ORIGINAL ARTICLES

Experiences With and Attitudes Toward Death and Dying Among Homeless Persons

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BACKGROUND: Homeless persons face many barriers to health care, have few resources, and experience high death rates. They live lives of disenfranchisement and neglect. Few studies have explored their experiences and attitudes toward death and dying. Unfortunately, studies done in other populations may not apply to homeless persons. Exploring these experiences and attitudes may provide insight into life, health care, and end-of-life (EOL) concerns of this population.

OBJECTIVE: To explore the experiences and attitudes toward death and dying among homeless persons.

DESIGN: Qualitative study utilizing focus groups.

PARTICIPANTS: Fifty-three homeless persons recruited from homeless service agencies.

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

RESULTS: We present seven themes, some of which are previously unreported. Homeless persons described many significant experiences with death and dying, and many participants suffered losses while very young. These encounters influenced participants' attitudes toward risks and risky behavior: e.g., for some, these experiences provided justification for high-risk behaviors and influenced their behaviors while living on the streets. For others, they may be associated with their homelessness. Finally, these experiences informed their attitudes toward death and dying as well as EOL care; homeless persons believe that care will be poor at the EOL.

CONCLUSIONS: Findings from this study have implications for addressing social services, health promotion, prevention, and EOL care for homeless persons, as well as for others who are poor and disenfranchised.

BACKGROUND

Homeless persons suffer a disproportionate amount of illness and injury—with greater severity—compared to the general population, and, in some cases, compared to other populations living in poverty.[1–6] Homeless persons have the highest mortality rates in developed nations, regardless of age or sex—they die at rates from three to ten times the general population.[7–10] They also suffer from premature mortality, with an average age of death in Atlanta, San Francisco, and Seattle of 44, 41, and 47, respectively,[11,12] compared to the national average of 76.5.[13] Given conservative estimates of several hundred thousand to several million homeless adults[14,15]—with indications that the prevalence is rising[16]—this represents an enormous personal and public health crisis. Compounding this crisis are the enormous barriers to health and health care faced by unhoused populations.[4–6]

Unfortunately, little is known about the experiences and attitudes of homeless persons toward death and dying. Three studies have examined homeless persons and end-of-life (EOL) care, and these have revealed some information about experiences and attitudes toward death and dying. One demonstrated that homeless persons are eager to address EOL issues,[17] a second study surveyed EOL desires of homeless persons,[18] and a third measured attitudes toward ICU care.[19] These studies are limited, however, by their small or homogenous populations and their focus on a specific aspect of EOL care.

There are several reasons to hypothesize why homeless individuals might have unique perspectives on death and dying borne of their unstable and disenfranchised life experiences: for example, high rates of poor health and inability to access goods and services that contribute to health and well-being. Another may be the epidemiology of homeless death—an awareness of the fragility of life when living without safe and stable shelter should have an impact on attitudes and beliefs. Alienation from loved ones and institutions may influence these attitudes as well, especially when some of this alienation is the result of well-documented poor provider attitudes and

treatment towards homeless persons.[20–22] Finally, there are additional concerns raised by the unique personal and cultural characteristics of homelessness. Given the immediacy of basic human needs, their thoughts beyond daily survival may be different than those who do not worry about food or shelter.

Exploring the experiences and attitudes of homeless persons toward death and dying is important for several reasons. First, it may reveal how death impacts the condition of homelessness; previous studies have focused on such associations as past incarceration,[23,24] socioeconomic circumstances,[25–27] and a history of abuse[28–30] with homelessness. Experience with death —and its potential to be both an economic and psychological stressor—has not been considered widely as a correlate of homelessness, but may influence life trajectories and experience with homelessness. Also, homeless people are known to engage in highly risky behavior such as needle sharing and trading sex for commodities;[31–34] experiences and attitudes toward death and dying may have an impact on how homeless people assess risk and risky behavior. In addition, experiences and attitudes toward death and dying may reveal experiences and attitudes about toward health care and providers and institutions of care. Finally, one significant shortcoming in the EOL literature is a lack of knowledge about the attitudes toward death, dying, and EOL care of underserved populations.[35]

OBJECTIVE

This study seeks to explore homeless persons' experiences with and attitudes toward death and dying. We hypothesized that they would have experiences and attitudes that are different from other populations, and that these experiences and attitudes would impact their approach to death, life, health, and medical care. This work is important because it explores the concerns of a population often ignored and has implications for other individuals who are poor in personal resources and face barriers to health care.

