Is This ACP? A Focus Group Study of Patient Experiences of Advance Care Planning

Amanda J. Reich, PhD, MPH[1], Stephen Perez, BA[1], Priscilla Gazarian, PhD, RN[1],
Noah D'Arcangelo, BA[2,3], Kristina Gonzales, BS[2,3], Phillip Rodgers, MD, FAAHPM[4],
Deepshikha C. Ashana, MD, MS, MBA[5], Joel S. Weissman, PhD[1], and Keren Ladin, MSc[2,3]

[1]Center for Surgery and Public Health, Brigham and Women's Hospital, One Brigham Circle, 1620 Tremont Street, Suite 2-016, Boston, MA 02120, USA; [2]Department of Occupational and Community Health, Tufts University, Medford, USA; [3]Research on Ethics, Aging, and Community Health (REACH Lab), Tufts University, Medford, MA 02155, USA; [4]Geriatric and Palliative Medicine, University of Michigan, Ann Arbor, USA; [5]Dept. of Pulmonary, Allergy, and Critical Care Medicine, Duke University, Durham, USA

BACKGROUND: To date, most research on patients' experiences with advance care planning (ACP) focuses on motivations to engage in discussions and how patients prepare. Gaps remain in understanding how non-critically ill Medicare patients perceive ACP encounters, including how they characterize positive and negative experiences with ACP.

OBJECTIVES: Understanding these patients' perceptions is imperative as Medicare has sought to incentivize provision of ACP services via two billing codes in 2016.

DESIGN: Qualitative focus group study. Thematic analysis was performed to assess participants ACP experience.

PARTICIPANTS: Medicare beneficiaries who had engaged in or were billed for ACP.

KEY RESULTS: Seven focus groups were conducted with 34 Medicare beneficiaries who had engaged in ACP across 5 US health systems. Participants described a spectrum of perceptions regarding ACP, and a range of delivery approaches, including group ACP, discussions with specialists during serious illness, and ACP in primary care settings during wellness visits. Despite being billed for ACP or having ACP services noted in their medical record, many did not recognize that they had engaged in ACP, expressed lack of clarity over the term "ACP," and were unaware of the Medicare billing codes. Among participants who described quality patient-centered ACP experiences, three additional themes were identified: trusted and established patient/clinician relationships, transparent communication and documentation, and an understanding that ACP is revisable. Participants offered recommendations for clinicians and health systems to improve the patient ACP experience.

CONCLUSIONS: Findings include actionable steps to promote patient-centered ACP experiences, including clinician training to support improved communication and facilitating shared decision-making, allocating sufficient clinical time for discussions, and ensuring that documentation of preferences is clear and accessible.

Other approaches such as group ACP and ACP navigators may help to support patient interests within clinical constraints and need to be further explored.

INTRODUCTION

Advance care planning (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.[1] In an effort to promote and incentivize ACP discussions, Medicare began reimbursing clinicians for ACP services in January 2016.[2] The two Current and Procedural Terminology (CPT) codes (99,497 and 99,498) allow clinicians to bill for visits where ACP is discussed for at least 16 min.[3] CMS describes ACP visits eligible for reimbursement as "voluntary face-to-face services between a Medicare physician or other qualified healthcare professional and a patient to discuss the patient's wishes if they are unable to make decisions about their care."[3] While legal documents such as advance directives (ADs) may be completed as part of this service, they are not required for reimbursement.

ACP experiences of older adults, who are not necessarily seriously ill, are not well understood. Past research on generally healthy, older patients and ACP has focused on the motivation and preparation for ACP services, exploring concerns for autonomy and a desire to avoid burdening caregivers.[4–7] Existing work has found that patients present with variable stages of "readiness" to discuss end-of-life planning.[8,9] Studies have found that, while patients generally express a desire for shared decision-making (where clinicians engage patients to elicit preferences), the degree of openness to ACP often depends on one's prognosis and experience with end-of-life care.[10,11] Openness to ACP in clinical encounters can be challenging and patients have reported a need to feel comfortable in order to share goals and concerns,[12] with family

or caregivers often playing an important role.[13] These findings can help to shape patient-centered care.

