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# Does End-of-Life Decision Making Matter?: Perspectives of Older Homeless Adults

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## Abstract

This qualitative pilot study explored perspectives, needs, and concerns relating to advance care planning among older homeless adults. Twenty-one older adults residing at a transitional housing facility in an urban area of the West coast were interviewed in person. Key emergent themes included discomfort with the topic trust in God's decisions, physicians preferred as decision makers, and planning is important but not an immediate concern. Further, people who are homeless want to be approached with sensitivity. Instead of simply eliciting life-sustaining treatment preferences of homeless people, health care professionals should assess their unique concerns and needs regarding death and dying, prepare them to consider their possible end-of-life situation, and assist them to plan in accordance with their needs.

## Keywords

homeless, older adult, end of life, advance care planning, perspective, cultural sensitivity

## Introduction

Advance care planning (ACP) is key to communicating end-of-life (EOL) treatment preferences with family and health care professionals and documenting them in case individuals are unable to make their own decisions.<sup>1</sup> It encourages them to exercise autonomous decisions that result in their EOL wishes being honored and reduces decision-making burdens on family and health care professionals. Despite good intentions, there has been a concern regarding its applicability to vulnerable populations such as those who are homeless.<sup>2,3</sup> The premise of quality EOL care encompasses family involvement in the patients' care, physicians honoring patients' wishes regarding life supports, and palliative care, preferably at home.<sup>2</sup> The homeless population who has insufficient resources on personal, social, and structural levels might face immense challenges in their ACP.

The homeless population is known to have poor health, limited medical access, risk behaviors, and lack of social/family support. An unstable living situation coupled with risk behaviors (eg, substance abuse) shortens life span and increases the probability of greater mortality when compared to the general population.<sup>4,5</sup> In particular, older homeless people aged 50 and older have a disproportionately higher likelihood of a higher mortality rate,<sup>6</sup> chronic medical conditions, and cognitive impairment.<sup>7-9</sup> Despite increasing vulnerability to chronic health conditions and acute/extensive care needs, very little is known about experiences and perspectives toward EOL care among older homeless adults. A few previous studies explored experiences of death and dying,<sup>3,10</sup> attitudes toward EOL care,<sup>10-12</sup> and effectiveness of EOL care interventions<sup>13</sup> in a

homeless population, and they provide helpful insights regarding challenges homeless people face in planning for EOL care. Nonetheless, no study has focused on this topic among older homeless adults. Although death occurs in all age groups, it becomes a more imminent issue for older adults. Homeless older adults who struggle to meet basic needs might have a different perspective toward ACP, demanding different approaches in working with this population. Eliciting perspectives and needs toward ACP among older homeless adults might help practitioners and researchers alike to further develop culturally appropriate interventions for this vulnerable population. Accordingly, this study explores the views, concerns, and needs regarding ACP among older homeless adults.

## Methodology

### Study Design and Sample

In this qualitative study, residents at a transitional housing facility in an urban city of the West coast were interviewed in person. A transitional housing facility is temporary housing where homeless adults aged 60 and older stay up to 3 months in transition to permanent housing. The eligibility criteria of the

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participants were age 60 years and older, English speaking, and cognitively intact. Participants' mental status was assessed by the Short Portable Mental Status Questionnaire (SPMSQ).<sup>14</sup> A letter explaining the purpose of study was mailed to the director of the study site. Upon approval, case managers left the invitation letter on each resident's door or introduced the study in person during their contacts. Among the total 36 residents at the site, 12 residents did not respond, 2 declined, and 1 was hospitalized during the study period which resulted in 21 participants.

### Data Collection

Data were collected via face-to-face interviews by the researcher at a private office using a semistructured questionnaire. Interview questions included Have you ever thought about the possibility of dying? What are your concerns? What would you want your providers to do if you could no longer talk to them about your preferences? Interviews lasted about 40 to 50 minutes. Each interview was audiotape recorded and then transcribed by a research assistant. This study was approved by the institutional review board (BLINDED FOR REVIEW IRB# 448042).

### Data Analysis

A grounded theory approach<sup>15</sup> was used to identify emergent themes in the data. The 2 authors read the manuscript independently and developed the initial coding scheme question by question in an open coding method looking for patterns in the data. Then, conceptual themes were developed and led to creation of major categories. The authors reiteratively reviewed the manuscript to identify any additional coding. The authors compared the coding results, validating the major findings. The few discrepancies to surface were discussed until consensus was reached.

