## Title

A Toolkit for Community-Based, Medicaid-Funded Case Managers to Introduce Advance Care Planning to Frail, Older Adults: A Pilot Study.



## Journal

Journal of palliative medicine, 24(3)

## ISSN

1096-6218

## Authors

Nouri, Sarah S
Ritchie, Christine
Volow, Aiesha
et al.

## Publication Date

2021-03-01

## DOI

10.1089/jpm.2020.0200

Peer reviewed

JOURNAL OF PALLIATIVE MEDICINE
Volume 24, Number 3, 2021

DOI: 10.1089/jpm.2020.0200

# A Toolkit for Community-Based, Medicaid-Funded Case Managers to Introduce Advance Care Planning to Frail, Older Adults: A Pilot Study

Sarah S. Nouri, MD, MPH,[1] Christine Ritchie, MD, MSPH,[2] Aiesha Volow, MPH,[3] Brookelle Li, BA,[3] Shireen McSpadden, MNA,[4] Kelly Dearman, JD, MA,[5] Ashwin Kotwal, MD, MS,[3] and Rebecca L. Sudore, MD[3]

## Abstract

***Background:*** Advance care planning (ACP) among frail, older adults receiving in-home care is low. Leveraging case managers to introduce ACP may increase engagement.
***Objective:*** Pilot an ACP-Toolkit for case managers and their clients.
***Design:*** Feasibility pilot of an ACP-Toolkit for case managers to introduce ACP and the PREPAREforYourCare .org website and advance directives.
***Setting/Subjects:*** Case managers from four local aging service organizations who referred English-speaking clients ≥55 years old.
***Measurements:*** Using validated surveys (five-point Likert scales), we assessed changes in case managers' attitudes, confidence, and readiness to facilitate ACP and clients' readiness to engage in ACP from baseline to follow-up (one-week) using Wilcoxon signed-rank tests.
***Results:*** We enrolled 9 case managers and 12 clients (median age 69 [standard deviation 8], 75% minority race/ethnicity). At follow-up, case managers' confidence increased (3.2 [0.7] to 4.2 [0.7]; $p = 0.02$), and clients' readiness increased (2.8 [1.5] to 3.4 [1.4]; $p = 0.06$). All case managers agreed the Toolkit was easy to use, helped start ACP conversations, and would recommend it to others. All clients found the Toolkit easy to understand and were comfortable with case managers using it. Nearly all clients (92%) would recommend it to others. Suggestions for improvement included offering the Toolkit in other languages and disseminating it in clinical and community settings.
***Conclusions:*** The ACP-Toolkit resulted in higher case manager confidence in facilitating ACP and client readiness to engage in ACP, and usability was high. A brief ACP-Toolkit may be a feasible solution to increase ACP engagement among frail, older adults receiving in-home care.

**Keywords:** advance care planning; case managers; community-based; vulnerable populations

## Introduction

Advance care planning (ACP) is associated with higher patient and family satisfaction[1–3]; however, engagement in ACP is low among older adults.[4,5] Despite recommendations,[6] introducing ACP in clinical settings remains infrequent due to limited time during clinical visits and lack of clinician training.[7–9] There are further barriers to ACP for older adults who are socially isolated or homebound and may have inconsistent access to care.[9,10] It is therefore important to develop new models outside the clinical setting to engage this vulnerable population.

Divisions of [1]General Internal Medicine and [3]Geriatrics, Department of Medicine, University of California, San Francisco, San Francisco, California, USA.
[2]Division of Palliative Care and Geriatric Medicine, Department of Medicine, Massachusetts General Hospital and Harvard Medical School, Boston, Massachusetts, USA.
[4]San Francisco Department of Disability and Aging Services, San Francisco, California, USA.
[5]San Francisco In-Home Supportive Services Public Authority, San Francisco, California, USA.
Accepted July 7, 2020.

