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Empowering Older Adults to Discuss Advance Care Planning During Clinical Visits: The PREPARE Randomized Trial

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Abstract

BACKGROUND/OBJECTIVES: A patient-directed, online program (PREPARE for Your Care [PREPARE]; prepareforyourcare.org) has been shown to increase advance care planning (ACP)

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SUPPORTING INFORMATION

Additional Supporting Information may be found in the online version of this article.

documentation. However, the mechanisms underlying PREPARE are unknown. Our objectives were to compare the efficacy of PREPARE plus an easy-to-read advance directive (AD) vs an AD alone to increase active patient participation in ACP discussions during clinic visits and to examine effects of active patient participation on ACP documentation.

DESIGN: Audio recordings of postintervention primary care visits from two randomized trials (2013–2016).

SETTING: Seven primary care clinics at a veterans affair and safety-net hospital in San Francisco, CA.

PARTICIPANTS: English- and Spanish-speaking adults, aged 55 years and older, with two or more chronic/serious conditions.

INTERVENTION: PREPARE plus an easy-to-read AD or an AD alone.

MEASUREMENTS: The primary outcome was the number of active patient participation utterances about ACP (eg, asking questions, stating preferences) measured by the validated Active Patient Participation Coding Scheme. We examined differences in utterances by study arm using mixed effects negative binomial models and utterances as a mediator of PREPARE's effect on documentation using adjusted logistic regression. Models were adjusted for health literacy, prior care planning, and clinician.

RESULTS: Among 393 participants, the mean (SD) age was 66 (8.1) years, 120 (30.5%) had limited health literacy, and 99 (25.2%) were Spanish speaking. PREPARE plus the AD resulted in 41% more active patient participation in ACP discussions compared with the AD alone (mean [SD] = 10.1 [16.8] vs 6.6 [13.4] utterances; incidence rate ratio = 1.41; 95% confidence interval = 1.00–1.98). For every additional utterance, participants had 15% higher odds of ACP documentation, and active patient participation accounted for 16% of PREPARE's effect on documentation.

CONCLUSIONS: The PREPARE program and easy-to-read AD empowered patients to actively participate in ACP discussions during clinical visits more than the AD alone. Increased activation was associated with increased ACP documentation. Therefore, PREPARE may mitigate barriers to ACP among English- and Spanish-speaking older adults.

TRIAL REGISTRATION: 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; aging; patient participation; patient-physician communication

Advance care planning (ACP) is a process whereby patients discuss their goals for medical care with their providers and surrogate decision makers.[1] Beginning the ACP process prior to a medical crisis is particularly important for older adults with multiple comorbid conditions.[2,3] However, ACP rates are still low among older adults, particularly among minority populations.[4–6] Barriers to ACP include the lack of clinician time, particularly in

the primary care setting, the lack of clinician training, and the tendency for patients and providers to avoid ACP discussions.[7–9]

PREPARE for Your Care (PREPARE; prepareforyourcare. org) is a patient-directed, online program in English and Spanish that is designed to empower people to initiate ACP discussions with their clinicians, family, and friends and to prepare individuals for complex medical decision making.[10–12] PREPARE was created with and for diverse older adults and is written at a fifth-grade reading level. Based on social cognitive and behavior change theories, PREPARE includes interactive content and video stories that foster communication skill building by modeling how to choose and prepare a surrogate decision maker, how to clarify values related to medical care, and how to communicate medical wishes to surrogates and clinicians.[10–12] To foster communication skill building, PREPARE includes interactive content and video stories that model how to engage in ACP behaviors. PREPARE also creates a “Summary of My Wishes” that includes participants’ answers to interactive questions about values and helps individuals complete easy-to-read advance directives (ADs) if they are ready to do so. The Summary of My Wishes and ADs can be used as communication prompts with clinicians, and prompts have been shown to increase patients’ communication and decision-making involvement during clinical visits.[13–16] In two prior randomized trials comparing PREPARE plus the easy-to-read AD vs the AD alone, PREPARE increased ACP documentation in the electronic health record (EHR) and patients’ self-reported engagement in ACP among English- and Spanish-speaking older adults.[17,18] These results were achieved with no additional clinician or health system interventions.

