

Engagement in Steps of Advance Health Care Planning by Homeless Veterans

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Communicating health care preferences in advance, so that wishes can be honored if the person becomes unable to participate in decision-making, is especially important for vulnerable populations such as homeless veterans. Hospitals are required to inform patients of their rights to document their preferences, but completion rates for advance directives are low. Conceptualizing advance health care planning as a series of health behavior steps emphasizing communication is recommended for improving engagement in advance health care planning. The authors used program evaluation data from psychoeducational groups with 288 homeless veterans to learn about their previous experience with different steps of advance health care planning and their personal goals for future steps. Results revealed a significant discrepancy between what these veterans reported they have done and information available to health care providers in the medical record: Only 26% had an advance directive in the medical record, but 70% reported they had thought about the care they would want, and almost half reported they had talked with a trusted other or named someone to make decisions for them. The most frequent goal endorsed by veterans attending groups was discussing advance health care planning with family or trusted others and/or naming someone to be a decision maker. These findings indicate a need for improved communication and documentation of veteran preferences about emergency and end of life care. Results are also consistent with interventions tailored to varying readiness for different steps of advance health care planning.

Keywords: veteran, homeless, advance care plan, advance directive

Homelessness is widely recognized as a significant problem for veterans. Surveys have found that veterans are overrepresented among the homeless population and that, on any given night, tens of thousands of veterans are homeless (Fargo et al., 2012; Hutt et

al., 2016). Risk factors associated with homelessness include social isolation, substance use, and other psychiatric disorders (Balslem, Christensen, Tuepker, & Kansagara, 2011; Montgomery, Dichter, Thomasson, Roberts, & Byrne, 2015; Tsai & Rosen-

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heck, 2015), as well as increased prevalence of chronic disease and hospitalization (Larimer et al., 2009). Not surprisingly, older veterans who are homeless have death rates much higher than the general population (Hutt et al., 2016; Schinka, Bossarte, Curtiss, Lapevic, & Casey, 2016). All these factors suggest that the homeless should be considered among the vulnerable populations most in need of planning in advance for the health care they would wish to receive if they become unable to participate in treatment decision-making (Leung, Nayyar, Sachdeva, Song, & Hwang, 2015).

Research studies show that advance health care planning (AHCP), the process by which individuals think about and communicate their preferences if they should become incapacitated, does facilitate receiving care consistent with one's preferences (Detering, Hancock, Reade, & Silvester, 2010; Silveira, Kim, & Langa, 2010). However, there are significant challenges to widespread adoption of AHCP. Hospitals are legally required to inform patients about their rights to make health care choices, but completion rates for advance directives (ADs) and durable powers of attorney are low (Cohen, McCannon, Edgman-Levitan, & Kormos, 2010). In addition to understandable reluctance of patients to consider and discuss end-of-life preferences, hospital executives interviewed about barriers to AHCP identified providers' lack of training and lack of time; one executive raised the concern that, because patients come to the hospital with hope of cure, asking them to do AHCP may cause them to wonder if providers are giving up on them (Garner, Goodwin, McSweeney, & Kirchner, 2013; Garner, Lefler, McSweeney, Sullivan, & Kirchner, 2015). Professionals serving homeless adults in Canada identified poor continuity of care and insufficient availability of end-of-life services as barriers in this population; to improve care, they recommended linkage to providers familiar with the homeless, more flexible approaches, and training (McNeil, Guirguis-Younger, & Dilley, 2012).

A study with outpatient veterans found that providing educational materials, motivational counseling, and encouragement from providers resulted in higher rates of completing ADs than only receiving a booklet (Pearlman, Starks, Cain, & Cole, 2005). With community homeless adults, focus groups revealed the same range of preferences on end of life care as the population at large (Tarzian, Neal, & O'Neil, 2005). Homeless adults in Minneapolis were receptive to private meetings about AHCP offered as part of a research project; those randomized to counseling (37.9%) were more likely to complete an AD than those who received documents and educational materials to complete on their own (12.8%; Song et al., 2010). A recent study with Canadian men in a homeless shelter found that 89% of those approached participated in a survey, and 50% then completed an AD with a trained counselor (Leung et al., 2015). These results are very encouraging, but the individual counseling interventions used in these studies are by nature time-consuming and expensive.

