



Barriers to Effective Communication about Advance Care Planning and Palliative Care: A Qualitative Study

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Purpose: The purpose of this study was to identify barriers to effective conversations about advance care planning (ACP) and palliative care reported by health care and community-based service providers in Massachusetts, USA. **Methods:** This qualitative research analyzed open-ended responses to two survey questions, inquiring about perceived barriers to having conversations about ACP and palliative care with patients and consumers. Data were collected between November 2017 and June 2019 from nine organizations in Massachusetts, including health care provider organizations, health insurers, community-based organizations, and a nursing education institution. Two researchers reviewed and coded the responses and identified common themes inductively. **Results:** Across 142 responses, primary barriers to ACP included hesitation and lack of understanding and knowledge, discomfort and resistance among service providers, lack of staff knowledge, difficulties with follow-up, and differences in ACP policies across regions. Common barriers to palliative care were misconceptions about palliative care and lack of knowledge, service providers' lack of preparedness, and limited policy support and availability. Challenges relevant to both ACP and palliative care were fear and discomfort around serious illness discussions, lack of knowledge and awareness, discussions that occur too late, and cultural and language barriers. **Conclusion:** Health care practitioners and community-based professionals reported consumer-, service provider-, and system-level barriers to facilitating conversations about ACP and palliative care with patients experiencing serious illness. There is a need for more tools and support to strengthen service providers' ACP and palliative care competencies and to promote a structured approach to health care planning conversations.

Key Words: Advance care planning, Palliative care, Qualitative research, Communication barriers

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INTRODUCTION

Advance care planning (ACP) and palliative care are important strategies for patient- and family-centered care in the

context of serious illness care [1,2]. ACP is “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” [3]. ACP guides future medi-

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cal decisions when patients face a medical crisis and become unable to express their care preferences. Palliative care is specialized medical care that supports patients with complex and serious illnesses, such as cancer or heart failure. It provides medical, social, spiritual, and communication support to manage pain and suffering and reduce symptom burden and stress associated with illnesses [4,5]. Both ACP and palliative care focus on improving communication between consumers and clinicians. However, ACP is applicable to individuals at all ages and stages of health, while palliative care is targeted to patients with serious illness [1].

Evidence suggests that ACP and palliative care can improve the quality of care and life for patients and the family, reduce health care costs, and reduce avoidable and/or unwanted health care utilization [6–9]. Despite documented benefits, the uptake of ACP is low and palliative care is underutilized [10]. Although there was an uptick in engagement around serious illness conversations at the height of the COVID–19 pandemic, lack of ACP and delayed utilization of palliative care services remain a problem [11,12].

In the United States, ACP policies, access, and utilization vary by state. Massachusetts is a leader in ACP and availability of palliative care services [13]. In Massachusetts, anyone who is 18 years or older has the right to direct their health care decisions and make a plan. Honoring Choices Massachusetts identifies the five ACP planning documents as health care proxy, personal directive (or a living will), durable power of attorney, medical orders for life–sustaining treatment, and comfort care/do not resuscitate [14].

Many health care and social services providers in Massachusetts are actively building capacity for ACP and palliative care through programs such as Honoring Choices Massachusetts and the Serious Illness Care Program [15–17]. Nine out of 10 hospitals of all sizes in Massachusetts have palliative care services, higher than the national average of 71.5% [13]. There are at least 25 community–based palliative care programs that have reported to the Center to Advance Palliative Care. These programs offer palliative care services in a range of community settings, including office–based practices, clinics, nursing homes, and/or home–based settings [18]. Despite the continued improvements in serious illness care delivery in Massachusetts, only 13% of adults in Massachusetts reported having

conversations with a health care provider about their end–of–life care wishes in 2018, and fewer than 20% discussed their wishes for care with a lawyer or financial planner [19]. Among those who did not have a conversation, 52% reported they wanted to have the conversation [19]. This suggests there are unmet needs and individuals are interested in having meaningful planning discussions about their preferences for care.

This study aims to explain barriers to initiating conversations about ACP and palliative care from the perspectives of health care and community–based service providers in Massachusetts, USA. This qualitative study provides a richer understanding of the factors that may hinder meaningful and timely care planning discussions. This study also provides insights on the directions and approaches of future interventions that would mitigate the barriers to effective care planning conversations when caring for patients with serious illnesses.