Prior studies have been limited to patients with serious illness,[10,12] or specific diagnoses[11,13] or populations[14], or focus on clinician perspectives[15] or specific modalities, like videos or group visits[16,17]. Few studies have focused on the patient experience of ACP, including what constitutes ACP, and perceptions of the billable ACP encounter. This qualitative study examined patient perceptions of ACP from a geographically diverse Medicare population to better capture the typical patient population in primary care and geriatrics practices across the USA. As CMS works to incentivize ACP, understanding patients' perspectives on what qualifies as successful ACP can inform best practices and ensure that clinicians, caregivers, and health systems support high quality, patient-centered care.

METHODS

We conducted seven focus groups to explore the spectrum of experiences among Medicare beneficiaries who engaged in ACP at five health systems across the USA. The Mass General Brigham Institutional Review Board approved this study. The authors followed Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines in the reporting of this study.[18]

Participant Recruitment

In collaboration with a study advisory panel consisting of leaders in health services research, experience in ACP, and palliative care (Appendix 1 in the Supplementary information), five health system sites were purposively selected to include a mix of size, region, and type (academic, public, and non-profit).

Inclusion criteria included Medicare beneficiaries who received ACP services and were English speaking. We defined ACP as conversations about preferences for future medical care if a person were to become seriously ill and asked participants to confirm they recalled a discussion with a member of their healthcare team during a phone screen for eligibility (Appendix 1 in the Supplementary information). We anticipated completing 3–6 focus groups to achieve data saturation, where no new information would be discovered.[19]

Within each of the five sites, participants were identified and purposively sampled with the assistance of a local site champion (an individual in a leadership role within the health system, such as a Chief of Palliative Care or Chief Medical Officer). At sites where clinicians provided patient contact information, we purposively recruited patients with a spectrum of positive and negative ACP experiences and were not limited to only healthy or ill patients. We adapted recruitment approaches, consistent with the preferences of

each health system. A description of strategies is available in Appendix 1 in the Supplementary information.

Guide Development

A social scientist with expertise in qualitative methods and palliative care (K.L.) guided the multidisciplinary study team (A.J.R, a health services researcher; P.G., a nurse researcher; P.R., a palliative care physician-researcher; D.C.A, a pulmonary critical care physician researcher; J.S.W, a health services researcher, and S.P., N.D., and K.G., research assistants) to develop a semi-structured focus group discussion guide based on clinical experience and literature review.[20] Key domains included the dynamics of ACP discussions, the perceived impact on care, satisfaction with ACP, preparation for ACP, consistency in preferences, documentation and accessibility, and recommendations for improvement. The guide was pilot tested with one focus group and revised for clarity and finalized to 15 items following deliberation with the research team (A.J.R., J.S.W., P.G., K.L.) (Appendix 2 in the Supplementary information).[21]

Focus Group Procedures

All groups were led in-person by a primary moderator experienced with conducting focus groups in health care settings, with at least one secondary research team member taking notes. Participants were first provided with a handout (Appendix 4 in the Supplementary information) describing key terms and concepts: ACP, documentation, healthcare proxy, advance directive/living will, and do not resuscitate (DNR)/Physician Orders for Life-Sustaining Treatment (POLST)/Medical Order for Life-Sustaining Treatment

Table 1 Health System Characteristics

Health system characteristics	N
Health systems	5
Region	
West	1
South	1
Midwest	1
Northeast	2
Type[1]	
Academic	4
Large-not for profit	1
Noted religious affiliation	
Yes	1
No	4
Bed count, mean (SD)[1]	1731.4 (988.2)
Total physician count, mean (SD)[1]	2765.2 (2462.0)

[1]AHRQ Comparative Health Systems Performance Initiative, 2019. Organization and Performance of Health Systems in 2016

(MOLST). They had an opportunity to ask questions prior to the focus group start. Demographic and basic healthcare and ACP data, including completion of documents, were collected (Table 3). Participants provided verbal consent and all focus groups were audio-recorded and professionally transcribed verbatim. Participants were compensated $75 for their time and any transportation costs, and a meal was provided. The secondary researcher took field notes and debriefed the full team after each focus group.

