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Barriers and Solutions to Advance Care Planning among Homeless-Experienced Older Adults

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Abstract

Background/Objectives: Older homeless-experienced adults have low rates of advance care planning (ACP) engagement despite high rates of morbidity and mortality. To inform intervention development, we examined potential barriers and solutions to ACP engagement.

Design: Cross-sectional qualitative study.

Setting: We recruited adults who were homeless in the prior three years and ≥ 50 years of age in the San Francisco Bay Area, and recruited clinical stakeholders from a national meeting of homeless providers. We analyzed qualitative data using thematic analysis.

Measurements: We conducted semistructured interviews with homeless-experienced older adults ($n = 20$) and focus groups with clinical stakeholders ($n = 24$) about perceived barriers and solutions to ACP engagement.

Results: Participants considered ACP important, reflecting on deaths of people in their networks who had died. Participant-identified barriers to ACP included poor ACP knowledge, lack of familial ties and social isolation, competing priorities, avoidance and lack of readiness, fatalism and mistrust, and lack of ACP training for clinical and nonclinical staff. They identified solutions that included framing ACP as a way to provide meaning and assert choice, providing easy-to-read written documents focused on the populations' unique needs, tailoring content and delivery, initiating ACP in nonclinical settings, such as permanent supportive housing, and providing incentives.

Conclusions: Both older homeless-experienced adults and clinical stakeholders believe that ACP is important, but acknowledge multiple barriers that impede engagement. By focusing on potential solutions, including capitalizing on opportunities outside of health care settings, focusing on the period after housing, and tailoring content, there are opportunities to improve ACP uptake.

Keywords: advance care planning; homelessness; older adults

Introduction

APPROXIMATELY HALF of homeless-experienced adults are age 50 years or older.¹ Compared with housed counterparts, they experience a higher mortality rate, dying 20–30 years earlier.² Advance care planning (ACP) is a process that supports adults in understanding and sharing values, goals, and preferences regarding future medical care.³ Despite increased

mortality and disease burden, few homeless-experienced older adults (those with a current or recent experience of homelessness) have discussed ACP wishes with others or completed advance directives (ADs).⁴ People experiencing homelessness face barriers to ACP, including mistrust in the health care system, limited health literacy, lack of longitudinal relationships with primary care providers (PCPs), and receipt of health care in resource-limited settings.^{5–7} They are more likely than

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the general population to report social isolation, substance use, and mental health disorders, which can impede engagement in ACP.⁴

Little is known about the barriers to ACP engagement among homeless-experienced older adults, or strategies to overcome them.⁸ While there are ACP materials designed for underserved populations, they do not target the full spectrum of ACP engagement for homeless-experienced older adults, who may face unique barriers.^{9,10} Therefore, to identify unique barriers to and solutions for ACP in this population, we conducted qualitative interviews and focus groups with homeless-experienced older adults and clinical stakeholders.

Methods

We conducted in-depth qualitative interviews with 20 homeless-experienced older adults and focus groups with 24 clinical staff members who care for homeless older adults. All participants provided written informed consent; the University of California, San Francisco Institutional Review Board approved the study.

Sampling and recruitment

Older homeless-experienced adult participants. We recruited participants from two sources, a purposive sample of 10 older adults recruited from the Health Outcomes of People Experiencing Homelessness in Older Middle Age (HOPE HOME) study in Oakland, CA,¹¹ and 10 patients at a clinic that serves people experiencing homelessness in San Francisco, CA.

HOPE HOME is an ongoing observational cohort study of 350 adults who were aged ≥ 50 years and homeless at enrollment.^{12–16} Between July 2013 and June 2014, we recruited participants who met the inclusion criteria, including age ≥ 50 years, currently homeless, English-speaking, and able to provide informed consent. The study follows participants every six months, whether or not they remain homeless.

From October 2016 to April 2017, we recruited HOPE HOME participants into the current study. We excluded participants with a score of ≥ 70 on the Modified Mini-Mental State Examination (3MS) at their last study visit.^{5,14} Between April 2017 and June 2017, we recruited from the clinic. Eligibility criteria included the following: homelessness in the prior three years, age ≥ 50 years, English-speaking, having ≥ 2 chronic conditions, having a PCP, and a score less than three on the mini-Cog.^{12,14,17} The 3MS and mini-Cog have comparable sensitivity, but the mini-Cog is shorter, and thus was more feasible for study staff to use in screening potential participants.^{18,19} We continued recruitment until we obtained thematic saturation.

