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English and Spanish-speaking Vulnerable Older Adults Report Many Barriers to Advance Care Planning

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Abstract

Background/Objectives: Advance care planning (ACP) rates are low in diverse, vulnerable older adults, yet little is known about the unique barriers they face and how these barriers impact ACP documentation rates.

Design: Validated questionnaires listing patient, family/friend, and clinician/system-level ACP barriers and an open-ended question on ACP barriers

Setting: Two San Francisco public/Veterans Administration (VA) hospitals

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Author Contributions: Ms. Phung and Dr. Sudore had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Study concept and design: Sudore, Phung.

Acquisition, analysis, or interpretation of data: All authors.

Drafting of the manuscript: Phung, Sudore.

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Study supervision: Sudore.

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Trial Registration: [ClinicalTrials.gov](https://clinicaltrials.gov) identifiers: “Improving Advance Care Planning by Preparing Diverse Seniors for Decision Making (PREPARE)” [NCT01990235](https://clinicaltrials.gov/ct2/show/study/NCT01990235) and “Preparing Spanish-speaking Older Adults for Advance Care Planning and Medical Decision Making (PREPARE)” [NCT02072941](https://clinicaltrials.gov/ct2/show/study/NCT02072941)

Participants: 1241 English and Spanish-speaking patients, aged 55, with two chronic conditions

Measurements: The open-ended question on ACP barriers was analyzed using content analysis. We conducted chart review for prior ACP documentation.

We used Chi-square/Wilcoxon rank-sum tests and logistic regression to assess associations between ACP barriers and demographic characteristics/ACP documentation.

Results: Participant mean age was 65 ± 7.4 years; they were 74% from racial/ethnic minority groups, 36% Spanish-speaking, and 36% with limited health literacy. A total of 26 barriers were identified (15 patient, 4 family/friend, 7 clinician/system-level), and 91% reported at least one ACP barrier (mean: 5.6 ± 4.0). The most common barriers were: (patient-level) discomfort thinking about ACP (60%), wanting to leave health decisions to “God” (44%); (family/friend-level) not wanting to burden friends/family (33%), assuming friends/family already knew their preferences (31%); (clinician/system-level) assuming doctors already knew their preferences (41%) and mistrust (37%). Compared to those with no barriers, participants with at least one reported barrier were more likely to be from a racial/ethnic minority group (76% vs. 53%), Spanish-speaking (39% vs. 6%), with fair-to-poor health (48% vs. 34%) and limited health literacy (39% vs. 9%) ($p < 0.001$ for all). Participants who reported barriers were less likely to have ACP documentation (adjusted OR = 0.64, 95% CI [0.42, 0.98]).

Conclusion: English- and Spanish-speaking older adults reported 26 unique barriers to ACP, with higher barriers among vulnerable populations, and barriers were associated with lower ACP documentation. Barriers must be considered when developing tailored ACP interventions for diverse older adults.

Keywords

barriers; advance care planning; vulnerable populations

Introduction

Advance care planning (ACP) is a process whereby people communicate their goals and preferences for future medical care. Ideally, ACP includes more than one-time completion of an advance directive; instead, it should be an ongoing process informed by multiple conversations with clinicians, caregivers, and family that evolve over time.¹⁻⁴ While prior research on the benefits of ACP has been mixed,⁵ some studies suggest that ACP reduces stress and anxiety among family members, improves end-of-life communication, increases the likelihood of receiving care aligned with stated wishes, and reduces hospitalizations before death.⁶⁻⁹

However, rates of ACP are low. Fewer than two thirds of older adults in the US have engaged in ACP discussions or documentation, with lower rates among non-English-speaking and racial/ethnic minority individuals.¹⁰⁻¹⁵ Clinician-related barriers to ACP include personal discomfort with discussing end-of-life care, fear of causing distress, lack of time and reimbursement, and lack of training.¹⁶⁻²¹ Thus far, patient-reported barriers include discomfort with the topic of dying, confusion with the legalese of advance directives, and

lack of knowledge about medical interventions at the end of life.²²⁻²⁴ However, these studies have been small, qualitative, and focused on particular chronic disease states such as chronic renal and lung disease, with minimal attention to unique barriers among diverse older adults.²⁵⁻²⁸

