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Empowering Patients with the PREPARE Advance Care Planning Program Results in Reciprocal Clinician Communication

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Abstract

Background: The patient-directed [PREPAREforYourCare.org](https://www.prepareforyourcare.org) program empowers patients to participate in advance care planning (ACP) discussions with clinicians. Our goal was to determine whether PREPARE could reciprocally increase clinician ACP communication.

Methods: In a secondary analysis of two trials evaluating efficacy of PREPARE plus an easy-to-read advance directive (AD) versus an AD alone, patients were included if they were 55 years old, English- or Spanish-speaking, and had 2 chronic conditions. We audio-recorded postintervention primary care visits and used the validated Clinician-Patient Participation Coding

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Scheme to calculate the number of clinician ACP utterances concerning information-giving, recommendations, or supportive talk. We examined differences by study arm using mixed effects negative binomial models, stratifying by language. To assess possible mediation, we adjusted for active patient participation (e.g., asking questions or stating preferences).

Results: 393 visits were audio-recorded (177 in PREPARE arm and 216 in AD-only arm). Recordings included 179 clinicians (mean 2.2 [SD 1.9] patients each). Patients' mean age was 66±8 years, 31% had limited health literacy, and 25% were Spanish-speaking. 67% of recordings included information-giving, 85% recommendations, and 62% supportive talk. PREPARE resulted in 51% more clinician supportive talk vs. the AD alone (mean 4.5 [8.9] vs 2.9 [6.0] utterances; incidence rate ratio 1.51 [95%-CI 1.02–2.24]). Effects were most pronounced among Spanish-speakers. There were no differences in information-giving or recommendations. After adjusting for active patient participation, no differences in supportive talk remained.

Conclusions: The patient-directed PREPARE program was associated with greater clinician supportive ACP communication with older adults compared to an AD alone; the effect was most pronounced among Spanish-speakers and was mediated by active patient participation. Thus, PREPARE helps patients be more engaged communicators, which in turn encourages clinicians to be more supportive of patients. Enhanced patient-clinician communication represents an important mechanism by which PREPARE may decrease disparities in ACP.

Keywords

advance care planning; patient activation; patient-provider communication; diverse populations; older adults

INTRODUCTION

Advance care planning (ACP), or the process by which people share their values, goals, and preferences for future medical care, is associated with higher patient and family satisfaction with end-of-life care and a higher likelihood of patients receiving care consistent with their goals.^{1,2} Yet, engagement in ACP is low among older adults, particularly among those experiencing systemic patterns of disadvantage, including persons of color and those with low socioeconomic status, limited English proficiency, and limited health literacy.^{3,4}

PREPARE for Your Care (PREPARE; prepareforyourcare.org) is a patient-directed, online program that is designed to prepare individuals for complex medical decision-making.⁵ It was developed with culturally diverse populations at a fifth-grade reading level, is based on social cognitive and behavior change theories, and includes interactive content and video stories. Two randomized controlled trials found that compared to an easy-to-read advance directive (AD) alone, PREPARE plus an easy-to-read AD increased ACP documentation, self-reported discussions with family/friends and clinicians, and directly observed active patient participation in ACP discussions during clinic visits among English- and Spanish-speaking older adults.^{6–8} Greater active patient participation in these discussions was also associated with greater ACP documentation.⁸

PREPARE may improve patient empowerment—or the extent to which patients utilize active participation behaviors (e.g., asking questions, expressing concerns, stating preferences)—

because it is designed to increase patient knowledge, address perceived barriers, and build communication skills and patient self-efficacy. PREPARE does not include any clinician-facing components. However, we hypothesized that increases in patient active participation may reciprocally increase clinician ACP communication, as has been shown in other non-ACP studies.^{9–11} Therefore, the objectives of this study were to determine whether PREPARE increases clinician participation in ACP discussions and whether patients' communication mediates clinician participation.

METHODS

This is a secondary analysis of data collected from 2013 to 2017 from two randomized controlled trials comparing the efficacy of the PREPARE website plus an easy-to-read AD versus the AD alone. The trial results and the methods have been previously published.^{6, 7} These studies were approved by the Institutional Review Boards of the University of California, San Francisco (UCSF). Written informed consent was obtained for all participants.