It is impossible to predict exactly what kind of future medical decisions may be needed for an individual. A recent review of AHCP best practices advocates conceptualization of AHCP as a process, with a focus on communication about values and preferences, and consisting of several discrete steps that include thinking about preferences and talking with trusted others and providers, not just completing a document (Bernacki & Block & the American College of Physicians High Value Care Task Force, 2014;

Pearlman et al., 2005; Sudore & Fried, 2010; Sudore et al., 2008; Tarzian et al., 2005). Sudore, Fried, and their colleagues have suggested adapting the transtheoretical model's stages of change to describe the AHCP process (Fried et al., 2010, 2012; Sudore et al., 2008). In this conceptualization, individuals move from precontemplation (being unaware or not thinking about AHCP) to contemplation (thinking about it but not yet taking action) to preparation and action (such as discussions with trusted family, significant others, and health care providers, and documenting preferences). This approach builds on research with stage-based interventions for other health behaviors and could potentially improve AHCP practices by using a theory-based motivational approach already familiar to many health care providers and leading to interventions most efficient and effective for individuals at various stages of readiness for action (Prochaska & DiClemente, 1992).

To improve access of larger numbers of veterans to information about AHCP and encourage them to consider actions consistent with their personal beliefs and values, we developed a psychoeducational group intervention, "My Life, My Choice." After we had successfully initiated groups with older veterans in primary care clinics, mental health providers invited the project staff to conduct AHCP groups for mental health treatment groups, which included many homeless veterans. In this study, we examined our program evaluation data from the homeless veterans who had participated in the project. We describe what we learned about these veterans' self-reported engagement in AHCP activities prior to participating in the groups, whether their self-reports were consistent with evidence in the medical record of ADs on file, and their priorities for future AHCP activities, as indicated by the personal goals they documented during the group meetings.

Method

Participants and Setting

This study was conducted as a secondary analysis of identified program evaluation data from a quality-improvement initiative, after the institutional review board and research committee at the Veterans Health Care Administration (VHA) facility approved use of the data set for research. Data from the quality-improvement project were limited to self-reported information about participants collected in the clinical setting during the relatively brief (30 to 50 min) group encounters and to demographic data extracted from the medical records by a project assistant. Participants in the quality-improvement project did not receive any compensation.

Participants in the current study were homeless veterans who voluntarily attended psychoeducational groups of 10 to 20 veterans led by social workers, nurses, psychologists, and other providers at their treatment sites. Groups were offered at a homeless day treatment center and as part of residential care treatment for substance use disorders and/or posttraumatic stress disorder. Group leaders were trained by the project coordinator, an expert in palliative care, to facilitate a specialized group session with veterans attending ongoing group activities (e.g., group medical visits, weight management groups, mental health groups). These specialized group visits were designed to allow veterans to discuss AHCP with trained professionals and each other in a friendly and

supportive environment. During the visits, veterans were encouraged to identify their personal readiness for AHCP, using a worksheet, and, if they wished, to set a goal for a next step consistent with their values and readiness. The leaders announced the purpose of the groups at the beginning of each meeting and explained attendance was voluntary (group leaders were also prepared to follow-up with any veteran who seemed emotionally upset). Participants received educational materials and VHA forms for ADs, and they also had the opportunity to meet with a social worker after the group, or schedule another time to complete an AD. Group leaders were not aware of the veterans' health status or whether they had previously completed any steps of AHCP. Of the 348 unique homeless veterans who attended one of the AHCP educational groups between January 2014 and July 2015, 288 completed the optional worksheet and served as the analytic sample for this study.

Measures

As part of the program evaluation that was incorporated into the overall AHCP initiative, limited demographic information about the participants, including age, gender, race, designation of "rural" or "urban" zip code of most recent address, designation as homeless, and documentation of an AD on file in VHA records was obtained through review of the VHA electronic medical record by an experienced project assistant. Zip-code locations were coded, using the federal government's Health Resources and Services Administration Data Warehouse website (<http://datawarehouse.hrsa.gov>). Homelessness status was coded by the project assistant, usually from the content of progress notes and homelessness screenings completed about the same time as group attendance, but occasionally from address notations. Self-reported AHCP engagement was assessed by participant responses to items on the worksheet completed during the first part of the meeting. These items, adapted from those used by previous investigators (Fried et al., 2012; Sudore et al., 2014), prompted participants to check whether, prior to attending the group, they had engaged in each of these AHCP activities: (a) "thought about what I would want if hurt, injured, or sick and could not communicate"; (b) "talked with someone I trust to make health care decisions for me"; (c) "named someone to make health care decisions for me"; (d) "discussed these topics with someone on my health care team, i.e., doctor, nurse, social worker"; and (e) "filled out an AD (a.k.a. living will) to guide those I trust to make health care decisions for me." A "yes" response was interpreted as engagement in the AHCP step represented by that item.

