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### Authors

Volow, Aiesha  
McMahan, Ryan  
Jin, Chengshi  
et al.

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## Health literacy matters more than experience for advance care planning knowledge among older adults

Sarah S. Nouri, MD, MPH<sup>a</sup>, Deborah E. Barnes, PhD, MPH<sup>b,c,d,f</sup>, Aiesha M. Volow, MPH<sup>d,e,f</sup>, Ryan D. McMahan, BS<sup>e</sup>, Margot Kushel, MD<sup>g,h</sup>, Chengshi Jin, PhD<sup>c</sup>, John Boscardin, PhD<sup>c,e</sup>, Rebecca L. Sudore, MD<sup>d,e,f,h</sup>

<sup>a</sup>Division of General Internal Medicine, Department of Medicine, University of California, San Francisco, San Francisco, CA, United States

<sup>b</sup>Department of Psychiatry, University of California, San Francisco, San Francisco, CA, United States

<sup>c</sup>Department of Epidemiology & Biostatistics, University of California, San Francisco, San Francisco, CA, United States

<sup>d</sup>San Francisco Veterans Affairs Medical Center, San Francisco, CA, United States

<sup>e</sup>Division of Geriatrics, Department of Medicine, University of California, San Francisco, San Francisco, CA, United States

<sup>f</sup>Innovation and Implementation Center in Aging and Palliative Care Research (I-CAP), University of California, San Francisco, San Francisco, CA, United States

<sup>g</sup>Division of General Internal Medicine, Department of Medicine, Zuckerberg San Francisco General Hospital and Trauma Center, University of California, San Francisco, San Francisco, CA, United States.

<sup>h</sup>Center for Vulnerable Populations, Zuckerberg San Francisco General Hospital and Trauma Center, University of California, San Francisco, San Francisco, CA, United States

### Abstract

**Background:** Advance care planning (ACP) engagement is low among vulnerable populations, including those with limited health literacy (LHL). Limited knowledge about ACP may be a modifiable mediator of the relationship between LHL and ACP. Our goal was to determine whether health literacy is associated with ACP knowledge.

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**Corresponding author:** Sarah S. Nouri, MD, MPH, sarah.nouri@ucsf.edu | 415-353-7900, 1545 Divisadero Street, Box 0320, San Francisco, California 94143-0320, sarah.nouri@ucsf.edu, Twitter: @sarahsnouri.

**Author contributions:** *Study concept and design:* Nouri, Barnes, Volow, McMahan, Kushel, Sudore. *Acquisition of data:* McMahan, Sudore. *Analysis and interpretation of data:* Nouri, Barnes, Jin, Boscardin, Sudore. *Preparation of manuscript:* Nouri, Barnes, Volow, McMahan, Kushel, Jin, Boscardin, Sudore.

**Conflicts of interest:** The authors have no conflict of interest or potential conflict of interest to disclose.

These results were presented as a poster at the American Geriatrics Society Annual Scientific Meeting in May 2019 and as an oral presentation at the Society of General Internal Medicine Annual Meeting in May 2019.

**Sponsor's role:** The sponsors did not play a role in the design, methods, subject recruitment, data collections, analysis, and preparation of manuscript.

**Design:** Cross-sectional.

**Setting:** A public health delivery system and Veterans Affairs Medical Center in San Francisco.

**Participants:** English- and Spanish-speaking patients (N=1400).

**Measurements:** ACP knowledge was assessed with seven validated multiple-choice questions. Health literacy was measured using a validated scale. Sociodemographic measures included age, gender, language, education, race, health status, and social support. Prior ACP experience was defined as having documented legal forms and/or goals of care discussions in the medical record. We used Kruskal-Wallis tests and linear regression to examine associations of ACP knowledge with LHL, prior ACP experience, and sociodemographic factors.

**Results:** Mean age of participants was 65 ( $\pm 10$ ) years, 48% were women, 34% had LHL, 32% were Spanish-speaking, 47% had high school education, and 70% were non-white. Mean 7-point knowledge scores were lower for those with limited versus adequate health literacy (3.8 (SD 1.9) vs 5.5 (SD 1.7),  $p < 0.001$ ). In multivariable analysis, ACP knowledge scores were 1.0 point lower among those with LHL; 0.6 points lower among Spanish-speakers and high school education; and 0.5 points lower among individuals of non-white race ( $p < 0.001$  for all). Knowledge scores were 0.02 points lower per year of older age ( $p = 0.007$ ) and 0.01 points higher per point of greater social support ( $p = 0.005$ ). Prior ACP experience was not associated with knowledge after adjustment ( $p = 0.7$ ).