We recruited participants 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. Participants were included if they were 55 years of age or older (due to accelerated aging among underserved populations), spoke English or Spanish, had at least two chronic medical conditions, and had four or more clinical encounters in the prior year. Exclusion criteria included conditions that significantly limit the ability to have an informed discussion (i.e., severe cognitive impairment, psychosis), lack of a telephone, or inability to answer informed consent teach-back questions within 3 attempts.^{6, 7} Participants were block randomized by adequate versus limited health literacy. Participants reviewed either the PREPARE program plus the easy-to-read AD (PREPARE arm) or the AD alone (AD-only arm) in research offices 1–3 weeks prior to a primary care visit. These were routine primary care visits; in other words, there was no requirement to discuss or focus on ACP. All participants received a reminder call about their upcoming visit 1–3 days prior, and those in the PREPARE arm were reminded to talk about the PREPARE materials with their PCP. We audio-recorded and professionally transcribed 393 out of the 1400 routine primary care visits (177 in the PREPARE arm, 216 in the AD-only arm). Primary care visits were eligible for audio recording if they occurred between 1 week and 6 months postintervention, if there were no restrictions on audio recording imposed by the healthcare institution or clinic, and if all individuals involved in the clinic consented to audio recording; details of the audio-recording procedures have been previously published.⁸

Measures

Using the validated Clinician-Patient Participation Coding Scheme,¹² the primary outcomes included the total number of clinician utterances about ACP during the primary care visit in the categories of 1) information-giving (e.g., explaining how ACP works and why it is important), 2) recommendations (e.g., clinician recommendations regarding treatment considerations or to complete an AD), or 3) supportive talk (e.g., asking for patients' preferences, supporting patient decision-making, and using supportive statements, such

as praise or encouragement). Utterances are the oral analogue of simple sentences and may be in the form of single words, independent clauses, and single sentences; they are analyzed as a continuous variable. Trained and blinded coders reviewed the portions of transcripts containing ACP discussions and calculated the number of clinician utterances about ACP in each of the aforementioned categories. Fifteen percent of transcripts were double coded; reliability was sufficient (intraclass correlation coefficient 0.71, 0.66, and 0.75 for information-giving, recommendations, and supportive talk respectively).

As has been previously described,⁸ we also coded transcripts for active patient participation using a validated coding scheme.¹² Active patient participation consisted of utterances that included 1) asking questions (e.g., “If I choose this option, would I still be able to go to the hospital if I have pneumonia again?”), 2) expressing concerns (e.g., “It is difficult to talk with my children about this”), or 3) making assertive comments such as making requests or stating preferences about ACP (e.g., “I would not want a feeding tube”). These forms of communication are considered *active* patient participation because they may prompt clinicians to accommodate or respond to patients’ stated needs, preferences, or opinions.^{12–14} Patient communication that was *not* coded as active patient participation may have included comments such as “I haven’t looked at the advance directive yet” and “I will have that notarized and bring it back next week.”

Health literacy was measured using the validated short Test of Functional Health Literacy (s-TOFHLA). Baseline ACP documentation was defined as the presence or absence of documentation in the medical record of an advance directive, living will, durable power of attorney, Physician Orders for Life-Sustaining Treatment forms, code status orders, or documented discussions with a provider about goals of care.^{6, 7} Other baseline patient characteristics included self-reported age, gender, language, education, race/ethnicity, health status, and income. Clinician characteristics were not available.

Statistical analyses

We compared baseline characteristics between intervention arms using unpaired t-tests or χ^2 tests. We calculated means and standard deviations for each outcome (i.e., information-giving, recommendations, and supportive talk), and assessed differences between study arms using Wilcoxon rank sum tests. To determine a clinically meaningful difference in the number of utterances, we calculated standardized effect sizes for outcomes that were significantly different by study arm. We used mixed effects negative binomial models to assess differences in each outcome by study arm. Models were adjusted for the health literacy blocking variable and baseline ACP documentation, clustered by physician, and stratified by English vs Spanish language. For models that demonstrated significantly different clinician utterances by study arm ($P < 0.05$), we adjusted for active patient participation to assess whether it mediated the relationship between the study arm and outcome. We used SAS 9.4 (SAS Institute Inc.) and Stata/SE 16.1 (College Station, Texas) for analyses.

RESULTS

Audio recordings included visits with 179 clinicians with a mean (SD) of 2.2 (1.9) patients each. Among 393 participants, mean (SD) age was 66 (8.1), 99 (25.2%) were Spanish-speaking, 120 (30.5%) had limited health literacy, and 120 (30.5%) had prior ACP documentation (Table 1). ACP-related information-giving occurred in 67% of recordings, recommendations in 85%, and supportive talk in 62%. Participant characteristics did not differ significantly between study arms; however, non-recorded patients at the safety-net hospital were more likely to have limited vs adequate health literacy (46.4% vs 37.3%; $P=0.03$) and be Spanish vs English-speaking (55.6% vs 41.9%; $P<0.001$).

