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Dying While Homeless: Is It a Concern When Life Itself Is Such a Struggle?

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INTRODUCTION

Society focuses much deliberation and energy to provide good end-of-life care and a “good death.” We have sought to identify the elements of quality end-of-life care, to quantify its delivery, and to institute interventions to improve end-of-life experiences. However, most of our conceptions and interventions to improve dying focus on individuals who have loved ones, reliable access to medical care, and stable homes.

Much of the provision of good end-of-life care is based on some fundamental assumptions. We assume, for example, that basic needs for food, clothing, and shelter are being met. Thus, we have identified advance-care planning and dying at home as important to a good death.¹ We assume that loved ones exist — or are desired. We have identified strengthening relationships as important for a good death.² We assume that we have some choices within our system of healthcare to improve how we die. Thus, we have identified symptom and pain management as important for a good death.³

We have, for the most part, not considered the viewpoints of those who die without loved ones by their side, without regular medical care, or without safe and stable housing—for example, our large population of homeless individuals. Homeless persons lack the basic connections to others, to resources, and to society that we believe are essential to a good death, and it is necessary to ask whether some of our assumptions fail to account for the lives of homeless people, many of whom are estranged from loved ones or disenfranchised from institutions of care and support.

A complete discussion of end-of-life care and death in this country needs to include homeless people for many reasons. First, there are many homeless people: estimates of the number of homeless persons in the United States on any given night range from several hundred thousand to several million.⁴ There are indications that the problem is getting worse; for example, there was a 13 percent increase in overall shelter needs in 2001.⁵

Homeless persons also suffer disproportionately from illness, having more medical diagnoses and morbidity than comparison groups.⁶ They suffer not only from common conditions, but also from conditions related to their exposure to the elements, violence, poor sanitation, and stress.⁷ It is no surprise then that homeless people die at higher rates than anyone else — more than three to four times the rate of age-matched controls.⁸ Many die of conditions that afflict all of us, but many also die of conditions directly related to the lack of shelter, such as violence and exposure.

Compounding this crisis is the fact that homeless people have poor access to medical care.⁹ The barriers to accessing care are many, and are both personal and institutional.¹⁰ Although there are no studies addressing end-of-life care for homeless persons, it can be presumed that the barriers that homeless people face in receiving general medical care would also function as barriers to receiving end-of-life care.

There are also many characteristics common to homeless populations that may create special needs and attention at the end of life. For example, substance abuse is very prevalent in the homeless population,¹¹ and the use of illicit substances may affect adherence to care plans as well as the efficacy of pain control.¹² The high prevalence of mental illness among homeless persons¹³ may also greatly influence their adherence to care plans, as well as their emotional and personal responses to dying.

Finally, there are additional concerns raised by the very different personal and cultural characteristics of homeless persons. Given the immediacy of basic human needs faced constantly by homeless people, their thoughts on issues beyond daily survival may be very different than those who do not need to worry about food or shelter. Thinking about, having preferences about, and planning for death are higher-order concerns, perhaps a luxury, if one worries about food, shelter, and safety on a daily basis. Many concerns that have been identified by experts and the public as essential to good end-of-life care or to a good death — such as achieving a sense of control or strengthening relationships — are higher-order concerns. If one's life is a daily struggle for basic existence, how might that affect one's views on death? How does the impoverished and basic existence that marks homelessness affect the moral imagination? Homeless persons might not be able or willing to think or plan about death — or be interested — or they may conceptualize death in extremely concrete terms, not able to consider more abstract worries such as closure, reconciliation, or spiritual peace.

Poverty and disadvantage have not been completely ignored in the search for good end-of-life care. However, the existing work is inadequate to fully portray the concerns of our most disadvantaged citizens. Understanding the viewpoints of people who are homeless regarding end-of-life issues will affect care and policy in several ways. It will help us attend to the needs of a substantial proportion of the population who have not been accounted for in the past. Elucidating the barriers to good end-of-life care experienced by homeless people may show barriers that other disenfranchised persons face. Finally, this information may offer insights into the most basic needs and wishes of all of us.