METHODS

1. Study design

This study analyzed qualitative data collected from a survey, employing content analysis to identify the barriers that impede effective communication regarding ACP and palliative care.

2. Participants

Nine organizations were identified by Honoring Choices Massachusetts program leadership for participation in the surveys as representative organizations with a diversity of roles and experience in ACP conversations. Honoring Choices Massachusetts collaborates with community–based organizations, health care providers, and other concerned groups by providing an introductory on–site training to a designated group of staff, free access to a range of ACP materials, and ongoing support as required.

Organizations that participated in our study include health care providers, payers, a nursing educational institution, and community–based organizations. These nine organizations share the mission of adopting a structured approach to ACP and integrating care planning conversations as part of their practice and culture. Four organizations were selected for participation as “new partners” of Honoring Choices Massachu–

setts that had not formally participated in ACP trainings prior to the survey. Five organizations were identified as “long-time partners,” who had been using the Honoring Choices Massachusetts training programs and toolkits for several years. Thus, these open-ended responses reflect a group of professionals with varying levels of ACP training and experience. The respondents included a mix of clinical and non-clinical roles from health care and community-based organizations. Clinical roles included nurse practitioners, care managers, social workers, and psychologists. Non-clinical roles included navigators, community liaison/outreach, financial planners, and administrators.

3. Data collection

We asked the following questions to survey participants between November 2017 and June 2019: (a) “In your experience, what are the biggest barriers to having conversations about ACP with patients or clients?” and (b) “In your experience, what are the biggest barriers to having conversations about palliative care with patients or clients?” The survey questions were administered as part of a larger study [20], which evaluated the impact and implementation of an educational program for ACP in Massachusetts provided by Honoring Choices Massachusetts. Surveys were administered on paper and electronically. The survey results represent pooled responses from four new partner organizations who were surveyed at two time points (about four months apart) together with five long-time partner organizations at one time point.

4. Data analysis

For survey responses that were collected on paper, handwritten responses were recorded into the electronic survey database. To perform qualitative data analysis, we followed the analytic steps delineated by Bradley, Curry, and Devers [21]. First, two researchers reviewed responses for understanding and identified a list of emergent themes. We first suggested dimensions that were relatively broad (consumer-, service provider-, and system-level) as a potential approach to group the responses after reviewing the responses. We also extracted more detailed concepts and themes that recurred throughout the responses. We then independently coded the data line by line in detail to evaluate whether the initial list of concepts and

themes was appropriate to capture the participants’ perspectives. Using the constant comparative method [22], we refined the dimensions of concepts by removing and combining identified themes and created a final list of codes. We applied our final list of codes using QSR Nvivo software and then re-reviewed the results of coding and reconciled minor differences through iterative discussion and consensus [21,22].

Respondents referred to those they assist with or provide services for by a range of terms (such as patient, client, consumer, or member) based on their organizational mission and nature of their work. Drawing from the Honoring Choices Massachusetts frameworks to promote empowerment in health care and ACP [23], we have used the term “consumer” of health care and social services throughout, unless specifically referring to the patient-provider relationship or quoting a survey response directly.

The study was reviewed by the Tufts Health Sciences Institutional Review Board (#12703).

RESULTS

Health care and community-based professionals from nine organizations in Massachusetts provided a total of 142 responses. Participants were employees of health care provider organizations (n=22), health insurance companies (n=76), community-based organizations (n=30), and a nursing education institution (n=14).

1. Barriers to initiating conversations about Advance Care Planning (ACP)

Table 1 presents thirteen themes that emerged from our qualitative analysis of survey responses about barriers to ACP, organized by three levels of barriers: consumer level, service provider level, and system level.

1) Consumer-level barriers: hesitation, lack of understanding and knowledge, cultural and language differences, cognitive decline, and lack of social support

Hesitation presented a significant obstacle to discussing ACP. Hesitation was described as patients or families being “not willing,” “not ready,” or “very resistant” to have a conversation

Table 1. Barriers to Advance Care Planning.