Personal AHCP goals were recorded from another part of the worksheet completed near the end of the group session. In this section, participants were encouraged to consider and write down a next step they would like to take for their personal AHCP. The worksheet prompted participants to write when they would do this, how they would do it, where they would do it, and whom they would involve. Goal statements were reviewed by the project team to identify major categories mentioned most frequently. The most frequent categories included (a) AHCP discussion (talking about AHCP with family or trusted others or identifying trusted others); (b) talking with a provider (including any health care team member); (c) AHCP education (thinking or learning more about AHCP or discussing with an attorney); and (d) AD actions (checking,

getting a copy, filing, or updating an AD). Finally, goal quality ratings were assigned to the complete goal statements, based on review of the specific plans documented by the participants. Ratings ranged from one (lack of specific details) to five (specific about the action, who would be involved, and when and where the activity would be accomplished). After two project staff rated 41 worksheets, resulting in 24 (58.5%) exact matches and 18 (43.9%) ratings different by one unit, $\kappa = 0.621$ (indicating substantial agreement; Landis & Koch, 1977) (95% confidence intervals CI [0.451, 0.791]), only one of the raters rated the remaining goal statements.

Statistical Analyses

Descriptive statistics were used to characterize the study sample and engagement in the different steps of AHCP. To facilitate comparison of our sample with previous literature that focused on completion of an AD, we first compared demographic characteristics of subgroups with and without an AD on file, using the nonparametric Wilcoxon's rank sum test for continuous data (i.e., age) or chi-square tests for categorical data. For comparisons involving gender, Fisher's exact test was used due to expected cell counts being small. Associations between self-reported engagement in AHCP steps and demographic characteristics as well as associations of these self-reported AHCP steps with objective measures of AHCP engagement (presence of AD in the medical record and writing a personal goal during the group meeting) were examined, using chi-square or Fisher's exact tests (i.e., for gender). Participant demographics that were significantly associated in univariate analysis with having an AD on file in the medical record were then investigated in a multivariable logistic regression to examine independent predictors of documented AD. To investigate relationships with goal quality ratings, which were treated as ordinal, comparisons according to the type of goal and participant characteristics were made, using nonparametric two-sample Wilcoxon's rank sum tests or Kruskal-Wallis tests when there were more than two groups (i.e., for age group).

Results

The characteristics of all participants and subgroups, based on whether an AD was located in the VHA electronic medical record, are summarized in Table 1. Older homeless veterans and those with urban zip codes as last known address were more likely to have an AD than younger veterans and those with a rural address. Rurality, $\chi^2(1) = 6.01, p = .014$, and age group, $\chi^2(2) = 5.99, p = .050$, remained significant as independent predictors of having an AD on file in the multivariable logistic model; veterans living in rural locations had lower odds of having an AD on file than those living in urban areas (odds ratio [OR] = 0.42; 95% CI [0.21–0.84]), and veterans 20–45 (OR = 0.36; 95% CI [0.15–0.86]) and 46–60 (OR = 0.47; 95% CI [0.23–0.96]) years of age had lower odds of AD on file than those greater than 60 years of age. The agreement of self-reported AD and having an AD on file in the VHA medical record was imperfect; 28% of those who had an AD on file self-reported on the worksheet that they did not have one, while 24% of those who did not have an AD on file self-reported that they did have one (see Table 1).

Next, Figure 1 shows the percent of veterans who self-reported engagement in steps of AHCP prior to attending the group meet-

Table 1
 Characteristics of Participants Who Did and Did Not Have Advance Directive (AD) in VA Medical Record Prior to Group Meeting

Characteristic	All participants (<i>n</i> = 288)	With advance directive on file (<i>n</i> = 76)	Without advance directive on file (<i>n</i> = 212)	<i>p</i> value ^a
Age, median (IQR)	54 (45–58)	57 (50–60)	52 (42.5–57)	<.001
Gender, % female	5	4	5	>.999
Race, % minority	58	58	59	.945
Location, % rural	28	16	33	.004
Self-report AD on file, %	37	72	24	<.001

Note. IQR = interquartile range.

