Dying on the Streets: Homeless Persons' Concerns and Desires about End of Life Care

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BACKGROUND: There is little understanding about the experiences and preferences at the end of life (EOL) for people from unique cultural and socioeconomic backgrounds. Homeless individuals are extreme examples of these overlooked populations; they have the greatest risk of death, encounter barriers to health care, and lack the resources and relationships assumed necessary for appropriate EOL care. Exploring their desires and concerns will provide insight for the care of this vulnerable and disenfranchised population, as well as others who are underserved.

OBJECTIVE: Explore the concerns and desires for EOL care among homeless persons.

DESIGN: Qualitative study utilizing focus groups.

PARTICIPANTS: Fifty-three homeless persons recruited from agencies providing homeless services.

MEASUREMENTS: In-depth interviews, which were audiotaped and transcribed.

RESULTS: We present 3 domains encompassing 11 themes arising from our investigation, some of which are previously unreported. Homeless persons worried about dying and EOL care; had frequent encounters with death; voiced many unique fears, such as dying anonymously and undiscovered; favored EOL documentation, such as advance directives; and demonstrated ambivalence towards contacting family. They also spoke of barriers to EOL care and shared interventions to improve dying among the very poor and estranged.

CONCLUSIONS: Homeless persons have significant personal experience and feelings about death, dying, and EOL care, much of which is different from those previously described in the EOL literature about other populations. These findings have implications not only for homeless persons, but for others who are poor and disenfranchised.

KEY WORDS: bioethics; homelessness; end-of-life care; focus groups; poverty.
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BACKGROUND

There remain many deficiencies in how society addresses the needs of dying individuals.[1] One shortcoming is the fundamental assumptions behind end-of-life (EOL) care: it focuses on individuals with loved ones, health care, and a home. Society has not considered homeless persons, who often die without these resources. It is necessary to address EOL care in this population for several reasons. First, the high prevalence of homelessness in the United States, with estimates ranging up to several million,[2] and the disproportionate amount and severity of illness in this population[3,4] is a public health crisis. Homeless persons also suffer high mortality rates—several times the rate of domiciled populations[5–7]—and premature mortality (average ages of death in Atlanta, San Francisco, and Seattle are 44, 41, and 47).[8,9] In addition, homeless persons encounter many barriers to health care[10–12] and, it may be hypothesized, to EOL care. Homeless persons, for example, die with little medical care immediately prior to their deaths.[13] Finally, additional concerns are raised by the unique personal, cultural, and medical characteristics of homelessness. Given the immediacy of basic human needs while living without shelter, homeless persons' concerns beyond daily survival may be different from those of persons who do not worry about food or shelter.

Few studies have addressed EOL care for underserved or disenfranchised persons,[1] and existing work is limited as it reflects the concerns of people with health care and personal resources and relationships. Three studies have previously examined homeless persons and EOL care. One demonstrated that homeless persons are eager to address EOL issues,[14] and a second explored EOL scenarios among homeless persons.[15] A third study addressed ICU care preferences.[16] The first 2 studies, however, are limited by their small and homogeneous samples, and the third focused on one specific aspect of EOL care.

This work represents the first in-depth exploration of a homeless population and their attitudes towards EOL care. We hypothesized that they would have concerns different from those of other previously studied populations. We previously reported how life on the streets influences attitudes towards death and dying (Song et al. submitted for publication) The present paper's objective was to examine how homelessness influences concerns and desires about care at the time of death.

DESIGN

We conducted a qualitative investigation utilizing focus groups of homeless individuals. The study was funded by the NIH/

National Institute of Nursing Research and approved by the University of Minnesota Institutional Review Board.

PARTICIPANTS

Participants were recruited from 6 social service agencies that serve homeless persons in Minneapolis and St. Paul, MN. These agencies provide a variety of services, including food, shelter, and health care. Participants were required to be at least 18 years old, speak English, and able to give informed consent. Participants were required to have been homeless at least once in the last 6 months, ascertained by a demographic questionnaire consistent with the federal guidelines.[17]

Participants were recruited through a mixture of random and purposive sampling, utilizing key informants[18]; details of this procedure are detailed elsewhere (Song et al. submitted for publication). Six focus groups were held, with an average of 9 participants per group. Participants were compensated *$20. Interim analyses were conducted, and interviews were held until theme saturation was achieved.

MEASUREMENT

Interviews were conducted between July 2003 and January 2004. A semistructured interview guide consisting of open-ended questions was developed through a pilot study,[14] community consultants, and the EOL and homelessness literature (Table 1).

