Advance Care Planning: Challenges and opportunities for homeless experienced adults

Margot Kushel, MD
Professor of Medicine, UCSF
@mkushel

6/29/2017
Consensus Definition of ACP

Definition: “ACP is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding current and future medical care.

Goal: The goal of ACP is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.”

J Pain Symptom Manage. 2017 May;53(5):821-832
Homeless adults face barriers to ACP:

- Less likely have a PCP
- Higher mistrust in medical system
- Low health literacy, social isolation
- Mental health problems
- Life regret
High prevalence of worry about death

- High prevalence of worry about death
- More likely to die in an intensive care unit without surrogates
- Low rates of completion of advance directives
Homeless adults’ fears about dying

- **Universal:**
  - Inadequate pain relief
  - Unfulfilled wishes

- **Uncommon:**
  - Anonymous
  - Unmemorialized death
  - Inappropriate treatment of body/burial

Homeless report concerns

- Estrangement from family
- Lacking control at end of life
Objectives (My research project)

In a population-based cohort of older, homeless-experienced adults:

- Describe and quantify engagement in key Advance Care Planning behaviors
- Examine factors associated with Advance Care Planning engagement
Homeless experienced adults are able and willing to complete Advance Directive in study settings

- Noted the importance of ACP as a way to gain control at the end of life
- Are able and willing to complete advance directives with assistance
- Studies have been small and in research settings
- Not clear that results conveyed to healthcare teams in order to influence care
Methods: HOPE-HOME

- Population-based prospective cohort study
  - Homeless shelters
  - Subsidized/free food programs
  - Encampments
  - Recycling center

- Inclusion:
  - English-speaking
  - ≥ 50 years old
  - Homeless*
  - Informed consent by teach-back

- Interview every 6 months
Methods: Variable collection

- ACP questions at 18-month follow-up
  - or next attended
- Time dependent variables at corresponding interview
- Time constant variables at baseline
Methods: Independent variables

- Age, sex
- **Education:** ≥ High school
- **Health Literacy (HL) Status:** Adequate HL: ≥ somewhat confident filling out medical forms on own
- **Self-Reported Health Status:** Fair to poor health
- **Mental Health:** Depressive Symptoms (CES-D ≥16)
- **Social Support:** Number of close confidants (0, 1-5, 6+)
- **Regular Primary Care Provider**
ACP engagement outcomes

- **Potential surrogate**
  - Have someone they trust to make medical decisions

- **ACP Contemplation**
  - Thought about medical treatment preferences

- **ACP Discussions**
  - Ever discussed wishes with anyone

- **Surrogate Designation**
  - Formally named a person they trust

- **ACP Documentation**
  - Signed official papers about wishes
## Results

### Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>N = 275</th>
<th>Mean (SD), %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>58 (5.3)</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>75</td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>82</td>
<td></td>
</tr>
<tr>
<td>Education ≥ high school</td>
<td>76</td>
<td></td>
</tr>
<tr>
<td>Health status: fair to poor</td>
<td>53</td>
<td></td>
</tr>
<tr>
<td>Depressive symptoms</td>
<td>50</td>
<td></td>
</tr>
<tr>
<td>Social support contacts</td>
<td>-</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>29</td>
<td></td>
</tr>
<tr>
<td>1-5</td>
<td>61</td>
<td></td>
</tr>
<tr>
<td>6+</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Regular health care provider</td>
<td>54</td>
<td></td>
</tr>
</tbody>
</table>
## ACP Engagement

<table>
<thead>
<tr>
<th>ACP Engagement</th>
<th>N = 275 %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Potential Surrogate</td>
<td>61%</td>
</tr>
<tr>
<td>Thoughts about ACP</td>
<td>36%</td>
</tr>
<tr>
<td>ACP Discussions</td>
<td>22%</td>
</tr>
<tr>
<td>Surrogate Designation</td>
<td>18%</td>
</tr>
<tr>
<td>ACP Documentation</td>
<td>9%</td>
</tr>
</tbody>
</table>
Primary dependent variable

Designated surrogate or ACP documentation = 19%
## Factors Associated with ACP Engagement