Because ACP is an iterative process, we did not exclude participants with prior ACP experiences. We provided all study participants with a gift card worth \$25 for their participation.

Clinical stakeholders. We collaborated with the National Health Care for the Homeless Council (NHCHC) to recruit clinic staff who attended the 2017 NHCHC conference, and who reported working with adults ≥ 50 years old at a Health Care for the Homeless (HCH) clinic for ≥ 1 year. We provided focus group participants with \$50 gift cards.

Data collection

Interviews with homeless-experienced participants. We developed an interview guide based on our prior research^{9,10} (Supplementary Table S1). We conducted 60–90-minute semistructured interviews.

As background information about ACP, participants reviewed videos, a pamphlet, and an AD from the evidenced-based PREPARE for Your Care (PREPARE) online program (www.prepareforyourcare.org) developed with and for diverse and vulnerable populations.^{3,9,18,19} After reviewing these tools, staff asked participants whether and how the tools could be used or adapted to promote ACP among homeless-experienced older adults and whether they should be viewed in a group setting or presented individually by staff or peer facilitators.

Clinical-stakeholder focus groups. We conducted three 90-minute focus groups. We developed the interview guide based on the interviews with homeless-experienced participants, focusing on barriers and solutions to increasing ACP engagement (Supplementary Table S2).

Analysis

We conducted in-depth interviews with homeless-experienced adults and focus groups with clinical stakeholders to understand the experience of ACP for both homeless adults and clinical stakeholders and to receive feedback on novel ACP materials. We took an iterative and inductive approach to understand the barriers and facilitators to ACP for older homeless adults, and to inform future development of materials to improve ACP processes.

We audio-recorded and transcribed all interviews and focus groups. We imported transcripts into the ATLAS.ti qualitative research software and used qualitative thematic content analysis to identify themes. We then refined the coding scheme through serial review of the transcripts and discussions. Two researchers independently reviewed six (30%) of the transcripts and compared coding decisions. Based on near-perfect agreement, one researcher coded the remaining 14 transcripts.

Results

The majority (14 of the 20) of the homeless-experienced older adults identified as black; two-thirds were men, and 10 were homeless. The clinical-stakeholder groups included 10, six and eight participants, respectively. Focus group participants included the following: physicians ($n=5$), nurse practitioners (2), registered nurses ($n=5$), social workers or case managers ($n=9$), administrators ($n=1$), and psychologists ($n=2$). Homeless-experienced and clinical-stakeholder participants considered ACP important, explaining that they knew people who died while homeless. Both homeless-experienced and clinical-stakeholder participants described overarching barriers to ACP engagement, including poor ACP knowledge, lack of familial ties and social isolation, competing priorities, avoidance and lack of readiness, fatalism and mistrust, and lack of ACP training for clinical and nonclinical staff. Both homeless-experienced and clinical-stakeholder participants described potential solutions, including framing ACP as a way to provide meaning and assert

choice, providing easy-to-read written documents focused on the populations' unique needs, initiating ACP in nonclinical settings, tailoring content and delivery methods, and providing incentives.

Barriers to ACP

Homeless-experienced adults and clinical-stakeholder participants noted that a homeless-experienced person's limited health literacy and lack of knowledge about ACP interfered with the ability to engage in ACP. A homeless-experienced participant shared, "Most people don't talk about it, because I think most people don't know about it, like me." A clinical

stakeholder said, "I think the whole verbiage in ACP... it's difficult for this population to understand" (Table 1).

Homeless-experienced participants expressed concerns about engaging in ACP due to fractured familial ties and social isolation, "My family would probably be glad I was gone." Another noted that lack of connection to family can make it difficult to discuss ACP, "Because it hurts to think about it, that they don't have anyone." A clinical stakeholder explained that for many patients, "They were disowned" and "...maybe about 50%...tell us that there's nobody to call...."