This work represents a pilot project we conducted, which had three main objectives:

1. To explore whether homeless people have the desire to talk about and interest in end-of-life care, dying, and death;
2. To inform the development of a larger investigation into this issue, including the construction of an appropriate questionnaire;
3. To explore whether persons who experience homelessness have concerns about end-of-life care, dying, and death that are different from those that have been described in the literature.

We conducted three focus groups for this exploratory investigation: two groups included those who provide services to the homeless, and one group of homeless men. We hypothesized that homeless people are interested in talking about end-of-life care, dying, and death, and that an investigation into the concerns of homeless persons about these issues would raise different domains of concern than traditional end-of-life studies.

METHODS

PARTICIPANTS AND RECRUITMENT

Social workers from two service organizations that serve the homeless population in Minneapolis were recruited for this project — Loaves and Fishes, a nonprofit organization that provides free meals, and Anishinabe Waikagun, an extended-stay facility that serves those with chronic alcoholism who are homeless. Homeless participants were recruited from St. Stephen's, a large homeless shelter in Minneapolis.

All participants were required to be at least 18 years old, speak English, and be able to give valid informed consent. Homeless participants were required to have been homeless for the last six months. We defined "homelessness" according to the language of the federal guidelines, which define a homeless person as one who

lacks a fixed, regular, and adequate night-time residence and has a primary night-time residency that is: (A) a supervised publicly or privately operated shelter designed to provide temporary living accommodations. . . . (B) An institution that provides a temporary residence for individuals intended to be institutionalized, or (C) A public or private place not designed for, or ordinarily used as, a regular sleeping accommodation for human beings.¹⁴

The focus groups represent a convenience sample recruited during a pre-arranged visit to the organizations that participated in the study. The directors of each of the organizations initially approached individuals who they felt would be most likely to agree to participate, and who met the study criteria. The investigators explained the project to the potential participants as a group, and then obtained informed consent from each participant. Homeless participants were offered and paid \$20 for the session.

STUDY DESIGN AND MEASUREMENT

This project utilized a qualitative approach, which is ideal for exploring our hypotheses. Specifically, we employed the use of focus groups, which take advantage of group dynamics to elicit information that may not be obtained through individual interviews.¹⁵ The interviews were semi-structured, allowing participants to control the flow of discussion. This use of a qualitative approach is an attempt at a ground-up discovery; it is intended to allow the subjects to speak for themselves and not to have them respond simply to investigator-generated concerns.¹⁶ Domains of initial inquiry were derived from the literature on end-of-life care and dying. These domains included:

- Subjects' experiences with end-of-life care and dying (personal and other),
- The level of homeless persons' concern and willingness to talk about end-of-life issues,
- Subjects' conceptions of dying and a good death,
- Subjects' views on how investigators might best approach this issue in this population.

The University of Minnesota Human Subjects Committee approved all of the procedures in this project.

Interviews were conducted by the three investigators, all of whom were trained in qualitative methodology. The interviews were audiotaped and transcribed, and investigators took notes during the interviews to record nonverbal communication and other pertinent information.

DATA ANALYSIS

The transcripts were coded independently by the investigators through editing analysis, a process that involves close, repetitive readings of the transcripts for themes or domains.¹⁷ The investigators independently derived the preliminary domains during their initial analysis and coded the transcripts according to the domains. The investigators convened to revise and reconcile the independently derived domains, and the transcripts were recoded, using the revised domains. Discrepancies were discussed with all investigators, a process that further refined the characterization of the domains. Passages of text were extracted mutually to best characterize each domain.

TRUSTWORTHINESS

We employed several measures to ensure trustworthiness. First, we independently generated preliminary domains, and then met as a group to refine and reconcile differences. Next, we compared domains from this project with the literature and existing taxonomies of end-of-life care and dying established by experts, professional organizations, and patients. Finally, we recruited a person who provided services to the homeless and a homeless individual who was not involved with this pilot project to further validate our findings.