Studies demonstrate that ACP facilitation by social workers and community health workers results in greater ACP documentation and receipt of care consistent with goals among community-dwelling, older adults.[11–15] Collaboration with community organizations may also increase ACP among elders who are socially isolated or homebound.[16]

In preliminary work, we conducted focus groups with key community stakeholders (administrators, case managers, in-home caregivers, clients) from the San Francisco Department of Disability and Aging Services (DAS), a Medicaid-funded organization that provides in-home supportive services to homebound older adults.[17] Stakeholders agreed that ACP is highly important, and felt that case managers are best-positioned to introduce ACP given their established, ongoing relationships with clients and their scope of work, which includes assessing clients' needs and connecting clients with necessary support services.

Using this feedback, we created an ACP-Toolkit to help case managers introduce ACP and ACP tools to their clients. We describe a feasibility pilot study to determine whether the ACP-Toolkit was acceptable and whether it could increase case manager confidence and readiness to discuss ACP and client readiness to engage in ACP.

## Methods

### Setting and participants

We contacted case managers (by telephone, email, in-person) from four community organizations identified by DAS. Those who agreed to participate were asked to identify one to three clients and introduce the study using fliers and standardized scripts. We contacted interested clients to confirm their eligibility and willingness to participate.

Clients were included if they were English speaking, ≥55 years old, and receiving Medicaid-funded in-home care by an external or family/friend caregiver. Clients were excluded if they had a diagnosis of active drug or alcohol abuse, psychosis, dementia, or were unable to pass a telephone screen for cognitive impairment[18] or answer informed consent teach-back questions within three attempts.[19] Case managers (or their organizations) and clients were reimbursed $75 each. This study was approved by our Institutional Review Board. All participants provided written informed consent.

### ACP Toolkit

Using stakeholder feedback, health literacy principles, and Social Cognitive and Behavioral Change Theory (e.g., normalizing by using examples and motivational language),[20–22] we created a brief, easy-to-understand ACP-Toolkit.[23] The ACP-Toolkit includes step-by-step scripts for case managers to *introduce* ACP and refer their clients to patient-facing, evidence-based ACP tools, which clients can then use independently.[24,25] The tools include a pamphlet (referring to the PREPARE for Your Care ACP program), blank PREPARE easy-to-read advance directive (AD) forms, and the interactive PREPARE website, which have been found in randomized trials to increase ACP engagement.[24–26] We shared an optional five-minute video tutorial with case managers on use of the ACP-Toolkit. After the baseline survey, case managers met with clients in person to go through the ACP-Toolkit.

### Outcomes and measures

Feasibility outcomes included enrollment and retention rates and reasons for declining to participate. For case managers, study staff administered surveys at the time of enrollment (baseline) and one week after they met with their clients (follow-up range 7–51 days, mean 21, standard deviation [SD] 16). For clients, the same study staff administered surveys on the day they met with case managers (baseline) and one week later (follow-up).

We measured case managers' attitudes, confidence, and readiness to discuss ACP using five questions from a validated questionnaire (5-point scale, 5 representing highest agreement).[27] For clients, we used the validated 4-item ACP Engagement survey[27] (items averaged into a 5-point readiness score). To evaluate possible adverse effects, we screened clients for anxiety or depression using a validated tool.[28] We assessed usability of the ACP-Toolkit and the PREPARE materials (website, pamphlet, AD) from case managers and clients using closed and open-ended questions.

We obtained sociodemographic measures, including self-reported age, gender, race/ethnicity, educational attainment, health literacy,[29] computer literacy, and health status.