Little is known about barriers to ACP among diverse English and Spanish-speaking older adults. Understanding ACP barriers is important for developing educational materials for diverse older adults, as limited tools exist to meet the unique needs of diverse populations.^{29,30} In this study, we describe the ACP barriers self-reported by diverse older adults, the sociodemographic characteristics of participants reporting barriers, and the association between barriers and ACP documentation. We hypothesized that vulnerable participants were more likely to report ACP barriers compared to non-vulnerable participants, and that those reporting ACP barriers were less likely to have engaged in ACP.

Methods

In this cross-sectional study, we used baseline data from 1241 English and Spanish-speaking patients enrolled in two ACP randomized controlled trials (RCTs) from 2013 to 2017 in San Francisco public and Veterans Administration (VA) hospitals. This study was approved by the San Francisco VA and the University of California, San Francisco IRBs, and written informed consent was collected for all participants.

Participants and Enrollment Criteria

Participants included 1) 264 veterans enrolled from women's, geriatrics, and general medicine clinics at the San Francisco VA from April 2013 through July 2016; and 2) 977 study participants enrolled from four primary care clinics within the San Francisco Health Network (SFHN), a public-health delivery system, from February 1, 2014, to November 30, 2017. Patients were eligible if they were 55 years or older, spoke English or Spanish well or very well, and had at least two chronic medical conditions by medical record review, and completed all barrier survey items (see below). Full recruitment and study procedures have been previously published.^{14,15,31,32}

Outcomes

We created a list of 18 potential barriers from two sources. Twelve barriers were included from the Barriers to Advance Care Planning survey²¹, which consisted of yes/no questions such as, "Are you being held back from thinking about what you would want if you were to get very sick because thinking about it makes you nervous, sad, or uncomfortable?" or "because your doctor is too busy to talk with you about it?" These barrier items were included in participant surveys categorized as relating to the patient (n=6), friends and family (n=3), or their clinician/the health system (n=3). Six barriers were also included from the validated Processes of Change survey.³³ Participants were asked the extent to which they agreed with statements such as, "It would be hard to do ACP because there are too many options to consider for my end-of-life care" (barrier statement) or "I can count on my loved ones to help me with ACP" (facilitator statement). These barriers were then dichotomized from the original 5-point Likert scale (strongly disagree, disagree,

neither, agree, strongly agree) into yes (barrier statements: agree to strongly agree; facilitator statements: disagree to strongly disagree) and no statements (barrier statements: neither to strongly disagree; facilitator statements: neither to strongly agree). We also organized these barriers into patient-related (n=4), family/friend-related (n=1), and clinician/system-related (n=1) barrier categories. Validity, reliability, and scoring of these two survey measures have been previously published.³²

Participants could also report open-ended information about additional barriers. These open-ended responses were analyzed using thematic content analysis by one author (LP) and validated independently by two additional authors (RS & NS). The qualitative assessment of these open-ended responses revealed eight additional barriers. The barriers were organized into patient-related (n=5) and clinician/system-related (n=3) barrier categories.

In addition to reporting individual barriers, we created a measurement of total barrier burden for each participant. This was calculated by summing together the 18 close-ended and 8 open-ended barriers (i.e., possible maximum score of 26). We hypothesized that participants who reported more barriers would face more difficulty engaging in ACP and, therefore, have lower rates of ACP engagement. See supplementary material (Figures S1-S2, Table S1) for more detail on the instruments and coding method.