The sessions were audio-taped and investigators took field notes on the group process and nonverbal communication, which served to contextualize the interviews and verify congruence of verbal and nonverbal communication.[18] Audiotapes were transcribed, and Atlas ti software was used to facilitate analysis.

ANALYSIS

Investigators utilized a modified consensual qualitative research (CQR) approach to analyze data, which has proven effective in evaluating complex psychosocial phenomena.[19] This method involves an inductive analytic process to identify themes, which the team derives by consensus and verifies by systematically checking against the raw data.[19] This CQR approach incorporates a 3-step process to identify salient themes; details of CQR utilized by this team are provided elsewhere (Song et al. submitted for publication).

RESULTS

Fifty-three people participated in the 6 focus groups. The mean age of participants was 47, and 35% were female. Thirty-six percent were identified as Native American, 8% reported an advanced degree, and 40% responded that they experienced more than one living situation during the last 6 months (Table 2).

Main outcomes were participants' concerns about and wishes for EOL care. We found 11 themes grouped into 3 domains, by locus of concern: personal themes, relational concerns, and environmental influences (Table 3).

Table 1. Interview Guide for Focus Groups

Questions
General questions
Do you have any experience with a serious illness or injury or a close friend or relative who had a serious illness or injury or who has died?
Are you concerned about dying?
Do you think about dying, care while dying, or death? Is this an issue that concerns you?
Is this an issue that you would like to talk about more?
Specific questions
Do you have any one that you can talk to about these issues?
Probes: Do you have family that you are in contact with? Do you have friends that you trust? Do you know any social workers, service providers, or health care providers whom you trust?
What concerns do you have regarding dying, care at the end of life, and death?
Probes: Are you concerned about what happens to your body? Your health care? Pain, symptom management, discomfort?
Are you concerned about being stuck on life support? Are you concerned about dying alone?
If you were sick or dying, are there people you trust or love that you can get support from? Who can make decisions for you?
Probes: Do you have family that you are in contact with? Do you have friends that you trust? Do you know any social workers, service providers, or health care providers whom you trust? Have you ever heard of a living will or durable power of health attorney?
Describe a "good death."
Probes: Where would you like to die? Who would you like to have by your side? Who do you need to make peace with? What would you like to have happen to your body? What are you afraid of when dying?
What stands in the way of you having a good death?
Probes: What stands in the way of good health care? What would you need to die in comfort and dignity? What are some problems with services that you have encountered?
What kind of services would you say would be needed so that homeless people might die in comfort and with dignity?

Personal Themes

This domain involves participants' experiences with and attitudes towards EOL care. These results represent internal dynamics and considerations—the experiences that have influenced participants' conceptions about EOL care, including their wishes and concerns about their own care. Within the "personal theme" domain, we found 6 themes: experience with EOL care, fears and uncertainties, advance care planning, preferences/wishes/hopes, spirituality/religion, and veteran status (Table 3).

Experience With End of Life Care. Participants consistently had experiences with serious illnesses and deaths of loved ones or acquaintances, or their own encounters with serious illness. These experiences influenced their beliefs and attitudes towards EOL care. Past experiences with death and EOL care were frequently poor and frightening:

> When she (my mom) got sick, they put her in a nursing home, and they denied me access...she deteriorated, she lost her hair, she was almost comatose...I never got to see her. What they did to her I'll never know. One thing I knew—when she saw me she said, 'Call a taxi; get me out of here.'...So everything right now is in a nightmare. I'm trying to find out how she died...nobody told me...In my mind I'm thinking she's still alive...I never thought I'd lose my mom, or not in this way, not this hideous mess that happened that I can't understand.

Table 2. Participant Demographics

Characteristics	%
Age, years	
<35	15
36–45	25
46–55	45
56–65	9
>65	6
Gender	
Female	35
Race	
Hispanic or Latino	2
Not Hispanic or Latino	2
American Indian or Alaskan Native	36
Asian	2
Black or African American	27
Native African	2
Hawaiian/other Pacific Islander	0
White	22
Not reported	7
Years of education	
5–8	8
9–11	39
12–15	32
16+	8
Not reported	13

This perception of EOL care as being out of the control of patients and family was common: "My mother lacked two weeks being 94 years old when she passed away. She was forced into a nursing home...She lost her freedom..." So, too, was the feeling that EOL care was unresponsive to the suffering party: "It was a situation where he didn't want to come out of there, living off the machine. When the time came for him to start to die, they wanted us to resuscitate him...That kind of weighed heavy on me because I thought I was letting him down. The last of his hours, he was kind of in pain. I just kept asking the doctor to give him something for his pain. They never did."