### Analyses

We conducted descriptive analyses of all measures. Using Wilcoxon signed-rank tests, we assessed changes from baseline to follow-up in case managers' attitudes, confidence, and readiness, as well as clients' readiness. Two reviewers evaluated open-ended data using thematic content analysis.[30]

Table 1. Client and Case Manager Characteristics

| | *Clients (n = 12)* | *Case managers (n = 9)* |
|---|---|---|
| Age, median (SD) | 68.5 (8.3) | 37.2 (10.4) |
| Women, *n* (%) | 5 (41.7) | 7 (77.8) |
| Race/ethnicity, *n* (%) | | |
| White | 3 (25) | 2 (22.2) |
| Black/African American | 4 (33.3) | 1 (11.1) |
| Asian/Pacific Islander | 1 (8.3) | 3 (33.3) |
| Multiethnic | 1 (8.3) | 0 (0) |
| Latino/Hispanic Mexican | 2 (16.7) | 3 (33.3) |
| Other | 1 (8.3) | 0 (0) |
| Education, *n* (%) | | |
| ≤High school | 6 (50) | 1 (11.1) |
| Some college or technical | 3 (25) | 1 (11.1) |
| College graduate | 2 (16.7) | 3 (33.3) |
| Graduate school | 1 (8.3) | 4 (44.4) |
| Limited health literacy, *n* (%)[a] | 3 (25) | — |
| Have access to the internet, *n* (%) | 5 (41.7) | |
| Limited computer literacy, *n* (%)[b] | 8 (66.7) | — |
| Self-reported health status, *n* (%) | | — |
| Fair/poor | 9 (75) | — |
| Good/very good/excellent | 3 (25) | — |

[a]Limited if answered not at all/a little/somewhat to "How confident are you filling out medical forms by yourself?"

[b]Limited if answered not at all/a little/somewhat to "How comfortable are you using the Internet?"

SD, standard deviation.

Table 2. Case Managers' Attitudes, Confidence, and Readiness About Facilitating Advance Care Planning at Baseline and Follow-Up

| | *Level of agreement with the following statements, mean (SD)*[a] | | |
|---|---|---|---|
| | *Baseline* | *Follow-up* | p |
| Job-related attitudes | | | |
| ACP is important for my clients to do | 4.67 (0.50) | 4.44 (0.53) | 0.32 |
| All staff who care for older clients should be trained to introduce ACP to clients | 4.56 (0.53) | 4.56 (0.53) | 1.00 |
| Helping clients access ACP should be an important part of my job | 4.44 (0.53) | 4.33 (0.50) | 0.57 |
| Confidence in ability to talk to clients about ACP | 3.22 (0.67) | 4.22 (0.67) | 0.017 |
| Readiness to talk to clients about ACP | 4 (1.00) | 4.11 (0.78) | 0.56 |

[a]Measured on an ordinal response scale (range 1–5; 5 signifying the highest agreement).
ACP, advance care planning.

## Results

### Feasibility and participant characteristics

We contacted 27 case managers from nine organizations; requiring 129 telephone calls, 144 emails, and 12 in-person meetings over 6 months. Of these, 9/27 (33.3%) case managers from 4/9 (44.4%) organizations participated. Organizations who declined to participate reported having clients with limited English proficiency or competing interests during the study period, which overlapped with the end of the fiscal year. Participating case managers reported contacting 23 clients, 12 of whom participated. All 9 case managers and 12 clients completed the study.

Case manager and client characteristics are presented in Table 1. Case managers averaged 37.2 years old (SD 10.4); 7/9 (77.8%) were women and racial/ethnic minorities. Clients averaged 68.5 years old (SD 8.3), 5/12 (41.7%) were women, 9/12 (75%) were racial/ethnic minorities, 3/12 (25%) had limited health literacy, and 8/12 (66.7%) had limited computer literacy.

### Case managers' attitudes, confidence, and readiness

Case managers' confidence in facilitating discussions about ACP increased from 3.2 (SD 0.7) out of 5 to 4.2 (SD 0.7) ($p = 0.02$). Attitudes and readiness were high at baseline and follow-up (Table 2).

### Clients' readiness

Clients' readiness to engage in ACP increased from 2.8 out of 5 (SD 1.5) to 3.4 (SD 1.4) ($p = 0.06$; Table 3). Two clients screened positive for depression at baseline, one of whom screened positive at follow-up.