To assess whether barriers were associated with baseline ACP documentation, we also conducted electronic medical record (EMR) review to assess whether the participant had engaged in any prior ACP. ACP documentation included both documented forms (i.e., advance directives, etc.) and orders and documented discussions (i.e., physician's notes that describe patients' wishes for medical care). We assessed prior ACP discussions and documents separately and as a composite measure. Two independent research assistants reviewed the medical record data to determine prior ACP engagement up to 5 years before the interview, and discrepancies were adjudicated by the principal investigator (RS).^{14,15}

Other Measures

We obtained self-reported participant characteristics including age, sex, race/ethnicity (dichotomized to White race and non-Hispanic/Latinx ethnicity vs. Black/African American, Asian/Pacific Islander, American Indian/Alaska Native, multiethnic, other race or Hispanic/Latinx ethnicity), educational level (less than or equal to a high school completion vs. beyond high school), US acculturation (birthplace outside vs. inside of the US), religiousness or spirituality (5-point Likert scale dichotomized as fairly-to-extremely vs. somewhat, a little, not at all), self-rated health and functional status (5-point Likert scale dichotomized as fair-to-poor vs. good, very good, excellent). We also assessed health literacy using the validated Short Test of Functional Health Literacy in Adults (sTOFHLA)³⁴ (dichotomized with a standard cutoff of ≤ 22 of 36 defined as limited health literacy vs. > 22 of 36 defined as adequate health literacy) and how patients preferred to make their medical decisions with their doctors using the Control Preferences Scale³⁵ to assess (making all decisions on their own: high decision control preference, sharing decision making: moderate decision control preference, or having the doctor make all decisions: low decision control preference). We also used the validated, modified 11-item Medical Outcomes Study Social Support Survey (MOS-SSS) to assess participant social support. MOS-SSS scores, which

ranged from 11 (no support) to 55 (full support), were then dichotomized into the lowest quartile versus higher quartiles.^{36,37}

Statistical Analyses

We used descriptive statistics to describe the study population, the frequency of each barrier, and the median barrier burden with interquartile ranges (IQR). We then used non-parametric bivariate statistics (Chi-squared test, Wilcoxon rank-sum test) to assess associations between demographic characteristics and presence of barriers, as well as between demographic characteristics and barrier burden. Bivariate and multivariate statistics (Chi-squared test, logistic regression) were then used to examine the relationship between prior ACP documentation and the presence of barriers/barrier burden. We then conducted an exploratory analysis to assess which close-ended barriers were most strongly associated with differences in documented ACP discussions and forms/orders. We used SAS, version 9.4 (SAS Institute Inc) and STATA version 16.0 (Stata Corp) for all analyses.

Results

Of the 1241 participants, the mean age was 65 ± 7.4 , 51% were women, 74% were from a racial/ethnic minority group, 36% were primarily Spanish-speaking, 65% were born outside the US, 36% had limited health literacy, 47% self-rated their health as fair-to-poor, and 32% had ACP documented in their medical record (Table 1).

Most Common Participant-Identified Barriers to Advance Care Planning

We identified a total of 26 barriers: 18 from survey responses and 8 additional barriers from open-ended responses. Of those, 15 barriers were related to the patient (10 close-ended, 5 open-ended), 4 barriers were related to family and friends (4 close-ended), and 7 barriers were related to clinicians or the health system (4 close-ended, 3 open-ended).

See Table 2 for all barriers. The three most commonly reported patient-level barriers included discomfort with thinking about ACP (748/1241, 60%), preference for leaving their health decisions to “God” (44%), and feeling overwhelmed with ACP options (42%). The three most common family/friend-level barriers included not wanting to burden friends or family (33%), believing family or friends already knew their preferences (31%), and not having someone with whom to discuss ACP (20%). The three most common clinician/system-level barriers included participants’ believing their doctor already knew their preferences (41%), being mistrustful of their doctor or the health system (37%), and feeling ill-informed about their health (18%). In addition to its inclusion as a close-ended barrier, the theme of mistrust was often echoed in the open-ended responses, with 21 participants making statements such as “I don't like my doctor. I don't think he cares about me,” and “You feel like a number because they are the ones that are educated.”

Other novel patient and clinician-level barriers were reported in qualitative analysis (Table 2). Patient-level barriers identified through open-ended responses included being new to the concept of ACP (n=18 “Never thought about it before”), procrastination (n=16, “I've been putting it off”), lacking information on ACP (n=15, “I do not have the information needed to make a proper decision,” “I do not know how to get the official forms, and I do not know

if I would be able to put the appropriate technical terms on the document to convey my wishes”), concerns about personal privacy (n=5, “I don’t like to talk about my personal stuff with some people”), and physical/cognitive challenges (n = 2, “I have been through pain and illness recently that makes it difficult to concentrate on this topic”).