^a Wilcoxon rank sum test for continuous variables (age); chi-square or Fisher's Exact test for categorical variables.

ing. More than two thirds (70%) reported they had thought about the care they wanted if ever unable to communicate their preferences; but less than half had discussed this with family or trusted others or had named someone to speak for them; and less than one third reported they had discussed AHCP with a member of the health care team. The line on the figure showing percent of veterans who had an AD in their record (26%) indicates the difference between prevalence of objective and self-reported AHCP activities.

Table 2 shows the associations between participant demographic characteristics and self-reported steps of engagement in AHCP prior to the group meeting with objectively measured data regarding AHCP, that is, the presence of an AD in the medical record and documentation of a personal AHCP next step goal during the group meeting). Age group (20–45, 46–60, and over 60), gender, and location for last address were not related to engagement in the self-reported steps of AHCP. Veterans of a minority race were significantly less likely to indicate that they had thought about their preferences if unable to communicate than Whites, $\chi^2(1) = 4.08, p = .043$; but there were no significant differences between races for the other steps of AHCP. As expected, those who self-reported they had an AD were much more likely to have an AD on file in the VHA medical record and to report having engaged in other steps of AHCP, than those who reported they did not have an AD. There was a trend for participants who wrote a personal AHCP goal as part of the group intervention to be more likely to report that they had previously thought about what they wanted if unable to communicate than

those who did not set a goal, $\chi^2(1) = 3.76, p = .071$. Those who reported they had previously talked to trusted others were less likely to document a personal goal during the group. Having completed other steps of AHCP prior to attending the group was unrelated to setting a goal for future AHCP actions.

The type of personal AHCP goals most frequently entered on the worksheets was AHCP discussion, including talking about AHCP with family or others and identifying a trusted other (33% of 150 total documented goals). The frequencies for other goal categories were 29% for AHCP education, which included learning more about AHCP and discussing AHCP with an attorney; 21% for talking with a provider; and 17% for other AD actions, including completing, updating, filing, or getting a copy of the AD. Goal quality ratings ($M = 2.9$, median = 3.0; range 1 to 5) were not significantly related to participant characteristics and were not different for the various goal categories (data not shown). Eleven (5%) of the 212 veterans who did not have an AD on file completed one shortly after attending the group; this number seems consistent with the previously noted 17% with a goal of an AD action.

Discussion

In this study of AHCP activities of homeless veterans, we found evidence confirming that—as with other populations—the majority had not executed an AD. However, we also found evidence of substantial self-reported engagement in other AHCP activities that could be considered preparatory steps for completing an AD, such as contemplating what health care they would want if unable to communicate their preferences, and having talked with someone and/or named someone to speak for them. The results add to the very sparse information in the literature about AHCP for the homeless (McNeil et al., 2012); we are not aware of any previous reports on this topic with homeless veterans. Our findings also support the recommendations of previous investigators to adopt a nuanced, process-oriented conceptualization of AHCP (Pearlman et al., 2005; Sudore et al., 2008; Tarzian et al., 2005), and appreciation that individuals have varying readiness for the different steps in this process. Notably, our results revealed a significant discrepancy between what the homeless veterans thought they had accomplished with regard to AHCP and what providers would find in the VHA medical record if searching for evidence of AHCP. These veterans and others who have accomplished preparatory

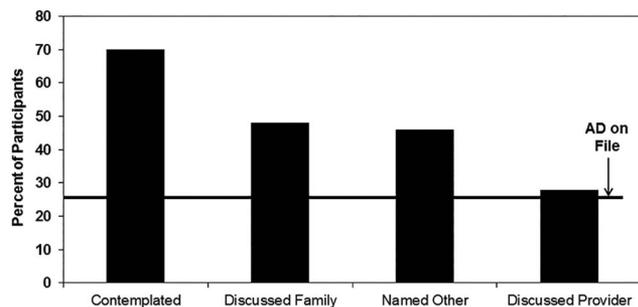


Figure 1. Percent of homeless veteran participants who had completed each step of advance health care planning.