**Conclusions:** Health literacy and sociodemographics are stronger predictors than prior ACP experience of ACP knowledge. This study suggests that providing easy-to-understand ACP materials is paramount and should be offered even if patients have previous experience with the ACP process.

## Keywords

health literacy; advance care planning; vulnerable populations

## INTRODUCTION

Advance care planning (ACP) is a dynamic process, including not only completing an advance directive, but also understanding and sharing values and preferences regarding medical care.<sup>1, 2</sup> While ACP has been associated with increased satisfaction in end-of-life care and a higher likelihood of patients receiving care consistent with their goals,<sup>3, 4</sup> engagement in ACP remains low, particularly among vulnerable older populations and those with limited health literacy.<sup>5, 6</sup>

Conceptual models of ACP, based on social cognitive and behavior change theories, have described moderator variables which may affect engagement in ACP, such as health literacy.<sup>7, 8</sup> They also describe mediator variables which must be improved to affect engagement in the ACP process, such as health-related knowledge.<sup>9, 10</sup> While many of the factors that influence an individual's health literacy are static, knowledge is modifiable. Therefore, knowledge is considered an important modifiable construct that can be changed in response to literacy-appropriate interventions.<sup>8</sup>

Limited health literacy (LHL) has been associated with poor health-related knowledge for many disease processes.<sup>11</sup> Small studies of homogeneous populations have demonstrated an association between ACP knowledge and completion of advance directives;<sup>12-14</sup> however, definitions of ACP knowledge have been inconsistent and ACP has been narrowly defined as the completion of a legal document.<sup>13</sup> Prior studies of ACP knowledge have not included vulnerable, ethnically diverse older adults, a range of key, fundamental aspects of ACP (e.g., designation of a surrogate decision maker), or explored the association of ACP knowledge with LHL.

To elucidate modifiable barriers of ACP among diverse older adults, this study aimed to determine whether LHL is associated with fundamental ACP knowledge in an ethnically diverse population of English- and Spanish-speaking older adults. We hypothesize that LHL is associated with lower ACP knowledge.

## METHODS

This is a cross-sectional study of baseline data collected from 2013 to 2017 from two randomized controlled trials evaluating the efficacy of [PREPAREForYourCare.org](https://www.preparesf.org) (PREPARE), a video-based, interactive ACP website versus easy-to-read advance directives. The trial results and the methods have been previously published.<sup>15, 16</sup> 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. All study materials and measures were available in English and Spanish. Spanish materials were pilot tested with the target population. Consent materials and questionnaires were administered by fluent English or Spanish speaking research staff.

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. Veterans were included if they were 60 years of age or older, spoke English, had at least 2 chronic medical conditions, had 2 or more visits with a primary care provider in the past year and 2 additional clinic, emergency department, or hospital visits in the past year. Patients at SFHN had similar inclusion criteria, except they were 55 years of age or older and were included if they spoke English or Spanish. Exclusion criteria for both studies included dementia or moderate to severe cognitive impairment using validated measures,<sup>17, 18</sup> blindness, deafness, delirium, psychosis, active drug or alcohol abuse within the past 3 months, lack of a telephone, or inability to answer informed consent teach-back questions within 3 attempts.

## Measures

The outcome, ACP knowledge, was assessed with a questionnaire consisting of 7 multiple-choice questions focused on key, fundamental, practical aspects of ACP including the role of appropriate surrogate decision makers, when to engage in ACP, and to whom one should share their ACP wishes (Table 1). The questionnaire was written at a 5<sup>th</sup> grade reading level, adapted from validated scales, and refined with input from experts in ACP, health literacy, and geriatrics and the target patient population (Cronbach's alpha=0.79).<sup>6</sup> The questionnaire

is analyzed on a 0 to 7-point continuous scale shown to increase in response to ACP interventions.<sup>6</sup>

The primary predictor variable, health literacy was measured using the validated short Test of Functional Health Literacy (s-TOFHLA). By convention, those with s-TOFHLA scores  $\leq 22$  were determined to have limited health literacy.<sup>19</sup>

We assessed prior ACP experience as a possible confounding variable, 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.<sup>15, 16</sup> We also assessed other patient characteristics including self-reported age, gender, language (English or Spanish), education (dichotomized as less than or equal to high school or greater than high school), race/ethnicity (dichotomized as white versus non-white), health status using a validated measure (dichotomized as fair-to-poor versus good-to-excellent),<sup>20, 21</sup> and finances using a validated measure (dichotomized as “enough” vs “not enough to make ends meet”).<sup>22</sup> Social support was measured with the validated 11-item Medical Outcomes Study Social Support Survey (MOS), with scores ranging from 11 (no support) to 55 (full support).<sup>23</sup> Study site (VA versus SFHN) was also included as an independent variable.