Competing priorities, both in life and in clinic visit, took precedence over engaging in ACP. One clinical stakeholder reported, "If somebody is coming to you [health provider]

TABLE 1. BARRIERS TO ADVANCE CARE PLANNING

Theme	Quote
Poor ACP knowledge	"In medical decision making, are they talking about the end of the medical bill?" ^a "When I die..I would like to have what they call a military funeral...I know I need to put that in writing so we know...I think that's what directives are about right?" ^a
Lack of familial ties and social isolation	"There's no family to get in touch with or nobody. My cousin doesn't want to get in touch with me..." "Well, who's there to tell? There is nobody to tell" ^a "What was not very appealing was that some of them didn't have anybody because they burned all their friendships. They couldn't even think about that one person. They wanted their case manager to be the end-of-life decision maker, they wanted their doctor to be the end-of-life decision maker" ^b
Competing priorities	"I go to my doctor regularly but people who are homeless or living in a shelter, the main thing is getting housed" ^a "But the thing is, see, being with no housing, I got to go someplace and brush my teeth. I got to go someplace and shave. I got to do this. I got to do that. So a lot of times I get tired of doing all that stuff and then I end up missing my appointment because of that" ^a "This is the real world. [Laughter] Exactly. Do you think people—and again, we're talking about homeless folks—do you think they'll have the patience to sit there for that?" ^a "Several of these kind of very, very important, very kind of overlooked, when you're in the exam room and you're worried about the fact that you have an ulcer that's going crazy or something, and that's what you're thinking about" ^b "He [my PCP] always seems to write a prescription and "I'll see you in a month" ^a "We [PCPs] all suffer from lack of time and resources in order to be able to do this effectively" ^b "The more time we had, the more...the smoother it is, the more time we have to touch them and then able to speak with them about their wishes. But I think for us too, in our clinic and time, it's huge" ^b "They have so many things they want to talk about...there's not time for that [ACP]." ^b
Avoidance and lack of readiness	"Don't ride the broom with me...don't predict my death" ^a "It's just not something that I want to talk about"... "Death, I don't really talk - I wanted - when it's time to go, it's time to go" ^a
Fatalism & mistrust	"You're not going to get your wishes anyway" ^a "It [my wishes] isn't her [PCP] business." ^a "They [insurance company] could put me in the raggiest thing they have. [Laughter] I know...it [AD] sound good, look good. But it's not going to be like that" ^a "There are still so many of our people who are so devalued that they really don't believe that. They don't even believe it about themselves. They don't even believe that they are worth something and that they deserve to make this decision and that they deserve to have these choices." ^b
Lack of ACP training for clinical and nonclinical staff	"Training for staff at the hospitals, shelters, really anywhere to be able to navigate these conversations is important. I mean, just talking with some of our staff, I feel like they're really ill-equipped and not comfortable with navigating conversations around advanced care planning... It should be common knowledge and it's not ... But I think folks in helping professions, we should be equipped. We should have those readily available and I don't think that we do." ^b "What happens to me when I die?" It was very traumatizing to the staff to not be able to have an answer. So a lot of this initiative [staff training] didn't come [for] the consumers. It actually came to actually support the staff with how they were feeling kind of helpless." "It's interesting to see also how we often don't know as the mental health providers, in some ways we just were not trained or we're not focusing on these conversations in general." ^b

^aHomeless-experienced participant.

^bClinical-stakeholder (i.e., physician, nurse practitioner, nurse, social worker or case manager, administrator, psychologist) participant.

and they have a million things that they need help with, right now they're going to be kicked out of their house and can't get food, ACP is going to fall very far on that list."

Many homeless-experienced participants avoided talking about death, believing discussions about death to be taboo or bad luck, saying "I don't want to jinx myself." Others did not feel ready to have conversations about death, saying "Not right now because I'm not right there yet. I'm not." A clinical stakeholder reported: "Some people just really don't want to have that conversation."

Homeless-experienced participants expressed fatalism about ACP, saying "Nobody [is] going to give a damn whether they live or die, so why should they?" and "If you're on the street you're not taking care of yourself [...] A lot of things you're not doing, so this wouldn't really matter." Homeless-experienced participants did not trust that the health care system would honor their wishes, even with ADs: "You're not going to get your wishes anyway...you're not."