DESIGN

We conducted a qualitative investigation utilizing focus groups of homeless individuals. The study was approved by the University of Minnesota Institutional Review Board.

PARTICIPANTS

Participants were recruited from six social service agencies, which serve homeless persons in Minneapolis and St. Paul, Minnesota. These agencies provide a variety of services, including food, shelter, and health care. Participant inclusion criteria included being at least 18 years old, able to speak English, and give informed consent. Participants were also required to have been homeless at least once in the previous 6 months, ascertained by a demographic questionnaire consistent with federal guidelines defining homelessness.[36]

Participants were recruited through a mixture of random and purposive sampling, utilizing key informants.[37] Before the investigators' visit, the directors of each of the service organizations approached individuals who met the inclusion criteria. However, others present during the investigators' visit were invited to participate. Focus groups were limited to a maxi-

mum of 10 participants, which has been recommended to maximize exchange between participants but not dilute participation.[38] Six focus groups were held at different homeless social service agencies, with an average of nine participants per group (range 7–10). Participants were compensated $20 for their time. Interim analyses were conducted, and interviews were held until theme saturation occurred; theme saturation is defined as the point in measurement when no new themes emerge during interview sessions.

MEASUREMENT

Interviews were conducted between July 2003 and January 2004. Each group was conducted in a private room. A semistructured interview guide consisting of open-ended questions was developed through a pilot study,[17] input from community consultants, and the EOL and homelessness literature (Table 1).

The sessions were audiotaped, 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.[37] Audiotapes were transcribed, and Atlas t.i. software was used to facilitate analysis.

ANALYSIS

Investigators utilized a modified consensual qualitative research method[39,40] to analyze data, which has proven effective

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 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 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 you like to have happen to your body? What are you afraid of when dying?
• What stands in the way of you from 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?

in evaluating complex psychosocial phenomena. This method involves a three-step inductive analytic process to identify themes, which the team derives individually and by consensus and verifies by systematically checking against the raw data.[39,40] First, investigators each independently code two transcripts assigning code words to reflect the meaning of a coherent phrase, sentence, or paragraph. Next, all the investigators meet to review codes and to create a list of codes through consensus to be used in analyzing all transcripts. Each transcript is then analyzed by one investigator and reviewed by a second investigator for consistency in assignment of code words. During this process, the researchers may also identify additional codes.

A graduate student auditor, who did not participate in data collection or interviewing, entered assigned codes and corresponding data using Atlas t.i. software, and reviewed the resulting list of codes and text for consistency. All discrepancies were reviewed and revised as necessary by the entire team; reconciliation and consensus minimizes issues of interrater reliability. Finally, the entire team reviewed all data in an iterative process and developed themes that captured related codes. Once the final list of themes were identified, investigators independently then cooperatively created a model that combined related themes into a smaller number of domains that describe homeless persons' experience and attitudes toward death and dying and/or attitudes and preferences related to EOL care. This paper describes the domains and themes that focus on experience and attitudes toward death and dying among homeless persons.

RESULTS

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

We present seven themes grouped into two domains, defined by locus of experience: personal (internal) and relational (to other people) (Table 3).

Domain A: Personal Themes

These themes represent participants' experiences with death, dying, and serious illnesses of loved ones and acquaintances; personal experiences with serious illness that cause reflection of one's life and mortality; and attitudes toward death and dying. Many of the attitudes appear related to previous experiences with death and dying as well as living on the streets in a dangerous and unhealthy environment.[41,42] In addition, this domain includes themes that describe how past experiences and current attitudes affect daily life and participants' behaviors.

Theme 1: Early Loss. One striking and important finding was the significant personal experience with loss early in life: "I'm 40 years old, but I have been experiencing death in my family since 14, all the way to 40, three times in a row, maybe six times in a month…" These exposures appeared to have informed participants' beliefs and attitudes toward death and dying as well as toward life. For example, this initiated a pattern of loss or dysfunction for some: "…I had twin sisters

Table 2. Participant Demographics

Characteristics	Percent
Age (years)	
<35	15
36–45	25
46–55	45
56–65	9
>65	6
Sex	
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

that got killed in '93, and they 15. Made me go downhill. I couldn't take it. Enough is enough…once they died, the twins, and I'm the last one. I'm going to make sure that I keep moving. I'm going to end up worse out here…" For others it related to a sense of fatalism: "I found my baby brother dead in a tub. He was floating upside down…and I held in my arms… There's been a lot of death around me for many years, as a child and as an adult. So I've come to terms with it, and I sometimes welcome it at the oddest times when I'm using…"

Many individuals expressed the belief that deaths—particularly early ones—may have contributed to their present homelessness:

> That was rough because when I lost my mom, I was only 15 years old. At that time; I was taken away…When they took me to a psychiatrist they said, this child is normal, and yet I was stuck in the state hospital for 19, 20 years…[then] I was homeless.