We hypothesize that PREPARE led to higher ACP documentation compared to the easy-to-read AD alone through increased active patient participation and empowerment in ACP discussions fostered by the communication skill-building components of the program. However, this is not known. Validated instruments have been created to measure active patient participation during patient-clinician discussions. The Active Patient Participation Coding Scheme uses audio-recorded data to determine how often patients ask questions, express concerns, and state preferences.[19–21] Studies have shown that active patient participation in medical visits is associated with improved emotional health, physiologic outcomes, more support from clinicians, and better patient understanding of treatment options.[22–25]

The objective of this study was to compare the efficacy of PREPARE plus an easy-to-read AD with the to increase active patient participation in ACP discussions (ie, asking questions, expressing concerns, stating preferences) using audio recordings from postintervention primary care visits. We hypothesized that participants randomized to the PREPARE plus AD arm would have greater active patient participation in ACP discussions compared to the AD alone. We also examined the association between active patient participation in ACP discussions during primary care visits and ACP documentation in the EHR. We hypothesized that greater active patient participation in ACP discussions would be associated with greater ACP documentation.

METHODS

This is a secondary analysis of two single-blind, parallel-group, comparative efficacy trials, comparing the PREPARE website plus an easy-to-read AD vs the AD alone.[17,18] Participants were randomized at the patient level. Because limited health literacy is associated with lower ACP engagement, participants were block randomized by adequate vs limited health literacy. The methods for both of these trials have been previously published.[11,12] Participants included English-speaking adults 60 years and older who were enrolled in a trial from three primary care clinics at the San Francisco Veterans Affairs Medical Center (SFVA) from 2013 to 2016. Participants also included English- and Spanish-speaking older adults 55 years and older who were enrolled in a trial from four primary care clinics associated with Zuckerberg San Francisco General Hospital and the San Francisco Health Network, a public health delivery system, between 2014 and 2017. This study was approved by the University of California, San Francisco, Institutional Review Board and the SFVA, and written informed consent was obtained using a teach-to-goal process.[17,18]

Participants and Enrollment Criteria

To be eligible, participants had to have two or more chronic or serious medical conditions, to be seen by their primary care provider (PCP) at least twice in the past year, and have two additional inpatient, outpatient, or emergency department visits. Exclusion criteria included conditions that significantly limited the patient's ability to have an informed discussion with their provider (ie, severe cognitive impairment, hearing impairment), not having a telephone for reminder calls, and the inability to answer teach-back questions involved in the consent process (Figure 1).[11,12]

Intervention

As previously described, participants were randomized to review the PREPARE program plus an easy-to-read AD or the AD alone in research offices 1 to 3 weeks prior to a primary care visit.[17,18] The patient-directed, online PREPARE program was designed with input from patient and caregiver stakeholders and is written at a fifth-grade reading level. It provides video stories and communication skill building by demonstrating how to identify one's wishes and how to communicate those wishes with clinicians and surrogates. It also includes conversation starters and prompts to encourage participants to share their wishes.[10–12] The easy-to-read AD was also designed with input from patient and caregiver stakeholders, and, in contrast to standard ADs written beyond a 12th-grade level,[26,27] the form includes text written at a fifth-grade reading level, pictures that help explain the text, and prompts to share the AD with clinicians and surrogates.[28] All participants received a reminder call about their upcoming clinic visit 1 to 3 days prior to the visit. Participants in the PREPARE arm were also reminded to speak with their PCP about the PREPARE materials. The intervention included no additional clinician- or system-level interventions. Clinicians gave permission for their patients to be enrolled in an ACP study, but they were not educated about ACP, PREPARE, or the AD interventions.