Clinician/system-level barriers from open-ended responses included lacking continuity of care (n=7, “the doctors come and go so quick, I just don’t bring it up. I have a new one every couple of months”), language barriers (n=5, “doctor doesn’t speak Spanish so [we] can’t really communicate”), and waiting for others to initiate ACP discussions, (n=5, “It has not come up with the doctors,” “The topic doesn’t come up unless someone initiates it”).

Barriers and Participant Characteristics

Of the 1241 participants, 1126 (90.7%) reported at least one barrier to ACP. Compared to those with no reported barriers, participants with at least one reported barrier were more likely to be from a racial/ethnic minority group (76% of participants with at least one barrier were a racial/ethnic minority vs. 53% of participants with no barriers, $p<0.001$), born outside the US (66% vs. 48%, $p<0.001$), primarily Spanish-speaking (39% vs. 6%, $p<0.001$), non-college-educated (53% vs. 20%, $p<0.001$), with limited health literacy (39% vs. 9%, $p<0.001$), fair-to-poor self-rated health (48% vs. 34%, $p < 0.001$), low levels of social support (27% vs. 6%, $p<0.001$), and low decision control preferences (10% vs. 1%, $p<0.001$). The percentage of participants who reported at least one versus no barriers did not differ significantly by age, sex, or degree of religiousness/spirituality.

Barriers and ACP Documentation

Compared to participants with no prior ACP documentation, those with prior documentation still reported at least one ACP barrier (92% vs 87%, respectively, $p = 0.04$). Having at least one ACP barrier also affected the rate of ACP documentation. Participants reporting at least one barrier were less likely than those reporting no barriers to have ACP documented in their EMR, including documented discussions and forms/orders (31% of participants with at least one barrier had documented ACP vs. 44% of participants with no barriers, $p = 0.004$). In an unadjusted logistic regression, participants who reported at least one barrier had lower odds of having documented ACP in the EMR compared to participants with no barriers (odds ratio (OR) = 0.59, 95% confidence interval (CI) [0.40, 0.87]). This relationship remained significant after adjusting for the eight demographic factors listed above (OR = 0.64, CI [0.42, 0.98]). Results were similar in magnitude when assessing documented ACP discussions and ACP forms/orders separately (documented discussions: unadjusted OR = 0.60, CI [0.38, 0.95]; adjusted OR = 0.68, CI [0.42, 1.11]; documented forms/orders: unadjusted OR = 0.53, CI [0.35, 0.81]), adjusted OR = 0.59, CI [0.37, 0.92]).

Barrier Burden

The mean number of barriers, or barrier burden, was 5.6 (± 4.0) out of 26. Scores were right-skewed, with 233 participants (19%) reporting 10 or more barriers. Barrier burden was higher among participants who reported being female, a racial/ethnic minority, born outside the US, primarily Spanish-speaking, non-college-educated, and having limited health literacy, poorer health, lower levels of social support, and lower decision control preferences.

Barrier burden did not differ based on age or degree of religiousness/spirituality (see Table 3).

Prior total ACP documentation (documented discussions and forms/orders) was not associated with differences in barrier burden (5 (\pm 6) barriers among participants with prior ACP vs. 5 (\pm 6) among participants with no ACP, $p = 0.19$), nor were the subset of documented ACP discussions associated with differences in barrier burden (5 (\pm 7) vs. 5 (\pm 6), $p = 0.39$). However, prior documentation of ACP forms/orders was associated with less barrier burden (4 (\pm 6) vs. 5 (\pm 6), $p = 0.03$). In unadjusted and adjusted logistic regressions, barrier burden was not associated with prior total ACP (OR = 0.98, CI [0.95, 1.01]; OR = 1.01, CI [0.97, 1.05]), or ACP discussions (OR = 0.99, CI [0.95, 1.03]; OR = 1.03, CI [0.98, 1.08]). In unadjusted logistic regression, barrier burden was associated with lower odds of documented forms/orders (OR = 0.96, CI [0.93, 0.997]), but not in adjusted analysis (OR = 0.99, CI [0.95, 1.03]).