Table 2
Steps of Advance Care Planning: Number and Percent of Participants From Demographic and Diagnostic Subgroups Who Report Having Completed Each Step

Characteristic	All participants <i>n</i> (column %) (<i>n</i> = 288)	Thought about preferences if could not communicate <i>n</i> (row %) ^a (<i>n</i> = 259)	Talked with trusted other to make decisions <i>n</i> (row %) ^a (<i>n</i> = 282)	Named someone to make decisions <i>n</i> (row %) ^a (<i>n</i> = 281)	Discussed with healthcare team <i>n</i> (row %) ^a (<i>n</i> = 281)
Age group					
20–45	73 (25)	50 (77)	40 (56)	35 (49)	22 (31)
46–60	174 (60)	109 (70)	77 (45)	78 (46)	49 (29)
>60	41 (14)	22 (58)	18 (45)	16 (41)	8 (20)
Gender					
Female	13 (5)	8 (80)	6 (46)	5 (38)	3 (23)
Male	275 (95)	173 (69)	129 (48)	124 (46)	76 (28)
Race					
Minority	166 (58)	96 (65)*	74 (46)	79 (49)	41 (25)
White	118 (42)	82 (77)*	59 (51)	49 (42)	37 (32)
Location					
Rural	82 (28)	57 (70)	43 (53)	42 (52)	25 (31)
Urban	206 (72)	124 (70)	92 (46)	87 (44)	54 (27)
Self-report have an advanced directive					
Yes	106 (37)	86 (93)*	88 (85)*	91 (87)*	62 (60)*
No	179 (63)	94 (57)*	46 (26)*	37 (21)*	17 (10)*
Advanced directive on file at VHA					
Yes	76 (26)	61 (86)*	57 (75)*	54 (73)*	40 (53)*
No	212 (74)	120 (64)*	78 (38)*	75 (36)*	39 (19)*
Documented personal goal during group					
Yes	154 (53)	101 (75)	63 (42)*	61 (41)	37 (25)
No	134 (47)	80 (65)	72 (55)*	68 (52)	42 (32)
Total	288 (100)	181 (70)	135 (48)	129 (46)	79 (28)

Note. VHA = Veterans Health Administration. For participant characteristics, four participants were missing race; three were missing self-reported advanced directive. The completion rate for questions regarding ACP steps ranged from 90% (259/288) to 98% (282/288). For “thought about preferences if could not communicate,” 27 of 29 were missing due to form version change; only 2 were missing due to nonresponse.

^a Row percentages, i.e., the percent of participants who reported having done the specified ACP step. For example, 80% of females thought about preferences if could not communicate compared to 69% of males.

* $p < .05$ for comparison of percent of participants reporting having done the specified ACP step according to participant characteristics using chi-square or Fisher’s Exact test.

steps in AHCP but have not documented their preferences may not understand that their wishes cannot be honored if no surrogates have been named and the health care system has no evidence of their preferences.

The readiness of some homeless veterans attending the groups to engage in AHCP in our clinical quality-improvement project is illustrated by the remarks of a veteran who stated that he was very glad that we had brought this program to the Day Treatment Center. He explained that he had been worried about what would happen to him if he ever had to go to the hospital and could not speak for himself. He stated that, “I want to do this right now!” and completed an AD after the meeting. In a previous study, social work-led groups for veterans attending primary care appointments and individual counseling interventions with homeless adults also facilitated completion of ADs (Dipko, Xavier, & Kohlwes, 2004; Leung et al., 2015). However, the readiness of the veteran to complete an AD was unusual. The most frequently recorded personal goals of our participants involved preparatory steps rather than AD actions, a finding consistent with observed progression in stages of change for AHCP in a pilot study of Web based AHCP promotion for older adults (Sudore et al., 2014). It is appropriate for people to take the time to think about what they want and talk to others before they complete the AD. As with other health

behaviors, the most effective interventions for AHCP will probably require repeated encounters and support for taking the next step (Pearlman et al., 2005; Sudore & Fried, 2010).

