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Engaging Diverse Older Adults with Cognitive Impairment and Caregivers in Advance Care Planning: A Pilot study of the Interactive PREPARE Website

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Abstract

Introduction: Engaging patients with cognitive impairment in advance care planning (ACP), including completing advance directives and naming health care proxies, before they lose decision-making capacity is important.

Methods: We determined the feasibility of the [PREPAREforYourCare.org](https://www.prepareforyourcare.org) ACP program among 20 diverse older adults with mild-to-moderate cognitive impairment and their caregivers in a one-week, pre-post pilot. We examined ease-of-use, satisfaction, and feasibility using validated scales, and change in ACP Engagement scores, including knowledge, contemplation, self-efficacy, and readiness subscales (5-point scales), from baseline to 1-week.

Results: Participants were on average 70 years old (SD=9.0), 45% Spanish-speaking, 60% had limited health literacy, and 15% felt comfortable using the internet. Patients and caregivers rated PREPARE a mean of 8.6 (SD=1.6) and 9.4 (SD=1.1) on the 10-point ease-of-use scale, 4.7 (SD=0.4) and 4.7 (SD=0.3) on the 5-point satisfaction scale, and 4.9 (SD=0.4) and 4.8 (SD=0.6) on the 5-point feasibility scale, respectively. ACP engagement scores increased for 16 of 20 (80%) patients (p=0.03) and 16 of 20 (80%) caregivers (p=0.18). Caregivers experienced increased knowledge (3.8 to 4.7, p=0.002) and self-efficacy (3.6 to 4.5, p=0.034) for ACP.

Discussion: The PREPARE website was feasible and may facilitate ACP engagement among diverse older adults with cognitive impairment and their caregivers.

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Keywords

Older adults; Advance Care Planning; Dementia; Cognition; Caregivers

INTRODUCTION

Dementia is a terminal medical condition affecting 5.8 million American adults.¹ Yet, older adults with dementia have often not engaged in advance care planning (ACP), with rates ranging from 37%-54% in community samples, and lower rates for minorities and those with a lower socioeconomic status.^{2,3} ACP, including conversations about goals of care, designation of a power of attorney (DPOA) for healthcare, and formal advance directives, is particularly important for people with dementia given their progressive inability to participate in complex decision making.⁴ Lack of ACP can increase the likelihood of medical interventions that are inconsistent with patient's goals of care, such as intensive care unit (ICU) admissions and mechanical ventilation, throughout the disease trajectory and at the end of life.⁵ Moreover, caregivers are frequently unaware of patients' preferences and poorly prepared to make complex or unanticipated decisions over the illness trajectory,⁶ leading to caregiver distress and guilt.⁷

Mild cognitive impairment (MCI) or mild-to-moderate dementia may be a practical timeframe to introduce ACP interventions as individuals generally have preserved ability to participate in informed decision-making.⁸ However, several challenges exist in engaging persons with dementia and their caregivers in ACP. Most ACP materials, including advance directives, are written beyond a 12th-grade reading level resulting in high cognitive burden and low rates of completion, particularly among individuals with low health literacy.⁹ Cognitive impairment may compound barriers to readability.¹⁰ Additionally, many ACP materials do not address the unique importance of surrogate decision-making in dementia, which is crucial for effective ACP.¹¹⁻¹³

To address these needs, we developed the [PREPAREforYourCare.org](https://www.PREPAREforYourCare.org) program (PREPARE), a patient-centered, interactive website that uses video stories and modeling of ACP behaviors and easy-to-read, advance directives in English and Spanish.¹⁴ In diverse primary care settings of adults without cognitive impairment, PREPARE plus the easy-to-read advance directive resulted in significant improvements in ACP documentation in the medical record and self-reported engagement in ACP behaviors compared to the advance directive alone.^{15,16} This study aimed to test the acceptability of the PREPARE program among diverse older patients with mild-to-moderate cognitive impairment and their caregivers, and to assess preliminary evidence for whether PREPARE can engage these individuals in ACP.