Because experiences contributed to an attitude that care is imposed, most interventions are seen as an unwanted and invasive: "After I saw my mom die, I'm almost thinking alone would be better. I don't want to be hooked up to tubes and all that crap when it comes time for me to go." Loss of control was a common concern, "Once I got real sick and got [put] in a nursing home. I don't care how old I was, I can't deal with not having my freedom. There's no way. I need to be free...once you're in a nursing home or hospital you lose control."

Fears and Uncertainties. Participants expressed many fears and uncertainties similar to those of domiciled people: "Don't prolong my life. I don't want to carry on laying there as a vegetable..." However, the derivation of these fears may be different in this population—a combination of experience and the impotence and indignity of homelessness: "I was thinking of my friend Jeff wound up under the bridge. They look at it like another junkie guy, but he was trying really, really hard to work every day. And just to see him treated with little dignity was [not] right..."

Another common fear was dying anonymously, which may be unique to this population: "It makes a difference when you're homeless and you're dying by yourself. You're here by yourself, no one to care"; and, "Me? I just want to be remembered by somebody." A dreaded consequence expressed by many was that their passing, and life, would go unnoticed and without memorialization. Similar fears include not being found and dying in a public place: "I wouldn't want to be under a bridge. If you die somewhere and not be found."

Participants also expressed many misconceptions and uncertainties about surrogate decision-making, persistent vegetative states and heroic treatments, and advance care planning: "A good buddy of mine that used to be a street person...fell out and ended up in a coma...There [were] doctors and nurses... calling, asking anybody to come down and say you were his family, just so you could sign a waiver to pull the plug." This was one of many urban EOL myths expressed by participants.

Another common concern was the final disposal of their body, a fear that appears unique to this population; they believed a homeless, disenfranchised person's body would be anonymously cremated, buried in a common grave, or used in medical experimentation: "I don't know if the city will just take me to the furnace down there and burn me." Participants were not aware of Minnesota state law that forbids cremation without consent of patient or family.

Preferences, Wishes, and Hopes. Participants expressed preferences and hopes, many echoing those articulated in the mainstream EOL literature, such as a wish for reconciliation with loved ones or avoiding heroic interventions. However, the wish for companionship had a unique twist in this disenfranchised population. While some desired reunion with their families, many more simply wanted anyone compassionate at the time of death, whether homeless friends or even anonymous care providers: "I would wish someone to be there, especially since I know my folks won't be."

Given the misconceptions and fears about body disposal, there were explicit and detailed desires that participants' bodies be laid to rest in a personally and culturally acceptable manner. Native Americans, for example, often stated a preference that their body be taken to native lands for proper burial.

Another common desire expressed was that EOL care focus on symptom management, particularly pain control. At the end of a long dialogue on pain control, one participant summed up the prevailing mood: "I'm kind of on the same page as him...if I'm dying, just give me my drugs. Make sure I'm loaded; then I'm cool. I'm not going to sell it to anybody; I just want to...Let me go in peace."

Finally, participants desired simply to be treated with respect: "deal with us not as some sleaze bag out for trouble, but we are just homeless." A lack of respect fostered fear of dying among subjects: "Right now I'm afraid of dying mostly because I don't have nothing. It's like a disgrace or shame to me to die that way...Even though I can't hear it and I won't know it, talking about, 'He was a tramp. He was a no-good tramp.'"

Advance Care Planning. A major finding is the importance of advance care planning and documentation for this isolated population: "My fear is being found on the street, but no one knowing how to help me or who I am." It appears that this desire for advance care planning arises from several concerns. One is, as reflected above, anonymity and estrangement. Given the belief that EOL care is paternalistic and unresponsive, advance care planning was also seen as a way to maintain control: "In '73, I was actually declared brain dead...I regained consciousness...my only real fear about death is that the

