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Quality and Satisfaction With Advance Care Planning Conversations Among English- and Spanish-Speaking Older Adults

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Abstract

Background: Little is known about the patient-reported quality of and satisfaction with advance care planning (ACP) conversations with surrogates and clinicians among English- and Spanish-speaking older adults, or the potential disparities associated with ACP communication satisfaction.

Objectives: To determine patients' perceived quality of and satisfaction with ACP surrogate/clinician conversations and associated patient characteristics.

Design: Cross-sectional baseline data were used from two ACP trials, 2013–2017. Outcomes included self-reported ACP conversation quality (“general” vs. “detailed”) and communication satisfaction (5-point Likert scale). Associations were determined by chi-squared and *t*-tests.

Setting/Subjects: Subjects were primary care patients ≥55 years with chronic/serious illness in the United States.

Results: Of 1398 patients, mean age was 65.6 years (± 7.7), 46% women, 32% Spanish speaking, 34% had limited health literacy, and 589 (42%) reported conversations with surrogates and 216 (15%) with clinicians. Of these, less than half rated the conversations as detailed high quality (clinician: 43%; surrogate: 37%). Five-point communication satisfaction scores were higher with detailed versus general conversations (e.g., surrogates: 4.4 vs. 4.1, $p=0.001$; clinicians: 4.4 vs. 4.2, $p=0.18$) and more often reported by men versus women [(4.4 (0.8) vs. 4.0 (1.0), $p=0.003$]; those with adequate versus limited health literacy [4.4 (0.8) vs. 4.0 (0.9), $p=0.002$]; and English versus Spanish speakers [4.5 (0.7) vs. 3.5 (0.9), $p<0.001$].

Conclusions: Among English- and Spanish-speaking older adults, ACP conversations were infrequent and most were general in quality. Higher quality detailed conversations resulted in greater communication satisfaction. Interventions are needed to improve conversation quality, particularly for Spanish-speaking patients and those with limited health literacy. Trial Registrations: ClinicalTrials.gov identifiers: “Improving Advance Care Planning by Preparing Diverse Seniors for Decision Making (PREPARE)” NCT01990235 and “Preparing Spanish-Speaking Older Adults for Advance Care Planning and Medical Decision Making (PREPARE)” NCT02072941.

Keywords: advance care planning; communication satisfaction; disparities; older adults

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Introduction

ADVANCE CARE PLANNING (ACP), a process by which people prepare for communication and medical decision making,¹ results in greater patient and family satisfaction with end-of-life care.^{2–5} In the past, use of outdated definitions of ACP focused on code status and has resulted in some mixed evidence about the benefits of ACP.^{6–8} However, over the past decade, several larger trials and studies have demonstrated that ACP results in goal-concordant care, improved satisfaction with communication and medical, and improved surrogate distress.^{1,5,9–15}

Despite the demonstrated benefits of ACP, older adults in the outpatient setting report that ACP conversations with clinicians occur only ~50% of the time,¹⁶ and surrogates are often unaware of patients' wishes.^{11,13,17,18} This is particularly true among older adults who are vulnerable to experiencing systemic patterns of disadvantage (henceforth referred to as vulnerable), such as those with limited health literacy and Spanish speakers.^{14,15,19,20} Barriers to ACP discussions in the outpatient context include a lack of time and training for clinicians,²¹ and lack of empowerment among vulnerable populations.^{22–24}

Little is known about the characteristics of English- and Spanish-speaking older adults who have ACP conversations with their family, friends, or clinicians. In addition, little is known about the patient-reported quality of these conversations, such as whether they engaged in detailed or only general conversations with potential surrogate decision makers or clinicians. Therefore, the objective of this study was to describe the frequency of patient self-reported conversations with potential surrogates and clinicians among a culturally diverse cohort of English- and Spanish-speaking older adults with serious and chronic illness.

We also describe participants' perceived quality of the conversations (i.e., detailed vs. general) and satisfaction. We hypothesized that patients who may experience systemic patterns of disadvantage, such as those with limited health literacy and Spanish speakers, would report lower quality conversations and satisfaction with communication.