Multiple strategies were used to ensure rigor of the study. Although there was a limited number of participants due to their transitional living circumstances, a member check was used to confirm the final data. Prolonged engagement with the participants was conducted, creating a rapport between the researchers and the participants as well as a deeper knowledge of the study sites.<sup>16</sup> During our preliminary visits, we participated in the activities at the study sites, spoke with seniors, and met with the key personnel (eg, director) to enhance our understandings about the organizational culture and social settings.

### Measures

Prior to the qualitative interviews, participants were interviewed with a structured questionnaire assessing social support (availability of a potential caregiver, and the number of family they contact at least once a month), health and mental health issues, and sociodemographic information. The qualitative interview guide was constructed based on the previous studies with homeless population.<sup>3,10,17</sup>

### Findings

**Participant Characteristics.** The majority of the participants (n = 18) were male and the mean age was 65 years. More than half of the participants were whites (n = 11), followed by blacks (n = 5) and Latino/Hispanics (n = 3). Nine (42.9%) participants reported to be divorced, the majority (n = 19; 90.5%) reported to have annual income of less than \$10 000, and more than half (n = 13; 57.1%) had some college or college education, followed by high school graduation (n = 6; 28.6%). In regard to the chronic illness, participants have been told by a doctor that they have hypertension (n = 16; 76.2%), arthritis (n = 12; 57.1%), a heart problem (n = 7; 33.3%), and mental health problems (n = 10; 47.6%). More than half (n = 13; 61.9%) reported that they have been admitted to an intensive care unit in the past.

About 71% of the participants (n = 15) have ever lived on the street prior to moving to the transitional housing. Almost half (n = 10; 47.6%) reported no family/relatives whom they contact at least once a month, and 12 (57.1%) participants reported having no potential caregiver when they are critically ill. The main themes emerged in the qualitative study include (1) EOL topic is uncomfortable; (2) God plans EOL care; (3) physicians are preferred as decision makers; (4) EOL care is not a priority; and (5) people who are homeless want to be approached with sensitivity (Table 1).

**The EOL Topic is Uncomfortable.** In this study, participants viewed death as a natural part of life cycle, yet many of them say they avoid talking about death. We go through our cycles, birth, life, death, as all creatures do, as all living organisms do . . . and I think as a general rule . . . (pause) . . . We shun it. We want to push it aside and deny it . . . I'm in that same category (#5). Thoughts on death negatively influence their state of emotions in addition to other difficulties in their life. Everybody wants to live you know . . . I find if I dwell on it, it gets depressing . . . I get depressed enough you know (#11).

Participants believed that the way they think and speak is associated with the consequences in life. The ACP involves thinking about death, which may create negative energy and cause undesirable life events. A participant elaborated on his hesitance toward ACP.

I probably might do that (ACP) but I don't wanna . . . it's just like energy. That's why I said I don't look at life like that . . . we have to watch what we say because we manifest what we say through our mouth. And in dealing with the Bible, it talks about putting a bridle on your mouth, it can come back to haunt you. So I've been very careful with that (#9).

### God Plans EOL Care

Spirituality and religiosity were important components in defining life and death. Death and dying were perceived to be temporary matters, and many thought dwelling on the EOL situation was undesirable. *If I believe what God says about death and where you're gonna go after, I shouldn't really dwell*

**Table 1.** Participants' Sociodemographic and Health Information (n = 21).

	N	M (SD)/ %
Age		65.0 (4.0)
Male	18	85.7%
Race		
White	11	52.4%
Black	5	23.8%
Latino/Hispanic	3	14.3%
Other	2	9.5%
Marital Status		
Divorced	9	42.9%
Never Married	6	28.6%
Separated	3	14.3%
Married/live together	2	9.5%
Widowed	1	4.8%
Education		
Less than high school	2	9.5%
High school graduate	6	28.6%
Some college/college graduate	12	57.1%
Post graduate	1	4.8%
Income		
Less than \$10 000	5	23.8%
\$10,000-\$19 999	14	66.7%
More than \$20 000	2	9.5%
Religion		
Baptist/Protestant /Pentecostal	17	81.0%
Catholic	2	9.5%
Atheist	2	9.5%
Have a primary doctor (yes)	16	76.2%
Health Conditions		
Hypertension	16	76.2%
Arthritis	12	57.1%
Heart Problem	7	33.3%
Diabetes	4	19.0%
Stroke	4	19.0%
Cancer	3	14.3%
Lung problem	2	9.5%
Psychological problem	10	47.6%
Hospitalized at ICU in the past	13	61.9%
Living/Social Context		
Have lived on the street	15	71%
Having a potential caregiver (yes)	8	38.1%
# of family whom they contact at least once a month		
None	10	57.6%
1-2	4	19%
3-4	3	14.3%
More than 5	4	19%

Abbreviations: M, mean; SD, standard deviation.

on the ... 'cause it's just ... this is temporary. I have to remember this is temporary (#11). With faith in God, facing the EOL was not a concern for participants. Seen as omniscient and providential, God was the protector preventing them facing negative life events and a guide for their future. *I don't think God is going to let me become a vegetable or to have a major illness (#18). It is up to God. I am not concerned about it [end-of-life care] (#13).*

The participants felt unequivocally that God is in control of life and death and governs one's life. When one's destiny is

already predetermined by God, planning the future was an unnecessary act. A participant corroborated these thoughts.