Clinical-stakeholder participants attributed this fatalism to the stigma, mistrust, and poor relationships. Clinical stakeholders recognized that homeless-experienced adults feel judged and believe that health care providers "Don't feel that their lives are valuable, they don't care what happens to them." Many homeless-experienced participants reported poor relationships with their physicians, "To me, I don't see him as my doctor really."

Clinical stakeholders discussed a lack of ACP training in clinical and nonclinical settings (e.g., shelters, permanent supportive housing [PSH]). Homeless-experienced participants and clinical stakeholders agreed that clinicians are "Really ill-equipped and not comfortable with navigating conversations around ACP... It should be common knowledge and it's not." Clinical stakeholders reported that, "If the provider doesn't initiate the conversation, then to the patient it's not important." They suggested that non-PCP staff may be best suited to have ACP conversations due to PCPs' lack of daily interactions with homeless older adults, which they described as a barrier to close relationships. Some clinical stakeholders recommended having a "dedicated" champion, but warned, "You got to have the right person that really is passionate about it, not just that's assigned," as ACP could "End up kind of rote if it is a task that is led by someone who maybe doesn't have a very well-established relationship with the patient."

Solutions

Homeless-experienced older adults said that ACP could be affirming, "This [ACP] will make them come up out of that despair that they're in. That 'nobody gives a damn about me.'" One homeless-experienced participant emphasized "Everyone that has half a brain is going to know that is important. I do count. I am worthwhile. I am worthy. I am a human and I get my rights" (Table 2).

Clinical-stakeholder participants discussed ways to reframe ACP discussions to inspire hope and promote dignity using such phrases as "taking charge of your health" and "choice" as a way to empower patients. Clinical stakeholders wanted to frame conversations around decision-making rather than death, "[I] tend to not even use the verbiage 'ACP'. I just talk about their wishes and goals," and to normalize the process.

Both homeless-experienced and clinical-stakeholder participants discussed tailoring documents to the health literacy

needs of people experiencing homelessness and relating the content to their everyday concerns. For example, some suggested including arrangements for pets, documenting who the individual would (and would not) want to be contacted after the patient died, wishes for their funeral, and how they wished to be remembered.

Due to competing priorities, homeless-experienced and clinical-stakeholder participants felt that people experiencing homelessness should have the opportunity to engage in ACP outside of the clinic visit. Both homeless-experienced and clinical-stakeholders explained that it would be more realistic to engage homeless adults in ACP after they adults regain housing. A clinical stakeholder explained, "A lot of people have this sense of foreshortened future...that improves when you see someone become housed or other stabilization factors occur." Homeless-experienced and clinical-stakeholder participants reported that PSH (subsidized housing that includes on-site or closely linked voluntary services for chronically homeless individuals) is a viable option to implement ACP.²⁰ PSH is "a little bit of an easier place to do it [ACP] because you have an ongoing relationship, and at a certain point it is not as much crisis oriented...and the clients can think a little bit more about those kind of things, less day-to-day survival." A clinical stakeholder discussed why PSH would be an ideal location* stating, "There's so many people dying there, and they're just struggling...I feel like it's such an ideal place to be bringing—[ACP]—where I'm thinking, "God, why are we not doing this?"

Homeless-experienced participants who had recently regained housing described how watching the videos in the privacy of their own homes would make them more comfortable, whereas several reported a willingness or preference to watch the videos in a group setting. Homeless-experienced and clinical-stakeholder participants discussed a need for flexible strategies, including group and one-on-one visits, peer counselors, and licensed clinicians. Homeless-experienced participants suggested using incentives for homeless-experienced adults, including cash or gift cards, transportation, or food to engage in ACP. Clinical stakeholders described clinic-wide incentives, "If the clinic reaches a certain number of people who we talk to about ACP, we get a monetary incentive... I think actually it is working."

Homeless-experienced participants described the PRE-PARE videos on the website as informative, valuable, and a "starting point" for engaging in ACP. Some participants explained that the trauma associated with their experiences with death made some of the videos difficult to watch. Others described them as motivating, "I think it's pretty good. It's giving me something to think about, I hadn't thought about it that much in depth, and "It hit the nail on the head...so, yes, it's a very good video." Some suggested the testimonials could be adapted to homeless-experienced individuals' life experiences and relationships.