Methods

We used cross-sectional baseline data from 2013 to 2017 from two randomized controlled clinical trials evaluating the efficacy of PREPAREForYourCare.org, a video-based interactive ACP website.^{25,26} The trial results and the methods have been previously published.^{25–27} These studies were approved by the institutional review boards of the University of California, San Francisco, and the San Francisco Veterans Administration. All study materials were available in English and Spanish and administered by English- or Spanish-speaking research staff. Written informed consent was obtained for all participants using a teach-to-goal process.²⁸

Participants

Participants were recruited from primary care clinics at the San Francisco Veterans Affairs Medical Center (VA) and the San Francisco Health Network (SFHN), a public health delivery system. To be included, patients had to be aged 55 years or older, English or Spanish speaking, have at least two chronic or serious medical conditions, and to have at least

four clinical visits in the past year. Participants were excluded if they had dementia, severe cognitive impairment using validated measures,^{29–31} blindness, deafness, delirium, psychosis, or active drug or alcohol abuse within the past three months as this may have limited the patient's ability to have an informed discussion with their provider.

Participants were also excluded if they did not have a telephone for reminder calls or could not answer the informed consent teach-back questions. Finally, we excluded individuals with missing outcome data ($n=2$).

Covariates

We collected the following participant characteristics at baseline: self-reported age, English and Spanish languages, marital status, and health literacy (s-TOFHLA) (dichotomized into adequate [scores 23–30] vs. limited [scores of 22 or less]).^{32–34} The data collection process has been previously described.¹⁴ Given known disparities in ACP among different racial and ethnic groups,^{35–37} we asked participants about their self-identified race and ethnicity for descriptive purposes.

Outcome measures

We assessed self-reported ACP conversations with a family member or friend the participant reported may be able to help with medical decision making (defined as a "surrogate") and with clinicians. Prior ACP conversations were considered to have occurred if participants reported yes to the following questions: "have you talked with your (surrogate/clinician) about whether or not certain health situations would make your life not worth living" or "have you ever talked with your (surrogate/clinician) about the kind of medical care you would want if you were very sick or near the end of life?"

To determine quality of these ACP conversations, we assessed whether participants considered them to be only "general" conversations or "detailed," and thus, higher quality conversations. We also assessed satisfaction with communication with two questions included in an average 5-point scale: "when you talked with your (surrogate/clinician) about your medical wishes, how satisfied were you that (a) you were able to share your most important concerns and (b) your decision maker/clinician really understood what was important to you?" The response options ranged from "not at all," "a little," "somewhat," "fairly," and "extremely" on a 5-point Likert scale.

Statistical analyses

We conducted descriptive analyses of all socio-demographic measures. We then used *t*-tests and chi-squared tests to test of bivariate differences and associations between patients' sociodemographic characteristics and self-reported ACP conversations, whether the conversations were reported as "general" (low quality) versus "detailed" (high quality), and communication satisfaction scores. We also measured the difference between general versus detailed conversations and communication satisfaction using *t*-tests. Multivariable models were created to adjust for associated demographic variables and communication quality. All analyses were conducted using SAS 9.4 (SAS Institute) and STATA 15.1 (Stata Corp.). All tests of statistical significance were two sided and *p*-value was set at 0.05.

Results

Of 1398 participants, the mean age was 65.6 years (± 7.7), 45.9% were women, 33.9% had limited health literacy, and 31.8% were Spanish speaking (Table 1). Overall, 42% ($n=589$) of participants reported prior ACP conversations with a surrogate decision maker. Of these participants, 42.6% reported having a detailed high-quality conversation. Participants who reported having a detailed ACP conversation with surrogates were more likely to have adequate versus limited health literacy (65.5% vs. 34.5%, $p=0.01$).

There were no differences in English or Spanish language. The mean satisfaction scores for participants who reported having a conversation with a surrogate was 4.3 (0.9). Surrogate conversation satisfaction scores were higher among men versus women [4.3 (0.9) vs. 4.1 (0.9), $p=0.01$], those with adequate versus limited health literacy [4.4 (0.8) vs. 4.0 (1.0), $p<0.001$], and English versus Spanish speakers [4.4 (0.8) vs. 3.8 (0.9), $p<0.001$]. Satisfaction scores were also higher for participants who reported having detailed versus general ACP conversations with surrogates [4.4 (0.9) vs. 4.1 (0.9), $p<0.001$]. Associations between satisfaction and these variables remained significant in our multivariable models, $p<0.05$.