These early deaths left many orphans, something some could not recover from: "I've been pretty much homeless all my life. My parents died, and I was in an orphanage and I lived in different homes, but I never have no place to call home…" According to the man who lost his twin sisters: "But then they passed on…so, I've been on the street since I was 14…I've been out on the streets in Chicago for 14 straight years." Indeed this link was so strong that one person likened death to homelessness: "It's just like dying, it happens. All of a sudden, I look up and I'm homeless; I'm in a shelter; I'm eating at the shelter; I'm dealing with other homeless people." This fatalistic attitude was common.

Theme 2: Experience with Death. Nearly all subjects had personal experience with the death or deaths of loved ones, friends, or acquaintances on the streets. Most could remember a number of deaths within the previous few months: "I can't

Table 3. Domains and Themes of Experiences and Attitudes Toward Dying and Death

	Definitions	Representative quote(s)
Domain: personal themes		
Early loss	Experience with death early in life	"The first time I saw my first family member die, I was about 14 and I was real scared. When I saw my second body...I got used to it." "My mother and my little brother got killed when I was 15. A train hit my dad's car on the passengers' side. That I didn't understand and I probably never will."
Experience with death	Experience with deaths of loved ones, friends, and acquaintances on the streets	"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, then died. Me and him, being about the same age, it made me fear for my life." "That hurt an awful lot. It was hard to regroup because it wasn't just her. In a 12 month period, 13 of us were dead."
Fears and uncertainties	Concerns and fears about death, 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." "No, if I can't find nowhere, I'll be somewhere where nobody could find me."
Coping strategies	Attitudes, thoughts, or behaviors directed toward and resulting from the fears of dying and death	"When you get up in years, you start thinking about your family...those issues come up in your mind, and you kind of shunt them off because they hurt; they bother you. You try to ignore them because you can't do anything about them..." "I prepare myself by the fact everybody that sits around here, everybody that's sitting in this room, we've all go that big thing coming." "Actually a lot of people that drink [inaudible] those problems—crash out. They don't want to think about that. Then you wake up and start really thinking about it [inaudible]." "You have to have a better respect for living when you know how easy it is to go."
Personal life-threatening experiences	Previous personal experiences with serious illness or injury	"In '73, I was actually declared brain dead...I regained consciousness...my only real fear about death is that the doctor tried too aggressively to keep me alive, and because of this, I created a living will." "It was the same thing pretty much. I got out [of the hospital] and I'm walking, really sick, carrying my bags, and there was nowhere really to go...the doctors made it clear that my life was not their problem..." "It makes a difference when you're homeless and you're dying...You're here by yourself..."
Approach to risk	Attitudes toward mediating or engaging risk based on the ubiquity of death	"It means some guys get heavy on the bottle; some get heavy on the drugs; some doggone start it because of the all stress from the dying around us." "My goal is to get me some kind of burial plan." "I'm looking around, taking account of my surroundings, making sure I don't get jumped." "You really need to talk to your children between 40 and 50 and let your children know how you feel."
Domain: relational themes		
Relationships with strangers	How individuals' relationship with institutions and its representatives influence their views of death, dying, and wishes for care	"You have either got to be killing yourself in front of them, or you can't get any help. Sometimes, like with this friend, you get so mad because they make it so obvious they don't 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 in homeless, just to feel what it's like to, if just to say 'I know this buy; 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." "Some [doctors] are great and some are really cold hearted, but some are like, don't bother us. It's basically we know you are for it and we don't care that much."

even count how many I've lost even last year, dying, being killed..." Often these deaths were traumatic and anonymous: "Someone got the hell beat out of him last week and they left him there to rot. And when someone died in their sleep. They got no medical attendant or nothing like that." and "I've seen over a hundred people die. Basically a lot of it was for nothing. They were outside cold, alone, frozen, beat to death, hung, whatever." Besides the emotional pain of these deaths, they were important in how subjects viewed, for example, the process of dying while homeless: "...a friend of mine...has AIDS. He just got into some housing... you have to wait outside till maybe 9:00 to 9:30, till they let you in, no matter what the weather. He died of pneumonia." Another example: "A guy told me, 'did you hear about Becky?' I said no. He said they found her in a landfill dead. She was murdered, thrown in the dumpster and she got compacted." Death on the streets can be more traumatic and demeaning than deaths that domiciled people may experience.

