	0	2
5–15 years	3	0	4
No answer	1	0	1
Number of patients seen weekly			
<10	1	0	1
10–30	4	3	1

avoidance, and defensiveness. Facets of patient resistance included failure to acknowledge an overall trajectory of decline that is interspersed with repeated instances of short-term recovery, maintenance of hope, and an emotional equation of hospice with acquiescence to death.

An APRN (#01) vividly described a patient whose experience illustrates difficulty in acknowledging one's own downward trajectory when prior instances of recovery are easily recalled:

> He was resistant. He didn't really want to talk about end-of-life because he has gone through a lot. I mean, he's like he's survived an accident and grew up in Maine and so he's like this warrior type. . .He just really feels invincible even at like 84 or five and the daughter was the one who can see the decline and was very, very verbal about it to me. He just keeps bouncing back. So he's like, 'Ah, I don't know. I just, I just keep going'. This is what he said. And then privately in the hallway, [the daughter] is like, 'Yeah, I know where we're headed'. He's on IV milrinone for God sake.

Throughout her interview, an APRN (#02) repeatedly spoke about the sustenance of hope, the importance of supporting patients as they fight for their lives, even if the treatments they seek have low probability for success. When describing situations in which she would not initiate end-of-life conversations, she stated:

> I think again, when the patient is not ready for it. And the family and I think that's as best as I can say it. If they are not ready and that is not an option, I would not ever initiate that conversation. When I have patients that come in and they're going through their eighth round of chemo and they're doing their stem cells and they're doing everything they can to live, I'm going to support it. So I would never say to them, 'well gosh the mortality rate is 95%. Why are you doing this?'

Participant (#002), a physician, elaborated:

> And I think the last thing is that hospice itself has a type of bad rap among people, so when you say hospice to somebody, they're like 'oh my God, you're giving up on me. You're going to put me in a coffin'. They don't understand that it's not like tomorrow. This is a conversation that, we've had people on hospice who go six months or longer and are still on hospice and are still alive, so it is an idea again. It's not necessarily, there is physician education and population education that has to happen, so it makes it harder.

Participants spoke about overt familial opposition and disinclination due to avoidance of the unacceptable (death), protection from fear and loss of hope, uncertainty about high-stakes decision-making, and reluctance to let go. Participant (#05), an APRN, described a situation in which a

discussion about end-of-life care seemed admittedly logical but was still rejected:

> . . .Yeah, avoidance. 'I'm going to get better'. So I went over and I spoke with the daughter again. 'Your mother had been in the hospital so many times. She's losing weight. She's this, she's that. We have a question that we ask ourselves. Would we be surprised in six months, a year if our patient would pass away? And if we say no, it's time to really ramp it up, try to get hospice involved'. And so I had the discussion with the daughter and she said she 'wouldn't be surprised either', but she would not. And she was the POA. She would not accept the hospice referral.

Participant (#005), a physician, described '. . . families' hesitation to bring this up or have it discussed. Out of fear of scaring the patient. We're taking away all hope for the patient'. Additionally, Participant (#003), a physician, described familial worry about not making the best decision on behalf of their loved one. To this sentiment, Participant (#07), an APRN, spoke of a son who 'wanted his dad to be comfortable, but he also wanted dad to live forever, because he wasn't ready to let go. . .'.

Insufficient time. Insufficient time as manifested by short office visits was reported as a conversational barrier by ($n = 6$) participants. Three participants elaborated that time deficit can also act as a barrier when providers and patients wait until too long into the disease process to talk, compromising the conversation with haste.

Participants were clearly frustrated upon speaking to the constraining effect of inadequate time during tightly scheduled, 15-min office visits. There was significant consistency in their statements about time constraint, describing challenges inherent to managing the complexities of comorbidity, while allowing for nuanced, unhurried discussion about prognosis and end-of-life goals.

Participant (#08), an APRN, acknowledged that 'It's probably the most frustrating part of my job. There's just not enough time'. In her interview, she repeatedly circled back to the issue of inadequate time, explaining:

> I just feel like in primary care, the time, it's just that time because 15 minutes for a patient, depending, most times it's less than 15 minutes by the time you get through. I'm not one to rush through the visit. I

do take my time because I *want* to take my time, but sometimes it's *stressful* because you know that you have to get to the next room.