<table>
<thead>
<tr>
<th>Participant Characteristics</th>
<th>AOR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>African American</strong></td>
<td>4.5 (1.3-15.3)</td>
</tr>
<tr>
<td>(Ref: non-African American)</td>
<td></td>
</tr>
<tr>
<td><strong>≥ High School</strong></td>
<td>2.3 (1.1-5.3)</td>
</tr>
<tr>
<td>(Ref: less than high school)</td>
<td></td>
</tr>
<tr>
<td><strong>Social support</strong></td>
<td>-</td>
</tr>
<tr>
<td>(Ref: 0 confidants)</td>
<td></td>
</tr>
<tr>
<td>1-5 confidants</td>
<td>1.7 (0.7-3.7)</td>
</tr>
<tr>
<td>6+ confidants</td>
<td>3.6 (1.1-11.2)</td>
</tr>
</tbody>
</table>
Limitations

- Recruitment from one city
- All items recorded from self-report
- ACP questions asked at 18 months
  - Those who were loss to follow up were most likely to be socially isolated
  - 12 cohort members died before the 18 month interview and may have reflected most sick
Conclusions

Compared to older adults in the general population, homeless adults have:

• Lower prevalence of potential surrogate
• Low engagement with ACP
Conclusions

Unlike the general population:

- PCP wasn’t associated with completed ACP
  - Multiple competing priorities
  - Less interest
  - Provider misconceptions

African Americans were more likely to have completed ACP

- Different pathways into homelessness experienced by African Americans
Implications

Clinicians should engage homeless-experienced patients in ACP discussions

• Missed opportunity during healthcare visits

ACP interventions for homeless patients should be tailored:

• Low prevalence of potential surrogates
• Lower educational attainment and low literacy
• Multiple competing priorities during primary care visits

Future direction

• Use qualitative methods to understand barriers and facilitators
Methods

- Analysis of evaluation data from attendees at psychoeducational groups for homeless veterans
- Attendance voluntary
- Groups focused on Advance Care Planning
- Participants encouraged to identify readiness for ACP and set a goal
- Study analyzed data from worksheets completed by veterans
  - demographic characteristics, homelessness status, self-reported ACP engagement, personal ACP goals
- Looked at Advance Directive completion in VA records
Results

- 288 homeless veterans completed worksheets
- Median age 54, 95% men
- 58% “minority”
- 28% rural
Results

- 70% reported having thought about care at end of life
- 48% reported having talked to trusted friend or family; 46% had named someone
- 31% had spoken with health care provider
- 26% had an AD in record
  - Little agreement with self report of who had AD
Results

- Non-white veterans less likely to have thought about their preferences, but no differences for other steps
- Older veterans and those from urban areas more likely to have an AD
Discussion

- Homeless veterans were interested in ACP activities and had thought about it, but little communication with healthcare professionals or filling out of forms
- Willing to discuss in group settings
- Need to improve discussions about ACP in homeless adults
- Increasing importance as homeless population ages
To develop ACP processes for homeless experienced adults

- Did 20 consumer in-depth interviews in SF Bay Area (Oakland and SF)
  - Used as starting point for discussions
    - Low literacy advance directive (Rebecca Sudore MD)
    - Prepare website (www.prepareforyourcare.org)
- Held three focus groups (at this meeting)

- Exploring: experiences with EOL care, ACP; barriers to ACP; facilitators to ACP; logistics of ACP
  - For consumers, got feedback on low literacy AD, prepare pamphlet and prepare
ACP Targets for Intervention

ACP

Clinician or Facilitator

Healthcare System

EHR

Patient
Easy-to Read Advance Directives

RCT:
- Doubled completion rates
- Overwhelmingly preferred

FREE
10 languages

Being updated for all 50 states

California Advance Health Care Directive

This form lets you have a say about how you want to be treated if you get very sick.

This form has 3 parts. It lets you:

Part 1: Choose a medical decision maker.

A medical decision maker is a person who can make health care decisions for you if you are too sick to make them yourself.

Part 2: Make your own health care choices.

This form lets you choose the kind of health care you want.

This way, those who care for you will not have to guess what you want if you are too sick to tell them yourself.

Part 3: Sign the form.

It must be signed before it can be used.

You can fill out Part 1, Part 2, or both.

Fill out only the parts you want. Always sign the form in Part 3.

2 witnesses need to sign on page 11 or a notary public on page 12.

YOUR NAME: ___________________________
PREPARE

Online Advance Care Planning Tool

Rebecca L. Sudore, MD
Professor of Medicine, UCSF
Welcome to PREPARE!