For ACP-related information-giving and recommendations, there were no differences by study arm in the number of utterances in unadjusted and adjusted analyses, overall and when stratified by language (Table 2).

For ACP-related supportive talk, in unadjusted analyses the number of utterances was higher in the PREPARE arm (mean 4.5 [SD 8.9]) compared to the AD-only arm (2.9 [6.0], $P=0.04$; Table 2), with a standardized effect size of 0.20.¹⁵ When stratified by language in unadjusted analyses, the trend remained but was not statistically significant. After adjusting for health literacy, baseline ACP documentation and clustering effects by clinician, PREPARE resulted in 51% more clinician ACP-related supportive utterances compared to the AD-only arm (4.4 [95% CI 3.2–5.7] versus 2.9 [2.0–3.9]; IRR 1.51 [1.02–2.24], $P=0.04$). The difference by study arm was more pronounced among Spanish-speakers (PREPARE: 4.2 [1.8–6.6] versus AD: 1.7 [0.7–2.8]; IRR 2.44 [1.33–4.46], $P=0.004$), but was non-significant among English-speakers (Figure 1). After adjusting for the potential mediating effects of active patient participation, the number of utterances overall and among English-speakers by study arm was no longer significant. However, among Spanish-speakers the number of utterances remained significantly higher in the PREPARE vs the AD-only arm (IRR 1.80 [1.15–2.80], $P=0.01$) (Figure 1).

DISCUSSION

To the best of our knowledge, this is the first study to directly assess clinician ACP communication in response to a patient-directed ACP program. We found that PREPARE, an entirely patient-directed, online ACP program that includes easy-to-read ADs, significantly increased clinician supportive talk about ACP compared to an AD alone. This increase was fully mediated by active patient participation in the overall study cohort and among English speakers. While the standardized effect size was small, PREPARE does not include any clinician-facing components, and the results nevertheless demonstrated that empowering patients to talk about ACP in turn helped facilitate clinician communication. Furthermore, our prior research⁸ showed that this increased patient empowerment was associated with greater ACP documentation in the medical record.

Patient-clinician communication impacts health outcomes directly and indirectly, including through patients feeling “known” and trusted, building rapport, and increasing agency and motivation.¹⁶ Thus, the effects of PREPARE specifically on increasing reciprocal clinician

supportive talk are paramount in the context of ACP discussions. While clinician supportive talk was higher in the PREPARE vs the AD-only arm, there were no statistically significant differences for clinician information-giving or recommendations. This may be because both PREPARE and the easy-to-read AD were designed to include explanatory information about ACP and to help guide patients in decision-making, thereby reducing the need for further fact-based communication (i.e., information-giving and recommendations) and allowing for more emotionally focused communication (i.e., supportive talk).

Interestingly, even after adjusting for active patient participation, the effect of PREPARE on clinician supportive talk persisted among Spanish speakers. It is possible that unmeasured variables, such as language concordance or presence of an interpreter or family member, influenced the degree of clinician communication. Additionally, the number of clinician utterances for supportive talk and recommendations were about the same for English and Spanish speakers in the PREPARE arm; however, they were two times higher for supportive talk and four times higher for recommendations in English versus Spanish speakers in the AD arm. These findings suggest that a written document may not be as effective as PREPARE in encouraging ACP discussions between clinicians and Spanish-speaking patients. Furthermore, these stratified analyses for clinician supportive talk and recommendations suggest that PREPARE enhanced patient-clinician communication particularly among Spanish speakers compared to the AD arm. This finding may represent an important mechanism by which PREPARE can help reduce health disparities in ACP, which is particularly important given the known poorer quality of patient-clinician communication among people with limited English proficiency.¹⁷

This study has several limitations. It was conducted in one city and we did not have clinician demographic information, potentially limiting generalizability. However, the study included an ethnically and racially diverse patient population from two health systems. In addition, audio recording rates were lower among Spanish speakers and those with limited health literacy, which may have resulted in selection bias.