Exploratory Analysis: Barriers Most Predictive of Prior ACP Documentation

Participants who reported the following barriers were less likely to have documented ACP forms or orders in their medical record than those without these barriers: mistrust of doctors/the health system (18% vs. 24%, $p = 0.01$), discomfort thinking about ACP (19% vs. 25%, $p = 0.02$), feeling too busy to engage in ACP (16% vs. 23%, $p = 0.02$), a preference for leaving health decisions to “God” (19% vs. 24%, $p = 0.03$), and a belief that ACP goes against a lifestyle of living in the moment (18% vs. 23%, $p = 0.04$), Table 4. Participants who believed family or friends already knew their preferences and reported this as a barrier, versus those who did not, were more likely to have documented ACP discussions in their medical records (22% vs. 16%, $p = 0.02$).

Discussion

To our knowledge, this is the largest study to explore barriers to ACP among diverse English and Spanish-speaking older adults and the first to describe barrier burden. Of the 26 barriers identified, the most common included discomfort with thinking about ACP, wanting to leave health to God, not wanting to burden friends or family, mistrust in clinicians, and believing doctors already knew participants’ preferences. Racial/ethnic minorities, Spanish speakers, non-college-educated participants, participants with limited health literacy, and participants with less social support were more likely to report at least one barrier to ACP, as well as a higher barrier burden, compared to their less vulnerable counterparts.

The presence of at least one barrier was significantly associated with lower rates of prior ACP documentation, including documented ACP discussions and forms/orders. Specifically, three barriers—mistrust in clinicians or the health system, discomfort with thinking about ACP, and preference for leaving health decisions to “God”—were associated with lower rates of documented ACP forms/orders. Of note, higher rates of ACP discussions were found among participants who self-reported the barrier that friends and family already knew their ACP preferences without having discussed them. Reporting this barrier during the study may reflect participants’ realization during the study that they may have had a false sense of confidence of being “done” with ACP after documenting or discussing their wishes with a

clinician, and that they had not yet engaged in the important ACP behavior of discussing their wishes with family and friends.

Many barriers reported in this study were consistent with those cited in prior studies (discomfort with thinking about ACP, wanting to leave decision-making to “God”/family/ doctors, perceiving clinicians as unavailable for discussion, not believing ACP to be relevant or urgent).^{24,28,38-44} Some unique barriers obtained through qualitative analysis in this study included lack of resources to act on ACP wishes, privacy concerns, lack of continuity of care, and language barriers. In addition, some barriers have been identified in prior studies, including focus groups that we previously conducted, that were not reported by participants in this trial, namely: conflation of medical and financial planning^{39,41,45} and the taboo nature of discussing death^{21,38,39,46} These barriers should be included in future surveys and studies as well.

Several barriers reported in this and prior studies are particularly relevant to underserved populations, including a lack of information on ACP (e.g. access to health-literacy tailored material)^{24,38,42,47} and a profound mistrust in clinicians and the health system (e.g. concerns wishes would not be followed).^{40,42,48-50} Additionally, Hong et al. found that ACP engagement was lower among racial/ethnic minorities and those with lower health literacy.⁴⁷ We build on these findings by assessing barrier burden and showing that vulnerable individuals (e.g. racial/ethnic minority, non-US-born, lower health literacy, non-college-educated) reported a greater number of distinct barriers to ACP compared to less vulnerable individuals.

Our analysis also suggests that the impact of reported barriers on ACP engagement is highly individual and variable. The broad majority of participants with prior ACP documentation continued to report at least one barrier to ACP. While the presence of at least one barrier significantly predicted lower ACP documentation, we did not find an association with barrier burden (i.e., increased number of barriers). When assessed individually, only a few barriers were significantly associated with lower ACP documentation (e.g., mistrust in clinicians/health system); however most individual barriers were not associated with ACP documentation in this cohort. ACP is a complex process that involves many behaviors. For instance, patients may have designated a surrogate but not yet thought through their values and preferences. For some patients, the presence of one barrier may be powerful enough to keep them from engaging in ACP, whereas other patients may have several barriers but are still able to engage in some ACP behaviors. For example, patients who only experience the barrier of mistrust may still not be able to engage in ACP. Alternatively, patients who experience a language barrier with their physician may still be able to engage in ACP if they have access to a translator or support from family and friends.