PREPARE is a program that can help you:

- make medical decisions for yourself and others
- talk with your doctors
- get the medical care that is right for you

You can view this website with your friends and family.

Click the NEXT button to move on.
Creating PREPARE

- Created with and for the community

- Easy to understand
  - 5th-grade reading level, large font
  - Voice-overs & closed captioning

- Range of video stories/experiences:
  - Tailored to
    - Surrogate availability
    - Decision making preferences

* Sudore RL et al., J Pain and Symptom Management, 2012
5-Steps of PREPARE

1. Choose a Medical Decision Maker
2. Decide What Matters Most In Life
3. Choose Flexibility for Your Decision Maker
4. Tell Others About Your Wishes
5. Ask Doctors the Right Questions

Your Action Plan
How to Ask Someone to Be Your Decision Maker

You can watch this video with your friends and family.
How to Ask Someone to be Your Decision Maker

How to say it:

"My doctor thinks it is important to choose someone to help make medical decisions for me in case I get sick in the future and cannot make my own decisions. If this happens, would you be willing to work with my doctors to help make medical decisions for me?"

This is one example. Your situation may be different.
How to Tell Others

How To Tell Others About Your Wishes
How to Ask Questions

How To Ask Doctors the Right Questions
Methods

- Interviewed 10 participants in HOPE HOME
  - Homeless at study entry
  - 50 and older
  - Recruited people who
    - Had at least two chronic medical problems
    - Had a PCP

Interviewed 10 (9 done as of today) patients at TWUHC
  HCH clinic in SF
  Have been homeless in past 3 years; have 2+ medical problems
Experiences

Consumers reported a lot of experiences with death and concerns about death

They recognized situations in which ACP/AD would have helped

- “They [doctors and family] would have left me alone…I would have showed them the paperwork…this is what she wants, not dragging her from here to here and that, but I was unprotected and I didn’t know none of this.”

They shared concerns about dying:

- “I don’t want to die hungry. I don’t want to die hungry, cold and alone.”
Barriers to participating in ACP

FATALISM: sense that death is inevitable and that no one will attend to their wishes, anyway

“Wish not to even know about it…I’m gonna live until I die – it’s gonna happen anyway.”

“You don’t have that choice because they don’t tell you that your insurance don’t cover that…[My sister] she only want the best nursing home for me, [but] “Oh no we’re going to put him here.” They could put me in the raggediest thing they have.”

“When you’re on the street you’re not taking care of yourself most of the time, there’s a lot of things you’re not doing, so this really wouldn’t matter. And you’re not gonna get your wishes anyway.”
Barriers

LIFE REGRET

“I actually don’t give a damn about death. What – what bothers me is my past… there’s just a lot to try to atone…”
Barriers

COMPETING PRIORITIES

- Hard to do when homeless (but interested when in PSH)

“[When] a senior’s homeless—this would really be hard for them, I think... they’re old and they’re out there and I think the longer you stay out there, the harder you get. It was difficult to come back inside…It messes with your mind, you tend to lose your thinking process.”

“People who are homeless or living in a shelter, the main thing is getting housed… when you’re getting back on your feet again…you start thinking about things that are important like this.”

To “actually follow through on it [ACP] that might have been a little iffy; because when I was homeless, everything financially was about finding a place.”

“Priorities [for the homeless] are making their day go by easier. That is their main and most prominent priority. They also don’t believe nobody going to give a damn whether they live or die, so why should they?”
Barriers

Lack of trust

- Case management - “They’re just doing their job...a lot of them act like they care...but I’d say for 75 percent of them, it’s just a job...it’s a lot of ‘Sign right here, go to this class,’ and nothing comes of it. It’s a lot of bullxxx and I’m an angry black man again.”

“...People don’t ask the homeless the right things...Things that interest the homeless...they don’t ask them the important things. ‘What is important to you right now?’”

- “He doesn’t do anything, doesn’t know what’s going on with me...he’s not a hands-on doctor.”

Wouldn’t talk to his case manager about ACP – “we don’t know each other that well.”
Barriers

LACK OF EMPATHY/UNDERSTANDING

“The main problem I believe that homeless people face is lack of empathy by others…some people will figure help is to *tell* you how to run your life. All you just can do is *offer* someone a different option.”