### Usability

Case managers found the PREPARE tools easy to use (Table 4). All found that the ACP-Toolkit took just the right amount of time to present, and nearly all (88.9%) felt it contained the right amount of information. All (100%) agreed that the ACP-Toolkit helped start conversations about clients' medical decision makers and goals for medical care, and would recommend the ACP-Toolkit and PREPARE materials to other case managers and clients. Case managers suggested offering the ACP-Toolkit in more languages, and organizing group presentations at senior centers and assisted living facilities to increase reach.

All clients used the pamphlet, 11/12 (91.7%) used the AD, and 2/12 (16.7%) used the website after case managers presented the information. Clients rated all materials highly for ease of use and helpfulness (Table 4), specifically noting materials were ''very easy to understand,'' avoided ''loaded language about dying,'' and were divided into short, manageable sections. All (100%) were comfortable with their case managers discussing ACP. Several noted that they trusted their case managers, and knew their case managers cared about them and their health. Clients enjoyed these discussions because it helped them think of ACP as a way to ''have control over [their] life.''

## Discussion

A brief ACP-Toolkit increased case managers' confidence in introducing ACP to homebound, seriously ill older adults.

Table 3. Clients' Readiness to Engage in Advance Care Planning at Baseline and Follow-Up

| | *Baseline (n = 12)* | *Follow-up (n = 12)* | p |
|---|---|---|---|
| Composite readiness score, mean (SD)[a] | 2.75 (1.51) | 3.38 (1.40) | 0.06 |
| Readiness to officially designate a surrogate medical decision maker, mean (SD) | 2.83 (1.80) | 3.42 (1.51) | 0.3 |
| Readiness to talk to medical decision-maker about care preferences, mean (SD) | 3.00 (1.65) | 3.50 (1.57) | 0.2 |
| Readiness to talk to doctor about care preferences, mean (SD) | 2.33 (1.44) | 3.08 (1.62) | 0.2 |
| Readiness to sign advance directive and/or POLST specifying care preferences, *n* (%) | 2.83 (1.80) | 3.50 (1.45) | 0.2 |

[a]Measured on an ordinal response scale (range 1–5; 5 signifying the readiest).
POLST, physician's orders for life-sustaining treatment.

Table 4. Usability of Study Materials

| | *PREPAREforYourCare.org website* | *Easy-to-read advance directive* | *Pamphlet* |
|---|---|---|---|
| Case managers ($n=9$) | | | |
| Ease of use, mean (SD)[a] | 7.7 (1.4) | 7.3 (1.8) | 8.9 (1.2) |
| Clients ($n=12$)[b] | | | |
| Ease of use, mean (SD)[a] | 10.0 (0) | 7.5 (2.3) | 8.0 (2.2) |
| Comfortable using, mean (SD)[c] | 5.0 (0) | 3.9 (1.1) | 4.8 (0.5) |
| Found helpful, mean (SD)[c] | 4.5 (0.7) | 4.2 (0.8) | 4.3 (0.7) |
| Would recommend, mean (SD)[c] | 3.0 (2.8) | 4.0 (1.2) | 4.2 (1.2) |

[a]Measured on an ordinal response scale (range 1–10; 10 signifying easiest).
[b]Two clients used the website, 11 the advance directive, and 12 the pamphlet. Means reflect only results of those who used each component during the one-week follow-up period.
[c]Measured on an ordinal response scale (range 1–5; 5 signifying most comfortable/helpful/would recommend).

Usability of the ACP-Toolkit and PREPARE materials was rated highly among case managers and clients from racially and ethnically diverse backgrounds, the majority of whom had limited health or computer literacy.

Case managers' confidence to facilitate ACP increased significantly, even after using the ACP-Toolkit with only one to two clients. Likely due to ceiling effects and potential selection bias, attitudes and readiness did not increase significantly. Clients' readiness to discuss ACP increased to a similar magnitude found in prior studies,[27] although did not reach statistical significance likely due to small sample size and relatively high baseline readiness scores. Nearly all clients reviewed the pamphlet and AD within one week. Only two reviewed the PREPARE website, which has been shown to result in significantly higher ACP engagement compared with the AD alone.[24,25] This may be because clients with limited computer literacy need more support to access the website.