Thus, to achieve broader gains in ACP adoption, a one-size-fits-all approach is less likely to be effective for vulnerable older adults. Efforts to improve ACP engagement will instead need to be nuanced, complex, and tailored to the individual. For example, we found pervasive distrust in the health system. Thus, rather than relying solely on clinicians to introduce ACP, there should also be efforts outside the clinical setting to empower individuals to learn about ACP. Educational materials should be written with

easy-to-read language and devoid of medical jargon, as barriers were disproportionately found among those with lower educational and health literacy levels. Interventions for vulnerable populations should also address common misconceptions about ACP and facilitate discussion with family and friends. Additionally, given the larger burdens found among primarily Spanish-speaking participants, ACP materials need to be appropriately culturally translated. Follow-up studies will be needed to assess whether tailored ACP interventions may be effective at addressing these unique barriers.

Limitations

The study was limited to older adults living in the San Francisco Bay Area and may not be generalizable to other populations. While several barriers were identified through thematic content analysis of open-ended responses, we were not able to assess the frequency of these barriers across all study participants, nor to compare them to the close-ended barriers included in the survey. Future studies may include these additional open-ended barriers as part of larger quantitative studies. This study also relied on self-reported survey data and may not fully capture the barriers to engaging in ACP, especially barriers that are emotionally laden, stigmatizing, or related to cultural values. While planned for future analysis, it was beyond the scope of this study to explore differences in the 26 individual barriers by demographic characteristics. In the exploratory analysis, some findings may have occurred by chance.

Conclusion

English- and Spanish-speaking older adults reported 26 unique barriers to ACP and the presence of at least one barrier was associated with lower rates of prior ACP documentation. Racial/ethnic minorities, Spanish speakers, and participants with limited health literacy were more likely to report higher barrier burden compared to their less vulnerable counterparts. Tailored solutions for vulnerable populations are needed, such as empowering individuals who mistrust the health system to learn about ACP with easy-to-understand, culturally translated educational tools.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Key points:

- Diverse English and Spanish-speaking older adults report 26 unique barriers to advance care planning, including discomfort with thinking about advance care planning and mistrust in clinicians.
- Barriers to advance care planning were more commonly reported among traditionally vulnerable groups of participants, such as Spanish speakers and individuals with limited health literacy.
- Individuals who reported barriers to advance care planning had lower odds of advance care planning documentation, including both legal forms (e.g., advance directives) and documented discussions with their provider.

Why does this paper matter?

This study describes barriers to advance care planning (ACP) as reported by a large sample of diverse, English- and Spanish-speaking older adults. The study found that barriers were more commonly reported among vulnerable populations and were associated with lower ACP documentation.

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Table 1:

Participant Characteristics

Participant Characteristic	Total N = 1241	1 Barrier N = 1126	No Barriers N = 115	P-value ^e
Age, mean (SD)	65 (7.4)	65 (7.5)	66 (6.8)	0.19
Women, No. (%)	635 (51.2)	583 (51.8)	52 (45.2)	0.18
Non-white race or Latinx ethnicity, ^a No. (%)	919 (74.1)	858 (76.2)	61 (53.0)	<0.001
Place of birth outside US, ^b No. (%)	801 (64.6)	746 (66.3)	55 (47.8)	<0.001
Educational level High school, No. (%)	623 (50.2)	600 (53.3)	23 (20.0)	<0.001
Limited health literacy, ^c No. (%)	445 (36.0)	435 (38.8)	10 (8.7)	<0.001
Primary Language, Spanish, No. (%)	442 (35.6)	435 (38.6)	7 (6.1)	<0.001
Fairly to extremely religious or spiritual, ^d No. (%)	871 (70.4)	785 (69.9)	86 (74.8)	0.28
Low social support (measure of social support score in lowest quartile <30) (11=no support to 55=full support), ^e No. (%)	301 (24.8)	294 (26.7)	7 (6.3)	<0.001
Self-rated health/functional status, fair to poor, ^c No. (%)	583 (47.1)	544 (48.5)	39 (33.9)	0.003
Low decision control preference (i.e. physicians make all medical decisions), ^c No. (%)	113 (9.1)	112 (10.0)	1 (0.9)	0.001
Documented advanced care planning (ACP) in the electronic medical record, No. (%)	403 (32.5)	352 (31.3)	51 (44.3)	0.004
Documented discussions about ACP, No. (%)	226 (18.2)	195 (17.3)	31 (27.0)	0.011
Legal forms and orders (e.g. advance directive, POLST), No. (%)	269 (21.7)	232 (20.6)	37 (32.2)	0.004