Numerous experiences with death and dying causes homeless people to believe that death is ubiquitous, and should be expected at any moment: " It's [death] been all in my pocket. Every time I reach in there for change, I pull him up." According to another participant: "You keep your eyes open, because death is around every corner." Because of the ubiquity of death, it informs every aspect of their lives. Many individuals echoed this sentiment about thinking about death on a continual basis and the effect it has on their every action: "Hell, yeah, you think about death all the time. Every day. Every second. And you do everything you make sure you avoid it."

Theme 3: Personal Life-threatening Experiences. Finally, many participants had suffered serious illnesses or injuries themselves; such "brushes with death" created expectations about how, or from what disease process, one might die: "When they first tell you, you've got cancer, it's like the floor dropped out from under you. You be like the big C, it's the big D, death. As soon as they say cancer, you say, I'm going to die. You don't expect nothing to be fixed." It is reflection on these experiences that influence and inform participants' fears, hopes, and wishes about medical care, death, and dying, as well as their behaviors in the form of risk management (below). These illnesses also demonstrated how isolating life on the streets can be: "I had cancer also, just last year. I was really sick. My fear was being alone here because my children ain't here. I'm truly alone."

Theme 4: Fears and Uncertainties. The great many deaths witnessed by participants and the danger of the streets create many fears; participants describe a life living in fear of death: "I don't know who may kill me. I don't know what I may walk up on, and that's my fears that I have...something terrible is going to happen." Homelessness becomes a life filled with fear: "Everywhere I slept, I was scared that somebody was going to come and kill me."

Theme 5: Coping Strategies. For many individuals, the burden of witnessing so many deaths led to a sense of fatalism and seemed a way of coping with the pain and fear these caused: "Man, so many deaths. You could take the best care of yourself, and you could walk out there...and, all of a sudden, a car hits.

That's something you never planned on...so why worry about it?" Death is so ubiquitous and seemingly arbitrary that many shrug and accept its inevitability: "I don't think of my death, but I'm ready for it if it comes. It don't bother me. I ain't scared. I have no feelings about death because I know it's going to happen, I seen it so much. I ain't scared of it."

Another coping mechanism frequently expressed was emotional detachment; deaths caused many to become even more isolated. "I think I get close—like Rick, I've known him about a year, he's pretty cool, so I hang out with him, [inaudible] dies, so I push away, saying damn, he might drop dead on me." Many described becoming emotionally distant from the numbing effects of repeated deaths: "I think when you're homeless and you're out on the street so long, you're surrounded by grief and death and a lot of stuff. It makes you cold. It makes you unfeeling towards people." and: "I can't get close to no one after what I've seen." This isolation was also caused by the feelings of being a burden on others, expressed by many and exemplified by these quotes: "I've stayed away from my family, because I feel I'm doing better for them just staying away from them..." and "I don't want my family to suffer and pay when I die..."

Subjects described many other internal strategies to cope with their death-related fears, including humor, issue avoidance, and maintaining pride: "The things you're talking about —death—that's the thing about us Natives; we take something sad and make it funny. That's a survival technique." Another related a different coping strategy, living 1 day at a time: "You've just got to focus, taking one day at a time just trying to focus, trying to keep your sanity because you don't know [inaudible]."

Theme 6: Approach to Risk—Risk Management and Risky Behaviors. We found two paradoxical responses to homelessness. Some became more careful: "I just feel that now it's different because of me having such a near-death experience. I find myself, when I get up in the morning now...I'm more careful, look around..." There was general acknowledgement that death was "right around the corner." Thus, most had strategies to avoid it such as managing health conditions, sticking together, and staying sober or clean: "That's why we all kind of like to stay together. You stay together for safety." One begins to live in "survival mode, because I have a survival instinct in me that tells me when it's time to move instead of sitting around..."

Whereas most participants took precautions to avoid illness, violence, and death, others, however, citing its inevitability, rationalized risky behaviors. According to one participant, "I ask you, what's more dangerous? Living on the streets or getting high, even shooting. You know nothing, man." Another reason to engage in risky behaviors is desire to escape the terrible life and death on the streets: "It's hard to think about if you're going to make it through the day. That's what I did, just drink to forget about everything. Stay drunk" Some use substances for a final escape from the death that is part of their daily lives: "You wouldn't actively take your life, but kind of one day at a time, keep doing the self-destructive stuff..."

