

# UCSF

## UC San Francisco Previously Published Works

### Title

Surrogate decision-makers from historically marginalized populations have lower levels of preparedness for care planning.

### Permalink

<https://escholarship.org/uc/item/2zq9n6k1>

### Journal

Journal of the American Geriatrics Society, 72(2)

### Authors

Li, Lingsheng

Barnes, Deborah

Nouri, Sarah

et al.

### Publication Date

2024-02-01

### DOI

10.1111/jgs.18732

Peer reviewed



# HHS Public Access

Author manuscript

*J Am Geriatr Soc.* Author manuscript; available in PMC 2025 February 01.

Published in final edited form as:

*J Am Geriatr Soc.* 2024 February ; 72(2): 559–566. doi:10.1111/jgs.18732.

## Surrogate decision-makers from historically marginalized populations have lower levels of preparedness for care planning

Lingsheng Li, MD MHS<sup>1</sup>, Deborah E. Barnes, PhD MPH<sup>1,2</sup>, Sarah Nouri, MD MPH<sup>3</sup>, Ying Shi, PhD<sup>1,4</sup>, Aiesha M. Volow, MPH<sup>1</sup>, Mariko Feuz, DO<sup>5</sup>, Brookelle H. Li, BA<sup>1</sup>, Rebecca L. Sudore, MD<sup>1,4</sup>

<sup>1</sup>Division of Geriatrics, Department of Medicine, University of California, San Francisco, CA, USA

<sup>2</sup>Department of Epidemiology & Biostatistics, University of California, San Francisco, CA, USA

<sup>3</sup>Division of Palliative Medicine, Department of Medicine, University of California, San Francisco, CA, USA

<sup>4</sup>San Francisco Veterans Affairs Health Care System, San Francisco, CA, USA

<sup>5</sup>University of Iowa-Des Moines Internal Medicine Residency Program, Des Moines, IA, USA

### Abstract

**Background:** Surrogate preparedness for medical decision-making is an important part of care planning. This study examined preparedness and engagement among historically marginalized surrogates.

**Methods:** Surrogates were included if they were named medical decision-makers by patients 55 years at a San Francisco safety-net and Veterans Affairs hospital. We assessed preparedness for medical decision-making by asking if surrogates had been formally asked to be the medical decision-maker, if patients had discussed medical wishes with surrogates, and if the surrogate role and these medical wishes had been documented. We assessed surrogate confidence and readiness using a modified Surrogate ACP Engagement Survey. We used Wilcoxon rank-sum tests to measure the association of engagement scores with surrogate characteristics.

**Results:** Of 422 surrogates, their mean age was 53 years (SD  $\pm$ 14.5), 73% were from minoritized groups, 38% were Spanish-speaking, and 15% had limited health literacy. For preparedness outcomes, 13% of surrogates were not formally asked to play this role, 46% reported the patient had not discussed end-of-life medical wishes, and 51% reported there had been no formal

---

**Corresponding author:** Lingsheng Li, MD MHS, Lingsheng.li@ucsf.edu, 4150 Clement St, Building 1, Room 306B, San Francisco, CA 94121, Twitter handle @lingshengli.

Author Contributions:

- (1) Study concept and design: Brookelle Li, Lingsheng Li, Aiesha Volow, Rebecca Sudore.
- (2) Acquisition of subjects and/or data: Brookelle Li, Aiesha Volow, Rebecca Sudore.
- (3) Analysis and interpretation of data: Lingsheng Li, Ying Shi, Aiesha Volow, Rebecca Sudore.
- (4) Preparation of draft: All authors.

**Conflict of Interest:** All authors report no conflicts of interest.

Prior presentations:

- American Geriatric Society Annual Scientific Meeting. Presidential ePoster Session. May 2021.
- Annual Assembly of Hospice and Palliative Care. Scholar Poster. Feb 2022.

documentation of the surrogate role. Surrogates reported higher confidence 4.43/5 (SD±0.64) than readiness 3.70 (1.22) for decision-making ( $p<0.001$ ). Confidence and readiness scores were lower among historically marginalized participants.

**Conclusion:** More resources are needed to prepare surrogate decision-makers from historically marginalized communities for discussing patient’s goals of care and treatment preferences.