### Statistical analyses

We conducted descriptive analyses of all sociodemographic measures. We used Kruskal-Wallis tests to examine bivariate associations between ACP knowledge scores and sociodemographic measures. For multivariable analyses, we used multiple linear regression and, *a priori*, included age, prior ACP experience, and site, as well as any sociodemographic variables associated with ACP knowledge in bivariate analysis. For our final model, we assessed linear regression model assumptions by checking residual values for a linear association with the outcome, normal distribution, and equal variance across values of the outcome. Individuals with missing data were excluded from the final model; because they constituted a small proportion of the population (just over 5%), we did not conduct multiple imputation.

## RESULTS

The average correct percentage of the 7 knowledge questions was 70% (Table 1). Thirty four percent of the 1400 participants had LHL and 34% had prior experience in ACP (i.e. prior documentation of wishes in the medical record) (Table 2). The mean age of participants was 66 years (SD 7.7), 48% were women, 70% identified as non-white, 32% were Spanish-speaking, 47% had a high school degree or less, 45% had fair or poor health status, 21% reported having limited finances, and the mean social support score was 38.7 out of 100 (SD 11.7).

The mean ACP knowledge score was 4.9 (SD 1.9) out of 7. In bivariate analyses, knowledge scores were lower for those with limited versus adequate health literacy (3.8 versus 5.5,  $p < 0.001$ ); women versus men (4.5 versus 5.2), Spanish versus English language (3.8 versus 5.4), less than or equal to high school versus higher educational attainment (4.1 versus 5.6);

non-white versus white race (4.5 versus 5.8); fair-to-poor health status versus good-to-excellent (4.6 versus 5.1); limited versus adequate finances (4.5 versus 5.0); and SFHN site versus VA (4.6 versus 5.7) ( $p < 0.001$  for each; Table 3). ACP knowledge scores were higher for those with versus without prior ACP experience (5.1 versus 4.8,  $p = 0.02$ ) and for higher social support (0.024 higher ACP knowledge score per 1-point increase in social support on the MOS scale; 95% CI 0.015-0.032,  $p < 0.001$ ). Age was not associated with ACP knowledge in bivariate analysis.

In multivariable analyses, adjusted for all the aforementioned patient characteristics associated with knowledge in bivariate analysis as well as age, limited health literacy compared to adequate health literacy remained independently associated with lower ACP knowledge scores. LHL had the strongest association with ACP knowledge compared to other variables in the model with a 1.0-point lower ACP knowledge score ( $p < 0.001$ ) (Table 3). Other variables in the model associated with ACP knowledge to a lesser degree included (in order of association) Spanish language, education, non-white race, age, site, and social support (Table 3). Prior ACP experience, gender, finances, and health status were no longer associated with ACP knowledge. In our final model, all linear regression assumptions were met.

## DISCUSSION

In this study, LHL was independently associated with poor knowledge of key, fundamental aspects of ACP after controlling for prior ACP experience and sociodemographic factors. This is the first study, to our knowledge, to demonstrate that LHL may be a more powerful moderator of ACP knowledge than prior ACP experience, including prior documented legal forms, orders, and discussions in the medical record. After adjusting for sociodemographic variables, including LHL, prior ACP experience was not associated with ACP knowledge.

These findings may be due in part to the high literacy level of most advance directives and ACP health education materials (i.e., beyond a 12<sup>th</sup> grade reading level), despite an average 8<sup>th</sup> grade reading level among US adults.<sup>6, 24</sup> Health literacy is considered a moderator of health-related knowledge, and knowledge is considered a mediator of health outcomes.<sup>10</sup> For example, increasing knowledge of chronic diseases (e.g., hypertension, diabetes, and asthma) among those with LHL results in improved health outcomes, (e.g., medication and appointment adherence and lower morbidity).<sup>11</sup> While studies are limited and results are mixed, education-based interventions have been shown to increase patients' knowledge about ACP, and ACP knowledge has been associated with a higher rate of completion of advance directives.<sup>12, 13</sup> Given the role of knowledge as a mediator for improved health outcomes, ACP interventions that increase knowledge are critical, particularly for patients with limited health literacy.