Themes	Illustrative quotes
Consumer	
Hesitation of consumer and family	<p>“Patient [s] associate ACP with imminent death and are scared/not open to talking about dying.”</p> <p>“Fear of facing what the prognosis might be”</p> <p>“They don’t want to talk without family present.”</p> <p>“They often state they are not ready.”</p> <p>“Denial/guilt of family members”</p>
Lack of consumer understanding and knowledge	<p>“They believe that it is enough that family knows their wishes.”</p> <p>“Members ‘think’ they know how the process works regardless of what we explain to them.”</p> <p>“Knowledge deficiency about the existence of the documents”</p>
Cultural or language issues	<p>“Explaining to a consumer in the easiest language without offending the consumer and/or cultural choices”</p> <p>“Cultural barriers/language barriers limit education/encouragement abilities.”</p> <p>“Cultural differences make it difficult for members to choose to understand the need for the forms.”</p>
Healthy people	<p>“People who are healthy do not believe they need to do this.”</p> <p>“Breaching the topic of death and dying especially to healthy patients who are convinced that they don’t need to consider these yet”</p>
Consumers perceive as unimportant	<p>“They think it is not important at that time.”</p> <p>“Lack of interest”</p>
Cognitive decline	<p>“Cognitive issues of patient”</p> <p>“Dementia”</p>
Lack of consumer social support	<p>“Some of my patients do not have a person they can ask to be their HCP.”</p>
Service provider	
Comfort of professional	<p>“Providers being scared of how patient/families will react”</p> <p>“Hurting a member’s pride, not wanting to make as though they are unhealthy or elderly”</p>
Physician communication or resistance	<p>“The doctors not wanting to initiate it because they then feel they are giving up”</p> <p>“Physician resistance”</p> <p>“Physicians not being forthcoming about patients’ prognosis- ‘sugar coating’”</p> <p>“Doctors have not given patients necessary information about their condition and prognosis especially with CHF”</p>
Insufficient staff knowledge	<p>“Confusing info about what is legal”</p> <p>“I’m a little uncertain if ‘advance care planning’ is referring to HCP as well as MOLST forms etc., or just MOLST.”</p>
Systems	
Time constraints	<p>“Time with patients is limited.”</p> <p>“Sometimes clients do not have the time to discuss.”</p>
Too late	<p>“I work in an intensive care unit and conversations are often had too late especially individuals with chronic illnesses.”</p>
Implementation challenges and follow up	<p>“One big barrier is having the document (HCP, MOLST) to return to the office completed once handed to patient”</p> <p>“It differs from state to state and have [sic] a lot of non-Massachusetts members.”</p>

ACP: advance care planning, HCP: health care proxy, CHF: congestive heart failure, HCP: health care proxy, MOLST: medical orders for life-sustaining treatment.

about end-of-life or dying. “Fear” of facing death was a barrier, with some patients associating it with “imminent death” or being “scared/not open to talking about dying.” Lack of knowledge about ACP was also frequently noted, “members think that they know how the process works regardless of what we explain to them” and “they believe that it is enough that family knows their wishes.” Cultural and language issues were often reported as a challenge. Cultural differences between the consumer and the professional made it difficult to communicate about the necessity of ACP and the importance of documenting their wishes for care. One respondent

expressed concerns about explaining the concepts without “offending the consumer and/or cultural choices.” Not having certain planning forms in the consumer’s language also created a barrier to initiating conversations. In addition, respondents reported that consumers tended to perceive ACP as unimportant when they are healthy and have no serious illnesses that require immediate medical attention. Some respondents noted greater challenges with ACP when patients have a lack of cognitive ability or a lack of social support, so adults are not able to appoint a health care agent.

2) Service provider-level barriers: discomfort of professionals, physician resistance, and lack of staff knowledge

Several responses identified barriers at the service provider level, such as the discomfort of professionals, physician resistance, and insufficient knowledge among staff about ACP. Service providers expressed their discomfort in initiating the conversation, as they are “scared of how patient/families will react” or that they do not want to hurt “a member’s pride.”

Some participants noted that physicians are not transparent about their patients’ conditions or prognosis, or that they are hesitant to initiate conversations because they “feel they are giving up” on the patient. Insufficient knowledge among staff on ACP often led to hesitation and discomfort among professionals, “I am not too comfortable to discuss because of lack of knowledge.” There was also a general desire for more resources, tools, and information about ACP and its relevant forms.

Table 2. Barriers to Palliative Care.