Audio-Recording Procedures

Eligible participants were asked during the consent process whether their next primary care visit could be audio recorded. Patients were excluded from audio recording if they had not had a primary care visit within 6 months of viewing the interventions, their primary care appointment was within a week of viewing the interventions, or their healthcare institution posed restrictions on audio recording (eg, not allowed, group medical visit, or after-hours clinic visits; Figure 1).

Prior to the primary care visits, clinicians were asked to consent to audio recording either by email or in person. Both the patient and the clinician needed to consent to audio recording. If a family member or caregiver was present, they also needed to provide written informed consent for audio recording. Once consent was obtained, research staff, blinded to study arm, placed audio recorders in the examination room, waited outside until the encounter was completed, and then retrieved the recording. Study staff used software to remove personal identifying information from the recording. Recordings were uploaded to a secure drive and professionally transcribed verbatim.

Outcome Measures

The primary outcome was the total number of active patient participation utterances about ACP during the primary care visit. Utterances are verbal units of participation included in an individual's "turn" in a discussion.[19–21] An utterance is the oral analogue of a sentence and could include single words (eg, answering "yes" to a question), independent clauses, and single sentences. For example, "I want my daughter to be my surrogate" is one utterance, whereas "I'd like to talk to my family first, and then I'll decide about whether to donate my organs" would be two utterances. The number of possible utterances in a clinical visit is unlimited and analyzed as a continuous variable.[21,29]

Transcripts were first reviewed to identify portions containing ACP discussions. ACP discussions began when the patient or clinician specifically mentioned ACP, the PREPARE study, or PREPARE materials. Although most ACP discussions occurred in a single episode, some interactions included multiple episodes of ACP discussion; all episodes were excerpted. Trained and blinded coders reviewed the excerpts and coded them using the Active Patient Participation Coding Scheme, a validated method of coding patient utterances.[19–21] Utterances were defined as "active patient participation" communication behaviors if they included: (1) asking questions, (2) expressing concerns (eg, fears, worries, negative feelings), or (3) responding with assertiveness (eg, stating preferences, making requests, introducing topics to discuss).[21] These components are considered active forms of communication because they interject patients' needs, preferences, and wants into the conversation, which, in turn, often prompts clinicians to be responsive to the patient's needs.[19–21] For example, question utterances included, "If I were to get sick and couldn't make a decision for myself, are there risks involved with blood transfusions?" Expressions of concern utterances included negative emotions (eg, sadness, anger), worries, concerns, or frustration (eg, "It's very difficult to talk to my family because they are emotional people"). Assertive utterances included statements in which patients state preferences, make requests, or introduce topics (eg, "I don't want to be fed by tubes or anything like that.") For each

clinical encounter, we summed these three types of active patient participation to create an aggregate measure. We also analyzed the three components of activation separately. As a secondary outcome, we assessed the total number of utterances about ACP, including those that were active (ie, questions, concerns, assertiveness) as well as other utterances, such as giving general information to the clinician (eg, "Well, I have been thinking about it") or providing context (eg, "My daughter lives near me.")

Six coders participated in three, 2-hour training sessions on how to code using the Active Patient Participation Coding Scheme. Once coders surpassed 85% agreement in coding transcripts involving ACP discussions, each was assigned a portion of the transcripts to code independently. Of the transcripts, 15% were double coded, and reliability (assessed by intraclass correlation coefficients [ICCs]) was high for overall active participation (ICC = 0.81), asking questions (ICC = 0.83), acts of assertiveness (ICC = 0.76), and the total number of utterances (ICC = 0.85). Reliability was moderate for expressions of concern (ICC = 0.47) due to the limited number of these utterances (Supplementary Table S1).