METHODS

Recruitment and Data Collection

Participants were recruited from primary care clinics within the Zuckerberg San Francisco General Hospital (ZSFG) from May 25, 2018 to October 16, 2018. We primarily identified patients through administrative data and obtained their clinicians' permission to recruit

them. In addition, recruitment occurred through posted flyers, in-person, phone, text messages or mailed letters based on potential participants' preferences. Interested and eligible participants scheduled baseline interviews in onsite research offices on the day of a clinic visit or in their homes to facilitate ease of participation. The University of California, San Francisco Institutional Review Board approved the study, and written informed consent was obtained using a teach-to-goal process in English and Spanish.¹⁷

Participants and Enrollment Criteria

Participants were eligible if they were 55 years or older; self-reported speaking English or Spanish well; had 2 visits with a primary care provider in the past year (i.e., established care); 2 additional inpatient, outpatient, or emergency department visits in the past year (i.e., marker of illness); and 2 chronic medical conditions. Patients had to screen positive for mild-to-moderate cognitive impairment determined by the Short Portable Mental Status Questionnaire (SPMSQ) followed by the Mini-Cog 3-item recall.^{18,19} Mild-to-moderate cognitive impairment was defined as 3-7 errors on the SPMSQ followed by 1-2 errors on the 3-item recall. Participants were excluded if they had eight or more errors on the SPMSQ or were unable to remember any items on the 3-item recall. Additional exclusion criteria included patients deemed by their physicians as too physically or mentally ill to participate, blindness, deafness, psychosis, delirium, active drug or alcohol abuse, self-reported vision impairment (i.e., unable to read a newspaper), lack of a phone, or inability to answer informed consent teach-back questions within three attempts. Participants had to be able to refer a caregiver, defined as someone they trust to make medical decisions if needed. Caregivers were excluded if they reported a history of dementia, other major neurological or psychiatric disorder, or screened positive for cognitive impairment by an SPMSQ score of three or more errors or any errors on the Mini-Cog 3-item recall. Participants with prior ACP experiences were not excluded because ACP wishes can change, and the study goal was to assess feasibility.

Intervention

We conducted a 1-week feasibility study where patient-caregiver dyads were given an easy-to-read advance directive (AD) and asked to review the PREPARE website in English or Spanish. Details of these interventions and prior efficacy trial results have been published.^{14,15} Briefly, the AD and PREPARE were co-developed with diverse, older adults and written at a 5th grade reading level to minimize cognitive burden. PREPARE is a patient-centered, interactive website that uses video stories and modeling of ACP behaviors. Containing 5 steps, PREPARE was designed to allow users to decide which of the 5-steps are right for them. To ensure a standardized dose and administration in this study, participant dyads were asked to attempt to review all 5 steps and the AD in research offices or their homes with research staff present. In prior studies the AD took approximately 10 minutes to review, and the PREPARE website took 60 minutes to review. To decrease the potential cognitive load at one sitting, participants and caregivers were allowed to conduct the interview and review materials over multiple sessions within the same day or 1-2 days apart.

Feasibility

The feasibility of recruiting cognitively impaired diverse older adults and their caregivers in dyads was assessed through the eligibility rate, refusal rate, recruitment effort (e.g., number of calls and chart review, etc), and 1-week retention rate. Patients and caregivers were asked to independently rate PREPARE and the AD on a 10-point ease-of-use scale (10 being the easiest), and a validated 3-item feasibility scale (comfort reviewing materials, helpfulness, and likelihood of recommending materials, items averaged for range: 1-5 points with 5 representing higher feasibility).²⁰ Self-reported acceptability was assessed by asking respondents 5 yes/no questions: whether they enjoyed answering study questionnaires, reviewing study materials, being in the study, would recommend the study to others, or the study felt burdensome (no considered a positive response) (summed to create a 0-5-point scale).

In addition, we asked participants and caregivers which of the materials was most helpful and which they would recommend to family/friends (options: Website, AD, or Not Sure). One dedicated staff member obtained open-ended feedback from patients and caregivers on the language, length, and potential information gaps of materials. A second staff member administered the intervention and questionnaires and took field notes of participants' behavior. We measured potential adverse outcomes including depression (PHQ-2) and anxiety (GAD-2).^{21,22}

ACP Measures

Several surveys were administered at baseline and 1-week separately for patients and caregivers. We administered a validated 7-item general ACP knowledge multiple-choice questionnaire (Cronbach $\alpha=0.79$) at baseline and 1 week and report the percentage of items answered correctly.²³ The questionnaire is written at a fifth-grade reading level and assesses knowledge of key principles of ACP and the role of surrogate decision makers (Supplementary Table 1).