### Keywords

Surrogate decision-maker; advance care planning; care planning continuum

---

## Introduction

Advance care planning (ACP) is evolving as a part of the continuum of care planning focused on preparing both patients and surrogate decision-makers (surrogates) for communication and medical decision-making.<sup>1</sup> The field has also recognized the importance of outcomes and experiences of surrogate decision-makers over the life course.<sup>1,2</sup> Prior research has shown that 70% of older patients may lack decision-making capacity at some point in their treatment trajectory.<sup>3,4</sup> In an ideal scenario, a designated surrogate is informed, accepts this role, and then engages in conversations with the patient about their goals for medical care prior to the patient losing decision-making capacity. However, up to 40% of patients who need surrogate decision-making had never previously appointed a surrogate,<sup>3</sup> and over 40% of patient/caregiver dyads reported never having had a conversation with each other about quality versus quantity of life.<sup>5</sup>

When left unprepared, surrogates may experience a range of negative emotions –stress, anxiety, guilt, and depression—that extend beyond the decision-making process.<sup>6,7</sup> ACP interventions have shown positive changes for affecting medical decision-making for patients and improving satisfaction, quality of life, and mental health outcomes for surrogates and family members.<sup>3,8–11</sup> Thus, in seeking to empower surrogates and develop future interventions to alleviate their distress during the decision-making process, it is important to consider and understand whether designated surrogates feel prepared and ready to make medical decisions. Further, it is worth specifically examining the experiences of surrogates in historically marginalized communities, such as People of Color and those with limited English proficiency, particularly given the alarming disparities in ACP engagement and healthcare access.<sup>12,13</sup> The purpose of this study was to explore surrogate-reported preparedness and engagement (e.g., confidence and readiness) in care planning among a diverse cohort of surrogates for adults 55 years of age with chronic illnesses.

## Methods

### Participant Recruitment

This study was a secondary analysis of data collected from two randomized controlled trials conducted in primary care clinics at the San Francisco Veterans Affairs Medical Center (SFVAMC) and Zuckerberg San Francisco General Hospital (ZSFG) from 2013 to 2017. The trials were designed to evaluate the efficacy of the online [PREPAREForYourCare.org](https://www.preparesf.org) (PREPARE) ACP program and the PREPARE easy-to-read advance directives to help older

English and Spanish-speaking patients engage in ACP.<sup>14–16</sup> These studies were approved by the Institutional Review Boards of the University of California, San Francisco (UCSF) and the San Francisco Veterans Affairs (VA) Medical Center. All participants provided informed consent and all study materials were provided in Spanish and English.

Patient participants were eligible for the trials if they were ≥ 55 years old, spoke English or Spanish well or very well, had ≤ 2 chronic medical conditions, had established care with a primary care provider, and ≤ 2 additional outpatient, inpatient, or emergency department visits in the past year, as previously described.<sup>14,17</sup> Surrogates were eligible for baseline interviews if the patient participant agreed they had someone in their life who could help make medical decisions if needed and the patient provided permission to contact the potential surrogate participant. Patients were asked to refer potential surrogates who were Spanish- or English-speaking and 18 years of age or older and to provide the surrogate's contact information and preferred mode of contact. Referred surrogates were contacted up to three times, either by phone, email, mail, or in-person if they accompanied the enrolled patient to clinic. All surrogate interviews were conducted over the phone and occurred at the time of the last study follow-up for patient participants.

Surrogates were excluded if they self-reported dementia, blindness, or deafness; limited language proficiency in Spanish or English; lack of a telephone for screening and interviews<sup>14</sup> and, as determined by study staff, if they screened positive for delirium, psychosis, or moderate-to-severe cognitive impairment using the SPMSQ<sup>18</sup> and modified Mini-Cog.<sup>19</sup> Surrogates were offered a \$50 honorarium for the interview.

### Participant Characteristics

We collected self-reported surrogate data including age, gender, education, language preference (i.e., English or Spanish), health status (5-point Likert scale dichotomized as “fair-to-poor” versus “good-to-excellent”),<sup>20</sup> and whether they had ever accompanied the patient participant to medical appointments. Health literacy was measured using a single, validated question about confidence filling out medical forms (dichotomized as “not at all-to-somewhat” versus “quite a bit-to-extremely confident”).<sup>21</sup> Surrogate relationship with the patient was collected as a part of patient participant surveys. Given demonstrated disparities in ACP among racially and ethnically minoritized older adults,<sup>12,13,22</sup> we asked surrogates to report their self-identified race and ethnicity, categorized as: Latinx/Hispanic, Black/African American, Asian/Pacific Islander, Multiethnic, American Indian/Alaska Native). We dichotomized race/ethnicity into minoritized vs. non-minoritized populations.