Themes	Illustrative quotes
Consumer	
Giving up, equating hospice with palliative care	<p>“People tend to hear hospice instead of palliative care.”</p> <p>“misconception that palliative care and hospice are the same, fear that palliative care means you are imminently dying”</p> <p>“I think patients assume palliative care is equivalent to hospice and they think they will stop receiving life-saving or prolonging care.”</p> <p>“They think that palliative means giving up.”</p>
Fear and denial due to uncertainty of prognosis	<p>“People are living longer now and some have optimism that things will improve.”</p> <p>“Many individuals and families have an unrealistic view of their or their family members’ prognosis.”</p> <p>“Lack of education about prognosis and health conditions”</p> <p>“Members are afraid of talking about their failing health and about dying.”</p> <p>“Patients/family not ready to discuss”</p> <p>“Fear of the unknown”</p> <p>“Denial of the life process”</p>
Lack of understanding and awareness - patient side	<p>“People are not sure of the options and they do not typically wish to discuss.”</p> <p>“Patients not understanding what palliative care is and having to explain everything to them”</p> <p>“People are less informed about what palliative care is”</p>
Family dynamics	<p>“Lack of family support”</p> <p>“Family disagreement”</p>
Culture, religion, beliefs, and language	<p>“Client’s personal belief system/culture”</p>
Service provider	
Lack of experience with palliative care - provider side	<p>“Too uncomfortable for questions, lack of knowledge”</p> <p>“Lack of experience in palliative care”</p> <p>“Have not heard to do this as of yet. Need info!”</p>
Difficult and uncomfortable to explain palliative care	<p>“Trying to explain palliative care and have people understand it”</p>
Care team and physician’s reluctance	<p>“Care team not on board with conversation - doc, nurses hesitant to discuss”</p> <p>“Some MDs are reluctant to consider palliative care.”</p> <p>“Doctors saying the patient isn’t ready for that.”</p>
Systems	
Timing and too late	<p>“Waiting till termination to initiate conversation”</p> <p>“Brought up too late”</p> <p>“High acuity/busy assignments”</p>
Limited tools and resources	<p>“Help! Tools!”</p> <p>“Need tools”</p>
Lack of available palliative care services or reimbursement	<p>“I feel that once my patients leave the hospital, there are not a lot of services offered in terms of palliative care. Some home agencies do a one-time consult, which is not enough.”</p> <p>“I don’t believe formal palliative care is a Medicare benefit, so I deal primarily with hospice, bridge to hospice, or recommendations in the community for pain management.”</p>

3) System-level barriers: time constraints, conversations that occurred too late, and implementation and policy challenges

Respondents commented that limited time with patients was a common issue, and that clients did not have enough time to discuss ACP. Relatedly, conversations often occurred too late, as one respondent noted: “I work in an intensive care unit and conversations are often had too late especially individuals with chronic illnesses.” Several challenges were related to the implementation of ACP, such as difficulty following up with consumers to complete ACP forms and return them to the office to keep on file. Moreover, respondents who worked with residents across state lines reported that the differences in policies between states posed an added barrier to ACP.

2. Barriers to initiating conversations about palliative care

Table 2 delineates barriers to having a conversation about palliative care grouped by 11 themes across the same three levels of barriers: consumer level, service provider level, and system level.

1) Consumer-level barriers: misconception, fear and denial derived from uncertainty of prognosis, lack of understanding, family dynamics, and cultural and religious barriers

Consumers often equated palliative care with hospice and end-of-life care, and therefore lacked a clear understanding of what palliative care involves and how it can be beneficial. Consumers “tend to hear hospice instead of palliative care” and believe that receiving palliative care meant they would have to “stop all treatment” or “stop receiving life-saving or prolonging care.” One participant noted a discrepancy between patients’ perceptions of palliative care and what it can provide, remarking that patients “don’t realize that the goal is to truly make them as comfortable as possible and give them the best QOL (quality of life)” (not included in Table 2).

Similar to the obstacles encountered with ACP, fear, hesitation, and discomfort were significant barriers to having discussions about palliative care. This included a “fear of the unknown” and a sense that consumers are not ready to discuss because of “denial” or an “optimism” that their situation

will improve. One participant explained, “Many individuals and families have an unrealistic view of their or their family members’ prognosis. This often allows them to cope with these tough times, but the reality should be softly approached with the focus on the best possible outcome.” Several respondents observed that these misunderstandings extended to the level of families, mentioning factors such as “family dynamics,” “family disagreement,” or the family not being prepared.