To patients, we administered a validated 15-item ACP Engagement Survey (Cronbach $\alpha=0.91$) (Supplementary Table 2), with each item rated on a 1 to 5-point Likert Scale and reported as an overall average 5-point score, with 5 points representing the most ACP engagement.²⁴ Validated subscales of the ACP Engagement Survey included a 6-item self-efficacy scale ("how confident") and a 9-item readiness scale ("how ready"). To caregivers, we assessed engagement in surrogate decision-making through a validated 21-item Surrogate ACP Engagement Survey (Cronbach $\alpha=0.94$) (Supplementary Table 3). This survey is divided into four validated subscales: 3-item knowledge ("how informed"), 5-item contemplation ("how much have you thought about"), 7-item self-efficacy, and 6-item readiness scales. We used previously validated effect sizes on the 5-point surveys to define changes as small (0.2-0.3 points), moderate (0.4-0.5 points), and large (0.6 points).²⁵

Demographic and Health Measures

Measured demographic characteristics included self-reported age, gender, race/ethnicity, marital status, and whether they were born in the US (i.e., a proxy for acculturation); self-rated overall health; and difficulty or inability to independently perform Instrumental

Activities of Daily Living (IADLs) or Activities of Daily Living (ADLs).²⁶ Socioeconomic measures of education and income were assessed by a validated 10-point income ladder,²⁷ self-report of income to “make ends meet” at the end of the month,²⁸ one validated health literacy question (i.e., confidence with forms),²⁹ and confidence using the internet.²⁶

Statistical Analysis

We characterized the sample using standard summary statistics. Next, we compared baseline and 1-week values using the Wilcoxon signed rank tests for continuous variables and the McNemar’s test for dichotomous variables given the small sample size and non-normal distributions. We did not conduct multivariate analysis or adjust for multiple comparisons as the goal of this feasibility study was to minimize type 1 errors (false negatives) rather than type 2 errors (false positives). Significance was characterized using 2-tailed p-values at 0.05. We used Stata 15 for all analysis.³⁰ All open-ended data was collected in written format. Qualitative thematic content analysis was conducted by two independent coders who synthesized codes into themes.³¹ We ensured trustworthiness by utilizing deductive and inductive coding, multiple coders, and maintaining records of changes.³² All transcripts were double-coded, and disagreements were adjudicated by consensus.

RESULTS

Recruitment and Sample Characteristics

Among 734 patients assessed for eligibility, 292 (40%) were ineligible based on administrative data, manual chart review or clinician assessment. Of the 442 who were potentially eligible, 319 (72%) did not respond to recruitment attempts, 99 declined participation (22%), and 4% were unable to schedule during the study period (Figure 1). To recruit the 20 patient-caregiver dyads, study staff needed to conduct 558 chart reviews, 732 phone calls, send three texts, mail one letter, and establish 57 in-person contacts. The 1-week retention rate for dyads who enrolled was 100%.

Patients had a mean age of 70 years (SD 9 years, range: 56-87), 85% identified as female, 50% were Latino/Hispanic, 35% black/African American, 45% spoke Spanish as their primary language, 60% had limited health literacy, and 85% did not feel comfortable with using the internet (Table 1). Caregivers were on average 57 years old (SD 17 years, range: 29-87), 70% were female, 45% were Latino/Hispanic, 40% were Black/African American, and 30% spoke Spanish as their primary language.

Feasibility

Both patients and caregivers reported the PREPARE website was easy to use, with median ratings of 9 and 10 out of 10 points, respectively (Table 2). Patients and caregivers similarly rated the PREPARE website as highly feasible with median scores of 4.7 and 4.8 points, respectively. Both patients and caregivers rated the intervention a median of 5 out of 5 points on the acceptability scale. Of the PREPARE and AD materials, 55% of patients reported the AD as most helpful, while 65% of caregivers reported PREPARE as the most helpful. Eighty percent of patients and 95% of caregivers reported they would recommend PREPARE and the AD to a family member or friend. The average time spent on all 5 steps of PREPARE,

review of the AD, and creation of an action plan was 102 minutes (Range: 60-133 minutes), and 2 (10%) of participant-caregiver dyads requested two visits to complete the material.

ACP Knowledge

One week after the intervention, patients and caregivers significantly improved their overall knowledge about ACP (Patients: 62% correct pretest to 82% posttest, $p=0.009$; Caregivers: 78% pretest to 94% posttest, $p=0.006$) (Supplementary Table 1). For patients, knowledge improved on the definition of a surrogate (50% to 85%, $p=0.008$), when to choose a surrogate (60% to 85%, $p=0.03$), and who to notify once a surrogate is chosen (50% to 85%, $p=0.008$). For caregivers, knowledge improved on when to choose a surrogate (70% to 95%, $p=0.03$), and who to tell once people decide on medical preferences (75% to 100%, $p=0.03$).