Table 3. Domains and Themes of EOL Care Expressed by Homeless People

Domain	Definitions	Representative quote(s)
Personal themes		
Experience with EOL care	Experience with deaths of loved ones, friends, and acquaintances on the streets or personal experiences with illness or injury, and the care received	I've had a lot of tragedy. My girlfriend died in my arms with my baby. She was four months pregnant at the time… and she comes back in my dreams. He had a stroke and was on dialysis. Me and him, being about the same age, it made me fear for my life.
Fears and uncertainties	Concerns and fears about dying and EOL care	Me? I'd just like to be remembered by somebody. The only thing I'm worried about is that I don't want to die on the streets. After I've passed, my biggest fear would be not making it back home to Canada and my reservation. …they'll throw you in a pauper's grave someplace and nobody's going to mourn you.
Preferences/ wishes/hopes	Possibilities related to what would be a "good death"	If that was to happen, I would want it to happen some place where it was noticeable. Yeah, you may be dead there for three, four years…I'll be somewhere where nobody could find me. But also, once you see the doctor, the doctor should spend a little more time and get to know you a little bit better and show a little more compassion.
Advance care planning/ documentation	Strategies to influence outcomes in the event of death or serious illness	You gotta have it wrote down, or else they'll do just what they want. I'm going to have one of those made out, a living will, because if I end up in the hospital, I don't think I'd want no life support keeping me alive. My will says that if I go into a diabetic coma or if I get hit by a car, they can start life-saving techniques, and then my brother Bob's name is on that. They are to call him and say John's in the hospital, doesn't look good; do you want to come down and sign the papers to pull the plug; we will try to keep him going for some time to see if he improves. If he doesn't improve, then come down. That is exactly how it's worded.
Spirituality/religion	Influence and role that an individual's spirituality or religious convictions has on dying and EOL care	Personally, death comes like peace, but like John said, we look forward to it if we're Christian because I can go and get my reincarnate body and dance without this one.
Veteran status	Thoughts about death and EOL care related to having served in the armed forces	Even though I'm a serviceman, if I was buried in a national cemetery, I feel that my soul would be lost. I went to get medical care, something that they guaranteed me for life. They looked at me and said, 'OK, you have an honorable discharge.' As a matter of fact, I have two. 'Do you have insurance on your job?' and I'm like, whoa. The insurance on my job, OK, when I signed these contracts you didn't say that my insurance would be primary. You said that you would take care of it. So the VA does nothing.
Relational themes		
Relationships with known people	How current relationships with family, friends, and peers affect desires and fears about dying and EOL care	Most of these guys, they don't want their family to know. They ask you what happened. Why are you homeless? What's the problem? But I notice that homeless people, or street punks, whatever you call them, whatever is right for them, prostitutes or whatever, sometimes these type of people, another street person they have known for years and seems more like a family member than their own family. For me that is considered a family member. They'd be there for me, but I wouldn't want them to make all them changes. It takes a lot of money to travel and I don't want them wasting money. Not because I ain't worth the money, but I don't want them.
Relationships with strangers	How individuals' relationship with institutions and its representatives influence their views dying and EOL care	Have a doctor, an intern, or even have a medical student for a doctor, come and work at a shelter for a week to two weeks, just to see how it is, to get woke up at 6:00 in the morning and booted out, and getting a cold bowl of cereal from the branch for breakfast, and just shadowing somebody that has been homeless or is homeless, just to feel what it's like to, if just to say 'I know this guy; he's homeless and this needs to be taken care of right away' and not making him wait. Then they will have an ideal of what it's like being homeless. The doctor called me a goddamn drug addict and told me to get the hell out of his office.

(*continued on next page*)

Table 3. (continued)

Domain	Definitions	Representative quote(s)
Communication tools/strategies	The communication between the subjects and their loved or valued ones, and strategies homeless persons have to communicate with loved ones during a health care crisis or if unable to communicate directly	My sister, I put her name on everything that I have. There can be contact with her and she will communicate with my daughter. My living will says my family will have no say or discussion of what is done. Basically, they don't know me, so why should they have a say in whether I live or not. I made sure to talk to him (nephew) on the telephone. It just came into my mind. I said, 'I'm going to leave this in your hands. I'm going down hill now.
Environmental		
Barriers/ facilitators to good EOL care	Barriers or facilitators identified by subjects to good EOL care	They don't give you proper medical care because they know you are homeless. They think because we live in the streets, we're all junkies that don't feel no pain. Even if your family is not around at the hospital, there are these great hospice people. If you could spend your last time talking with them...that would be a good death. Living without life insurance, who's going to put me away—stuff like that? I had cancer just last year. My fear was being alone because my children ain't here. But I had support from the people at Listening House, friends.
Participant-suggested interventions	Interventions suggested by participants to improve dying and EOL care for homeless persons	What we do need is a shelter somewhere between Minneapolis and St. Paul that would be fully staffed 24/7...and if you came out and just had surgery, you could go there...