In a previous study of engagement in steps of AHCP, Sudore and colleagues (2008) found that lower education level adults who were being followed at a San Francisco clinic for chronic disease were more likely to choose to discuss AHCP with family, friends, and providers; and those with fair-to-poor health and with higher levels of education were more likely to complete an AD. In our sample, rural veterans may have had fewer opportunities to learn about AHCP or to interact with providers who could encourage them to engage in the steps of AHCP. Our racial-minority homeless veterans (mostly African American) were less likely to report that, prior to attending the group, they had thought about their health care preferences should they be unable to communicate their preferences; but there were no race-group differences for other steps of AHCP. If Whites were more likely to have thought about what they wanted, we found no evidence that this had resulted in greater completion of other steps of AHCP.

More than half of participants in the psychoeducational groups wrote a personal goal for a next step of AHCP on their worksheet. Documenting a goal was not dependent on having completed any specific steps of AHCP prior to attending the group, suggesting

that group discussion can establish intentions for action among homeless veterans who were at varying stages of readiness to engage in AHCP. For our homeless veterans, goals of all types were similar in quality ratings; and the median value (2.9 on a scale of 1 to 5) suggested many goal statements included specific details, such as the person(s) with whom they would talk about AHCP, and where and when they planned to carry out their plan. In other health behavior research, these goal characteristics are associated with greater goal achievement (Mann, de Ridder, & Fujita, 2013). We believe our results suggest that a brief discussion in a group with other veterans can help homeless veterans begin problem-solving for various steps of AHCP. We recommend that providers desiring to promote AHCP have attractive, easy-to-read literature available; begin by asking veterans if they have thought about the care they would want to receive if they became ill or injured and unable to speak for themselves; and ask if they have talked with anyone about their preferences and/or identified someone to speak for them. With a capable leader, these questions can instigate supportive group discussions and lead comfortably to explanations of the value of a legal document in the medical record. With homeless veterans, we explained that, if they could not identify family members to name as surrogates for an AD, they could consider friends or other people in their lives that they trust. In future research, it will be important to learn how well the goals documented in our groups are translated to actions, and what additional interventions are needed to optimize AHCP readiness and goal achievement.

In recent years, mental health or psychiatric ADs have been developed to allow individuals to provide input in advance, if they are at risk for becoming incompetent due to a severe mental illness, such as schizophrenia, bipolar disorder, severe depression, or other condition characterized by (usually temporary and episodic) periods of psychosis (Srebnik & La Fond, 1999). Mental health advance directives share the common goal of more traditional medical AHCP of increasing individuals' ability to plan in advance for their health care if unable to speak for themselves. After expanding the quality-improvement project groups to mental health and homeless day treatment settings, we recognized the need to include content on mental health AD planning. An item specifically addressing previous experience with mental health AHCP was added to the group worksheet and is now included for all groups, regardless of the setting. Likewise, group leaders now explain the importance of mental health advance care planning as part of the educational intervention for all participants. As with traditional AHCP, researchers have documented many challenges implementing mental health ADs (Amering, Stastny, & Hopper, 2005; Kemp, Zelle, & Bonnie, 2015). In our experience, addressing this topic in a context along with physical health AHCP seems appropriate and nonstigmatizing and has not disrupted the flow of group process. Program evaluation including this new component was initiated about the time the data set was closed for the current analyses; and, therefore, no results were available to be included in this report.

Important strengths of this research include its exploration of a topic and population that have received little attention in the behavioral and health services literature. We believe the results are clinically meaningful and suggest that many homeless veterans may have taken some steps toward AHCP, but their preferences are not available in the VHA medical record. After a group discussion including other veterans, many were willing to write

down a personal goal for AHCP preparation or action. Our data do not explain why these veterans have not completed ADs when previously offered the opportunity. We can speculate that the usual care approaches we have observed of simply asking veterans if they wish to execute an AD does not work effectively or efficiently with veterans who have not yet reached a motivational stage of readiness for action. It is possible that veterans' interest and willingness to engage in mental health advance care planning may also be best engaged by motivationally tailored approaches, and this is an important topic for further study.

Our study had many limitations, including the very restricted data available from the quality-improvement project, which did not include health status or mental health diagnostic data. The study lacked follow-up to determine whether veterans achieved their personal goals and did not include the mental health-specific AHCP questions that have been added to recent groups. We hope that the findings will encourage future quality-improvement projects and research that can demonstrate the generalizability of our results and build on this knowledge to improve AHCP among veterans who are homeless, those who are receiving mental health treatment, and other veteran and vulnerable populations.

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