ACP Engagement

Among patients, there was a statistically significant increase in overall ACP engagement (mean change: 0.2, SD 0.7, $p=0.04$) (Table 3, Supplementary Table 2). Although this change was significant, the effect size was small because improvements seen in 16 of 20 (80%) of patients (average 0.4 point increase, moderate effect size) were offset by 4 (20%) patients who had an average 0.8 point decline from baseline to 1 week. Upon further investigation of the four patients who experienced declines, the most common reason for a decline in score was due to the participant initially reporting having “already completed” an ACP engagement step (score of 5) and on follow-up reporting they were “thinking about it” (score of 1). On review of field notes, one of the four participants intermittently fell asleep during the intervention, one participant relied on a caregiver for most navigation of the website and this caregiver was intermittently confused or distracted, one participant had challenges with eyesight (wore sunglasses during intervention and reported poor vision), and one participant had substantial technical challenges using a computer (and reported discomfort using the internet). However, all four participants experienced improvements in ACP knowledge.

Among caregivers, the change in overall surrogate engagement from baseline to 1 week was not significant (mean change: 0.3 points, $p=0.2$) (Table 3), however, there were significant increases in the knowledge subscale (mean change: 0.8 points, $p=0.002$) and self-efficacy subscale (mean change: 0.4 points, $p=0.03$) (Supplementary Table 3).

Open-ended Feedback and Field Notes

The majority of patient-caregiver dyads described the videos as helpful and relatable, that website and written materials were easy to understand, and that materials provided helpful suggestions for speaking with medical providers (Table 4). Several participants expressed discomfort with the intervention’s length and perceived repetition when asked to review all 5 steps as part of this study. This concern corresponded with field note observations of reduced attention, impatience, or lack of engagement:

“[The] website is long, maybe too long for 1 session.” -Caregiver

Caregivers were often able to facilitate attentiveness and comprehension, for example, by reiterating questions, emphasizing the importance of medical decisions, and summarizing key points made in videos.

In addition, several dyads mentioned difficulty navigating the computer, mouse, or touch screen and navigating to different pages on the website (Table 4). Caregivers frequently assisted patients (15 (80%)), unless they were themselves inexperienced in which case study staff provided assistance (5 (20%)). Finally, patients and caregivers asked about additional information on how to be a surrogate for a family member when one does not agree with their medical decisions or how to navigate complex family dynamics (e.g., how to choose one family member):

“[I want] more examples of when you have to choose one family member [or] the other. There could be conflict and some more videos could help.” –Patient

DISCUSSION

It was feasible to conduct this 1-week pilot study of PREPARE and easy-to-read AD among diverse English and Spanish-speaking older adults with mild-to-moderate cognitive impairment and their caregivers. Although the majority of participants had limited health and computer literacy, the PREPARE and AD intervention were rated as easy to use and were found to improve patients' and caregivers' general knowledge of ACP. Moreover, results provide preliminary evidence that the intervention improved ACP engagement for both patients and caregivers. The intervention had a particularly pronounced impact on caregiver knowledge and self-efficacy surrounding surrogate decision making. Consistent with prior literature detailing recruitment challenges for patients with cognitive impairment and their caregivers,³³ particularly for low-income and minority groups,³⁴ significant effort was required by study staff to recruit the 20 dyads; nevertheless, once enrolled, all dyads were retained at one week. Open-ended feedback provided insights for how to further adapt the administration of PREPARE intervention for adults with mild-to-moderate cognitive impairment and their caregivers, such as reducing the length of each session and dividing the information into one step of the program at a time, as PREPARE was originally designed to be administered.

To our knowledge, this is the first study to indicate high feasibility and acceptability of an online ACP program among dyads of persons with dementia and their caregivers. A 2019 systematic review identified four ACP interventions directed at older adults with dementia, yet all studies only recruited caregivers.³⁵ A subsequent 2019 pilot study of a psychoeducational, face-to-face ACP intervention among patient-caregiver dyads showed feasibility among a sample of primarily well-educated white participants.³⁶ Our study is novel in its investigation of an online program among socioeconomically and ethnically diverse, low-income English and Spanish-speaking older adults and their caregivers who are under-represented in dementia research.³⁴ Consistent with prior studies of the PREPARE website, findings suggest that the cognitive burden of our materials was, overall, low and feasible to administer to older adults with mild-to-moderate cognitive impairment.^{14,15} Caregivers, rather than staff, frequently took on supportive roles for patients with cognitive impairment by facilitating use of the computers, encouraging attentiveness, and regularly checking in for comprehension.