### Outcome Measures

To determine surrogate preparedness, we asked surrogates to report (yes/no) if the patient participant had formally asked them to be the medical decision-maker, if the patient talked to the surrogate about whether certain health situations would make their life not worth living, if the patient talked to the surrogate about what kind of medical care the patient would want if they were very sick or near the end of life, if the patient signed official papers (i.e. advance directive or durable power of attorney) naming the surrogate as the medical

decision-maker and/or documenting their medical wishes, and if the surrogate knew where the official papers were stored.

To determine engagement, we measured surrogate confidence (e.g., self-efficacy for decision-making in the future, 12-items) and readiness (e.g., ready to act now, 3-items) using a modified 15-item version of the validated, culturally vetted Surrogate ACP Engagement Survey,<sup>23</sup> with responses on a 5-point Likert scale ranging from 1 (indicating lowest level, “not at all confident” and “not at all ready”) to 5 (indicating the highest level, “extremely confident” and “extremely ready”).<sup>24,25</sup> We compared 3 items that corresponded between both the confidence and readiness domains from the Survey: (1) talking with the patient participant about whether or not certain health situations would make the patient’s life not worth living, (2) talking with the patient about the kind of medical care the patient would want if they were very sick or near the end of life, and (3) talking with the patient about how much flexibility the patient would want to give the surrogate to make medical decisions on their behalf. We also assessed whether patient participants reported formally documenting the surrogate or their medical wishes in an advance directive or other legal document.<sup>2,19</sup>

### Statistical Analyses

We described demographics and surrogate-reported preparedness with percentages and means  $\pm$  standard deviation (SD). The modified, validated Surrogate ACP Engagement Survey scores were based on average 5-point Likert scores, combined overall and analyzed for confidence and readiness subdomains. The threshold for a clinically meaningful difference in ACP Engagement Survey scores has been determined to be 0.2 and is associated with ACP conversations and documentation.<sup>25</sup> We used Wilcoxon rank-sum test to assess associations of the average confidence and readiness scores with surrogate demographic characteristics, hypothesizing that scores would be higher if surrogates reported that patients documented a surrogate and their medical wishes, and would be lower for historically marginalized surrogates, including those from minoritized groups, Spanish-speakers, and those who report lower education and limited health literacy. All quantitative analyses were conducted using SAS 9.4 (SAS Institute) and STATA 15.1 (Stata Corp).

### Results

Of the 1,400 patient participants, 625 (45%) referred a surrogate: 125 surrogates (20%) could not be reached, 59 (9%) declined, 6 (1%) were ineligible, 1 (0.07%) withdrew after enrollment, and 12 (2%) could not be scheduled in the study time frame, resulting in 422 (67%) referred surrogates who completed the study interview.

The mean age of surrogates was 53 years (SD  $\pm$ 14.5), 281 (67%) were women, 308 (73%) reported being from a minoritized group: 184 (44%) Latinx or Hispanic, 67 (16%) Black/African American, 22 (5%) Asian or Pacific Islander, 31 (7%) Multiethnic, and 4 (1%) American Indian/Alaska Native (Table 1). For the reported relationship to the patient, 144 (48%) were adult children, 55 (18%) were spouse/partner, and 44 (15%) were sibling. One hundred and sixty-three (39%) participants had a high school or less education attainment, 124 (38%) were Spanish-speaking, 74 (23%) reported poor health, and 50 (15%) reported

limited health literacy. Additionally, 268 (63%) had accompanied the patient participant to a doctor's appointment or hospital visit.

When asked about surrogate preparedness, 57 (13%) of the surrogates reported they were not formally asked by the patient participant to play this role, 159 (38%) reported the patient had not talk with them about whether certain health situations would make life not worth living, 195 (46%) reported the patient had not talked with them about what kind of medical care the patient would want if they were very sick or near the end of life, and 217 (51%) reported the patient had not signed official papers (e.g., advance directive or durable power of attorney) formally naming them as the surrogate decision-maker. Of the 140 surrogates (33%) who reported that the patient had signed official papers documenting their medical wishes at any time, 40 (32%) did not know where the forms were stored.