Overall, 15% ($n=216$) of participants reported prior ACP conversations with a clinician. Of these participants, 37% reported having a detailed high-quality conversation (Table 2). Participants who reported having a detailed ACP conversation with clinicians were more likely to have adequate versus limited health literacy (75.6% vs. 24.4%, $p=0.001$). The mean satisfaction scores for participants who reported having a conversation with a clinician were 4.2

(0.9). Clinician conversation satisfaction scores were also higher among men versus women [4.4 (0.8) vs. 4.0 (1.0), $p=0.003$], those with adequate versus limited health literacy [4.4 (0.8) vs. 4.0 (0.9), $p=0.002$], and English versus Spanish speakers [4.5 (0.7) vs. 3.5 (0.9), $p<0.001$] (Table 3).

Satisfaction scores were not higher among participants who reported having detailed versus general ACP conversations with clinicians [4.4 (0.8) vs. 4.2 (0.9), $p=0.18$]. In our multivariable models, significant associations between satisfaction and these variables remained for language and communication quality, $p<0.05$.

Discussion

Among older adults with chronic and/or serious illness, ACP conversations with surrogates and clinicians were infrequent, and more conversations occurred with surrogates rather than with clinicians. If the ACP conversations did occur, most were reported as general and of lower quality. Participants who reported higher quality detailed ACP conversations were more likely to report being satisfied with communication. Furthermore, Spanish speakers and those with limited health literacy, as well as women, are less likely to report high-quality communication with surrogates and clinicians and reported lower satisfaction with these conversations.

These results show ongoing disparities in ACP. Older adults who may experience systemic patterns of disadvantage, such as women, those with limited health literacy, and Spanish speakers, report lower communication quality and satisfaction with communication. These results are consistent

TABLE 1. PARTICIPANT CHARACTERISTICS OF PATIENTS WHO SELF-REPORTED AN ADVANCE CARE PLANNING CONVERSATION WITH A SURROGATE OR A CLINICIAN

| Participant characteristics | ACP conversations | | | | | | |
|-----------------------------|-----------------------------|---|----------------------------|------------------|---|----------------------------|--------------------|
| | Any ACP conversation, n (%) | ACP conversation with surrogates, n (%) | | | ACP conversation with clinicians, n (%) | | |
| | | Overall cohort (N=1398) | Any discussion n=589 (42%) | None n=809 (58%) | p | Any discussion n=216 (15%) | None n=1,182 (85%) |
| Age, mean (SD) | 65.6 (7.7) | 66.6 (8.2) | 64.9 (7.3) | <0.001 | 66.8 (8.5) | 65.4 (7.5) | 0.02 |
| Age, n (%) | | | | 0.003 | | | 0.07 |
| <65 Years | 802 (57.4) | 311 (52.8) | 491 (60.7) | | 112 (51.9) | 690 (58.4) | |
| ≥65 Years | 596 (42.6) | 278 (47.2) | 318 (39.3) | | 104 (48.2) | 492 (41.6) | |
| Gender, n (%) | | | | 0.01 | | | <0.001 |
| Women | 641 (45.9) | 246 (41.8) | 395 (48.8) | | 72 (11.2) | 569 (88.8) | |
| Men | 757 (54.1) | 343 (58.2) | 414 (51.2) | | 144 (19.0) | 613 (81.0) | |
| Health literacy, n (%) | | | | 0.002 | | | 0.61 |
| Adequate | 916 (65.6) | 412 (70.8) | 504 (62.7) | | 144 (67.6) | 772 (65.8) | |
| Limited | 470 (33.9) | 170 (29.2) | 300 (37.3) | | 69 (32.4) | 401 (34.2) | |
| Primary language, n (%) | | | | <0.001 | | | <0.001 |
| English | 954 (68.2) | 438 (74.4) | 516 (63.8) | | 169 (78.2) | 785 (66.4) | |
| Spanish | 444 (31.8) | 151 (25.6) | 293 (36.2) | | 47 (21.8) | 397 (33.6) | |

P-values <0.05 are bolded.