By empowering patients using theory-based, skill-building communication methods, the patient-directed PREPARE program significantly increased reciprocal clinician ACP supportive talk during primary care visits with English and Spanish-speaking patients. These findings were particularly notable among Spanish speakers. Future research is needed to better understand mechanisms beyond active patient participation that may contribute to these findings. Increasing clinician supportive talk is critical to patient-centered communication, which, fundamentally, is communication that is supportive and responsive to patients' individual needs and preferences. Research has consistently demonstrated that patients want and expect their primary care providers to discuss ACP, and that these discussions result in greater patient satisfaction with their clinicians.¹⁸ Moreover, while complete ACP engagement and documentation likely require both patient and clinician interventions, clinician interventions are often resource intensive. We found that in a resource-poor, safety-net health system, a solely patient-facing intervention moved the needle on clinician communication. Thus, by empowering patients, PREPARE reciprocally facilitates increased clinician communication about ACP and may reduce disparities in patient-clinician ACP communication.

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Impact statement:

In an analysis of audio-recorded visits between 393 older adults and 179 primary care clinicians, we found that the patient-directed [PREPAREforYourCare.org](https://www.prepareforyourcare.org) advance care planning (ACP) program significantly increased clinician supportive talk compared to an easy-to-read advance directive alone. This increase was fully mediated by active patient participation among English speakers and partially mediated among Spanish speakers, suggesting that empowering patients to talk about ACP reciprocally increases clinician communication. We certify that this work is novel.

Key Points:

- By empowering English and Spanish-speaking older adults to talk about advance care planning (ACP), the PREPARE ACP website reciprocally increased clinician communication.
- Effects were most pronounced among Spanish speakers; thus, PREPARE may reduce ACP disparities.

Why does this matter?

PREPARE improves patient-clinician communication that in turn can reduce ACP disparities.

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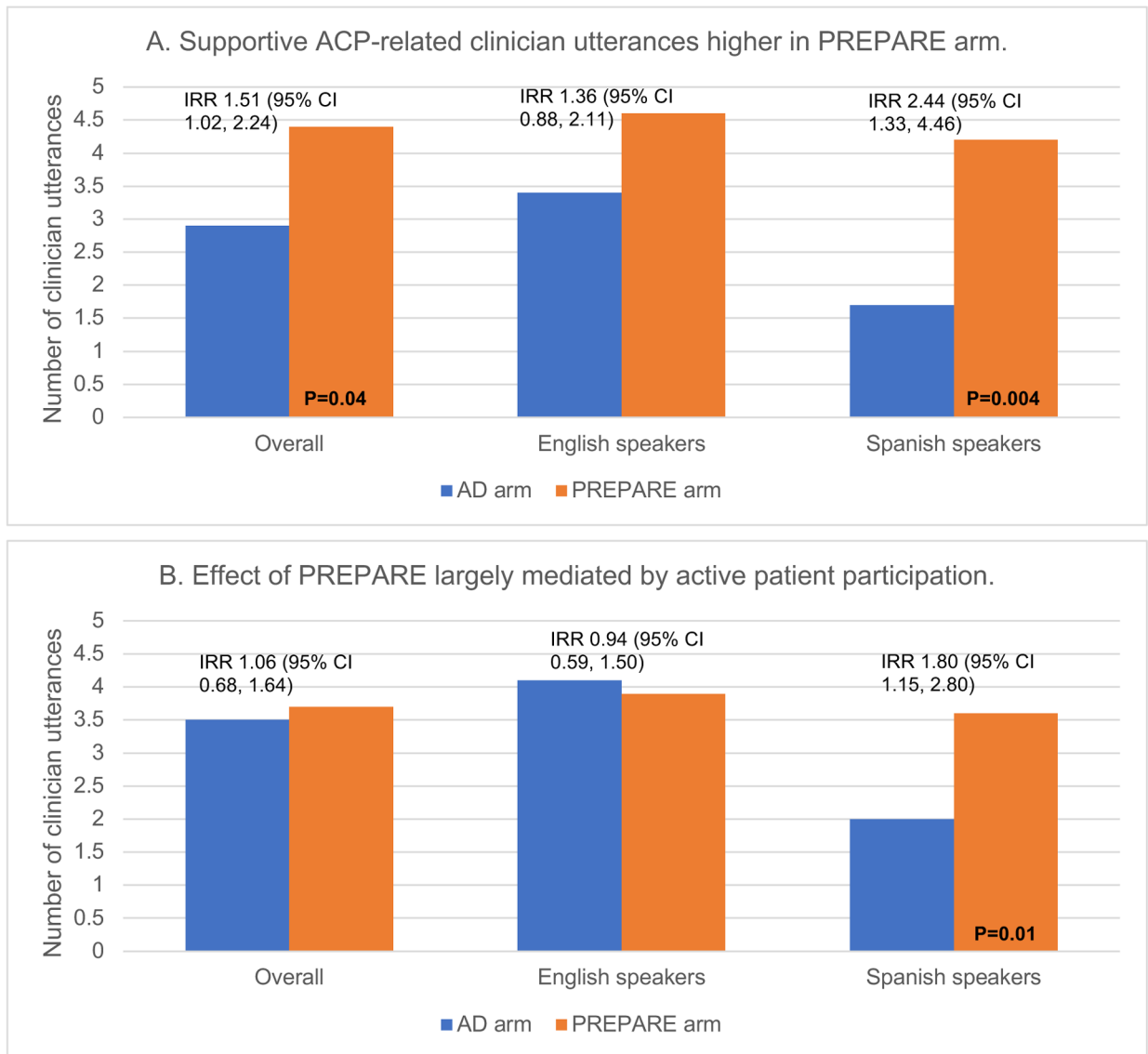