Homeless-experienced participants shared suggestions for improving materials and implementation including the following: shortened video and pamphlet length to maintain attention, using visual headers and clear steps to improve readability of the pamphlet, increasing availability of materials in housing, access to the Internet to view videos, and creating systems on-site at housing to allow the storage of their documentation and ability to share their information with their relatives. Some homeless-experienced participants

TABLE 2. SOLUTIONS

<i>Theme</i>	<i>Quote</i>
Frame ACP as a way to provide meaning and assert choice	<p>“So, it’s not just even about death. It’s about if you are sick, can’t make decisions for yourself, you end up in the hospital. Let’s just talk about who you’d want called and who you want not called.”^b</p> <p>“I bring this up, they’re like “Why did you bring this up?,” “I just think it’s important to talk about it while you’re nice and healthy.” And they’re like “Oh okay, great.” And that kind of breaks down some barriers I think, for them and for us.”^b</p>
Provide easy-to-read written documents focused on the population’s unique needs	<p>“I don’t think everybody that I know is academically inclined as I am. So they might have a little difficulty with that”^a</p> <p>“I think...it’s going to have to be something either very visual or like one word or two words that all of a sudden gets somebody like me who’s like in pain, dragging their stuff across the street to stop and take a glance at least.”^a</p>
Initiating ACP in nonclinic settings	<p>“They should have it at every senior housing.”^a</p> <p>“It needs to be mandatory. It does. Each SRO should have a file on every person that lives in that building. And the reason why I say this is because that person is trained, is educated, and went to school to do this. Having a designated son, daughter, auntie, or whoever it is regarding whoever is living in that apartment should have an alternative California Advanced Health care Directive. Because it’s right. It’s by law. It should be like that.”^a</p> <p>“Often the provider has the least close relationship with that person because our team works with them so much more closely on a daily basis”^b</p> <p>“And it’s perfectly doable, because if you can get people transitional housing, if you can get people food and clothing, you can help with medical directives”^b</p>
Tailor ACP content and delivery	<p>“We modified a document that I think I learned about at a health care for homeless conference that asked a little bit further questions about peoples wishes for funerals and how they like to be remembered, at a memorial service, those kind of things”^b</p> <p>“Be sure that you don’t alienate people by just saying, “Do you want your family to make a decision then?” Because you just have to be careful that we, again, are very inclusive in our language...the handout I think is more general and more inclusive than the videos. The videos are...not that open to different situations.”^b</p>
Provide incentives for staff and patients	<p>“We have been able to provide some incentives like a 5 dollar subsidy card or a 10 dollar Subway card once people have...gone through some of the groups that we offer.”^b</p> <p>“Yeah, but, you give some coffee...Water...Yeah, a little incentive...Just put some fruits out there.”^a</p> <p>“I think most of them will go for a \$25.00 gift certificate”^a</p> <p>“They teach you how you have that one person [peer counselor] keeps coming in for testing, and who is really engaged and then they bring other people for testing. For every patient that they bring, they get an incentive, and the patient gets an incentive. And that’s been working. Money talks.”^b</p>

^aHomeless-experienced participant.

^bClinical-stakeholder (i.e., physician, nurse practitioner, nurse, social worker or case manager, administrator, psychologist) participant.

reported that the AD was organized and straightforward to understand but that the decisions about their care were difficult: “Yeah, it’s straightforward, but not that simple. The decision’s not that simple.” Others felt that the AD was challenging for those with less literacy.

Discussion

In a qualitative study of homeless-experienced older adults and clinical stakeholders, we found agreement that ACP is important, but found multiple barriers to engagement. The barriers, including lack of knowledge, social isolation and mistrust, competing demands, and lack of training in ACP among staff within and outside the clinic setting, provide context to the low prevalence of completion of ACP among the growing population of homeless-experienced older adults.⁴ The participants suggested strategies to overcome these barriers, including reframing the discussion away from death to promote empowerment, moving the ACP discussions out of the clinic visit, capitalizing on the period after

housing, and using easy-to-read ACP materials tailored to the specific needs of homeless populations.