ACP documentation was measured using a composite variable that included documented discussions and legal forms (eg, ADs, living wills, and physicians' orders for life-sustaining treatment forms) completed at 3 months after the last follow-up trial interview (9 months for the VA trial and 15 months for the ZSFG trial).[17,18] ACP documentation was determined by two independent coders, and discrepancies were adjudicated by the principal investigator (R.L.S.).[17,18]

At baseline, participant characteristics, including age, sex, race/ethnicity, income, marital status, and educational level, were assessed through self-report; research assistants administered validated measures of health literacy, educational attainment, self-rated health, and functional status.[17,18]

Statistical Analysis

We compared baseline characteristics of the PREPARE plus AD vs AD-only arms using t-tests and χ^2 tests. Then, we calculated means and SDs for total active patient participation in ACP discussions and each active participation communication component (ie, questions, concerns, assertiveness) as well as the total number of utterances about ACP (ie, including active patient participation and other utterances) by study arm. We assessed the differences between study arms using Wilcoxon rank sum tests. We used mixed effects negative binomial models to compute incidence rate ratios (IRRs) and their 95% confidence intervals (CIs) to compare the PREPARE plus AD vs AD-only arms for each communication behavior outcome variable. All models were adjusted for the health literacy blocking variable, baseline documentation of ACP, and clustering by clinician. Next, we examined the relationship between active patient participation in ACP discussions and ACP documentation in the EHR using adjusted logistic regression. To assess the linearity of the relationship, we graphically examined the association between active patient participation and the log odds of ACP documentation using locally weighted scatterplot (lowess) smoothing, and we observed a threshold effect with a peak at 18 utterances. Therefore, we capped the count of utterances contributing to active patient participation at 18. Finally, we assessed whether active patient participation in ACP discussions mediated the effect of

PREPARE on ACP documentation using the Baron and Kenny method.[30] All analyses were conducted using SAS 9.4 (SAS Institute) and STATA 15.1 (Stata Corp). All tests of statistical significance were two sided.

RESULTS

Of 908 eligible participants, 393 (43%) had their clinic visit recorded, including 157/282 (55.7%) at the VA and 236/626 (37.7%) at ZSFG. The PREPARE arm included 177 participants, and the AD-only arm included 216 (Figure 1). Participant characteristics did not significantly differ between study arms (Table 1). Among the 393 participants, the mean (SD) age was 66 (8.1) years, 120 (30.5%) had limited health literacy, 99 (25.2%) were Spanish speaking, 170 (43.3%) reported fair to poor health, and 120 (30.5%) had prior ACP documentation in their EHR. Participant characteristics did not significantly differ between participants who were recorded vs not for the VA or ZSFG, except at ZSFG, non-recorded patients were more likely to have limited vs adequate health literacy (46.4% vs 37.3%; $P = .03$) and be Spanish vs English speaking (55.6% vs 41.9%; $P < .001$).

Effect of the Interventions on Patients' Communication

In unadjusted analysis, participants randomized to the PREPARE arm exhibited more active participation behaviors (ie, asking questions, expressing concerns, asserting preferences) (mean [SD] = 10.05 [16.84] utterances compared with patients in the AD-only arm, 6.61 [13.44] utterances; $P = .03$). In adjusted mixed effects models, adjusting for health literacy, prior ACP, and clustering by clinician, the number of active patient participation utterances was 41% higher in the PREPARE arm than the AD-only arm (adjusted IRR = 1.41; 95% CI = 1.00–1.98; $P = .05$) (Figure 2 and active participation subcategory findings [eg, asking questions, responding with assertiveness] in Supplementary Table S1). Participants in the PREPARE arm also had an adjusted 46% higher rate of overall patient utterances about ACP (including utterances coded as active and other) compared to the AD-only arm (IRR = 1.46; 95% CI = 1.06–2.0; $P = .02$).