2) Service provider-level barriers: lack of experience with palliative care, and care team and physician’s reluctance

Participants reported the provider care team’s lack of awareness and reluctance to consider palliative care as a treatment option at an earlier stage in the patient’s care as a common obstacle, reporting that “some MDs are reluctant to consider palliative care” and “doctors saying the patient isn’t ready for that.”

3) Systems-level barriers: timing, lack of available palliative care services, and lack of reimbursement

Some participants identified challenges related to timing, for example, “waiting ‘til terminal to initiate conversation,” or palliative care being “brought up too late.” The lack of available palliative care services and inadequate reimbursement for community-based palliative care hindered timely referrals to palliative care services, noting the lack of availability of palliative care services that offered more than a “one-time consult” but were not necessarily intended as a “bridge to hospice.”

DISCUSSION

Our study identified an array of barriers to ACP and palliative care conversations reported by health care providers and community-based professionals in Massachusetts in the USA. This study adds a meaningful contribution to the existing literature by surveying perceived challenges experienced by community-based professionals, not just physicians within hospital settings.

There were barriers specific to either ACP or palliative care; however, fear and discomfort among consumers and family members were common among both ACP and palliative care conversations. A lack of confidence among providers was

also common. Respondents noted misconceptions about palliative care as well as challenges obtaining a consensus on the benefits of palliative care among physicians and within a care team. As respondents expressed their general desire for more training and tools, our findings call for more systematic support and resources to change the culture around health care planning through streamlined and easily accessible tools and education. One example of such a tool is the “5 Things to Talk About,” a Conversation Guide Series for consumers and care providers by Honoring Choices Massachusetts, which offers a set of suggested questions that people can use to jumpstart conversations. The creation of the “Five Things to Talk About” Palliative Care Guide also aimed to address common misconceptions about palliative care, who it is for, and how it fits into a person’s care goals and choices [24].

Cultural and language differences were highlighted as a challenge to effective conversations. Culture affects care preferences, ways of coping with pain and dying, and how consumers and family members want to proceed with care planning discussions [25,26]. Respondents expressed their challenges navigating discussions about serious illnesses with consumers of different cultural and language backgrounds. While there has been emphasis on cultivating cultural sensitivity and cultural competence among health care providers in the USA to make health care more inclusive, additional work is needed to ensure these resources adequately meet their diverse needs and lived experiences [27]. Strategies to raise awareness about ACP and palliative care will need to be more culturally tailored and diversified [26].

There were different kinds of challenges specific to ACP versus palliative care. For example, lack of family or social support can result in an individual not having someone to assign as their health care proxy. Additionally, the importance of documentation in ACP creates difficulties in having consumers return their documentation of care preferences once completed. A unique challenge in palliative care was limited reimbursement. These unique challenges can inform policymakers about which levers are needed to increase the frequency and timeliness of both ACP and palliative care interventions. Importantly, for both ACP and palliative care, health care planning discussions are iterative processes and require sufficient time and rapport with a facilitator. They need to begin earlier in the

care continuum and involving community partners may help consumers to be more open to these conversations [28]. This is why understanding the barriers experienced by community-based professionals is critical.

This study has limitations. We anonymously surveyed the same four organizations at two time points without tracking individuals, so we do not know how many individuals participated the same survey questions twice versus just once. However, to yield as much richness in the survey responses as possible, we sought to include all responses as subjects for analysis since our primary goal was not to capture frequencies of responses, but qualitative insights. This study was an exploratory analysis about common barriers around health care planning conversations through the lens of community-based and health care professionals based in Massachusetts; hence, the generalizability is limited. The fear and discomfort at the consumer and family levels described in this study are based on the experience and perspectives of service providers, not obtained directly from consumers and family members. Future studies should examine and identify methods of support and educational tools that would be particularly effective for service providers to increase their knowledge and competence about ACP and palliative care services. Continued efforts to increase access to high-quality care planning and serious illness discussions will be needed to enhance patient satisfaction and quality of care.

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CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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AUTHOR'S CONTRIBUTIONS

Conception or design of the work: all authors. Data collection: SPF. Data analysis and interpretation: all authors. Drafting the article: HK. Critical revision of the article: SPF. Final approval of the version to be published: all authors.

SUPPLEMENTARY MATERIALS

Supplementary materials can be found via <https://doi.org/10.14475/jhpc.2023.26.2.42>.

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