I think as we plan for those things I think we are ... okay. If God has the answer to my life, when I'm going to die, I don't have to plan when I'm going to die. He already knows. And I believe he will give me the knowledge if it's through my sickness or whatever ... to understand that my death is near (#14).

### Physicians are Preferred as Decision Makers

Most participants reported not having EOL communications with physicians, but they had a clear preference for their physicians to be the decision maker regarding EOL care treatments. With their medical expertise and updated knowledge, the participants trusted their physicians to make the best decision for them. *I have not discussed anything with my doctor, but ... that's why he has that degree on his wall and I ... I leave that decision up to him (# 3).*

Lack of family/social support was a challenge that leaves limited or no option for designating a surrogate decision maker. Physicians were deemed to have a better knowledge about the participants' situation.

I want the doctors to do whatever they can and whatever they feel is the best thing to do. I have only my brother but he is in his 80s, and I'm not that close to him. I don't feel good about it (not having anyone to make the decision), but there's nothing I can do. I don't have anyone (#4).

### The EOL Care is not a Priority

The need for decision making in EOL planning was questioned. Death is a natural phenomenon, so planning for death was seen as unsuitable and out of place. *The EOL decision is not a real decision. Dead is dead. What is the sense in talking to them (doctors and family)? (#1).* Another participant compared the dire living situation of homelessness as an EOL situation. *Some of them don't really care about their ... their ... end of life because. many think that this is "end of life." What EOL are you talking about? ... I'm on the street and nobody cares about me (#13).*

Participants reported meeting basic needs as a primary task; thinking of the future beyond surviving day by day was unrealistic.

It's the people that I've talked to that live on the street ... it's uh ... they're just looking, you know, to get their food and stay warm and ... get a shower ... They're not really considering much beyond that (#6).

Current life circumstances determine the priorities in life; engaging in ACP might not be feasible when one struggles to survive today. The participant shared his view that engaging



in ACP might be a distant need for homeless people who are disenfranchised in multiple aspects of life.

Well, due to my life situation as it stands now, and the condition that I am in financially, socially, and a lot of things physically, but I gotta consider all these ... this composite of things. If things were different, financially ... uh ... if there was a significant other in my life ... if things were different, I would ... I would view this all completely differently ... Right now, it's not a priority. It could become a priority in the future. (#5).

### Approach Homeless People With Sensitivity

Despite the hesitancy and lack of desires for ACP, many participants viewed it as an important means to represent their wishes when they become incompetent. Planning for EOL situations was seen as even more important for marginalized people. *The more vulnerable you are the more ... the more you should really consider it, you know. If you're sleeping on the pavement, that's a pretty vulnerable situation* (#6). Another participant added that ACP is important for those who do not have an available health care proxy. *Who's going to take care of that for me? Who's going to know what my desires are? Surely you must think about something else other than living day to day out there cause you can die day to day, too* (#11).

A fear of signing the document was also addressed. Experiences with health care professionals' lack of sensitivity in approaching the EOL topic and witnessing other homeless people being treated in an undesirable way influenced participants' views toward ACP. A participant expressed his hesitancy about signing the document. *All I had was a burn and she (doctor) was talking about the advance directive and everything. So I must have said something to that effect. I had a friend who died and ... they cremated him. He was homeless and they cremated him. And I did not ... I do not want to be cremated* (#19).

Recognizing cultural differences serves as the basis for increasing sensitivity; health care professionals' caring attitudes were critical in gaining trust. A participant explained the importance of being connected with health care professionals.

So you approach them in their situation, on their level, and the most difficult [people] to deal with [who] need a lot of sensitivity are people on the street, which I've shared with you that all they need is show them that you care, show them that you are concerned about their life. It may not be something that affects them right now but [it] is going to affect them ... [it] is better to plan ahead (#13).