To our knowledge, only two other studies have evaluated case manager-led ACP programs. In one, a telephonic ACP program led by trained case managers resulted in goals-of-care discussions in a third of participants and completion of AD in over a quarter.[31] In another among older adults receiving in-home care in Australia, those who discussed ACP with their own case managers were more likely to complete goals-of-care discussions compared with those who were referred to ACP facilitators.[32] This underscores the importance of the case manager/client relationship in encouraging ACP engagement.[7,17] Clients in our study also noted feeling comfortable discussing ACP with their case managers because of mutual trust. However, in contrast to these other programs, the ACP-Toolkit provides easy-to-use scripts to introduce ACP and the PREPARE materials rather than engaging in goals-of-care discussions. Therefore, it does not require training. Given the large number of case managers involved in the care of homebound older adults in the United States, this shows promise as a scalable model for increasing ACP engagement, especially among vulnerable populations.

This study has limitations. It was conducted in one city, limiting generalizability. Clients were racially/ethnically diverse, but all were English speaking. While nearly half of organizations and a third of case managers we contacted participated in the study, the enrollment process was challenging due to competing organizational priorities. Selection bias likely resulted in enrollment of case managers and recruitment of their clients who already felt positively toward ACP.

The ACP-Toolkit was rated highly and increased case managers' confidence in discussing ACP and clients' readiness to engage in ACP. Case managers felt that ACP is an important part of their role and clients felt case managers were well positioned to introduce ACP. Future research is needed to evaluate the ACP-Toolkit with a larger cohort and longer follow-up period, determine whether it results in increased ACP documentation and discussions with clinicians, and assess the ACP-Toolkit in different settings and in other languages.

### Acknowledgments

The authors would like to acknowledge and thank the clients, case managers, case management supervisors, and their organizations for their collaboration.

### Funding Information

This study was supported by the National Palliative Care Research Center and Tideswell at the University of California, San Francisco. S.S.N. is funded in part by a National Research Service Award fellowship training grant (T32HP19025). R.S. is funded in part by the National Institute on Aging, National Institutes of Health (K24AG054415).

### Author Disclosure Statement

No competing financial interests exist.

### References

1. 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.
2. Silveira MJ, Kim SYH, Langa KM: Advance directives and outcomes of surrogate decision making before death. N Engl J Med 2010;362:1211–1218.
3. Nicholas LH, Langa KM, Iwashyna TJ, Weir DR: Regional variation in the association between advance directives and end-of-life Medicare expenditures. JAMA 2011;306:1447–1453.
4. Sudore RL, Lum HD, You JJ, et al.: Defining advance care planning for adults: A consensus definition from a multidisciplinary delphi panel. J Pain Symptom Manage 2017; 53:821.e1–832.e1.