^aOf the 919 non-white or Hispanic/Latinx participants, 519 (42%) identified as Hispanic/Latinx, 238 (19%) identified as Black/African American, 98 (8%) identified as Asian/Pacific Islander, 10 (1%) identified as American Indian/Alaska Native, 29 (2%) identified as multiethnic, and 25 (2%) identified as another race.

^bOne participant missing US acculturation data.

^cFour participants missing health literacy, self-rated health, and decision control preference data.

^dThree participants missing religiousness/spirituality data.

^e26 participants missing social support data.

^fIndependent t-test statistic was used to compare the mean age between those with no reported barriers vs. at least one barrier. For remaining demographics, Chi-squared test statistic was used to compare participants with no reported barriers vs. at least one barrier.

Table 2:**Participant-Identified Barriers to Advance Care Planning (ACP)**

Barriers provided in closed-ended surveys, n = 1241		
Patient-Level Barriers		
Thinking about ACP makes me nervous, sad, or uncomfortable	748	60%
I prefer to leave health decisions to God	546	44%
There are too many options to consider	521	42%
I am too healthy / It is not the right time to start ACP	475	38%
Wishes for end-of-life care might change	421	34%
I would rather leave medical decisions to doctors	394	32%
ACP goes against my lifestyle of living in the moment	349	28%
I will always be able to make treatment decisions	345	28%
I am too busy with other things	240	19%
I would rather leave any medical decisions to friends and family	151	12%
Family or Friend-Level Barriers		
I don't want to burden my family or friends	404	33%
Family and friends already know what to do without talking to them	385	31%
I have no one talk to about doing advance care planning	249	20%
Family and friends are too busy to talk about it	218	18%
Physician or Health System-Level Barriers		
My doctors already know what to do without talking to them	511	41%
I don't trust my doctors or the health system	460	37%
I don't know what is going on with my health	224	18%
My doctors are too busy to talk about it	184	15%
Additional barriers identified though open-ended responses,^a n=192		
Patient-Level Barriers		
I have never thought about ACP before	18	9%
I am procrastinating	16	8%
I lack information or understanding of ACP	15	8%
Personal privacy concerns	5	3%
Cognitive impairment from illness is getting in the way of ACP	2	1%
Physician or Health System-Level Barriers		
I lack continuity of care	7	4%
Language barrier exists between my doctors and me	5	3%
I am waiting for someone else to bring it up	5	2%

^aOpen-ended responses were provided by study participants. They were not preexisting items on the questionnaire.

Table 3:

Barrier Burden, by Participant Characteristic

Participant Characteristics		Barrier burden (0-26): Median (IQR)	P-value ^a
Age	<65	5 (6)	p = 0.76
	65	5 (7)	
Sex	Male	4 (5)	p = 0.001
	Female	6 (6)	
Race/ethnicity	White Non-Latinx	3 (4)	p < 0.001
	Non-White or Latinx	6 (6)	
Place of birth	Inside US	4 (4)	p < 0.001
	Outside US	6 (6)	
Educational level	Up to high school	7 (6)	p < 0.001
	Beyond high school	3 (5)	
Health literacy score	Limited	8 (6)	p < 0.001
	Adequate	4 (4)	
Primary language	English	4 (4)	p < 0.001
	Spanish	8 (6)	
Health/functional status	Fair to poor	6 (6)	p < 0.001
	Adequate	4 (6)	
Decision control preference	Low control preference	8 (5)	p < 0.001
	Medium-to-high control preference	5 (6)	
Social support score	<30 (lowest quartile)	6 (6)	p < 0.001
	30	4 (6)	
Religious or spiritual	Fairly-to-extremely	5 (6)	p = 0.86
	Not religious or spiritual	5 (6)	
Prior ACP (Discussions & Forms/Orders)	Prior ACP documented in EMR	5 (6)	p = 0.19
	No Prior ACP documented in EMR	5 (6)	
Prior Documented Discussion	Prior discussion	5 (7)	p = 0.39
	No prior discussion	5 (6)	
Prior Forms or Orders	Prior forms or orders	4 (6)	p = 0.03
	No prior forms or orders	5 (6)	