Analysis

A preliminary codebook was developed by AJR and SP based on the structure of the interview guide.[22] AJR, NAD, and KG independently coded the transcripts using the guide, and then identified emergent codes inductively. Codes were refined through deliberation. All transcripts were coded line-by-line independently by at least two members of the research team, one of whom was a doctoral-level researcher

(AJR), using NVivo11 software. AJR, NAD, and KG achieved coding consensus on all transcripts through discussion, with discrepancies arbitrated by KL. Subsequent to open coding, some categories were merged through focused coding. Codes were then organized into themes after deliberation among the research team (A.J.R., N.A.D., K.G., D.A., P.R., K.L.).[23] Saturation was achieved as no new data emerged in the seventh focus group.

RESULTS

Seven focus groups were conducted with 34 participants (range of 4–8 per group) at five health systems between August 2018 and December 2019 across the USA (Table 1). Focus groups lasted an average of 75.4 min (SD 15.3 min). Participants on average were aged 77 years (SD = 6.5 years); 85% were white; 65% were female. Most (58%) described their current health as at least "good" (Table 2). Participants reported a mix of health statuses,

Table 2 Participants' Characteristics

Participant characteristics						
Site	All	A&B	C	D	E&F	G
Patients, no	34	8	5	4	13	4
Age, mean (SD)	77.2 (6.5)	76.8 (8)	77.7 (8.5)	78 (8.5)	76 (4.9)	76 (2.6)
Gender, %						
Male	35.3	42.8	40	25	23	0
Female	64.7	57.2	60	75	77	100
Hispanic ethnicity, %	3.1	0	0	25	0	0
Race, %						
White	85.3	89	80	75	93	100
Black or African American	8.8	11	20	0	7	0
Asian	5.9	0	0	25	0	0
Insurance type, N (%)						
Medicare-only	5 (14.7)	0 (0)	0 (0)	1 (25)	4 (30.7)	0 (0)
Medicare and private	24 (70.6)	6 (75)	3 (60)	3 (75)	9 (69.3)	3 (75)
Medicare and other	3 (8.8)	2 (25)	1 (20)	0 (0)	0 (0)	0 (0)
Did not answer	2 (5.9)	0 (0)	1 (20)	0 (0)	0 (0)	1 (25)
Education, N (%)						
Some high school, but did not graduate	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
High school graduate or GED	4 (11.8)	1 (12.5)	0 (0)	1 (25)	1 (7.6)	1 (25)
Some college	2 (5.9)	1 (12.5)	0 (0)	1 (25)	0 (0)	0 (0)
Two- or 4-year degree	7 (20.6)	1 (12.5)	0 (0)	1 (25)	4 (30.1)	1 (25)
Graduate degree	19 (55.9)	4 (50)	1 (80)	1 (25)	8 (61.5)	2 (50)
Did not answer	2 (5.9)	1 (12.5)	0 (20)	0 (0)	0 (0)	0 (0)
Reported medical conditions, N						
Cancer	10	2	1	2	4	1
Diabetes	4	2	1	1	0	0
Heart	6	2	1	0	1	0
Autoimmune	9	2	0	0	2	0
Surgeries	5	0	1	2	1	0
Blood pressure	4	1	1	1	1	0
Other	2	2	0	0	0	0
Interview time, mean (SD)	75.4 (15.3)	77, 71	106	58	80, 66	69