“…People don’t ask the homeless the right things…Things that interest the homeless…they don’t ask them the important things. ‘What is important to you right now?’”
Barriers

LACK OF FOLLOW THROUGH

“Don’t leave it [ACP approach] open-ended, an opening for it to disappear and maybe never deal with it.”
Facilitators

Having opportunity to complete an advance directive is evidence that someone cares, that their life matters

- An AD “will make [the homeless] come up out of that despair that they in, that no one gives a damn about me.”

- “I would put in large letters, like we say – liked they say the word “Prepare,” I would just put an addendum that says ‘your life matters’.”
Ideas for implementation

Group visits

“Well, some people function best one-on-one. Some people, in order to draw them out, should be a group setting because then they’ll feel that simpatico and a bonding of some type that will draw them out to start thinking about those types of things. I would suggest starting out with a group and those who do not participate, it’s pretty indicative at that point that you probably would have to go one-on-one.”

“You get a chance to release your emotions; you get a chance to ask very personal questions. But then again, I’m saying a small group session because this is something sometimes people—people are scared to death, period, point blank. That’s it, and that’s all. And sometimes having someone with you is your stabilizing—It helps you look at it. People are more free to talk with somebody that they know and feel comfortable around.”
Ideas for implementation

Having brochures and low literacy advance directives available, but have someone available to discuss further

“They should have it at every senior housing and at your doctor’s office. I would keep a notice on a bulletin board and have one of the forms with the—what we call here the residential social worker at (PSH site). If you have this on the board, healthcare directive. Who takes care of you when you become ill? Would you like to appoint somebody to make decisions for you when you become too sick? See your residential social worker. “

“At a senior center where not only I can view it, but others can view it. And maybe we can have extensive conversation about it. Yeah, because there you can get more out of it because you have other input.”

"Primary care physician, also healthcare services that care to the needy, the homeless, the low income, disenfranchised people, a drop-in center or shelter. Something like that. Something at a shelter or drop-in clinic, and they announce themselves “My name is so and so, I am with so and so, and this is why I am here.”
Ideas for implementation

Having someone trained to assist with AD and engaging people in ACP

"Primary care physician, also healthcare services that care to the needy, the homeless, the low income, disenfranchised people, a drop-in center or shelter. Something like that. Something at a shelter or drop-in clinic, and they announce themselves “My name is so and so, I am with so and so, and this is why I am here.”
Ideas for implementation

Have a portal available with information:

I find that it would probably be best to give people a portal where they can read text on website or see video on a specific website or YouTube on living with diabetes for example, etcetera and then it would ask the question “Would you like a personal discussion with a professional?” And then leave that up to the desire. Do you want to see somebody or no? Leave it up to them....
Ideas for implementation

The PREPARE Video—idea of watching something ahead of talking to provider is appealing, but needed to be targeted better to needs

"Wouldn't have been difficult to watch when I was homeless, for a lack of something to do it would have been perfect. But then again, it hits home, and it makes you think, and thinking makes action."

"I would be thinking now it is time for me to go ahead, but I have been thinking about it, I think I go ahead and get it done. If I didn’t see the video I wouldn’t be more determined, make sure I just do it without...And I would put in some more testimonials or information on how to do it without family or friends."
Ideas for implementation

Health clinics and churches

“because anybody interested enough to come to a [clinic] means they have interest in their life. Or If you’re going to church, you have a sense of spirituality. Yes, church would be an excellent place, and if they’re going to come to church, they generally have a sense that “This is a sacred place. I’m not going to disrespect it.”
How to let people know you have filled out

Putting sticker to signal on one’s ID

Let’s say on my identification it says I’m an organ donor so I guess they would just take it from there; because you have that pink dot on your ID. Right, there could be another, say, green dot or some other sticker or something, right, on your ID that would let them know you have a medical decision maker in place.
Preliminary recap from focus groups

- Normalize and standardize in the workflow
- Messaging and Framing:
  - Campaigns, we all do ACP
  - Posters and ads
  - How to describe it?
- Incentives
  - Patients
  - Providers
  - Using Metrics and benchmarking
Preliminary recap of focus groups

- Peer mentors and CABs
- Groups
  - Dedicated ACP groups
  - Use of MLPs and lawyer groups
  - Tack onto existing groups about other topics
- One-on-one facilitation & or using the whole team
  - Trained facilitators
  - Providers
  - Other champions
YOUR IDEAS?