The consequence of haste due to time constraint may be great. Participant (#005), a physician, clearly stated that he rarely has end-of-life conversations in the primary care setting, and the primary reason for this is time:

> Because my end-of-life discussions are few and far between and mostly that's due to time constraints. Because in general when these patients come in to see me, they have multiple, multiple complaints and I have a 15-minute visit. And to do an end-of-life discussion with a patient would at least double the amount of time in the visit.

Participant (#001), a physician, explained how conversational delay affects the intensity of patient care:

> I also think one of the hindrances is we're not, we're not. . .getting to the patients soon enough in their disease course. We're not talking about goals of care and about expectations until the very end, and I don't know if that's a barrier that's just a fact. I don't know what the barrier is in that, probably time. . .and that's the worst situation to be in, because then you end up doing more than, you probably end up doing more than the person would have wanted, if they had thought it through ahead of time.

His colleague, a physician (#002), spoke about the value of a longer, ongoing conversation and visually described an experience with delayed conversation contributing to rushed, uncertain, and high-stakes decision-making '. . . in the last minute in the ICU, trying to decide in 30 minutes what to do, whether they need to be trached or not, or whether they need a PEG tube or not'.

Insufficient understanding of prognosis and associated expectations. Insufficient understanding of prognosis and associated expectations among patients and family members was the third most reported ($n = 6$) hindrance to conducting end-of-life conversations in the primary care setting. Operationally, this is knowledge deficit. Study participants described this as manifesting as challenge within navigating complicated medical documents with limited literacy, selective hearing, poor understanding of prognosis, unrealistic

Table 2. Thematic ranking barriers and facilitators from primary care providers (*N* = 14).

Barriers			Facilitators		
Rank	Theme	Number of providers reporting theme	Rank	Theme	Number of providers reporting theme
1	Resistance from patients and families	10	1	Established trusting relationship with provider	12
2	Insufficient time	6	2	Physical and/or cognitive decline and poor prognosis	11
3	Insufficient understanding of prognosis and associated expectations	6	3	Discussion standardization per Medicare guidelines	10

expectations for treatment and/or recovery, variations of educational attainment and understanding within sibling groups, and knowledge deficit of hospice's availability and purpose.

Participant (#006), a physician, discussed how time constraint can be further complicated by limited literacy:

> . . .So the only factors that stopped me from doing this or time and sometimes it's too, I do have patients who have limited literacy and so giving them an 18-page form and the MOLST form itself is very medical-ease. . .some people just don't understand. They're not going to read an 18-page document and understand it. And so you know, I feel like for a lot of people that's a real hindrance that I just don't have the time to sit and go through the whole form with them unless I make a separate appointment to do so.

Participant (#02), an APRN, discussed how selective hearing and poor understanding of prognosis helps to create unrealistic expectations for treatment and/or recovery:

> I always think of that. Their understanding of medicine is so limited some people. . . Because a lot of them will go to their visits with their oncologist or whoever and they're in and out and they hear two things. 'We could try something else. This might help you'. That's all they hear. They don't hear. 'But we're going to have to wipe your white blood cells down to nothing. And you may die from the treatment and you may not survive

getting out of the hospital' and they don't want to hear that.

Participant (#07), an APRN, spoke about missed opportunities due to misunderstandings about hospice availability and purpose:

> I think not enough people know that they have this benefit of hospice and palliative care. Not a lot of people use it still to this day. A lot of people think it means end-of-life six months and that's the qualifier. I think that's a hindrance because we know for fact that when people go on hospice, they live longer than those six months which can get us into sticky waters, but it's a better quality of life.

Facilitators reported in the interviews
Reported facilitators in descending order included established trusting relationship with provider, physical and/or cognitive decline and poor prognosis, and discussion standardization per Medicare guidelines (Table 2).

Established trusting relationship with provider. Established trusting relationship with provider was the most frequently (*n* = 12) reported facilitator for the conduction of end-of-life conversations in the primary care setting. Operationally this is defined as preestablished rapport and dependability. Study participants spoke of the importance of trust built over time, allowing for honesty, and easing interpersonal interaction during difficult times. Participant (#001), a physician, spoke to the beneficial nature of the doctor–patient relationship in primary care:

. . .and [I] really feel that the family medicine doc is really in the best position to have the conversations, because we know the patients well, often over many years. . . knowing a patient longitudinally over time makes them feel much more comfortable talking with you about end-of-life decisions.

Participant (#006), a physician, elaborated:

If they know that I have their best interests at heart and they know that I care about them and that I'm trying to do my best to make a difficult time in life, more *reasonable* or meaningful for them I feel like that facilitates it *greatly*.