Effect of Patients' Active Participation on ACP Documentation

Participants who were more actively engaged in ACP discussions during primary care visits were more likely to have their wishes documented in the EHR. For every increase in active patient participation utterances, participants had 15% greater odds of ACP documentation (odds ratio [OR] = 1.15; 95% CI = 1.10–1.20; $P < .001$) (Figure 3). When the ACP documentation components were examined separately, active patient participation resulted in 14% greater odds of documented discussions (OR = 1.14; 95% CI = 1.10–1.19; $P < .001$) and 7% greater odds of documented forms (OR = 1.07; 95% CI = 1.03–1.10; $P < .001$). Active patient participation in ACP discussions explained a portion of the effect of PREPARE on ACP documentation in the EHR. In previous work, participants in the PREPARE arm had increased ACP documentation compared to the AD alone (OR = 1.86; 95% CI = 1.21–2.88).[17,18] Adding active patient participation to the mixed effects analysis revealed that it accounted for 16% of the effect of PREPARE on ACP documentation (OR = 1.72; 95% CI = 1.07–2.76).

DISCUSSION

To our knowledge, this is the first study to analyze, through audio recordings, English- and Spanish-speaking older adults' active communication in response to a patient-directed ACP intervention. We found that PREPARE plus an easy-to-read AD was more effective in empowering patients to actively participate in ACP discussions during a primary care visit compared to the AD alone. These findings provide evidence that the theory-based, skill-building communication features of the PREPARE program may activate and empower patients and help to mitigate barriers to ACP discussions with patients' medical providers. In addition, greater active patient participation in ACP discussions was associated with greater ACP documentation. Patient participation within the clinical encounter also explained part of the previously demonstrated relationship between the PREPARE intervention and ACP documentation in the EHR.[17,18]

These results are important given the low rate of ACP engagement and lack of empowerment within clinical encounters for older adults, particularly among low-income and Spanish-speaking populations.[4–6,31] Previous studies have measured important aspects of ACP and end-of-life care conversations, including self-reported frequency of conversations,[32,33] patient ratings of the quality of the conversation,[34,35] and patient care choices arising from the conversation.[36,37] In addition, several ACP interventions have shown the ability to increase ACP communication between patients and medical providers.[38–44] However, these self-reported assessments, unlike the direct observation in this study, may have introduced recall bias. Direct observation in this study allowed us to quantify the amount of patient activation within the visit and to quantify how actively and how often patients interjected their own perspective, preferences, and needs into the conversation. Empowering patients to engage within clinical encounters is important as empowerment can improve clinical outcomes and results in better alignment of care with patients' preferences.[22–25] This novel audio-recorded analysis and our findings are aligned with the paradigm shift of ACP from a one-time event (ie, an AD) to being considered as a broader set of communication and decision-making behaviors.[1,45]

These results also provide insight into how the patient-directed PREPARE program and easy-to-read AD directly empower patients. Both tools were designed with and for diverse communities who have found traditional ACP materials and ADs, often written at and beyond the 12th grade level, difficult to read and understand.[8,9,26,27] The easy-to-read AD and the PREPARE online program, both written at a fifth-grade reading level, provide patients with accessible language to discuss their medical wishes with their designated surrogates and clinicians.[10–12] In addition, PREPARE was designed to motivate and empower patients by addressing the modifiable mediators needed to effect behavior change, including knowledge, outcome expectations, perceived barriers, skill building, and self-efficacy.[46] The theory-based program shows people, through video examples, how to discuss ACP and provides video and written prompts to discuss their wishes with clinicians and surrogates. Other studies have demonstrated the power of video stories to engage patients in ACP,[36,47] and the power of patient prompts prior to medical visits to encourage patient activation.[13–16] Our findings suggest PREPARE's behavioral approach, videos, and prompts used to foster patient engagement all play an important role in facilitating active patient

involvement in ACP discussions. In fact, we found that much of the patients' participation was assertive, in which patients stated preferences, made requests, or introduced topics, corresponding with the communication skills learned in PREPARE.