Race/ethnicity categories of the cohort ($n=1398$): Latino/Hispanic: 531 (38.0%); White: 424 (30.3%); Black/African American: 266 (19.0%); Asian/Pacific Islanders: 104 (7.4%); multiethnic: 36 (2.6%); Other: 25 (1.8%); Native American: 10 (0.7%); Unknown: 1 (0.1%); declined to state: 1 (0.1%).

ACP, advance care planning; SD, standard deviation.

TABLE 2. PARTICIPANT CHARACTERISTICS OF PATIENTS WHO SELF-REPORTED A DETAILED OR GENERAL ADVANCE CARE PLANNING CONVERSATION WITH A SURROGATE OR A CLINICIAN, AND OVERALL SATISFACTION WITH ADVANCE CARE PLANNING CONVERSATIONS

| Participant characteristics | ACP communication quality | | | | | |
|--|---|---------------------|------------------|---|---------------------|--------------|
| | ACP communication quality with surrogates (N=589) | | | ACP communication quality with clinicians (N=216) | | |
| | Detailed high quality | General low quality | p | Detailed high quality | General low quality | p |
| Overall cohort, n (%) | n=251 (43%) | n=338 (57%) | | n=80 (37%) | n=136 (63%) | |
| Age, mean (SD) | 66.3 (8.2) | 66.8 (8.1) | 0.49 | 66.1 (8.0) | 67.3 (8.7) | 0.32 |
| Age, n (%) | | | 0.68 | | | 0.88 |
| <65 Years | 135 (53.8) | 176 (52.1) | | 42 (52.5) | 70 (51.5) | |
| ≥65 Years | 116 (46.2) | 162 (47.9) | | 38 (47.5) | 66 (48.5) | |
| Gender, n (%) | | | 0.52 | | | 0.69 |
| Women | 101 (40.2) | 145 (42.9) | | 28 (35.0) | 44 (32.3) | |
| Men | 150 (59.8) | 193 (57.1) | | 52 (65.0) | 92 (67.7) | |
| Health literacy, n (%) | | | 0.01 | | | 0.001 |
| Adequate | 163 (65.5) | 249 (74.8) | | 42 (53.9) | 102 (75.6) | |
| Limited | 86 (34.5) | 84 (25.2) | | 36 (46.1) | 33 (24.4) | |
| Primary language, n (%) | | | 0.28 | | | 0.38 |
| English | 181 (72.1) | 257 (76.0) | | 60 (75.0) | 109 (80.1) | |
| Spanish | 70 (27.9) | 81 (24.0) | | 20 (25.0) | 27 (19.9) | |
| Satisfaction score, 5-point Likert, ^a mean (SD) | 4.4 (0.9) | 4.1 (0.9) | <0.001 | 4.4 (0.8) | 4.2 (0.9) | 0.18 |

P-values < 0.05 are bolded.

^aThe 5-point Likert response options ranged from “not at all,” “a little,” “somewhat,” “fairly,” and “extremely.”

with other studies that demonstrate that lower ACP engagement is associated with these same characteristics.^{14,35–39} It also builds on other studies demonstrating that patients with limited health literacy and limited English proficiency report worse patient–clinician communication overall.^{34,40}

Additional attention and interventions may be needed to support these vulnerable populations in ACP and specifically, to ensure all patients have access to high-quality detailed conversations, if they wish, which may enhance communication satisfaction.