Physical and/or cognitive decline and poor prognosis. Physical and/or cognitive decline and poor prognosis was the second most often ($n = 11$) reported facilitator for end-of-life conversations in the primary care setting. Operationally, this is diminished physical and/or cognitive health and low likelihood of significant recovery. For study participants, physical and cognitive decline primarily manifested as repeated hospitalization, multiple falls, and confusion. Less frequently, it was described as caretaker burden, compromised quality of life or independence, inadequate symptom management, confinement to bed, unexplained weight loss, or loss of senses/enjoyment in eating. Study participants spoke about being motivated by the need to understand patients' treatment goals within the context of shortened life expectancy due to illness or chronic disease, physical and/or cognitive decline, and diminished quality of life. Within this, timeliness is enhanced by patients' and families' sense of personal relevancy as they slowly realized that they were becoming overwhelmed by the mounting challenges of debility. Participant (#05), an APRN, said:

We don't get very many patients that sign up with the notion that they may not get better and they're receptive to a hospice referral. . .It takes multiple exacerbations of their heart failure or their COPD and for them to just be so debilitated that they know that they're nearing the end of their life.

Participant (#02), an APRN, described how cognitive decline and/or decreased quality of life can mutually motivate both providers and families to converse:

I had another elderly gentleman a couple of months ago really end stage cognitive decline,

Alzheimer's still fairly ambulatory. His wife and daughter came in and they said 'he's declined so much, he doesn't know who we are, who he is, what's going on. We'd like to consider hospice'. . . So I think my decision is a little bit led by where the patient and the family are.

Participant (#02) further elaborated: 'So my experiences, I really have to say when I really got to thinking about this are mainly with families that realize the decline, realize that they can no longer care for the patient'. Participant (#07), an APRN, described how physical decline facilitates her end-of-life conversations with patients:

So, generally for me, it was when they went to the hospital a lot. If we had more than three hospitalizations in the last six months, that's a signal to me. Or a fall with a hip fracture, *a lot* of falls. Or, we're having a lot of pain, and we can't manage it. So, we usually, even knowing the hospice guidelines is usually what directed my conversations, knowing how they would qualify, and *usually* I would talk about what were their goals at that point. Many of them had goals to not go to the hospital. The moment I heard that, that's when we started the conversation.

Standardization of discussion per Medicare guidelines. Standardization of discussion, particularly per Medicare guidelines, was the third most often ($n = 10$) reported facilitator of end-of-life conversations in the primary care setting. Operationally this is 'to bring in to conformity, with a standard especially in order to assure consistency and regularity'.[36] Participant (#03), an APRN, explained 'I also bring it up every year. So I think that's what precipitates the conversations. Part of Medicare's annual Medicare wellness exam requires that you discuss advanced directives'.

Differences among providers

All seven themes were endorsed by both physicians and APRNs. However, some themes were endorsed more heavily by one provider group than the other. The themes most often endorsed by physicians generally focused more on process and knowledge deficit while the themes most often endorsed by APRNs focused on emotional readiness and physical wellbeing.

Among conversational barriers, a higher percentage of physicians agreed more with the themes of insufficient time; and insufficient understanding of prognosis and associated expectations.

Table 3. Thematic ranking barriers and facilitators by primary care provider type (*N* = 14).

Barriers				Facilitators			
Rank	Theme	Physician (*n* = 6)	APRN (*n* = 8)	Rank	Theme	Physician (*n* = 6)	APRN (*n* = 8)
1	Patient and/or family resistance	2	8	1	Established trusting relationship with provider	5	7
2	Time deficit	3	3	2	Physical and/or cognitive decline and poor prognosis	4	7
3	Insufficient understanding of prognosis and associated expectations	3	3	3	Discussion standardization per Medicare guidelines	5	5

Meanwhile, the APRNs unanimously endorsed resistance from patients and families. Among conversational facilitators, physicians strongly favored standardization of discussion while APRNs showed strong agreement for physical and/or cognitive decline and poor prognosis. There was nearly equal endorsement between groups for established trusting relationship with provider (Table 3).