EOL end of life

doctor tried too aggressively to keep me alive, and because of this, I created a living will."

For some participants advance care planning meant discussion with significant others and/or appointment of a proxy; however, the most cited forms of advance care planning included written documentation of wishes or contact information, personal identification, or written directive or other advance care planning document. One participant voiced a typical strategy to dictate circumstances of his death: "In my wallet, I have a card with my sister's name and a phone number. Do I want to be buried in Minnesota? Hell no!"

When speaking of surrogate decision-makers, nearly all who had thought of this issue or who had appointed one chose surrogates who were not related; they were most often service providers; friends; and, occasionally, romantic partners.

Spriituality/Religion. Spirituality and religion were means of finding comfort and solace when confronting death while homeless: "Can you die alone? I remember when Bill Cosby's son died on the street...nobody came to touch him and hold him, but if he's a child of God, then God was holding him and taking him home." Despite the physical reality of dying alone, religion made it possible to believe that, spiritually, one was not alone.

Veteran Status. Many opinions about EOL care related to prior military experience. Participants identified veteran status as either a positive or negative factor. Some, for example, felt reassured they would have care or even a grave provided by the U.S. government: "If I drop dead or die or get my head blown off, if my parents don't do it or my family, put me in the national cemetery, too, with other veterans, my brothers." Others feared poor VA care or did not want burial in a veteran's cemetery.

Relational Themes

A second major domain was "relational themes," which we organized into 3 categories: relationships with known people, relationships with strangers, and communication tools/strategies. This domain captures how current personal and institutional relationships affect attitudes towards EOL care.

Relationships with Known People/Burden to Others. Relationships were described as complex, fractured, or nonexistent. Many were estranged from their family of origin. Some homeless persons viewed dying as an opportunity for reconciliation, though they were uncertain whether this would happen: "Truthfully, I couldn't honestly say who would and who wouldn't [be there]. I'll just have to see when I get there...Sometimes when they say they'll be there, they're never there."

A majority of participants did not want contact with their families while dying or after their deaths. There were several reasons for this preference, including the assertion that their families, "abandoning" them in life, had no right to claim a relationship or authority in death: "I got 6 sisters and five brothers...but, dead is dead. So don't cry; help me while I breathe, not when I'm stiff and frozen." This rejection extended into surrogate decision-making: "My living will says my family will have no say or discussion of what is done. Basically, they don't know me, so why should they have a say in whether I live or not." Others feared that their families would not be compassionate: "They'd be saying, 'bury him like he lived,' or 'we don't want nothing to do with him.'" Some did not want to be a burden on their families, either emotionally or financially, or feared revealing their circumstances and homelessness: "When I die, don't tell them. I don't want them to know that I'm homeless." Finally, many others did not want their families contacted because they had found, while living on the streets, trusted friends and service providers to serve as surrogates.

Relationships with Strangers. Most respondents commented that society, including police, medical professionals, and social service agency staff, does not treat them with respect or compassion. When discussing physicians, one respondent insisted: "We are homeless. They say, 'well this guy's homeless…You ain't got to worry about it.'" They cited slow and poor service at health care facilities, and felt betrayed by the social services system. Based on these experiences, they expected poor care at the EOL: "He'd a died more dignified if they [the counselors] actually sat down and listened to him, instead of saying, 'we're too busy; get out of here…'"

However, not all comments were negative. Compassionate providers were described gratefully. Several respondents claimed a particular social service provider as their most trusted confidant and indicated that this individual should be contacted as a surrogate decision-maker. "John," said one respondent, referring to a street case manager, "knows what I want. I trust him."

Communication Tools/Strategies. Those who did wish communication or reconciliation at the EOL had different strategies to insure that this occurred. These strategies were often inventive and adapted to the disenfranchised lives many led. Many, for example, carried phone numbers of loved ones or left them with various social service providers. Although in jest, this comment demonstrates how difficult communication may be: "If I was going to die in three months, I'd probably rob a bank…I figure if I robbed a bank, I would get caught. [My family] heard about it in the newspaper and call me up…"

Environmental Factors

Our final domain's common thread is the environment in which dying occurs and the structural boundaries of EOL care. We organized it into 2 categories: barriers/facilitators to good EOL care and participant-suggested interventions.