5. Harrison KL, Adrion ER, Ritchie CS, et al.: Low completion and disparities in advance care planning activities among older medicare beneficiaries. JAMA Intern Med 2016;176:1872–1875.
6. *Committee on Approaching Death: Addressing Key End of Life Issues. Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life.* Washington, DC: The National Academies Press, 2014.
7. Tilburgs B, Vernooij-Dassen M, Koopmans R, et al.: The importance of trust-based relations and a holistic approach in advance care planning with people with dementia in primary care: A qualitative study. BMC Geriatr 2018;18: 184.
8. Ahluwalia SC, Levin JR, Lorenz KA, Gordon HS: Missed opportunities for advance care planning communication during outpatient clinic visits. J Gen Intern Med 2012;27: 445–451.
9. Schickedanz AD, Schillinger D, Landefeld CS, et al.: A clinical framework for improving the advance care planning process: Start with patients' self-identified barriers. J Am Geriatr Soc 2009;57:31–39.
10. Diamant AL, Hays RD, Morales LS, et al.: Delays and unmet need for health care among adult primary care patients in a restructured urban public health system. Am J Public Health 2004;94:783–789.
11. Wang CW, Chan CLW, Chow AYM: Social workers' involvement in advance care planning: A systematic narrative review. BMC Palliat Care 2017;17:5.
12. Pearlman RA, Starks H, Cain KC, Cole WG: Improvements in advance care planning in the veterans affairs system: Results of a multifaceted intervention. Arch Intern Med 2005;165:667–674.
13. Nedjat-Haiem FR, Carrion IV, Gonzalez K, et al.: Implementing an advance care planning intervention in community settings with older Latinos: A feasibility study. J Palliat Med 2017;20:984–993.
14. Calista J, Tjia J: Moving the advance care planning needle with community health workers. Med Care 2017;55:315–318.
15. Litzelman DK, Inui TS, Griffin WJ, et al.: Impact of community health workers on elderly patients' advance care planning and health care utilization: moving the dial. Med Care 2017;55:319–326.
16. Cortez DM, Harding K, Koutouratsas L, et al.: Advance care planning for the homeless: A community collaboration. Narrat Inq Bioeth 2017;7:E14–E15.
17. Feuz MA, Odierna DH, Katen M, et al. Leveraging in-home supportive services programs to engage people in advance care planning: Input from staff, providers, and client stakeholders. J Palliat Med 2019;22:1430–1438.
18. Erkinjuntti T, Sulkava R, Wikström J, Autio L: Short Portable Mental Status Questionnaire as a screening test for dementia and delirium among the elderly. J Am Geriatr Soc 1987;35:412–416.
19. Sudore RL, Landefeld CS, Williams BA, et al.: Use of a modified informed consent process among vulnerable patients: A descriptive study. J Gen Intern Med 2006;21: 867–873.
20. Bandura A: Self-efficacy: Toward a unifying theory of behavioral change. Psychol Rev 1977;84:191–215.
21. 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 2013;47:674–686.
22. Fried TR RC, Robbins ML, Paiva A, et al.: Stages of change for the component behaviors of advance care planning. J Am Geriatr Soc 2010;58:2329–2336.
23. PREPARE Tools for Providers & Organizations. PREPARE for Your Care Web site: https://prepareforyourcare.org/resources. (Last accessed June 16, 2020).
24. Sudore RL, Boscardin J, Feuz MA, et al.: Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: A randomized clinical trial. JAMA Intern Med 2017;177:1102–1109.
25. 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;178:1616–1625.
26. Sudore RL LC, Barnes DE, Lindquist K, et al.: An advance directive redesigned to meet the literacy level of most adults: A randomized trial. Patient Educ Couns 2007;69: 165–195.
27. Sudore RL, Heyland DK, Barnes DE, et al.: Measuring advance care planning: optimizing the advance care planning engagement survey. J Pain Symptom Manage 2017; 53:669.e8–681.e8.
28. Lowe B, Wahl I, Rose M, et al.: A 4-item measure of depression and anxiety: Validation and standardization of the Patient Health Questionnaire-4 (PHQ-4) in the general population. J Affect Disord 2010;122:86–95.
29. Chew LD, Bradley KA, Boyko EJ: Brief questions to identify patients with inadequate health literacy. Fam Med 2004;36:588–594.
30. Vaismoradi M, Turunen H, Bondas T: Content analysis and thematic analysis: Implications for conducting a qualitative descriptive study. Nurs Health Sci 2013;15:398–405.
31. Boettcher I, Turner R, Briggs L: Telephonic advance care planning facilitated by health plan case managers. Palliat Support Care 2015;13:795–800.
32. Detering KM, Carter RZ, Sellars MW, et al.: Prospective comparative effectiveness cohort study comparing two models of advance care planning provision for Australian community aged care clients. BMJ Support Palliat Care 2017;7:486–494.

Address correspondence to:
*Sarah S. Nouri, MD, MPH*
*Division of General Internal Medicine*
*Department of Medicine*
*University of California, San Francisco*
*1545 Divisadero Street, Box 0320*
*San Francisco, CA 94143-0320*
*USA*

*E-mail:* sarah.nouri@ucsf.edu