Full understanding of ACP is needed for informed consent and to ensure that patients' wishes are honored.<sup>25</sup> Based on our findings, clinicians cannot assume that patients who have prior ACP experience, including documented wishes in the medical record, have key, fundamental knowledge of the process or their options. Studies exploring the relationship between ACP knowledge and prior ACP experience are limited, and primarily include small

qualitative or quantitative studies of homogeneous populations, do not include definitions of ACP beyond advance directives, or do not adjust by health literacy or language.<sup>12, 13, 26</sup> In a study evaluating the quality of Physician Orders for Life-Sustaining Treatment (POLST) decisions, there was discordance between patients' current preferences and knowledge about their prior documented POLST orders.<sup>27</sup> In addition, a study among older hospitalized adults found that in nearly 70% of cases, documented orders regarding treatment intensification (including code status) were discordant with patients' current preferences or understanding.<sup>28</sup>

To ensure informed consent of their choices, clinicians can employ health literacy best practices.<sup>29</sup> These include the "ask-tell-ask" method,<sup>30</sup> which can be used to ask patients what they already know about ACP and about their prior wishes, and to tailor the information to their educational needs. Best practices also include the "teach-back" method<sup>31</sup> used to ask patients to describe, in their own words, understanding about their wishes and options. These practices would need to be used universally, for patients who do or do not have prior ACP experience.

We also found independent relationships between ACP knowledge and other sociodemographic factors, including Spanish language and non-white race, similar to other studies.<sup>32, 33</sup> Prior studies, however, did not assess health literacy, preferred language, finances, or social support. Reasons for these associations may overlap with reasons why these groups have lower rates of ACP, including differences in access to care and varying levels and acculturation and cultural differences.<sup>32, 34, 35</sup> Although acculturation was not considered in our analyses, the association between language and ACP knowledge may support the role of cultural differences as an explanatory mechanism. These findings emphasize the need for easy-to-understand and culturally and linguistically appropriate ACP materials.

This study has some limitations. The generalizability of our findings may be limited as it was carried out in only two health care systems in one area of the country. Because this is a cross-sectional study, we are unable to infer causality between ACP knowledge and health literacy, prior ACP experience, and other sociodemographic variables. We chose to define prior ACP experience using objective chart review to capture personal ACP experiences that were extensive enough to have been documented. While this definition may decrease recall bias, not including self-report may have introduced misclassification bias. While the ACP knowledge questionnaire was adapted from validated measures, there are no established clinical cutoffs when interpreting the scores. Nevertheless, we demonstrated a 1-point difference on a 7-point scale, and this difference is meaningful when considering the questionnaire assesses knowledge of fundamental aspects of ACP.

In summary, health literacy is an important predictor of ACP knowledge, more so than prior ACP experience. Other sociodemographic factors such as race/ethnicity and Spanish language were also associated with ACP knowledge, but to a lesser degree than health literacy. To ensure full informed decision making in the ACP process, clinicians should assess patients' understanding of ACP, including those who have previous experience with the ACP process. Future studies are needed to determine whether low literacy, culturally-

and linguistically-appropriate ACP interventions can increase key fundamental knowledge in ACP among diverse, vulnerable older adults.

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All authors listed have contributed sufficiently to the project to be included as authors, and all those who are qualified to be authors are listed in the author byline.

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**Table 1.**

## ACP Knowledge Questionnaire Focusing on Key, Fundamental Aspects of ACP.

Questions	Answered correctly, n (%)
1. A medical decision maker is sometimes also called a health care proxy or a durable power of attorney for healthcare. What is a medical decision maker?	843 (60.2)
a. A friend or family member who can handle your money for you if you are unable	
b. A friend or family member who can help make medical decisions for you if you are unable*	
c. Your doctor	
d. I am not sure	
2. For most people, when is the best time to choose a medical decision maker?	1055 (75.4)
a. Ahead of time, before they get sick	
b. Only when they get sick and have to come to the hospital	
c. Only if the doctor asks them to do it	
d. I am not sure	
3. For most people, who would be the best medical decision maker?	1227 (87.6)
a. Someone who is good with counting money	
b. Someone who lives far away	
c. Someone who can be trusted to talk with doctors about that person's medical care	
d. I am not sure	
4. Do people need to formally ask someone to be their medical decision maker?	912 (65.1)
a. No, this person should already know without having to ask	
b. No, if it is already on a legal form, people do not need to formally ask someone to do it	
c. Yes, so this person has time to ask questions and prepare	
d. I am not sure	
5. For most people, when a medical decision maker is chosen, who needs to know about it?	948 (67.7)
a. The bank	
b. The doctors	
c. No one, it is personal	
d. I am not sure	
6. If a person grants their medical decision maker total flexibility to make medical decisions on their behalf, what does flexibility mean?	898 (64.1)
a. That the medical decision maker should be easier to get along with	
b. That it is OK for the medical decision maker to change the person's past medical decisions if it is in the person's best interest	
c. That it is OK to move that person's money between different bank accounts	
d. I am not sure	
7. When people decide on what quality of life means to them and what kind of medical care they want in the future, who should they tell?	954 (68.1)
a. No one, this is personal	