The overall, average Surrogate ACP Engagement score was 4.29 (SD±0.63) out of 5 (Table 2). When comparing average scores between the confidence (for decision-making in the future) and readiness (for decision-making now) subdomains, we found that surrogates reported higher confidence than readiness (4.43 (0.64) versus 3.70 (1.22),  $p<0.001$ ) for surrogate decision-making. Surrogates also reported higher confidence than readiness for the individual items of talking with the patient participant about whether certain health situations would make the patient's life not worth living (4.41 (1.07) versus 3.68 (1.47)), about the kind of medical care the patient would want if they were very sick or near the end of life (4.53 (0.83) versus 3.75 (1.35)), and about how much flexibility the patient would have wanted to give the surrogate to make medical decisions on their behalf (4.52 (0.88) versus 3.66 (1.34)),  $p<0.001$  for all.

Surrogate ACP Engagement Survey scores were higher if patient participants reported formal documentation of the surrogate's role versus no documentation (4.39 (SD ± 0.59) versus 4.15 (0.65),  $p<0.001$ ), and if they reported formal documentation of their medical wishes versus no documentation (4.40 (0.61) versus 4.16 (0.62),  $p<0.001$ ) (Table 3). Overall, average surrogate ACP engagement scores were lower for minoritized versus non-minoritized participants (4.17 (0.64) versus 4.61 (0.45),  $p<0.001$ ); among Spanish- versus English-speakers (3.87 (0.70) versus 4.38 (0.50)); those with high school education versus higher attainment (4.00 (0.68) versus 4.46 (0.52)); and those who reported limited versus adequate health literacy (3.73 (0.72) vs 4.25 (0.59)),  $p<0.001$  for all.

## Discussion

In this study of designated surrogate decision makers for older adults with chronic illnesses, preparedness for medical decision-making was low, with close to half of surrogates reporting that the patient had not discussed their medical preferences for end-of-life care; over 50% of surrogates reporting that the patient had not signed official papers documenting the surrogate role, despite the majority of potential surrogates having accompanied patients to medical appointments. As a measure of surrogate ACP engagement, confidence was rated higher than readiness in discussing patient's goals of care and treatment preferences. Surrogate ACP engagement scores were lower among historically marginalized populations, which includes minoritized and Spanish-speaking individuals, and surrogates with limited

education and health literacy. However, engagement scores were higher if the patient had formally documented the surrogates' role and had documented their medical wishes.

Although 87% of surrogates in this study reported being aware of their role as surrogates, the large number of surrogates who were unaware of the patient's medical preferences echo findings from previous studies.<sup>3,5,13</sup> Interviews with experienced surrogates have found that informing family and friends of one's wishes and verifying understanding of the surrogate's role can help prepare surrogates for making complex medical decisions.<sup>27,28</sup> Even though all surrogates in this study were identified by the patient participant, many surrogates had not been asked or informed of their role by the patient. Furthermore, of the surrogates who reported that the patient had signed official forms documenting their medical wishes, over a third of surrogates did not know where the forms were stored. Notably, lack of preparedness does not reflect lack of involvement in care as we found that over 60% of surrogates had accompanied the patient to a doctor's appointment or hospital visit. Clinicians can encourage patients to invite their surrogates to clinic visits. These visits are then a great opportunity to talk about care planning and provide care planning and other resources that can help improve surrogate preparedness. While it is important to facilitate communication between the patient and surrogate about treatment decisions, clinicians can also partner with the surrogate to help them identify patient's core values that may inform end-of-life and in-the-moment decisions.<sup>2</sup> Additionally, there are systems-level approaches for training physicians and interdisciplinary clinicians (e.g., nurses, social workers, chaplains) on tailoring care planning to an individual's life course while decreasing surrogate distress.<sup>1</sup>

The Engagement Survey scores show that surrogates' confidence in making decisions in the future is higher than their readiness to make surrogate decisions if they had to act now. Overconfidence is considered as a barrier to ACP since it does not reflect understanding of patient's wishes nor alleviate surrogate burden.<sup>29,30</sup> Surrogate overconfidence has been demonstrated by others,<sup>29</sup> and a randomized controlled trial of two strategies for preparing surrogates found no correlation between knowledge of patient's wishes and surrogates' confidence.<sup>31</sup> This suggests that surrogates need education about their role and help with preparation, which is a highly nuanced process that requires ongoing communication and support from others.<sup>27,32-34</sup> We found that surrogate engagement was higher when the patient participants reported documentation of surrogate and medical wishes, further highlighting that patient-surrogate communication should be an area of focus in care planning.