RESULTS

A total of 20 participants in three focus groups participated in the pilot study (nine service providers and 11 individuals who identified themselves as homeless). Table 1 describes the various domains elicited through the interviews, as well as the various components of each domain. Components of each domain were found in each focus group, another assurance of the trustworthiness of the data. The domains that the investigators formulated through analysis were as follows. (All quotations were directly transcribed from the interviews.)

CONTEXT OF DEATH

There was much discussion about the context of death among this homeless population. Death appears to be ubiquitous — frequently on the minds of homeless people and a part of life living on the streets. Death was also characterized as sudden and often violent.

Homeless person: They're [homeless people are] kind of like buffalo. They're out in a herd back in the buffalo hunting days. There's this great big herd of buffalo and they're all standing there chewing on the grass and all of a sudden you hear a shot ring out and a buffalo standing right next to you goes "oh," hits the dirt because he's been shot. And the other buffalo look over there and turn back and keep on eating the grass. And then another shot rings out and the guy on the other side of you goes "oh."

Homeless person: You can be walking down the street . . . or you can see me walking down the street and all of a sudden, lights out.

CONCERNS AND FEARS ABOUT DYING AND DEATH

Homeless participants revealed many concerns and fears about dying and the circumstances of their deaths. As noted above, there was great concern about dying violently. There was also a great deal of concern about dying alone and dying on the streets.

Homeless person: If I was to die, and die here in Minnesota, I do think about death. I could see myself in that bed and nobody around, and to be that would be really sad.

There were many concerns expressed about what happens to the physical body after death and whether certain traditions were carried out.

Service provider: One of the guys that stayed at St. Stephen's for quite a few years came up to me one day and said, "What will happen to me when I die?" And I didn't know, I mean because he was smiling, and I said, "Well, you'll make a pose or something." I tried to make a joke of it. Then he said, "No, I mean what will happen to my body? Who will take care of me?" He said, "I want to be buried in my, you know, in my Native ways . . ."

BARRIERS TO CARE AND END-OF-LIFE CARE

Both service providers and homeless persons described many barriers to healthcare. Some of the most difficult barriers to overcome are institutional or societal, and are strongly influenced by prejudice, discrimination, and poor attitudes on the part of service providers, while other barriers are personal, such as a mistrust of medical providers and the medical system.

Homeless person: With me — I've seen a couple of guys die since I've been here, and my main concern is that people know that they need help, and they ask for help, and they can't get it. . . . Two or three days later, people ask, "Where's what-you-call-him?" "Oh, he dropped dead." It's like they just kick you to the curb. You don't exist, basically, the way that some of the medical field looks at it. You walk into a hospital sometimes, and because you're not dressed right, you get shunned.

Table 1
Concerns of Homeless Persons Regarding Death, Dying, and End-of-Life Care

Context of death:

- Death is sudden.
- Death is ubiquitous.
- Death is often violent.
- Suicide can be common.
- Many have experience with or first-hand knowledge of death.

Concerns and fears about dying and death:

- Don't want to die alone, but this is very possible.
- Don't want to die in pain.
- Afraid that death may be a violent one.

Concerns and desire for advance planning:

- Fear of inappropriate/prolonged medical "care."
- What will happen to me if no one can speak for me?
- Do not want nursing home or other institutional care.
- Don't want to lose freedom when dying.
- Fear that body will not be respected or taken care of.
- Fear that death rituals of one's culture may not occur.
- Fear that no one will be there to view body.

Barriers to care and end-of-life care:

- Prejudice and poor attitudes from physicians and other providers.
- Undocumented status or running from law.
- Personal barriers include mistrust and lack of knowledge of medical system.
- Resistance to change that might be beneficial.

Interpersonal relationships, models, and communication:

- Would like to talk about death and dying.
- Have poor familial relationships.
- Wish that family may show up during dire illness or death, but fear that they would not.
- Fear that family may not know wishes leading to poor surrogate decision making.
- Peers might help to a certain extent, but no assumptions of this help.
- Many without trusted peers .