Barriers/Facilitators to Good EOL Care. Health care professionals' attitudes were most often cited as a barrier to good EOL care, while others found care inaccessible or inadequate because of financial or insurance insufficiencies. Because of poverty, even the simplest aspects of EOL care cause worry in this population: "My goal is to get me some type of burial plan. *$300 won't bury nobody at this table. Then I wouldn't mind it so much, but right now I'm afraid of dying mostly because I don't have nothing." Inappropriate care also resulted because of preconceptions about homeless persons, such as the denial of pain medication for fear of abuse. Respondents also complained about the lack of respite or hospice facilities and programs; once discharged from the hospital, they only have shelters to go to.

Participant-Suggested Interventions. Finally, participants suggested many interventions to improve care for dying homeless people. Some were educational, directed towards both health care providers and homeless people. Another frequently suggested intervention was some form of advance care planning or document to preserve autonomy: "It's a legal document. Let's say that's your wish, but it's not written anywhere, and someone says, 'keep him on the respirator.' They [would]…unless you written it down." Indeed, any kind of identification was considered essential and encouraged for a disconnected population. Finally, homeless participants demanded special accommodations to facilitate dying among this population.

DISCUSSION

In our study, homeless participants demonstrated more differences than similarities in their attitudes and beliefs towards EOL care compared to other populations studied.[20–25] First, many participants have had personal experiences with death, dying, and EOL care. These experiences led them to view EOL care as paternalistic, unresponsive, and poor. Other unique concerns expressed include fear of dying anonymously, without memorialization or remembrance; fear of not being found or identifiable in death; and worry about the final resting place of their bodies. These concerns are all new to the EOL literature.

Another unexpected finding is participants' advocating advance care planning, especially the appointment of surrogate decision-makers and the preparation of advance care documents, such as living wills. These findings are interesting, given the current disfavor toward advance care documents[1] and the intuition that homeless individuals would not value or utilize documentation. According to participants, documents serve different functions among a population that is anonymous, voiceless, or lacks obvious surrogate decision-makers.

Important relational findings were also expressed. Though some participants wished reconcilement and contact, a greater number did not want their families contacted when seriously ill, when dying, or after death. These desires derived from several different reasons, including avoiding emotional and financial burdens on their families, shame, and anger over abandonment. Many had made surrogate decision-making plans that did not include family.

Relationships with institutions also figured prominently in the EOL experiences and desires of homeless persons—which is expected given the role institutions play in the daily lives of homeless persons, providing food, shelter, and other necessities. These relationships were occasionally positive. Participants spoke of trusted service providers, such as shelter personnel, some of whom were even designated as surrogate decision-makers. Most often, though, relationships with systems of care were described as poor, and contributed to give views of dying.

Participants spoke of "environmental" contexts or contributors to EOL care, noting multiple barriers to EOL care, including poor relationships, lack of insurance or finances, poor health care, lack of respect, and lack of knowledge of available resources or rights. Some participants, though, cited factors that led to satisfactory health care experiences or positive expectations of EOL care, such as advance care planning, facilitation of health care by social service workers, and physician advocacy.

Finally, subjects suggested interventions for improving EOL care for homeless or underserved persons. These included patient and provider education, advance care planning, living wills and other documentation, and special programs and facilities for dying or seriously ill homeless persons. A Medline and web search yields no reports of specific efforts focused on dying homeless individuals. Clearly, interventions are needed to serve this population.

The recent NIH state-of-science statement on improving EOL care reported that insufficient research has focused on individuals from different cultural and socioeconomic backgrounds.[1] While there is a growing body of evidence that these individuals may experience disparities in EOL care,[23–29] relatively little attention has been paid to the desires of these populations or interventions to improve their care.[1] Our study provides new and important information on EOL issues among homeless persons, among the most unfortunate of overlooked populations.

Our study's limitations include the selection of subjects from one urban area, a high number of Native Americans represented, and potential selection bias, as our participants are those who accessed service providers. The findings of our study are not necessarily generalizable. Rather, our data are exploratory, examining a previously unknown health-related phenomena: we are among the first to characterize in-depth the EOL concerns and desires of a vulnerable and disenfranchised population from their perspective.

CONCLUSIONS

Our study demonstrates that homeless persons have extensive, and often unique, concerns about dying and EOL care. The experiences and circumstances of homelessness inform and influence a view of death and EOL care unlike previously reported findings in the study of EOL care. Our work has implications for further study of this population, as well as study of other underrepresented and underserved populations. This work also suggests examining interventions to improve care for this and other vulnerable populations.

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