^aWilcoxon rank-sum test was used to determine significance.

Table 4:

Association between Individual Barriers and Prior ACP Documentation

Barrier	Total Participants		Participants with Documented ACP Discussions			Participants with Documented ACP Forms/Orders		
	Reported	Not Reported	Reported N (%) ^a	Not Reported N (%) ^b	P-value ^c	Reported N (%)	Not Reported N (%)	P-value
Patient-Level Barriers								
Thinking about it makes me nervous, sad, or uncomfortable	748	493	131 (18%)	95 (19%)	0.433	145 (19%)	124 (25%)	0.016
Prefer to leave health in God's hands	546	695	92 (17%)	134 (19%)	0.271	103 (19%)	166 (24%)	0.033
Too many options to consider	521	720	89 (17%)	137 (19%)	0.381	105 (20%)	164 (23%)	0.268
Too healthy / Not the right time for ACP	475	766	75 (16%)	151 (20%)	0.082	92 (19%)	177 (23%)	0.120
Wishes for end-of-life care might change	421	820	75 (18%)	151 (18%)	0.795	79 (19%)	190 (23%)	0.075
Would rather leave medical decisions to doctors	394	847	73 (19%)	153 (18%)	0.844	86 (22%)	183 (22%)	0.930
ACP goes against lifestyle of living in the moment	349	892	58 (17%)	168 (19%)	0.363	62 (18%)	207 (23%)	0.036
I will always be able to make treatment decisions	345	896	57 (17%)	169 (19%)	0.339	70 (20%)	199 (22%)	0.462
Too busy with other things	240	1001	35 (15%)	191 (19%)	0.105	39 (16%)	230 (23%)	0.023
Would rather leave medical decisions to friends and family	151	1090	33 (22%)	193 (18%)	0.216	27 (18%)	242 (22%)	0.227
Family or Friend-Level Barriers								
Don't want to burden family or friends by talking about it with them	404	837	65 (16%)	161 (19%)	0.178	81 (20%)	188 (22%)	0.334
Family and friends already know what to do without talking to them	385	856	85 (22%)	141 (16%)	0.018	88 (23%)	181 (21%)	0.498
No one talk to about ACP	249	992	50 (20%)	176 (18%)	0.393	53 (21%)	216 (22%)	0.867
Family and friends are too busy to talk about it	218	1023	36 (17%)	190 (19%)	0.474	41 (19%)	228 (22%)	0.258
Clinician or System-Level Barriers								
Doctors already know what to do without me talking to them	511	730	99 (19%)	127 (17%)	0.375	121 (24%)	148 (20%)	0.152
Don't trust doctors or health system	460	781	80 (17%)	146 (19%)	0.566	81 (18%)	188 (24%)	0.008
Don't know what is going on with my health	224	1017	38 (17%)	188 (18%)	0.593	44 (20%)	225 (22%)	0.415
Doctors are too busy to talk about it	184	1057	29 (16%)	197 (19%)	0.351	42 (23%)	227 (21%)	0.682

^aDenominator: Number of participants who endorsed the barrier (Total Participants - Reported column).

Numerator: Number of participants who endorsed the barrier and had documented ACP discussion.

^bDenominator: Number of participants who did not report the barrier (Total Participants - Not Reported column).

Numerator: Number of participants who did not report the barrier and had documented ACP discussion.

^cChi-squared test was used to determine significance.