TABLE 3. PARTICIPANT DEMOGRAPHICS ASSOCIATED WITH FIVE-POINT SATISFACTION SCORE OF HAVING AN ADVANCE CARE PLANNING CONVERSATION WITH A SURROGATE OR A CLINICIAN

| Participant characteristics | ACP communication satisfaction (N=782) | | | | | | | |
|-----------------------------|--|-----------|--------------|------------------|--|-----------|--------------|------------------|
| | ACP communication satisfaction with surrogates | | | | ACP communication satisfaction with clinicians | | | |
| | n (%) | Mean (SD) | Median (IQR) | p-Value (mean) | n (%) | Mean (SD) | Median (IQR) | p-Value (mean) |
| Overall cohort | 577 (74) | 4.3 (0.9) | 4.5 (4–5) | <0.001 | 205 (26) | 4.2 (0.9) | 4.5 (4–5) | <0.001 |
| Age | | | | 0.58 | | | | 0.20 |
| ≤65 Years | 306 (53) | 4.2 (0.9) | 4.5 (4–5) | | 109 (53) | 4.2 (1.0) | 4.5 (4–5) | |
| >65 Years | 271 (47) | 4.3 (0.9) | 4.5 (4–5) | | 96 (47) | 4.3 (0.7) | 4.5 (4–5) | |
| Gender | | | | 0.01 | | | | 0.003 |
| Women | 244 (42) | 4.1 (0.9) | 4.0 (4–5) | | 70 (34) | 4.0 (1.0) | 4.0 (3.5–5) | |
| Men | 333 (58) | 4.3 (0.9) | 4.5 (4–5) | | 135 (66) | 4.4 (0.8) | 4.5 (4–5) | |
| Health literacy | | | | <0.001 | | | | 0.002 |
| Adequate | 406 (71) | 4.4 (0.8) | 5.0 (4–5) | | 134 (66) | 4.4 (0.8) | 4.5 (4–5) | |
| Limited | 166 (29) | 4.0 (1.0) | 4.0 (3.5–5) | | 69 (34) | 4.0 (0.9) | 4.0 (3–5) | |
| Language | | | | <0.001 | | | | <0.001 |
| English | 428 (74) | 4.4 (0.8) | 5.0 (4–5) | | 158 (77) | 4.5 (0.7) | 5.0 (4–5) | |
| Spanish | 149 (26) | 3.8 (0.9) | 4.0 (3.5–4) | | 47 (23) | 3.5 (0.9) | 4.0 (3–4) | |

P-values < 0.05 are bolded.

Missing data were minimal: health literacy data were missing for 10 patients (1.2%) and satisfaction data were missing for 9 patients (1.1%).

IQR, interquartile range.

This study has several important limitations. First, generalizability may be limited to one geographic region. Nonetheless, the sample was sociodemographically diverse. In addition, the categorization of ACP conversations as detailed or general was by patient report only, and there was no formal objective assessment of the quality of these ACP conversations. Furthermore, due to the involvement of multiple clinicians in the care of patients with chronic/serious illness, the patient report of satisfaction with communication with clinicians may be subject to recall bias.

In addition, clinically significant differences in satisfaction surveys have not yet been validated. Finally, although other populations may be a risk for lower quality conversations and satisfaction with communication, this study was not designed or powered to examine other populations.

Conclusions

Among older adults with chronic and/or serious illness, ACP conversations with surrogates and clinicians were infrequent and most were rated of lower quality. Participants who reported having more detailed or higher quality ACP conversations with surrogates were more likely to be more satisfied with communication. Yet Spanish speakers, women, and those with limited health literacy reported less frequent conversations and lower quality and satisfaction. This study highlights critical gaps in access to ACP conversations among older adults who experience systemic patterns of disadvantage. Support for these patients, such as increasing language concordance between patients and clinicians, is needed to foster high-quality ACP conversations to improve patient's satisfaction with communication.

Authors' Contributions

L.P.G. contributed to conceptualization (lead), writing—original draft (lead), formal analysis (equal), and writing—review and editing (lead). D.E.B. was involved in conceptualization (supporting) and methodology (equal). N.G. carried out conceptualization (supporting), writing—original draft (supporting), and writing—review and editing (equal). A.M.V. was involved in writing—review and editing (equal). Y.S. took charge of formal analysis (lead) and writing—review and editing (equal). B.L. carried out writing—review and editing (equal). R.L.S. was in charge of conceptualization (equal), methodology (equal), writing—original draft (supporting), and writing—review and editing (equal).

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Author Disclosure Statement

No competing financial interests exist.

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