### Discussion

The results of this study featured the unique situations of homeless people, which impact their perspectives toward ACP. The participants' concerns and needs in planning EOL care were related to their disenfranchised circumstances. Participants expressed discomfort discussing death, which has also been supported by other studies.<sup>18-20</sup> Death and dying remains taboo,

making individuals reluctant to engage in ACP.<sup>20</sup> Although the participants did not disapprove the idea of ACP, they had an aversion to death with fear it would cause negative emotions. Aversion to planning for death might be related to the homeless individuals' witnessing or experiencing the deaths of family and friends.<sup>10,21</sup> In addition, perceived discrimination in health care might create discomfort for participants in thinking of death or signing documents from EOL discussions due to fear of being treated unfairly, possibly of having life-sustaining treatments being withdrawn or withheld during their final days of life due to their marginal life circumstances. Although death might be an uneasy topic for everyone, for homeless individuals, death may encompass divergent meanings. Previous multiple losses and exposure to violence create uncertainty about the future and fear of death, which also impact their EOL care.<sup>17,22</sup>

Consistent with other studies,<sup>18,23,24</sup> our participants viewed death and dying as a matter of God's domain. The participants who believed life and death are in divine hands viewed ACP as against their religious practice and even contradictory to their faith.<sup>10,23</sup> With faith in God, anxiety about potential irreversible conditions during the final stage of life was not necessary. The importance of religiosity/spirituality in the participant's attitudes toward ACP needs to be recognized. A holistic approach that incorporates a religious/spiritual component as a part of ACP process will be necessary.

The majority of participants preferred their physicians to be the decision maker when they become incompetent to make their own decision, similar to a previous study,<sup>25</sup> where physicians were deemed to make the most appropriate decision. Another significant reason for our participants' reliance on physicians as decision makers stemmed from lack of surrogate decision makers. Physicians might form part of their limited support network. However, EOL decision making falls on doctors when patients' wishes are unknown and that can become burdensome. Thus, health care professional's active engagement in a dialog eliciting patients' concerns (eg, discrimination by the medical system, fear of death) and their EOL treatment preferences will be crucial. Given that some might respond negatively to such a topic, actively listening to the patients' values toward ACP and exploring options in a collaborative manner can provide an opportunity to build a trusting relationship.<sup>26</sup> In particular, assisting patients to recognize ACP as a means to represent their wishes in the absence of a potential decision maker, think about their values and goals in ACP, and provide emotional support might enhance patient/health care provider communication.<sup>27</sup>

One important finding was that many recognized ACP as useful but did not consider it their priority concern. As addressed above, day-by-day survival was a main concern and challenge for participants. Hence, worry about adverse medical conditions or losing the ability to make decisions while struggling to meet basic needs was not realistic. This supports the concerns regarding current practice of ACP addressed by Song and colleagues<sup>2</sup> for this special population who might have difficulty thinking beyond mere survival. Nonetheless, some homeless individuals have concerns about death and are receptive to the idea of EOL care,<sup>3,28</sup> but the domains of their

concerns are different than the general population and require a different approach. Similarly, our participants also recognized the importance of ACP. Despite their reluctance, some participants thought ACP was even more important for vulnerable people like themselves.

In working with this population, participants suggested a culturally sensitive approach, specifically, an individually tailored approach that considers their circumstances and conveys understanding of their values. There has been a growing recognition about the value of the process of ACP, yet much current practice still focuses on outcomes such as completion of the advance directive document. Homeless individuals' level of motivation and perceived ability to engage in ACP might vary with their situational circumstance, so preparing them to consider death and dying might be an important first step to take. In doing so, engaging in EOL communication gradually and over time can facilitate reaching better future decisions.<sup>29,30</sup>

### Limits and Future Directions

This study has some limitations in the interpretation of findings. Study participants were selected from one transitional housing facility. The older homeless adults at other settings (eg, homeless shelter, drop-in center, street, etc) with a different physical environment (eg, shorter stay, violence) might have different views toward ACP. Another limitation is the health status of the participants. Despite our participants' chronic health conditions, the majority of our participants were ambulatory. Perspectives toward ACP vary by health status, so that individuals with serious illness are more receptive toward planning EOL care. Thus, future studies recruiting older homeless adults from multiple sites and settings will yield diverse perspectives in ACP.

### Conclusion

This study is one of the few to investigate the concerns and needs of a vulnerable homeless population regarding ACP. Although ACP is not considered an immediate concern by all and is beyond the interest of a few, others view ACP as a critical concern in their at-risk situation. Efforts to promote ACP need to include exploring a potential health care proxy, providing resources and planning in accordance with needs. Health care professionals who build strong rapport and develop a culturally sensitive approach with this special population of older adults can improve responsiveness to individual needs and ensure better decision making for homeless persons.

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### Authors' Notes

Eunjeong Ko is an assistant professor at school of social work, San Diego State University, and Holly Nelson-Becker is a professor at school of social work, Loyola University.

### Declaration of Conflicting Interests

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