Table 3 Participant Questionnaire

Patient health care questionnaire	N=34 (%)	A&B	C	D	E&F	G
	N (%)	8	5	4	13	4
How would you rate your overall health? (N)						
Poor	0	0	0	0	0	0
Fair	5 (15)	1 (12.5)	1 (20)	2 (50)	1 (7.7)	0
Good	10 (29)	3 (37.5)	0	1 (25)	4 (30.7)	2 (50)
Very good	10 (29)	3 (37.5)	0	1 (25)	5 (38.5)	1 (25)
Excellent	6 (18)	1 (12.5)	1 (20)	0	3 (23.1)	1 (25)
Did not answer	3 (9)	0	3 (60)	0	0	0
Who do you consider to be your main healthcare provider? (N)						
Primary care doctor	30 (88)	8 (100)	3 (60)	3 (75)	12 (92.3)	4 (100)
Specialist	2 (5)	0	1 (20)	1 (25)	0	0
PCP and specialist	1 (3)	0	0	0	1 (7.7)	0
Nurse	0	0	0	0	0	0
Someone else	0	0	0	0	0	0
I don't have a main healthcare provider	0	0	0	0	0	0
Did not answer	1 (3)	0	1 (20)	0	0	0
How often does your main healthcare provider explain things in a way that is easy to understand? (N)						
Never	0	0	0	0	0	0
Sometimes	3 (9)	0	0	2 (50)	1 (7.6)	0
Usually	4 (12)	0	0	1 (25)	2 (15.3)	1 (25)
Always	26 (76)	8 (100)	4 (80)	1 (25)	10 (76.9)	3 (75)
Did not answer	1 (3)	0	1 (20)	0	0	0
Have you had an ACP discussion with a member of your health care team? (N)						
Yes, with my main health care provider	18 (53)	6 (75)	1 (20)	1 (25)	7 (53.8)	3 (75)
Yes, with another member of my healthcare team	2 (5)	0	0	0	2 (15.3)	0
Yes, both my main provider and another member of my team	2 (5)	0	1 (20)	0	1 (7.7)	0
No	8 (23)	1 (12.5)	2 (40)	2 (50)	3 (23)	0
I don't know	2 (5)	0	0	1 (25)	0	1 (25)
Did not answer	2 (5)	1 (12.5)	1 (20)	0	0	0
How satisfied were you, overall, with the ACP discussions(s) you've had with a member of your healthcare team?						
Very satisfied	15 (44)	6 (75)	1 (20)	0	6 (46.2)	2 (50)
Somewhat satisfied	8 (23)	0	0	1 (25)	4 (30.7)	1 (25)
Somewhat dissatisfied	0	0	1 (20)	0	0	0
Very dissatisfied	0	0	0	0	0	0
Did not answer	11 (32)	1 (25)	3 (60)	3 (75)	3 (23)	1 (25)
Which of the following forms have you completed (or were completed for you)? (N)[1]						
Living will: yes, no, I don't know						
Yes	27 (79)	7 (87.5)	3 (60)	2 (50)	11 (84.6)	4 (100)
No	3 (9)	0	1 (20)	1 (25)	1 (7.7)	0
I don't know	1 (3)	0	0	0	1 (7.7)	0
Did not answer	3 (9)	1 (12.5)	1 (20)	1 (25)	0	0
Health care proxy: yes, no, I don't know						
Yes	21 (62)	5 (62.5)	0	1 (25)	11 (84.6)	4 (100)
No	4 (12)	2 (25)	3 (60)	0	1 (7.7)	0
I don't know	3 (9)	0	1 (20)	1 (25)	1 (7.7)	0
Did not answer	6 (18)	1 (12.5)	1 (20)	2 (50)	0	0
Advance directive: yes, no, I don't know						
Yes	19 (56)	7 (87.5)	2 (40)	1 (25)	9 (69.2)	0
No	3 (9)	0	1 (20)	1 (25)	2 (15.3)	1 (25)
I don't know	5 (15)	0	1 (20)	1 (25)	0	2 (50)
Did not answer	7 (20)	1 (12.5)	1 (20)	1 (25)	2 (15.3)	1 (25)

Table 3 (continued)