Our results also echo prior findings that ACP engagement is associated with socio-demographic factors, health literacy, family and cultural values.<sup>12,13,22,35</sup> The social and racial disparities in surrogate preparedness among our study participants who identify with minoritized groups, who are primarily Spanish-speakers, and who report lower education attainment and health literacy highlight the importance of addressing systemic inequities that impact surrogates' preparedness for decision making. The patient-surrogate relationship may also evolve over time depending on individual experiences, overall comfort level for engaging in difficult conversations, and the number of people who play a role in the decision-making process.

This study has some limitations. The patient participants and surrogates were recruited from two health care systems in a single city in Northern California, which limits the generalizability of our observations. Furthermore, surrogates were primarily Spanish- and English-speaking individuals, which limits our understanding of the experiences of surrogates who speak other languages and have different social and cultural backgrounds. It is also possible that the named surrogates who could not be reached during study recruitment may have had different experiences in preparedness and engagement compared to the study participants. Since surrogate interviews were conducted over the phone, we do not know if the patient was also present, which may have biased surrogates' responses.

ACP is an important and fluid process along the care planning continuum, and there are many ways for clinicians and the healthcare system to prepare, engage, and empower surrogates for medical decision-making in every life stage.<sup>1</sup> Beyond being informed of their role, this study demonstrates that surrogates need better preparedness and resources for learning how to communicate with patients and other family members about medical wishes, helping patients with medical planning, and making medical decisions. More efforts are also urgently needed to improve surrogate preparedness and engagement in communities affected by social and health inequity.

## Acknowledgements

This study was funded in part by the U.S. Department of Veterans Affairs Health Services Research & Development (#11-110-2), the National Institute on Aging (R01 AG045043), and the Patient-Centered Outcomes Research Institute (CDR-1306-01500). Dr. Li is supported by the National Institute on Aging (T32-AG000212). Dr. Nouri is funded in part by the National Institute on Aging (R03AG073989) and the National Palliative Care Research Center Kornfeld Scholars Program. Dr. Sudore is funded in part by the National Institute on Aging, National Institutes of Health (5K24AG054415-07).

### Funding sources:

This study was funded in part by the U.S. Department of Veterans Affairs Health Services Research & Development (#11-110-2), the National Institute on Aging (R01 AG045043), and the Patient-Centered Outcomes Research Institute (CDR-1306-01500). Dr. Li is supported by the National Institute on Aging (T32-AG000212). Dr. Nouri is funded in part by the National Institute on Aging (R03AG073989) and the National Palliative Care Research Center Kornfeld Scholars Program. Dr. Sudore is funded in part by the National Institute on Aging, National Institutes of Health (5K24AG054415-07).

## References

1. Hickman SE, Lum HD, Walling AM, Savoy A, Sudore RL. The care planning umbrella: The evolution of advance care planning. *J Am Geriatr Soc.* n/a(n/a). doi:10.1111/jgs.18287
2. Fried TR. Giving up on the objective of providing goal-concordant care: Advance care planning for improving caregiver outcomes. *J Am Geriatr Soc.* 2022;70(10):3006–3011. doi:10.1111/jgs.18000 [PubMed: 35974460]
3. Silveira MJ, Kim SYH, Langa KM. Advance Directives and Outcomes of Surrogate Decision Making before Death. *N Engl J Med.* 2010;362(13):1211–1218. doi:10.1056/NEJMs0907901 [PubMed: 20357283]
4. Sessums LL, Zembrzuska H, Jackson JL. Does This Patient Have Medical Decision-Making Capacity? *JAMA.* 2011;306(4):420–427. doi:10.1001/jama.2011.1023 [PubMed: 21791691]
5. Fried TR, Zenoni M, Iannone L, O'Leary J, Fenton BT. Engagement in Advance Care Planning and Surrogates' Knowledge of Patients' Treatment Goals. *J Am Geriatr Soc.* 2017;65(8):1712–1718. doi:10.1111/jgs.14858 [PubMed: 28317097]