Figure 1. Number of clinician utterances of ACP-related supportive talk, overall and stratified by English and Spanish speakers, by study arm (AD versus PREPARE), and by model. Panel A shows results of models adjusted for health literacy and prior ACP documentation; Panel B shows results of models adjusted for health literacy, prior ACP documentation, and active patient participation.

Table 1.

Baseline Patient Characteristics.

Patient Characteristics ^a	AD-only arm (N=216)	PREPARE arm (N=177)
Age, mean (SD)	66.0 (8.2)	66.8 (8.1)
Women, n (%)	87 (40.3)	57 (32.2)
Race/ethnicity, n (%)		
Non-Hispanic white	72 (33.3)	57 (32.2)
Latinx	70 (32.4)	58 (32.8)
Black/African American	47 (21.8)	32 (18.1)
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, ^b high school or less, n (%)	93 (43.3)	77 (43.5)
Spanish speaking, n (%)	57 (26.3)	42 (23.7)
Limited health literacy, ^b n (%)	66 (30.7)	54 (30.5)
Self-rated health, ^b fair-to-poor, n (%)	90 (41.9)	80 (45.2)
Prior ACP documentation, n (%)	86 (39.8)	69 (39.0)
Legal forms (i.e., advance directives) and orders (i.e., POLST), n (%)	51 (23.6)	48 (27.1)
Documented discussions about ACP, n (%)	54 (25.0)	35 (19.8)
Site, n (%)		
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)

^aThere were no significant differences in any participant characteristics by study arm (AD versus PREPARE).

^bData missing for one participant for education, limited health literacy, and self-rated health.

Table 2.

Clinician ACP utterances in audio recordings with patients randomized to the easy-to-read Advance directive (AD)-only arm or the PREPARE plus an AD-only arm.

ACP utterance type	Unadjusted analyses			Models adjusted for health literacy and prior ACP documentation	
	<i>AD-only</i>	<i>PREPARE</i>	P-value	<i>AD-only</i>	<i>PREPARE</i>
	Number of utterances, mean (SD)	Number of utterances, mean (SD)		IRR (95% CI)	IRR (95% CI)
Information giving					
Overall	5.8 (13.1)	6.8 (19.3)	0.96	1.00 (Ref)	1.06 (0.65, 1.74)
English	6.3 (13.7)	7.7 (21.5)	0.86	1.00 (Ref)	1.11 (0.61, 2.02)
Spanish	4.5 (11.2)	4.1 (8.4)	0.71	1.00 (Ref)	0.98 (0.44, 2.19)
Recommendations					
Overall	0.66 (2.2)	0.72 (1.8)	0.13	1.00 (Ref)	1.10 (0.63, 1.93)
English	0.82 (2.4)	0.72 (1.7)	0.37	1.00 (Ref)	0.92 (0.48, 1.77)
Spanish	0.19 (0.9)	0.71 (2.0)	0.12	1.00 (Ref)	3.51 (0.88, 14.0)
Supportive talk					
Overall	2.9 (6.0)	4.5 (8.9)	0.04	1.00 (Ref)	1.51 (1.02, 2.24)
English	3.3 (6.4)	4.6 (9.0)	0.14	1.00 (Ref)	1.36 (0.88, 2.11)
Spanish	1.7 (4.3)	4.1 (8.6)	0.17	1.00 (Ref)	2.44 (1.33, 4.46)

AD = advance directive

PREPARE = the online PREPARE for Your Care program plus easy-to-read advance directives

Statistically significant findings (P<0.05) are in bold font.