Patient health care questionnaire	N = 34 (%)	A&B	C	D	E&F	G
	N (%)	8	5	4	13	4
MOLST or POLST: yes, no, I don't know						
Yes	4 (18)	1 (12.5)	0	0	3 (23.1)	0
No	4 (18)	0	1 (20)	0	2 (15.4)	1 (25)
I don't know	11 (32)	4 (50)	2 (40)	2 (50)	2 (15.4)	1 (25)
Did not answer	15 (44)	3 (37.5)	2 (40)	2 (50)	6 (46.2)	2 (50)
Do you think your main healthcare provider knows the kinds of treatment you would want if you could no longer speak for yourself? (N)						
Probably not	6 (18)	0	0	2 (50)	2 (15.4)	2 (50)
Possibly yes	4 (12)	0	2 (40)	0	2 (15.4)	0
Probably yes	9 (26)	2 (25)	1 (20)	1 (25)	5 (38.4)	0
Definitely yes	13 (38)	5 (62.5)	1 (20)	1 (25)	4 (30.1)	2 (50)
Did not answer	2 (6)	1 (12.5)	1 (20)	0	0	0

[1]Documentation could be completed separately or as part of ACP discussion

and some had been diagnosed with serious medical conditions, including 10 who reported a prior or current cancer diagnosis and nine with autoimmune diseases. Participants reported engaging in a variety of ACP models, including one-on-one clinical discussions, an ACP clinic, and group ACP visits where a clinical team offered an open discussion of ACP topics and documentation forms with a group of interested patients.

Four themes emerged characterizing ACP experiences: lack of clarity over what constitutes ACP, ACP openness conditional on established doctor-patient relationships, lack of transparency in ACP communication and documentation, and an understanding that ACP is revisable. Participants also offered recommendations for clinicians, family/caregivers, and policymakers to improve the ACP experience.

Lack of Clarity About ACP

Patients and clinicians need to be consistent about what ACP means and transparent about when it is occurring. Participants' understanding and experience of ACP varied significantly. In the survey administered prior to the focus group, most indicated on the questionnaire that they had completed some form of documentation of wishes, including a combination of advance directives (56%), living wills (79%), and identification of proxies (62%). Yet, 29% of participants indicated that they had not engaged in ACP with a member of their healthcare team or were unsure (Table 3), despite having reported during the initial phone screen that they had previously participated in ACP. This doubt was expressed even by some participants who had been identified via claims data as having had a clinical encounter for which an ACP billing code was submitted to Medicare.

Participants described a wide range of definitions of ACP and some lacked clarity on what constitutes an ACP discussion. Some participants conflated planning efforts outside of their clinical encounters, such as estate planning or meeting with attorneys. Others recalled only brief or superficial discussions with a clinician. For example, when asked to describe their experience with ACP, one participant responded, "When I went through my divorce, my lawyer wanted me to get all my documents in order, that's when I got the Power of Attorney… the Health Care Proxy, the Will." (group G, participant 1). Another participant directly addressed confusion regarding ACP and whether they would engaged in it: "It's like speaking Latin or something…. A lot of us don't—you know, we may have done it [ACP], and we don't even know if we have done it is the problem. Because for some reason, when you're older and you have a health care issue, [clinicians] don't seem to get through to you really." (group E, participant 2).

Others described in-depth and iterative discussions that might include both clinicians and family/caregivers. One described ACP with her internist, "She's wonderful. She always sits and says, 'Okay, tell me what's gone on this year. And what are you thinking about? What bothers you?'" (group F, participant 5).

Relatedly, participants acknowledged they were not aware of the Medicare billing codes for ACP. When asked to reflect on their perceptions of the codes, a range of responses were reported. Some supported use of the code "I mean it's part of your healthcare. It's something that should be taken care of." (group A, participant 2), while others expressed that billing for ACP was not appropriate "…it appalls me to think that that's a billable moment in the course of my care. It would never have occurred to me that one would be billed for that question [have you had ACP]." (group C, participant 2). It is notable that those who expressed more resistance to the concept of billing for ACP also described less engaged and transparent ACP experiences.

Trusted and Established Clinician/Patient Relationships

The quality of the relationship between a clinician and patient strongly influenced perception of the ACP experience. According to one participant, "I think you have to have such a good relationship with your doctor before you have the conversation, and I think it only makes it just better." (group B, participant 4). Similarly, a participant emphasized the existing positive relationship with a clinician as a key factor in feeling comfortable and promoting a quality ACP discussion, "…you know, you've been with a doctor for a really long time, and you kind of grew up with them, and they spend a whole lot of time with you and they're a little bit more connected to you." (group F, participant 2).