6. Rogers AH, Lopez RP. Systematic Review Revisited, 2010–2020: The Effect on Surrogates of Making Treatment Decisions for Others. *J Palliat Care*. 2023;38(1):71–77. doi:10.1177/08258597221098124 [PubMed: 35603824]
7. Wendler D, Rid A. Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others. *Ann Intern Med*. 2011;154(5):336–346. doi:10.7326/0003-4819-154-5-201103010-00008 [PubMed: 21357911]
8. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. *BMJ*. 2010;340:c1345. doi:10.1136/bmj.c1345 [PubMed: 20332506]
9. Reinhardt JP, Chichin E, Posner L, Kassabian S. Vital conversations with family in the nursing home: preparation for end-stage dementia care. *J Soc Work End--Life Palliat Care*. 2014;10(2):112–126. doi:10.1080/15524256.2014.906371 [PubMed: 24835382]
10. Wright AA, Zhang B, Ray A, et al. Associations between end-of-life discussions, patient mental health, medical care near death, and caregiver bereavement adjustment. *JAMA*. 2008;300(14):1665–1673. doi:10.1001/jama.300.14.1665 [PubMed: 18840840]
11. McMahan RD, Tellez I, Sudore RL. Deconstructing the Complexities of Advance Care Planning Outcomes: What Do We Know and Where Do We Go? A Scoping Review. *J Am Geriatr Soc*. 2021;69(1):234–244. doi:10.1111/jgs.16801 [PubMed: 32894787]
12. Harrison KL, Adrion ER, Ritchie CS, Sudore RL, Smith AK. Low Completion and Disparities in Advance Care Planning Activities Among Older Medicare Beneficiaries. *JAMA Intern Med*. 2016;176(12):1872–1875. doi:10.1001/jamainternmed.2016.6751 [PubMed: 27802496]
13. Rao JK, Anderson LA, Lin FC, Laux JP. Completion of advance directives among U.S. consumers. *Am J Prev Med*. 2014;46(1):65–70. doi:10.1016/j.amepre.2013.09.008 [PubMed: 24355673]
14. Sudore RL, Barnes DE, Le GM, et al. Improving advance care planning for English-speaking and Spanish-speaking older adults: study protocol for the PREPARE randomised controlled trial. *BMJ Open*. 2016;6(7):e011705. doi:10.1136/bmjopen-2016-011705
15. Sudore RL, Knight SJ, McMahan RD, et al. A novel website to prepare diverse older adults for decision making and advance care planning: a pilot study. *J Pain Symptom Manage*. 2014;47(4):674–686. doi:10.1016/j.jpainsymman.2013.05.023 [PubMed: 23972574]
16. Sudore R, Le GM, McMahan R, Feuz M, Katen M, Barnes DE. The advance care planning PREPARE study among older Veterans with serious and chronic illness: study protocol for a randomized controlled trial. *Trials*. 2015;16:570. doi:10.1186/s13063-015-1055-9 [PubMed: 26654250]
17. Sudore RL, Boscardin J, Feuz MA, McMahan RD, Katen MT, Barnes DE. Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans. *JAMA Intern Med*. 2017;177(8):1102–1109. doi:10.1001/jamainternmed.2017.1607 [PubMed: 28520838]
18. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *J Am Geriatr Soc*. 1975;23(10):433–441. doi:10.1111/j.1532-5415.1975.tb00927.x [PubMed: 1159263]
19. Borson S, Scanlan JM, Chen P, Ganguli M. The Mini-Cog as a screen for dementia: validation in a population-based sample. *J Am Geriatr Soc*. 2003;51(10):1451–1454. doi:10.1046/j.1532-5415.2003.51465.x [PubMed: 14511167]
20. Shadbolt B, Barresi J, Craft P. Self-rated health as a predictor of survival among patients with advanced cancer. *J Clin Oncol Off J Am Soc Clin Oncol*. 2002;20(10):2514–2519. doi:10.1200/JCO.2002.08.060
21. Sarkar U, Schillinger D, López A, Sudore R. Validation of self-reported health literacy questions among diverse English and Spanish-speaking populations. *J Gen Intern Med*. 2011;26(3):265–271. doi:10.1007/s11606-010-1552-1 [PubMed: 21057882]
22. Hong M, Yi EH, Johnson KJ, Adamek ME. Facilitators and Barriers for Advance Care Planning Among Ethnic and Racial Minorities in the U.S.: A Systematic Review of the Current Literature. *J Immigr Minor Health*. 2018;20(5):1277–1287. doi:10.1007/s10903-017-0670-9 [PubMed: 29124502]