Our findings build upon the prior literature that found that people who are homeless have had extensive experience with death and have fears of dying alone and unremembered.⁸ Although these experiences may motivate ACP engagement, homeless-experienced older adults face many barriers to doing so. They contend with daily struggles to find shelter, food, and safety, making it difficult to focus on long-range planning.^{20,21} They are less likely to attend longitudinal scheduled health care visits, and when they do, they are likely to have multiple concerns that require attention. These competing demands, both in daily life and within the health care visit, likely drove the recommendation to initiate ACP outside of the clinical visit, preferably until after the individual obtains housing. Homelessness is an experience that may be intermittent or last years. While ideally, everyone should engage in ACP, it may be most realistic to focus ACP efforts on individuals who have regained housing, where there may be structured opportunities that can attend to their unique experiences and needs.

For those with long-standing homelessness with disabling conditions, PSH is an evidenced-based strategy that combines subsidized housing with voluntary supportive services. In 2017, over 300,000 U.S. adults lived in PSH,²² an increase of 47% from the prior year. Approximately 40% of PSH residents are aged 51 and older, and the population is aging.²² Compared with those who remain homeless, formerly homeless PSH residents have more stability and opportunity to develop relationships. The staffing structure at PSH sites provides an opportunity for nonclinic staff to initiate ACP discussions, with appropriate training. While people remain homeless, participants thought that competing life demands would complicate engagement. However, studies indicate that homeless-experienced adults staying in emergency shelters could, with coaching, complete ADs, but these studies did not examine the full process of ACP, which may be best addressed in PSH with peer or social work counseling or group visits.^{23,24} In either clinical or nonclinical settings, staff require training to feel comfortable initiating these conversations.

Participants discussed the challenge of addressing ACP for individuals estranged from their families. Social isolation and family estrangement are more common among people experiencing homelessness than in the general population.²⁵ However, in a prior study in older homeless-experienced adults, we found that 61% reported having a potential surrogate.⁴ Professionals working with homeless-experienced older adults should not assume that individuals do not have surrogates, but should acknowledge that to initiate ACP, it is not required to have a surrogate or to reach out to family, if the participant chooses to not do so.

We found that older homeless adults experienced fatalism and did not trust that the health care system would follow their wishes, even if they had an AD. People from groups who experience inequitable treatment in the health care system and resultant medical mistrust, including black and Native Americans, gender and sexual minorities, and people with mental health and substance use conditions, are overrepresented in the homeless population.^{22,26} Interventions to improve engagement with ACP should acknowledge these historical conditions and address mistrust. Reframing ACP as an opportunity for empowerment could engage this population.

Intervention research has focused on AD completion.^{23,24} Our study is innovative as it focused on ACP as a process. It examined potential changes by including clinicians' experiences and the appropriate timing (i.e., after adults regain housing). We assessed feedback on ACP materials (i.e., videos, pamphlet, and an easy-to-read AD) and gained insights on how to adapt ACP materials to fit the needs of older adults experiencing homelessness.

Limitations and strengths

Our study had several strengths, including addressing a novel issue (i.e., ACP feasibility for older homeless adults), including people with lived experience and diverse clinical stakeholders, having participants from diverse racial and ethnic backgrounds recruited from two sites, and thematic saturation. The study's limitations included recruiting from one region, double coding only 30% of transcripts, limiting our ability to conduct inter-rater reliability, lack of member checking, potential social desirability bias, and selection bias

due to convenience sampling. Our results may not be generalizable to older adults experiencing homelessness with cognitive impairment or to the U.S. homeless population.

Conclusions

The homeless population is aging. Older homeless-experienced adults and clinical stakeholders recognize the need to improve ACP engagement in this population. While there are barriers to completing ACP, strategies that could overcome these include moving conversations outside of the clinical encounter, focusing efforts after people regain housing, and recognizing that one may begin the ACP process even if socially isolated or estranged from family. Improving ACP engagement will require changes in the content, delivery, and location where ACP conversations occur. By addressing these barriers with viable solutions, it may be possible to increase engagement in ACP in a population at high risk for death.

Sponsor's Role

The content is solely the responsibility of the authors and does not necessarily represent the views of the National Institutes of Health.

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Author Disclosure Statement

The authors have no conflicts of interest.

Supplementary Material

Supplementary Table S1
Supplementary Table S2

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