In contrast, participants who felt they had more superficial relationships with their clinician or changed clinicians frequently described lower quality experiences of ACP: "Well, my experience with my PCP has been …She told me to bring in a copy [of Advance Directives], you know, but we didn't discuss anything. I have a little prejudice that nowadays you get so little time with your PCP, you know, unless you press them…you don't get very much feedback." (group G, participant 4). The participant expressed a desire to have a more in-depth discussion, but did not feel that her clinician relationship facilitated that.

Participants recommended that clinicians normalize ACP, and initiate in-depth discussions using an empathic and honest approach. As exemplified by one participant, "…we are not thinking about [ACP] independently…so at some point in the care system, this is a conversation that should be initiated by the doctors." (group B, participant 4). Other participants offered advice on direct approaches clinicians could take to open discussions, like asking questions: "I would say, 'have you had an end of life discussion? Would you like one?'" (group B, participant 2).

Transparency in ACP Communication and Documentation

Clear, direct, and honest communication was endorsed as key to positive ACP experiences. Good communication was characterized as providing open, transparent answers, and caring and active listening by the clinician. For example, one participant noted, "they are being professional, but sometimes there was a gentleness and caring that was in her voice. And it's not that she said, 'don't worry it will be alright.' It was, 'I'm really listening. I am respecting'. …and if you can convey that in your voice and eye contact, I think it will ease the conversation and it will flow." (group B, participant 3).

Mechanics of communication also mattered to participants: "my new doctor actually faced me in the appointment. … they—it was our first meeting—actually pulled up a chair and faced me. And then he would turn occasionally and swivel and put something in the computer. But basically,

we were having a chat." (group E, participant 3). Good communication extends to clarity in language and terminology. As one participant noted, "I love her because she's easy to talk to. She talks in regular people terms, you know, it's not a bunch of, you know, doctor terms." (group D, participant 2). Some participants noted that the language and terminology surrounding ACP seem to be constantly changing, making it difficult for them to engage in an informed conversation. One said, "Seniors are challenged in many ways, whether it's with a hearing issue or a communications issue or understanding all the medical terminology that's being thrown at you instead of just an old-fashioned country doctor approach where they sit down and talk with you and tell you in layman's terms or common-sense terms what needs to be done and what's going to happen when you take these medicines." (group D, participant 4). Another participant linked the language used as contributing to patient confusion regarding ACP, "I am concerned about (how) the language around this keeps changing… So, that is extremely confusing. And I don't know how you do it, what you do to educate people. That, you know, there's a Living Will. And there's Advanced Directives. And there's Advanced Care Planning." (group E, participant 7).

One participant who described a positive relationship with his clinician acknowledged that communication eroded when discussing ACP, "Conversation with him was he sort of deflected it a little bit, but he has always been open with me." (group C, participant 4). Another participant described similar avoidance from her clinician to explore preferences in-depth, "I also have a good PCP, but all she wanted was a copy of my documents. And she never really went into detail…(group G, participant 2).

Participants offered recommendations to improve communication and transparency. They expressed a preference to have information to review on their own time, to educate and empower themselves. One participant recounted a discussion with her clinician who provided a packet of written information (including copies of advance directives) before ACP, "I said I'm so glad that you gave me this. Because if I was to just walk in here and you just started asking me this stuff, this would have been a wasted appointment because I would have not known what to say. …They have to give us some time to think about those things, but we can't think about it if we don't know what the questions are." (group D, participant 2).