23. Sudore RL, Stewart AL, Knight SJ, et al. Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors. *PloS One*. 2013;8(9):e72465. doi:10.1371/journal.pone.0072465 [PubMed: 24039772]
24. Van Scoy LJ, Day AG, Howard M, Sudore R, Heyland DK. Adaptation and Preliminary Validation of the Advance Care Planning Engagement Survey for Surrogate Decision Makers. *J Pain Symptom Manage*. 2019;57(5):980–988.e9. doi:10.1016/j.jpainsymman.2019.01.008 [PubMed: 30684633]
25. Shi Y, Barnes DE, Boscardin J, et al. Brief English and Spanish Survey Detects Change in Response to Advance Care Planning Interventions. *J Pain Symptom Manage*. 2019;58(6):1068–1074.e5. doi:10.1016/j.jpainsymman.2019.09.004 [PubMed: 31539605]
26. Sudore RL, Schillinger D, Katen MT, et al. Engaging Diverse English- and Spanish-Speaking Older Adults in Advance Care Planning: The PREPARE Randomized Clinical Trial. *JAMA Intern Med*. 2018;178(12):1616–1625. doi:10.1001/jamainternmed.2018.4657 [PubMed: 30383086]
27. McMahan RD, Knight SJ, Fried TR, Sudore RL. Advance care planning beyond advance directives: perspectives from patients and surrogates. *J Pain Symptom Manage*. 2013;46(3):355–365. doi:10.1016/j.jpainsymman.2012.09.006 [PubMed: 23200188]
28. Bakke BM, Feuz MA, McMahan RD, et al. Surrogate Decision Makers Need Better Preparation for Their Role: Advice from Experienced Surrogates. *J Palliat Med*. 2022;25(6):857–863. doi:10.1089/jpm.2021.0283 [PubMed: 35076297]
29. Fried TR, Zenoni M, Iannone L, O’Leary JR. Assessment of Surrogates’ Knowledge of Patients’ Treatment Goals and Confidence in Their Ability to Make Surrogate Treatment Decisions. *JAMA Intern Med*. 2019;179(2):267–268. doi:10.1001/jamainternmed.2018.5299 [PubMed: 30477019]
30. Song MK, Ward SE, Lin FC. End-of-Life Decision-Making Confidence in Surrogates of African-American Dialysis Patients Is Overly Optimistic. *J Palliat Med*. 2012;15(4):412–417. doi:10.1089/jpm.2011.0330 [PubMed: 22468770]
31. Green MJ, Van Scoy LJ, Foy AJ, et al. A Randomized Controlled Trial of Strategies to Improve Family Members’ Preparedness for Surrogate Decision-Making. *Am J Hosp Palliat Care*. 2018;35(6):866–874. doi:10.1177/1049909117744554 [PubMed: 29186982]
32. Fritch J, Petronio S, Helft PR, Torke A. Making Decisions for Hospitalized Older Adults: Ethical Factors Considered by Family Surrogates. *J Clin Ethics*. 2013;24(2):125–134. [PubMed: 23923811]
33. Howard D, Rivlin A, Candilis P, et al. Surrogate Perspectives on Patient Preference Predictors: Good Idea, but I Should Decide How They Are Used. *AJOB Empir Bioeth*. 2022;13(2):125–135. doi:10.1080/23294515.2022.2040643 [PubMed: 35259317]
34. Sudore RL. Preparing Surrogates for Complex Decision Making: The Often Neglected Piece of the Advance Care Planning Equation. *JAMA Intern Med*. 2019;179(2):268–269. doi:10.1001/jamainternmed.2018.5280 [PubMed: 30477021]
35. Nouri SS, Barnes DE, Volow AM, et al. Health literacy matters more than experience for advance care planning knowledge among older adults. *J Am Geriatr Soc*. 2019;67(10):2151–2156. doi:10.1111/jgs.16129 [PubMed: 31424575]

**Key Points:.**

Surrogate decision-makers from historically marginalized communities report low preparedness and readiness to discuss goals of care and treatment preferences for older adults with chronic illnesses.