ACP is an iterative process that should be revisited over time.[1,45] Increasing active patient communication about ACP during busy primary care encounters may help lay a foundation for ongoing ACP discussions. By preparing patients prior to a medical visit, PREPARE may result in efficient communication in busy clinical settings and reciprocally empower clinicians to engage in discussions and document them in the EHR.[19–21] In fact, we found that active patient participation was more strongly associated with documented discussions than documented legal forms, alluding to the increase in discussions during the visit. Although it was beyond the scope of this study, future research should investigate the clinician's role in ACP communication within and across encounters. Clinician-patient communication is inherently a process of mutual influence, and clinician behavior may reinforce or inhibit the effect of an ACP intervention on patient participation.[19,48] Empowered patients may also reciprocally activate clinicians, leading to EHR documentation; however, further research is needed.

LIMITATIONS

This study took place in one geographic area of the United States, limiting its generalizability. However, it included diverse English- and Spanish-speaking patients from seven clinics from a VA and public hospital system. The recording rates also differed between the VA and ZSFG due to logistic issues (eg, distance from clinic), and, at ZSFG, were lower among Spanish speakers and those with limited health literacy, which may have introduced selection bias. In addition, this study focused on a single clinic visit and the long-term effects of active participation should be studied further. Although PREPARE resulted in greater activation, the easy-to-read AD also resulted in active participation. However, a control group was not included, so we were unable to discern differences between the AD-only arm and usual care. Although both arms received reminder calls and written prompts to discuss wishes with clinicians, only the PREPARE arm reminded participants to discuss the PREPARE materials. Although the reminder may have increased activation, it would not have been effective unless patients also felt empowered to act on the PREPARE content. Additional studies are needed to determine whether similar activation can be obtained without reminders. While reliability for the active participation composite measure was high, it was moderate for the subcategory of expressions of concern due its infrequent occurrence. Future studies may consider excluding expressions of concern from the analysis. Finally, although we did not assess clinicians' communication, we did adjust for any potential clustering effects by clinician.

CONCLUSIONS

The patient-directed, online PREPARE intervention is more effective in increasing active patient participation in ACP discussions with his/her primary care clinicians than an easy-to-read AD alone. Increased active patient participation in ACP discussions was associated with increased ACP documentation in the EHR and explained a portion of PREPARE's

effects on documentation. PREPARE empowers older adults with communication skills and, therefore, may help to mitigate barriers to patient-provider discussions and documentation of ACP, particularly among diverse English-and Spanish-speaking older adults in busy primary care settings.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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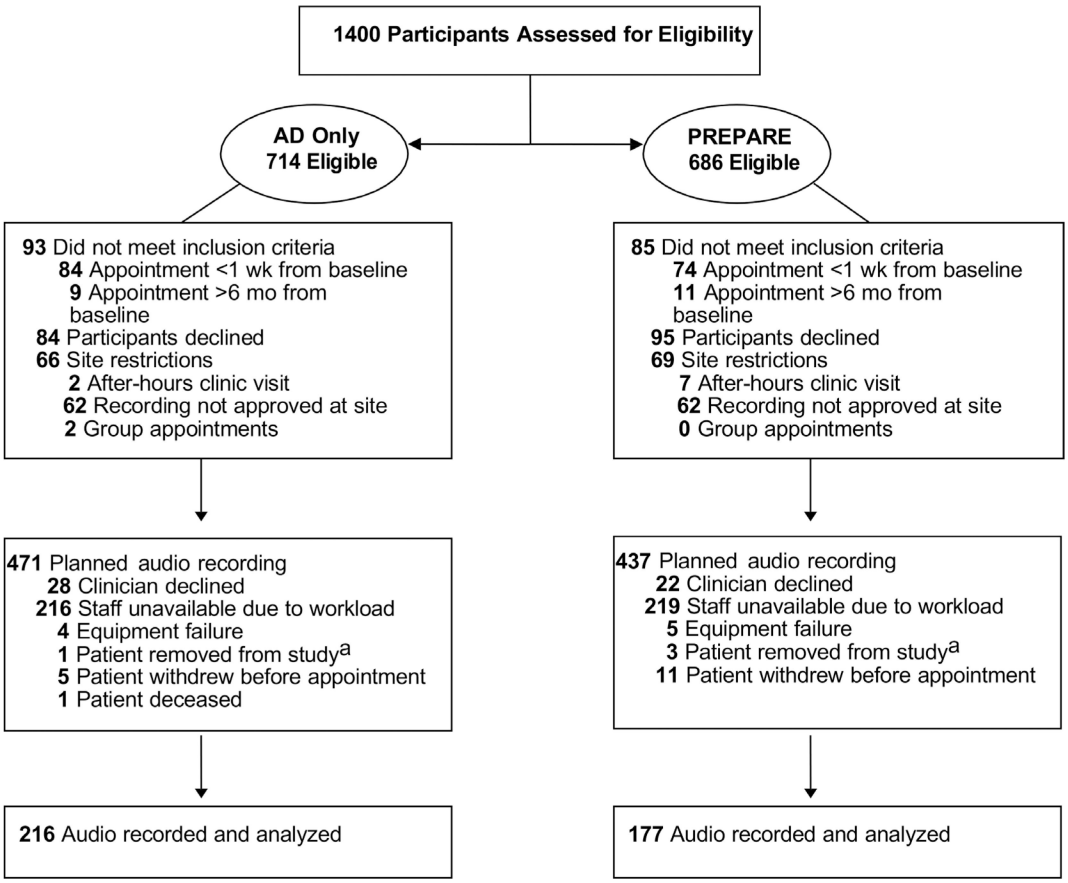