Some recommendations participants offered are relevant to the health system itself, by ensuring access to their ACP information. Many expressed uncertainty that their preferences would be honored subsequent to a discussion, even if documentation was completed. One noted, "I filled it [advance directive] out. And I had multiple copies made and gave it to every one of the doctors that is treating me and my primary care doctor I insisted sign and return it to me. But I still don't feel secure. I don't know why." (group

E, participant 2). Many participants lacked confidence in how key information is best accessed when necessary, and were frustrated by their own efforts to find their documentation within healthcare system portals. Another described the forms he had signed, "Where do I find that? How can I go into My Chart and see, when's the last time I signed this? And when I signed, is this what it means?" (group E, participant 7). While patients were not able to offer a clear consensus on the best way for health systems to establish responsive and accessible information sharing, there was agreement that systemic improvements are necessary to alleviate patient doubt surrounding ACP communication and transparency, documentation, and access.

Revisability of ACP

Patients perceived quality ACP as a collaborative process with their clinicians, one that could lead to shared decision-making about their care, including probing for patient preferences, weighing multiple options, and deliberation.[24] It was important for ACP to be perceived as revisable and understand that discussions were ongoing. For example, "Well for me especially because the conversation led me from one decision to kind of change it and really understand what I was doing, you know, as far as making those decisions. That was important." (part. 3). One participant appreciated that the clinician acknowledged that preferences may evolve over time and need to be revisited: "But I talked to him too, and he said, '…we will ask you again if you still have these thoughts.' But…he seemed to be very agreeable… and willing certainly to follow that. It's documented in my medical chart now." (group F, participant 6).

To facilitate and support ongoing discussions, participants described the importance of having another person, such as a caregiver, with them during ACP discussions. They may hear or remember points that the patient missed and can help with interpretation and review of the discussion afterwards. "I think the best way is to have somebody with you so you have another set of ears…So that you can—when you get out of that environment, you can go over what you have actually heard." (group G, participant 4). Another person shared that his spouse attends all his appointments, "I would submit that it's difficult to listen when you are talking …if you have a partner that can be there, that can focus on the dynamics of the situation and can help provide some feedback for that level of trust, that bond that may be going on." (group B, participant 2).

DISCUSSION

Medicare patients experience a spectrum of ACP services. This study identified over a quarter of participants who lacked clarity about whether they had experienced ACP. Many also felt that communication was problematic, indicating a need to improve availability of training for clinicians

and education for patients. Since some participants noted the value of having material to review prior to engaging in discussions, clinicians may consider how to address ACP across multiple visits and identify supportive resources. Additionally, a variety of decision tools are available to support shared decision-making.[25–27] Importantly, as the presence of family/caregivers was endorsed by participants as important to quality ACP, clinicians should ensure caregivers have an opportunity to be present for key discussions or share their preferences with them, based on patient preference. Family dynamics may be complex and clinicians should assess how that may influence ACP.[28]

Prior research indicates that while clinicians prefer to engage in shared decision making with patients, there is a perceived lack of understanding by the patient regarding prognosis and expectations.[10,29] Our findings suggest that patients can best engage in ACP when clinicians offer time for clear, transparent communication in a supportive environment. This is particularly relevant since participants expressed a range of experiences as ACP, and there was a lack of consensus on what should be considered billable services. It may be helpful for clinicians to take the time to define ACP during the course of regular wellness visits.

Since limited time is a significant barrier to quality ACP, health systems may consider strategies to reduce clinician time burden through team-based [30] or navigator-driven approaches. [31,32] Interprofessional teams including nurses and social workers offer models for collaboration in providing ACP, particularly for patients with serious illness.[33,34] One analysis of patient decision-making processes during ACP focused on preferences for life-sustaining treatment and found that diverse values among patients cannot be met with a "one-size-fits-all" approach.[35] Understanding individual preferences can be resource-intensive.