**Why does this matter?**

In many cases, caregivers are called on to make medical decisions for others, yet this study demonstrates that designated surrogate decision-makers from diverse social and cultural backgrounds are often unprepared for this role and lack confidence in making decisions for others. We need more research to determine how best to prepare surrogates from historically marginalized communities for care planning and medical decision-making.

**Table 1.**

## Surrogate Participant Characteristics

	Total (N=422)
	No. (%)
Age, mean (SD)	53 (14.5)
<65	315 (75.4)
65	103 (24.6)
Women	281 (66.8)
Race/ethnicity	
Latinx or Hispanic	184 (43.7)
White/Non-historically marginalized	113 (26.8)
Black/African American	67 (15.9)
Asian or Pacific Islander	22 (5.2)
Multiethnic	31 (7.4)
American Indian/Alaska Native	4 (1.0)
Relationship with the patient participant <sup>**</sup>	
Children	144 (47.7)
Spouse/Partner	55 (18.2)
Sibling	44 (14.6)
Friend	31 (10.3)
Parent	3 (1.0)
Other <sup>a</sup>	25 (8.3)
Educational level High school	163 (39.0)
Language	
English	192 (58.5)
Spanish	124 (37.8)
Self-reported poor health <sup>*</sup>	74 (22.6)
Limited health literacy <sup>*</sup>	50 (15.2)
Accompanied patient to doctor's appointment or hospital visit	268 (63.5)

<sup>\*</sup> Has missing data; n=328

<sup>\*\*</sup> Has missing data; n=302

<sup>a</sup> "Other" includes niece/nephew, cousin, brother-in-law, etc.

**Table 2.**

## Modified Surrogate ACP Engagement Survey

	Mean (SD)
Average overall confidence and readiness score (all questions on an average 5-point Likert scale) for all 15 subdomains (n=422)	4.29 (0.63)
Average score for the domain of confidence/self-efficacy (12 questions) (n=422)	4.43 (0.64)
Average score for the domain of readiness (3 questions) (n=422)	3.70 (1.22)
<b>Confidence/Self-efficacy (3 of 12 items that correspond with readiness questions)*</b>	
How confident are you that today you could talk with _[Participant]_ about whether or not certain health situations would make his/her life not worth living? (n=418)	4.41 (1.07)
How confident are you that today you could talk to _[Participant]_ about the medical care he/she would want if he/she were very sick or near the end of life? (n=420)	4.53 (0.83)
How confident are you that today you could talk to _[Participant]_ about how much flexibility he/she wants to give you in case you need to make medical decisions for him/her in the future? (n=419)	4.52 (0.88)
<b>Readiness (3-items)</b>	
How ready are you to talk with _[Participant]_ about whether or not certain health situations would make his/her life not worth living? (n=422)	3.68 (1.47)
How ready are you to talk with _[Participant]_ about the medical care he/she would want if he/she were very sick or near the end of life? (n=421)	3.75 (1.35)
How ready are you to talk with _[Participant]_ about how much flexibility he/she wants to give you in case you need to make medical decisions for him/her in the future? (n=421)	3.66 (1.34)

**Table 3.**

Average Overall Confidence and Readiness Scores by Surrogate Characteristics

Surrogate characteristics	Average Overall Confidence & Readiness Score, mean (SD)	p-value
<b>Patient documentation of surrogate</b>		
Yes (n=245)	4.39 (0.59)	<.001
No (n=177)	4.15 (0.65)	
<b>Patient documentation of medical wishes</b>		
Yes (n=221)	4.40 (0.61)	<.001
No (n=201)	4.16 (0.62)	
<b>Age</b>		
<65 (n=315)	4.25 (0.64)	<.02
65 (n=103)	4.40 (0.59)	
<b>Gender</b>		
Women (n=281)	4.29 (0.64)	0.40
Men (n=140)	4.26 (0.60)	
<b>Race</b>		
Non-Minoritized (n=113)	4.61 (0.45)	<.001
Minoritized groups (n=308)	4.17 (0.64)	
<b>Language</b>		
English (n=192)	4.38 (0.50)	<.001
Spanish (n=124)	3.87 (0.70)	
<b>Educational Level</b>		
>High school (n=255)	4.46 (0.52)	<.001
High school (n=163)	4.00 (0.68)	
<b>Health Literacy</b>		
High literacy (n=278)	4.25 (0.59)	<.001
Low literacy (n=50)	3.73 (0.72)	