Questions	Answered correctly, n (%)
<b>b.</b> If it is already on a legal form, people do not need to talk to anyone	
<b>c.</b> Only the medical decision maker	
<b>d.</b> Both the medical decision maker and their doctor	
<b>e.</b> I am not sure	

\* Each correct answer (italicized) is awarded 1 point.

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**Table 2.**

## Patient characteristics.

	<b>Total (n=1400)*</b>
Health literacy, <sup>^</sup> n (%)	
Adequate	915 (66.1)
Limited	470 (33.9)
Age, mean (SD)	66 (7.7)
<65, n (%)	709 (50.7)
65, n (%)	690 (49.3)
Gender, n (%)	
Male	758 (54.2)
Female	641 (47.8)
Language, n (%)	
English	955 (68.2)
Spanish	445 (31.8)
Education, n (%)	
High school	647 (47.0)
> High school	728 (53.0)
Race/ethnicity, n (%)	
White, non-Latino	424 (30.3)
African American	265 (19.0)
Latino	532 (38.0)
Native American	10 (0.7)
Asian/Pacific Islander	104 (7.5)
Multi/other	63 (4.5)
Self-reported health status, n (%)	
Good/Very good/Excellent	763 (55.2)
Fair/Poor	618 (44.8)
Finances, n (%)	
Adequate	1089 (78.9)
Limited	292 (21.1)
Social support, <sup>^^</sup> mean (SD)	38.7 (11.7)
Prior ACP experience	
Yes	481 (34.4)
No	918 (65.6)
Site <sup>°</sup>	
VA	413 (29.5)
SFHN	986 (70.4)

\* For variables in which total n = 1400, data is missing and excluded from analysis.

<sup>^</sup> Limited health literacy defined as short Test of Functional Health Literacy score < 22.

<sup>^^</sup> Medical Outcomes Study Social Support Survey; range from 11 (no support) to 55 (full support).

°  
VA=Veterans Affairs Medical Center; SFHN=San Francisco Health Network

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**Table 3.**

Advance care planning (ACP) knowledge by prior ACP experience, health literacy, and other sociodemographic variables in unadjusted and adjusted, multivariable analyses.

	Unadjusted analyses (n=1400)		Multivariable analyses (n=1316)*	
	Mean (SD)	p-value	Estimate (SE)	p-value
Health literacy <sup>^</sup>		<0.001		<0.001
Adequate	5.5 (1.7)		0	
Limited	3.8 (1.9)		-1.0 (0.1)	
Age	0.003 (0.007)	0.6	-0.02 (0.007)	0.007
Gender		<0.001		0.6
Male	5.2 (1.7)		0	
Female	4.5 (2.0)		-0.06 (0.1)	
Language		<0.001		<0.001
English	5.4 (1.6)		0	
Spanish	3.8 (2.0)		-0.6 (0.2)	
Education		<0.001		0.002
> High school	5.6 (1.6)		0	
High school	4.1 (2.0)		-0.6 (0.1)	
Race <sup>^</sup>		<0.001		<0.001
White	5.8 (1.5)		0	
Non-white	4.5 (1.9)		-0.5 (0.1)	
Self-reported health status		<0.001		0.2
Good/Very good/Excellent	5.1 (1.8)		0	
Fair/Poor	4.6 (2.0)		-0.1 (0.1)	
Finances		<0.001		0.1
Enough to make ends meet	5.0 (1.8)		0	
Not enough to make ends meet	4.5 (2.1)		-0.2 (0.1)	
Social support <sup>^^</sup>	0.024 (0.004)	<0.001	0.01 (0.004)	0.005
Prior ACP experience		0.02		0.7
Yes	5.1 (1.8)		0	
No	4.8 (2.0)		0.05 (0.1)	
Site <sup>°</sup>		<0.001		0.03
VA	5.7 (1.5)		0	
SFHN	4.6 (2.0)		-0.3 (0.1)	

\* No differences by any of the above variables between those with missing data versus those included in multivariable analysis.

<sup>^</sup> Limited health literacy defined as short Test of Functional Health Literacy score  $\leq 22$ .

<sup>^^</sup> Medical Outcomes Study Social Support Survey; range from 11 (no support) to 55 (full support).

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