As with prior studies of cognitively impaired patients and their caregivers, recruitment required substantial time and effort, requiring over 700 patients to be reviewed for a 20% participation rate among eligible patients who were contacted. While this is a lower participation rate than in the prior PREPARE trial (55%),¹⁵ this rate is consistent with prior studies which employed extensive recruitment efforts of patients with early-stage dementia and caregivers.^{33,37} Barriers to participation in our study likely included the high burden of caregiver needs for dementia,^{33,38} and were compounded by barriers to recruitment of low-income, underrepresented minorities, including limited health literacy, limited English proficiency and mistrust of research.³⁹ Recruitment was facilitated by using a multiple types of outreach efforts, providing culturally-sensitive materials, and accounting for low health-literacy. Notably, participants and caregivers reported the overall burden of participating in this study to be low with a 100% retention rate.

We also found that both patients and caregivers experienced improvements in ACP engagement and overall knowledge, which adds to evidence from a larger trial of PREPARE in English and Spanish-speaking participants without cognitive impairment.¹⁵ Compared to prior PREPARE trials where 98% of participants reported improved ACP engagement over 12 months, 80% of participants in this pilot study had an improvement over one week. As with the larger trial, it is possible that patients with cognitive impairment may achieve higher engagement over time.¹⁵ Notably, four patients (20%) had declines in their ACP engagement scores. As is well documented in psychological and educational literature,⁴⁰ and as we have seen in prior PREPARE 1-week pilot studies,¹⁴ it is possible that these “decliners” may have over-estimated their initial engagement, but subsequently learned that they were not yet ready or had not yet engaged in the full process of ACP.

Open-ended feedback and field observations provide guidance on how to adapt the administration of the PREPARE website for further study. First, shorter options may improve attention among patients with cognitive impairment. Compared to prior estimates of 60 minutes to review PREPARE plus 10 minutes for the AD,¹⁴ our sample required on average 103 minutes to review the materials, and two dyads opted to have two separate visits to complete their review of the intervention. PREPARE was designed to allow users to decide which of the 5 steps they prefer to review and when. For research purposes, we recommend researchers consider providing PREPARE steps and the AD one at a time and over time (approximately 10 minutes for each step) or, in pragmatic studies, allow patients and caregivers to choose the steps based on their need or interest. Second, we have made updates to the PREPARE website to enhance use, including shortening the videos and steps and including information and videos for how to use a computer and how to use the PREPARE program that were not available to the dyads in this study. Third, additional content specifically for surrogates, including addressing family dynamics, may be warranted, which our team is actively exploring.

This study has limitations. Due to the small sample size in one area of the country, generalizability is limited; however, our sample includes racially/ethnically diverse patients and caregivers. In addition, there was no control group limiting our ability to infer causal effects from our intervention, and the inability to blind study staff may have biased the assessments. Finally, study participants’ feedback about the study may have been affected

by social desirability and reporting bias, although study staff made efforts to not influence participants' interaction with the materials.