Health systems can facilitate these improvements by providing the resources necessary for clinicians to participate in relevant education or training. Multidisciplinary and systematic training can improve the quality of communication in ACP, [36,37] including education of patients and families.[38] Reliance on established relationships, as many participants described, is challenging in a system where care providers may be changed frequently. Importantly, patients should be aware that they are engaging in ACP in order to participate in quality discussions. Offering patients different modalities, such as videos, to support decisions can help reduce uncertainty, especially among those with lower health literacy.[39]

Health systems should also address ways to mitigate patient concerns or doubt that information about their care preferences will be available to clinicians when needed. Value of ACP is linked to accessibility-patients want assurance that preferences will be available. Areas of focus include strengthening systems to share documentation, interoperability of electronic health records, and clarifying how key decisions will be accessed by other members

of care teams or in emergent situations. A Delphi panel convened to identify successful outcomes of ACP discussions included "documents and recorded wishes are accessible when needed" as a top construct.[40] Participants in these focus groups expressed a lack of confidence that their information would be accessible, indicating that progress is still needed to address this component of successful ACP. Efforts to improve transparency and communication may also mitigate issues with patient confusion regarding whether they had engaged in ACP, and what those discussions should include (recommendations summarized in Table 4).

Limitations

Although this study presents a novel geographically diverse sample, the findings should be interpreted within the study's limitations. Our findings may not be generalizable to a broader Medicare population, due to limited participation from racial and ethnic minorities and beneficiaries with moderate or low education levels. While we made efforts to recruit participants with a broad array of ACP experiences, it is possible that those who had a negative experience were less motivated to participate and their perspectives may not have been captured.

There were differences in our sampling strategies across sites to accommodate local requirements. Selecting patients by having a primary care provider confirm they have had an ACP discussion with a patient, and obtaining approval to contact those patients from the clinician may bias the sample towards encounters that the clinician recalled as positive or productive. This limitation was mitigated by including other sampling strategies that did not depend on clinician referral (opting in and billing code data). Finally, while our inclusion criteria included patients who perceived that they have had an ACP discussion, it did not need to be recent, and it was revealed during the focus groups that their understanding of the term ACP was variable. This issue was further illustrated in questionnaire responses, where there were high non-response rates to items such as satisfaction with ACP or completion of forms. However, this is consistent with the finding associated with the

transparency in communication and documentation theme that patients are frustrated with changing language and terminology around ACP, making it difficult for them to stay informed.

CONCLUSIONS

Key recommendations from patients to improve the ACP experience include actionable steps for clinicians and specific policies that can be implemented at a health system level. Clinicians should facilitate shared decision-making during ACP discussions, offering resources for patients to review outside encounters, and include family and caregivers as appropriate. Health systems can facilitate improvements by supporting clinician training in communication, allocating sufficient time to deliver ACP services, and ensuring that electronic systems for documentation of preferences are accessible and available.

PARTICIPANT RECRUITMENT STRATEGIES

At one site, we first contacted primary care clinicians to request a list of patients who had completed ACP discussions (either billed or documented) for permission to invite patients to participate in the study by mail. At another site, patients were identified via the local ACP clinic, Patient and Family Advisory Council (PFAC), and volunteer clinic, and could opt-in by calling or emailing the research team. At two sites, we identified eligible patients via billing code data (i.e., Medicare beneficiaries who had been billed for an ACP discussion) and contacted patients using purposive sampling criteria. At one site, the health system patient registry (designed to identify participants and request data) was used to identify patients that had ACP listed in their progress notes. We then contacted their clinicians for approval to contact patients. Upon the clinician's approval, we sent an opt-in/out letter then called the patient.

Table 4 Summary of Recommendations

Health system recommendations	
Education	Offer and support clinician training in ACP
Reduce clinician time burdens	team-based, multi-disciplinary approaches and navigator-driven ACP
Availability of documentation	Ensure inter-operability of EHR and usability of ACP forms in records
Clinician recommendations	
	Provide patient education and offer diverse modalities (such as video) to support patient understanding of ACP
	Provide materials for patient review before discussion, provide patients a "heads-up" to allow time to prepare
	Include family/caregivers based on patient preference, or facilitate sharing of preferences if they cannot attend visit

Corresponding Author: *Amanda J. Reich, PhD, MPH; Center for Surgery and Public Health, Brigham and Women's Hospital, One Brigham Circle, 1620 Tremont Street, Suite 2-016, Boston, MA 02120, USA (e-mail: ajreich@bwh.harvard.edu).*

Declarations

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