Discussion

Findings within this study are confirmatory; consistent with end-of-life conversational barriers and facilitators that were previously described in the literature. Within this study, end-of-life conversational barriers relate to resistance from patients and families, insufficient time, and insufficient understanding of prognosis and associated expectations. Resistance is multi-focal and intertwined with insufficient understanding of prognosis and associated expectations. Patients with serious, and chronic illness describe still feeling 'well' as a significant barrier to conversation; likewise, primary care providers report that patients not feeling sick enough to engender relevancy is a potent conversational barrier.[37,38]

Jessica Zitter, MD, a physician practicing both critical and palliative care[15] describes: 'You cannot plan for a good death if you don't know that you're dying' (p. 107). The chronically ill often overestimate their life expectancy. Repeated illness exacerbation often leads to incomplete recovery and gradual downward trends that go unrecognized.[15,39] Meanwhile, patients and families adjust to increasingly lower plateaus until functional reserves are exhausted, and acclimation suddenly becomes impossible. APRN (#01) described a man who had repeatedly survived difficult circumstances. He has persisted, perhaps against the odds, although within an overall pattern of decline. Through the availability heuristic cognitive bias, instances of prior recovery are easily recalled and the perceived odds of continued recovery becomes magnified.[40] In this way death can come as a surprise, even among the chronically ill.[39]

In this study, knowledge deficit was multi-factorial and included limited literacy, selective hearing, poor understanding of prognosis, unrealistic expectations for treatment and/or recovery, variations of educational attainment and understanding within sibling groups, and misunderstanding of hospice's availability and purpose. Physician (#006) described how limited time can intersect with limited literacy. This is especially problematic as it can reinforce preexisting health inequalities. APRN (#02) described cancer patients who grasp onto the oncologists' suggestion that there are other treatments while not perceiving the lethality of the side effects. Selective hearing can work in tandem with willful blindness, resulting in exhausted and overwhelmed patients focusing their attention more narrowly as a means to cope.[41] This is exacerbated by the highly specialized, piecemeal nature of modern healthcare. Patients are seen by multiple consultants, each prognosticating about the specific organ system that they specialize in without synthesizing the information in a way that considers the overall well-being of the patient.[15,42] This presents an opportunity for the primary care provider to routinely meet with patients and families to discuss the broader implications for care.

Both general awareness and favorability toward hospice are high.[43,44] Yet, overestimation of life expectancy coupled with an often-oversimplified view of hospice often equate acceptance of hospice services as giving in to death.[44,45] In developing an 'acceptable regret model', researchers found that patients are often not amendable to hospice care until their probability of death reaches greater than 96%.[46] Tolerating very little uncertainty, patients and family members are often resistant to end-of-life discussion until it becomes emergently necessary.

Uncertainty can be an uncomfortable emotion, yet hope allows for uncertainty to be appraised positively, reducing anxiety.[47] Although providers may not want to adversely affect their patients' hope, Cohen *et al.* found that experience with end-of-life conversation and ACP did not decrease cancer patients' hope and may be associated with increased hope.[48] Partaking in ACP can increase patients' sense of self-efficacy during a very vulnerable time, reducing duress.[48] It could be beneficial for end-of-life education for healthcare providers to include greater emphasis on the reframing of hope within having increased control over one's own healthcare decisions.

While discussing barriers, study participants were most passionate about the constraining effects of time. Participants experience ongoing frustration while trying to successfully navigate the complexities of multiple comorbidities within the confines of 15-min appointment allotment. These concerns are consistent with the literature. In one study, time deficit in the form of appointment brevity was the most often reported barrier by 47% of primary care providers of patients with acquired immunodeficiency syndrome.[38] This finding is echoed by other studies for whom primary care physicians and specialists identified time deficit as their most potent conversational barrier.[21,49] There is little time for difficult, nuanced, end-of-life conversation, especially if its relevancy is still in abstraction.

Within this study, end-of-life conversational facilitators related to the nature of the provider–patient relationship and the immediacy of relevancy. Conversation was facilitated by authenticity that appreciates over time. While many factors contribute to procrastination, the more immediate the relevancy feels, the more likely the conversation will be prioritized as necessary.

Medicare is a health insurance program provided by the United States government that serves over 65 million people, including most citizens over 65 years old.[50] Medicare's inclusion of ACP as an optional, reimbursed topic for discussion during annual wellness visits has increased conversational frequency for study participants, encouraging the issue while alleviating social awkwardness.[51] The significance of this facilitator is poignant. One study describes how following the removal of end-of-life discussion reimbursement from a draft of the 2010 Affordable Care Act, less than 1% of 5199 Medicare beneficiaries reported having end-of-life conversations with their primary care physicians.[52] In 2016, Medicare instituted physician reimbursement for ACP and standardization of documentation of end-of-life conversation within annual wellness visits.[51] A nationwide examination of Medicare data between 2016 and 2018 found minimal billing for ACP. However, billing was highest among practices that employ a higher percentage of primary care physicians and care for a higher percentage of Medicare beneficiaries.[53] This study speaks to the positive impact of these interventions upon conversation facilitation.