In conclusion, in a pilot study of the PREPARE website and an easy-to-read AD among English- and Spanish-speaking older adults with mild-to-moderate cognitive impairment, limited health literacy, and low comfort using the internet, we found the intervention materials were feasible and acceptable to both patients and their caregivers. We provide preliminary evidence that these materials are effective in improving ACP engagement and general ACP knowledge for both caregivers and persons with mild-to-moderate cognitive impairment. Future ACP studies will need to plan for the effort required to recruit diverse older adults with cognitive impairment/caregiver dyads and consider how to provide the information over shorter sessions to lessen cognitive burden in this vulnerable patient and research population.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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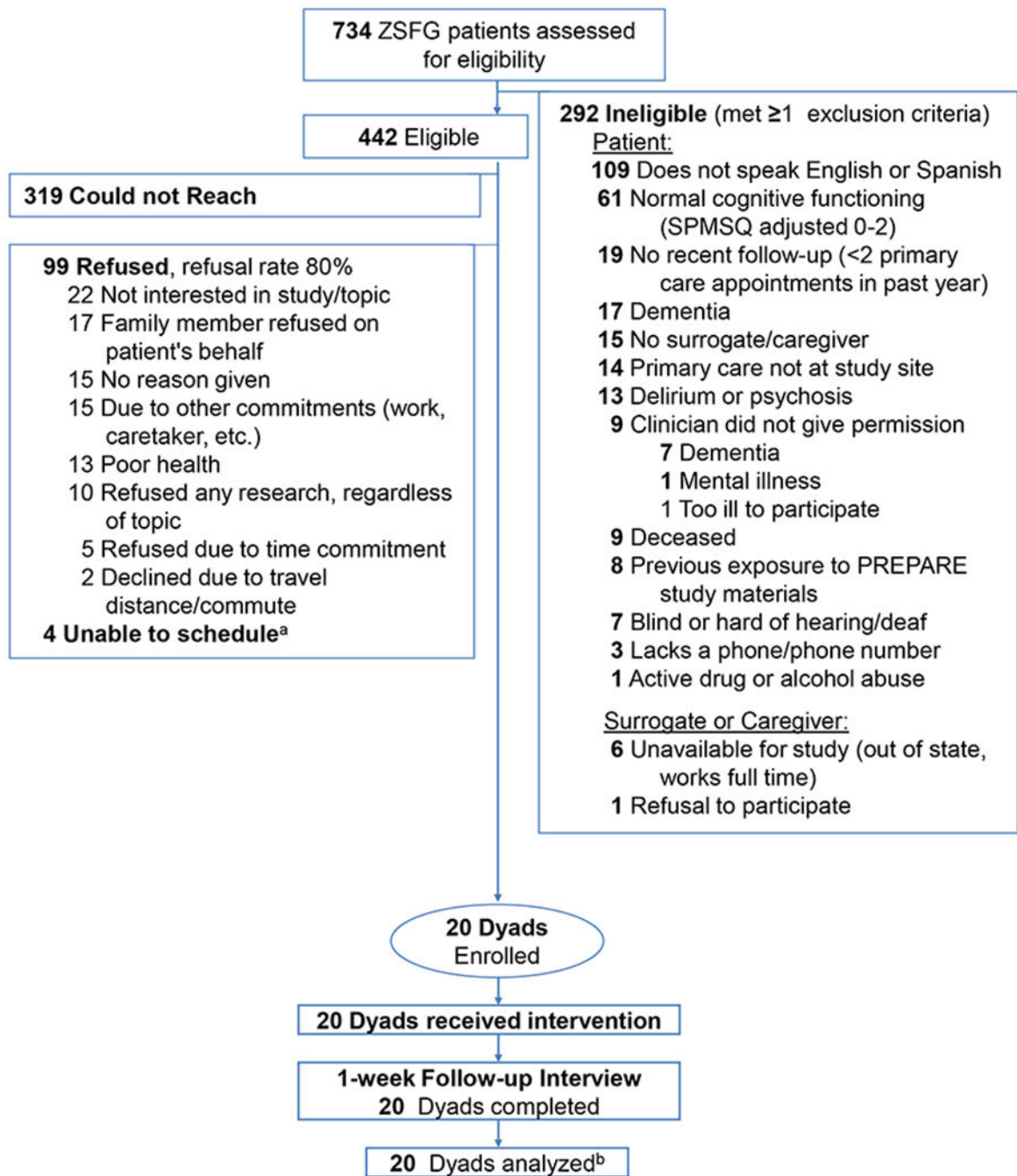


Figure 1. Screening, Recruitment and Follow-up of Trial Participant.

^aPatient willing to participate, but logistical issues (e.g., work, care taking, travel, illness, etc.) prevented scheduling

^bTotal retention rate was 100%

Table 1.

Sample characteristics (n = 20 patient-caregiver dyads)

		Patient N (%)	Caregiver N (%)
Sociodemographic characteristics			
Age	Mean (SD)	69.9 (8.9)	56.6 (17.2)
	Range	56-87	29-87
Female Gender		17 (85)	14 (70)
Race/Ethnicity	White/Caucasian	1 (5)	1 (5)
	Latino/Hispanic – Mexican	2 (10)	8 (40)
	Latino/Hispanic - Central American	8 (40)	1 (5)
	Asian/PI – Filipino	1 (5)	1 (5)
	Asian/PI – Japanese	1 (5)	1 (5)
	Black/AA – African	6 (30)	7 (35)
	Black/AA – Caribbean	1 (5)	1 (5)
Have Adult children		17 (85)	-
Married		8 (40)	-
Language	English	11 (55)	14 (70)
	Spanish	9 (45)	6 (30)
USA Born		7 (35)	-
Limited Health Literacy ^a		12 (60)	2 (10)
Education	<High School	5 (25)	4 (20)
	High School/GED	1 (5)	10 (2)
	Some College	9 (45)	11 (55)
	College Graduate	4 (20)	3 (15)
Income (Range 1-10) ^b	Ladder - Mean (SD)	5.3 (2.7)	6.3 (2.2)
	Not enough to make ends meet at end of month	7 (35)	7 (35)
Cognition			
Self-report Dementia		15 (3)	0 (0)
SPMSQ Score	Normal (0-2 errors) ^c	15 (3)	19 (95)
	Mild/Moderate impairment (3–7 errors)	17 (85)	5 (1)
Health/Function			
Self-rated health	Poor/Fair	12 (60)	6 (30)
	Good	8 (40)	9 (45)
	Very Good/Excellent	0 (0)	5 (25)