Figure 1.

Audio-recording Consolidated Standards of Reporting Trials diagram. AD indicates advance directive; PREPARE, PREPARE for Your Care (prepareforyourcare.org). [a]Removed patients include individuals deemed by staff to be too physically or mentally ill to participate.

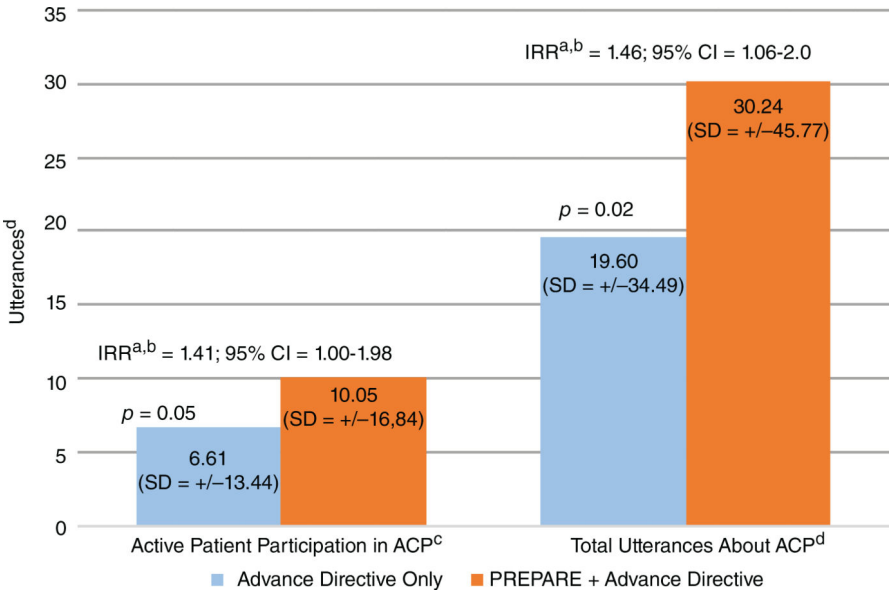

Figure 2.