The primary care setting is an ideal place to initiate conversations about future hospice use for many reasons. Primary care providers monitor patients' general well-being over time and are likely to appreciate trends. Preexisting trusting relationships with patients and their families facilitate candor. Furthermore, having multiple conversations within a familiar, lower-stakes context allows for increased understanding and reflection.[2,5] When end-of-life conversation is continually deferred until urgently necessary, it often occurs with hospital-based providers who are not well known to the patient or family. For example, conversation with emergency clinicians is often superficially treatment-focused rather than value-focused and may fail to reliably capture patients' actual wishes.[54]

Six physicians and eight APRNs took part in this study. There were commonalities and differences between the themes that were most highly endorsed within each practitioner group (Table 3). In general, the physicians favored themes related to process while the APRNs had greater preference for themes that considered the feelings and well-being of patients. These differences may

be philosophical. While the medical model heavily focuses upon the physical and biologic qualities of disorders, the nursing model focuses upon illness within a holistic context that includes functionality.[55]

Strengths, limitations, and future directions

Existing literature considers end-of-life conversational barriers from the points of view of community members and stakeholders, patients, physicians, culture, and theory.[2,18–25] Many studies about ACP focus on disease-specific populations.[26] This study adds to the existing literature by focusing on primary care and examining the patient population through a diagnostically inclusive rather than disease-specific lens, providing a broader perspective. Furthermore, this study uniquely considers the perspectives of both physicians and APRNs, an increasingly utilized group whose experiences are underrepresented in this literature.

There are limitations to this study. Sampling was purposeful in that each participant has relevant professional experience that was applicable to this study. However, it is a convenience sample as participants' professional memberships and interpersonal connections with one another greatly influenced their inclusion in the study. Half of the sample were drawn from two medical practices with four physicians belonging to one practice; and one physician and two APRNs belonging to a second practice. Like-minded individuals naturally gravitate toward one another, drawn by confirmation bias, decreasing diversity of thought.[41] Homogeneity persisted within the group as the sample is 85.7% Caucasian and 78.5% Christian. Most participants (71.5%) are in their 50s and 60s, leading to potential for like-minded generational perspective.[56,57] Greater demographic diversity within sampling would have increased the likelihood for capturing diverse perspectives. Differences between provider groups' experiences are examined, but the ability to draw conclusions is limited by the relatively small sample size of the study. Furthermore, data collection occurred before the COVID-19 pandemic and is reflective of the providers' pre-pandemic experiences with end-of-life conversation.

Resistance from patients and families was the most common barrier reported within this study. The subject matter of end-of-life conversations can be uncomfortable and end-of-life decision-making often happens within families. It would be beneficial for primary care providers to help facilitate end-of-life conversations in families for whom the conversations may not organically occur. They need a way to identify families at risk. A better understanding of what communication qualities hinder or facilitate difficult conversations in families may allow for the development of risk-assessment tools and increased conversational intervention at the primary care level.

Conclusion

Trust in one's provider is centric to end-of-life medical care. Theoretically, physicians and APRNs who work within primary care are among the providers who are the best situated to have thoughtful end-of-life goal-setting conversations with their patients. However, important barriers often make conversation difficult, and this study informs multiple avenues for future research. A significant barrier to end-of-life conversation in the primary care setting was resistance from patients and families in the form of aversion, avoidance and defensiveness, the equation of hospice with acquiescence to death, and the maintenance of hope.

End-of-life decision-making often occurs within families and a deeper investigation into conversation barriers and facilitators within families is warranted. Likewise, patients and families would benefit from improved education about hospice and palliative care intent and function, and reframing of the meaning of hope to include increased self-efficacy. Additionally, an examination of the feasibility of either longer appointment allotment or multiple appointment allotment could lead to increased facilitation of end-of-life conversations in the primary care setting, increasing congruency between patients' wishes and prescribed treatment plans.

Declarations

Ethics approval and consent to participate
All research methods were performed in accordance with relevant guidelines and regulations in the Declaration of Helsinki. This study was approved by the University of Delaware Institutional Review Board (IRB, # 1058497-4). Written informed consent was obtained from each participant prior to the interview.

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Supplemental material
Supplemental material for this article is available online.

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