		Patient N (%)	Caregiver N (%)
Mood ^d	Depression Screen – Positive	7 (35)	2 (10)
	Anxiety Screen – Positive	5 (25)	4 (20)
IADLs ^e	Number of impairments - Mean (SD)	2.7 (2.2)	0.55 (0.9)
ADLs ^f	Number of impairments - Mean (SD)	0.7 (1.0)	0.1 (0.3)
Difficulty walking several blocks		15 (75)	6 (30)
Relationship with Health Care, Technology			
PCP relationship	<1 year	1 (5)	-
	1–2 years	6 (30)	-
	>2 years	13 (65)	-
Prior Planning	Prior AD, living will, or DPOA	8 (40)	4 (20)
Decision making style with doctors	All Decisions on my own	2 (10)	6 (30)
	Doctor and I share equally	17 (85)	10 (50)
	Doctors make all decisions for me	1 (5)	4 (20)
Decision making style with family	All Decisions on my own	8 (40)	12 (60)
	Family/friends and I share equally	12 (60)	8 (40)
	Family/friends make all decisions for me	0 (0)	0 (0)
Internet comfort	Extremely/Quite	3 (15)	11 (55)

Abbreviations: SD – Standard Deviation, PI – Pacific Islander, AA – African American, SPMSQ – Short Portable Mental Status Questionnaire, PCP – Primary Care Provider, IADL – Instrumental Activities of Daily Living, ADL – Activities of Daily Living, AD – Advance Directive, DPOA – Designated Power of Attorney.

^aLimited health literacy was defined based on a one-question screen on confidence filling out medical forms on one's own.³¹

^bIncome was determined based on a validated 10-point income ladder,²⁹ and self-report of enough income to “make ends meet” at the end of the month.³⁰

^cIndividuals could screen normal on the SPMSQ and still qualify for the study if they had a diagnosis of cognitive impairment in their medical record.

^dMood was assessed using Physician Health Questionnaire-2 (PHQ-2) for depression and the Generalized Anxiety Disorder-2 (GAD-2) for anxiety.

^eIADLs included difficulty with using the telephone, transportation, shopping, meal preparation, housework/chores, laundry, medication management and managing finances.

^fADLs included difficulty with bathing, dressing, eating, transfer from bed to a chair, using a toilet, and walking several blocks.

Table 2.

Feedback on the PREPARE website and advance directive form

	Patient			Caregiver		
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)
PREPARE Website						
Ease-of-use (Range 1-10) ^a	8.6 (1.6)	9 (8-10)	9.4 (1.1)	10 (9.5-10)		
Feasibility (Range 1-5) ^b	4.7 (0.4)	4.7 (4.7-5)	4.7 (0.3)	4.8 (4.3-5)		
Advance Directive Form						
Ease-of-use (Range 1-10) ^a	8.4 (2.3)	9 (7-10)	8.8 (2.2)	10 (8-10)		
Feasibility (Range 1-5) ^b	4.9 (0.3)	5 (4.7-5)	4.9 (0.3)	5 (5-5)		
Overall Acceptability						
Acceptability (Range 0-5) ^c	4.9 (0.4)	5 (5-5)	4.8 (0.6)	5 (5-5)		

^aEase-of-use was determined through one item asking how easy it was to review the resource, on a scale of 1 to 10.

^bFeasibility was a 3-item scale asking about the comfort viewing, helpfulness, and likelihood of recommending the resource to others, with each item rated on a 1-5 scale and the overall score representing the averaged value.

^cAcceptability was a 5-item scale asking if respondents enjoyed answering materials, reviewing materials, being in the study, felt like the study was a burden, or would recommend the study to others (responses: yes/no); positive responses were summed to create a scale ranging 0-5 points.

Table 3.