Another risk management strategy is interest in or completion of advance care planning and documentation. For some participants this meant discussion with significant others and/or appointment of a proxy; for many others it meant some form of documentation of wishes or contact information. One participant voiced a typical strategy to dictate circum-

stances 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!" This need for some form of advance planning or documentation arose most often from the alienation and impotence felt by homeless participants: "Ain't no one going to step up (to speak for him), so I have to make some kind of arrangements."

Domain B: Relational

Theme 7: Relationships with Strangers (Including Health Care Providers). Unlike personal themes, which represent internal reactions and attitudes, relational themes describe interactions with other people. Attitudes about death and dying appear significantly influenced by interactions with health care providers. Homeless respondents generally stated that death-related experiences were associated with negative interactions with health care providers:

> Last week my brother died. He was homeless and he had stomach cancer. They took him to the hospital and they was trying to tell him that he's too far gone, so all they can do is cut his stomach out...Again, they said that's all they can do and they sent him. He said he felt good for about two weeks and then, all of a sudden, the medicine they was giving him—we figured it was medicine designed to take him out like that. He just went to sleep and didn't wake up. He died. They don't care.

Participants claimed society 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.'" According to another: "We're not even considered third-class citizens."

However, not all subjects' attitudes toward professionals were negative. A few compassionate and respectful health providers or social services staff were described in grateful terms: "I've been here for awhile and there's been different staff come and go...They're [all] wonderful. They are the most wonderful people."

DISCUSSION

This study identified previously unreported experiences and attitudes toward death, dying, and life among homeless persons. Given the epidemiology of homeless death, these results should not appear surprising, but—through the voices of our participants—are revealing and profound. One of the more interesting findings is the considerable experience among homeless persons with death, often while quite young. It is also interesting what impact these deaths may have had on their lives. Many correlations have been identified with homelessness,[23–30,43,44] including early childhood psychological trauma,[28,45] such as abuse and the death of a loved one or caregiver among the elderly homeless population.[44,46] However, the association between exposure to or experience with death early in life and homelessness—which our data suggests—has not been investigated.

Many of the death-related attitudes generated by the significant experience with loss, including fatalism, isolation, and poor attitudes toward providers and institutions, should be further investigated as possible contributors to continued homelessness. Similarly, great attention has been given to the prevalence and causes of high-risk behaviors in this population;[47–50] but experience with death is a relatively uninvestigated association.

The abundant personal experiences with death are associated with a number of responses. For some it caused further isolation. It is well known, for example, that institutional and societal attitudes contributes to the disenfranchisement of homeless persons,[20,21,42] and research has identified some predictors of loneliness in homeless persons;[51] however, it is less known whether the many deaths experienced by homeless persons further isolates them. Another response is the value given to advance care documents, such as living wills, which is particularly interesting given the current disfavor toward advance care documents[35] and the intuition that homeless individuals would not value or utilize documentation. However, as participants pointed out, documents that describe preferences appear to serve different functions and are more valuable to a population that is often isolated, anonymous, voiceless, or lacks obvious surrogate decision-makers.

Finally, it is clear that living on the streets is a dangerous and fear-provoking endeavor. Mental illness is strongly associated with homelessness,[52–54] but the direction of this association is unclear. Nevertheless, our study demonstrates that efforts to address fears about the likelihood and circumstances of death among homeless persons are justified. These may be directed toward making homelessness safer and toward preparing homeless persons to cope and advocate for themselves.

Strengths of this study include a significant sample size for a qualitative study in a homeless population and the use of a rigorous analytic methodology by an interdisciplinary research team. Limitations include participants recruited from one urban area, with a significant representation from the Native American community; the findings of this study are not necessarily generalizable to populations in other cities. In addition, sampling was limited to those who had a relationship with a social service provider. Homeless individuals estranged from organized services may have other or different viewpoints.

CONCLUSIONS

Our study demonstrates that homeless persons have extensive experience with and feelings about death and dying, and that these impact their daily lives. Our work suggests the need for further study of this population's death-related experiences, and how they impact perception of risk, homelessness, recidivism, perception and access to care, and health-related behavior. This work also suggests examining interventions to improve EOL care for this and other vulnerable populations. These include addressing experiences and attitudes toward death and dying with at-risk individuals, educating health care providers about factors such as the significant deaths and alienation experienced by homeless persons, and addressing homeless persons' disenfranchisement with the health care system at the EOL through methods such as advance care planning.

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