Active patient participation in advance care planning (ACP) discussions during clinical visits by study arm: PREPARE for Your Care (PREPARE; prepareforyourcare.org) plus the easy-to-read advance directive (AD) vs the AD alone. CI indicates confidence interval. [a]Incidence rate ratios (IRRs) adjusted for health literacy, prior advance care planning, and clustering by clinician. [b]Reference group for IRR is AD only. [c]Active patient participation is a cumulative count of utterances that combines questions, expressions of concerns, and assertive responses. [d]Utterances are verbal units of participation included in an individual's "turn" in a discussion and include a cumulative count of both active patient participation and other utterances about ACP, such as providing contextual information in response to question.

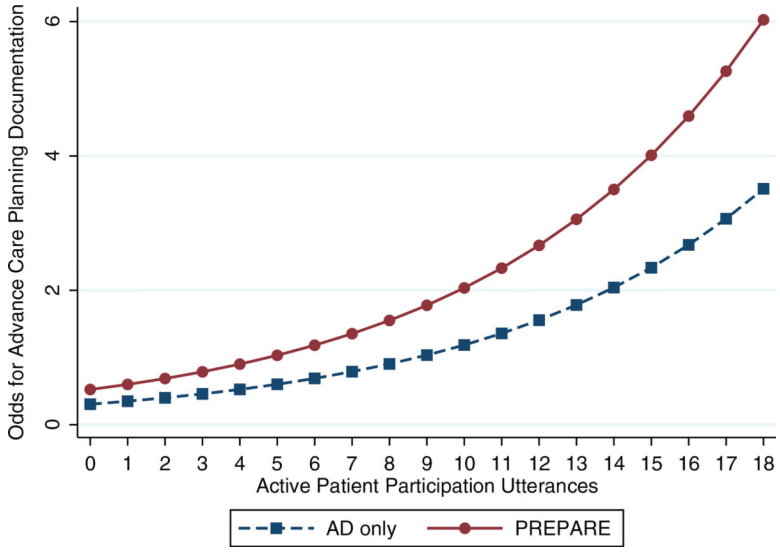

Figure 3.

Effect of patients' active participation on advance care planning documentation by study arm: PREPARE for Your Care (PREPARE; prepareforyourcare.org) plus the easy-to-read advance directive (AD) vs the AD alone.

Table 1.

Baseline Participant Characteristics

Participant Characteristics (N = 393)	AD Only (N = 216)	PREPARE + AD (N = 177)	*P* Value
Age, mean (SD), y	66.0 (8.2)	66.8 (8.1)	.35
Sex, No. (%) women	87 (40.3)	57 (32.2)	.10
Race/ethnicity, No. (%)			.60
White, non-Latino/Hispanic	72 (33.3)	57 (32.2)	
African American	47 (21.8)	32 (18.1)	
Latino/Hispanic	70 (32.4)	58 (32.8)	
Native American	4(1.8)	2(1.1)	
Asian/Pacific Islander	14(6.5)	20 (11.3)	
Multiethnic/other	9 (4.2)	8 (4.5)	
Education, high school or less, No. (%)[a]	93 (43.3)	77 (43.5)	.96
Spanish speaking, No. (%)	57 (26.3)	42 (23.7)	.81
Limited health literacy, No. (%)[a]	66 (30.7)	54 (30.5)	.97
Self-rated health, fair to poor, No. (%)[a]	90 (41.9)	80 (45.2)	.51
Prior ACP documentation, No. (%)	86 (39.8)	69 (39.0)	.87
Legal forms (ie, advance directives) and orders (ie, POLST), No. (%)	51 (23.6)	48 (27.1)	.43
Documented discussions about ACP, No. (%)	54 (25.0)	35 (19.8)	.22
Site, No. (%)			.27
San Francisco Veterans Affairs Medical Center	81 (37.5)	76 (42.9)	
Zuckerberg San Francisco General Hospital and San Francisco Health Network	135 (62.5)	101 (57.1)	

Abbreviations: ACP, advance care planning; AD, advance directive; POLST, physicians' orders for life-sustaining treatment; PREPARE, PREPARE for Your Care (prepareforyourcare.org).

[a]Data missing for one participant for education, limited health literacy, and self-rated health.