Change in Advance Care Planning Engagement from baseline to one week follow-up

	Mean Change (SD)	Median Change (IQR)	p-value
Patient			
Overall ACP Engagement (15 items)	0.2 (0.7)	0.1 (0.0-0.6)	0.04
Self-efficacy subscale (6 items)	0.0 (1.0)	0.0 (-0.2-0.5)	0.43
Readiness subscale (9 items)	0.1 (1.0)	0.0 (-0.2-0.6)	0.46
Caregivers			
Overall ACP Engagement (21 items)	0.3 (0.9)	0.1 (-0.2-1.0)	0.20
Knowledge subscale (3 items)	0.8 (0.9)	0.7 (0.0-1.3)	0.002
Contemplation subscale (5 items)	0.4 (1.1)	0.2 (-0.2-0.9)	0.12
Self-efficacy subscale (7 items)	0.4 (1.1)	0.1 (0.0-1.1)	0.03
Readiness subscale (6 items)	0.0 (1.1)	-0.2 (-0.8-1.0)	0.92

Abbreviations: ACP – Advance Care Planning

p-values represent results from Wilcoxon matched pairs signed-rank tests

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Table 4.

Stakeholder input and field observations from patient-surrogate dyads

Theme	Patient/ Surrogate	Illustrative Quotes from Patients and Surrogates
Participant Feedback		
Positive Feedback		
Video stories were helpful and relatable	Patient	“Seeing people explain themselves (videos), makes (it) easier for me to think of ways of doing so myself.”
	Surrogate	“Provides situations to help understand and navigate real life scenarios. Has many siblings so it was helpful to know how to decide and share the decision with the rest of the family.”
Easy to Understand Materials	Patient	“The videos are simple and to the point. The do not use any lawyer language to explain the message.”
	Surrogate	“It is very informative for people that have no idea of what an advance directive form is. The information is all in easy to read language.”
Speaking to doctors	Patient	“I enjoyed all the videos but I really enjoyed the videos of patient asking doctors questions.”
	Surrogate	“I really enjoyed the asking your doctors questions videos.”
Constructive Feedback		
Repetition or Length	Patient	“The information in the videos is very repetitive.”
	Surrogate	“Found it a bit redundant”
Technological barriers	Patient	“I’m not sure how to use computers”
	Surrogate	“The computer website may be difficult to navigate for me because I don’t have a computer.”
Challenging social situations	Patient	“How to deal with families (or family members) who are difficult to talk to (difficult people).”
	Surrogate	“I have to learn how to accept the medical decisions that my mother is making for herself. It’s hard to accept the decisions for medical care that my mom wants because I have different opinions.”
Field Observations		
Barriers		
Attention or Length	Patient	Patient sat quietly watching the content as surrogate navigated website. She tried her best to stay engaged but a few times she fell asleep for about 20 seconds.
	Surrogate	Patient and surrogate are both tired because they are yawning.
Impatience or lack of engagement	Patient	Patient started navigating website on her own. For much of this step, patient seemed impatient and just wanted to go over it as quickly as possible.
	Surrogate	Surrogate’s arms are crossed. She started to look at phone. Patient started leaning in and watching videos, but was confused and her answers to the website questions contradicted her surveys answers and expressed wishes. Surrogate wasn’t concerned with the contradiction – just wanted to get through the interview.
Technological Barriers: Computer	Patient/ Surrogate	Both patient and surrogate do not know how to use the mouse. Had to teach them how to use mouse/touch screen. They were distracted with using the computer, and missed content on first few pages.
	Patient	Patient does not feel comfortable with computers in general, but with touch screen she’s able to navigate quite well.
Technological barriers: Navigating the website	Patient	Patient was getting used to the touch screen, scrolling down to hit the “next” button, but slow at clicking on video and hitting the “play” button again. RA had to help scroll down so patient and surrogate can view scales while slide was being narrated.
	Surrogate	Surrogate needed directions initially on how to navigate between pages and exit out of pop-up videos. Surrogate asked how to open pop-up windows for videos. Surrogate accidentally skipped to next page instead of playing the 2nd video story, but was able to navigate back and finish watching the other two videos.

Theme	Patient/ Surrogate	Illustrative Quotes from Patients and Surrogates
Surrogate Supporting the Patient		
Facilitating Technology	Surrogate	Surrogate started navigating a step, and the patient took over as needed. The surrogate helped the patient understand some response choices, and then the patient would click on answers.
Encouraging Patient Attentiveness	Surrogate	Patient was fidgeting with finger/hand throughout, and looking at the screen 90% of the time. For the questions, the surrogate re-iterated the question-and-answer options to the patient or asked to verify her answers.
Facilitating Comprehension	Surrogate	Daughter/surrogate recapped the videos to make sure her mother understands. Surrogate answered the website questions and filled out the optional box explaining why the decisions were important. Patient followed along and gave her input and surrogate edited accordingly.