Meaning of life and death:

- Freedom is essential.
 - Acceptance of death.
 - Fatalism.
 - The will of God.
 - In the face of certain death, one must still have hope.
 - The importance of the afterlife.
 - The importance of religion and God.
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INTERPERSONAL RELATIONSHIPS, MODELS, AND COMMUNICATION

Participants repeatedly spoke about communication and the lack of meaningful dialogue. The interviews demonstrated willingness, eagerness, and need to talk about end-of-life care, dying, and death.

Service provider: I mean I've heard a million stories . . . it started me being very saddened, wondering. I have family. I will be cared for in a way that I request. And people that I sit with every day won't simply because they haven't money or family. . . . They don't have anyone to talk to about this stuff, but you can see how important it was for him to have something done when he died.

Despite this willingness and need to talk about these issues, there was much indication that individuals did not have the trusting relationships that are necessary for such discussion. Family relationships, for example, frequently were described as poor or nonexistent.

Homeless person: Right now, I have left my folks. They know where I'm at. I got a brother here and he just saw me down the way, but there's no love there. The part that scares me, even though I lived a longer life, and I didn't expect to live a long life, is growing up with nine sisters in my family and I got a half-brother, and that still separates me. But to leave this world, I've been here seven years, and have no family to come by and visit me. They won't even stop by. As I get older, I'm saying, "Wow, I might die." This dying bit, and I don't have no one. They'll be there when I'm dead and gone, but who wants to wait till you're dead to be around?

Peers were discussed as possible sources of comfort and support, if not as surrogates to make decisions. However, many persons experiencing homelessness appear to be isolated and lacked trusted peers or companions.

Homeless person: I know my junkie friends aren't going to come down to visit me, and my drinking friends.

THE MEANING OF LIFE AND DEATH

Participants focused a great deal of their thoughts and discussion around the meaning of life and death, or put the concerns discussed above into a spiritual context. One commonly occurring theme was the acceptance and inevitability of death. This inevitability of death was either the will of God or the result of fate.

Homeless person: Because I can't change it. I can't change why it's snowing right now, why it rains. I can't change it; I'm not God. I can't do nothing about it. If I were sick, I could take some medicine to try to live longer, but I can't do nothing about it. If the good Lord is ready for you, ain't nothing you can do about it.

Homeless person: It's just not your day. Even though you are surrounded by death and you manage to live through it, it just ain't your day. But you are born one day and you're going to die one day. I'm saying that it ain't my day. When I pass away, which I'm going to do, that's my day.

While death is certain, and one must accept this fate, one must, however, still have hope, manage risks, and prevent death, and live life as much as possible, according to the participants.

Homeless person: But if that time's gonna come, it's gonna come, so I'm going to enjoy my life the best way I can, and try to help other people enjoy theirs too. I'm not going to be ducking around, being afraid, because life is part of death and death is part of life.

Religion, God, and the afterlife were commonly expressed concerns and themes. Much of the discussion occurred in the context of religion and God, and the afterlife had particular importance. Many participants fear the afterlife and desire time to prepare for it.

Homeless person: I know I believe in the Creator and the bible, but I feel that I want more time to get myself together and be ready because I feel that right now I'm going to be judged and I ain't ready.

DISCUSSION

Both experts and the public have sought to identify the elements of quality end-of-life care. A complete review of these efforts is beyond the scope of this article; however, a summary is useful to demonstrate how the perspectives of disadvantaged persons may not have been fully considered in previous conceptual and empirical work in this area. In reviewing what we know about care and dying and the end of life, it becomes apparent that there are gaps in our understanding, particularly when it comes to addressing persons of low socioeconomic status.

Singer and colleagues summarized the domains of quality end-of-life care from three expert perspectives.¹⁸ There is considerable overlap in a policy statement endorsed by a number of healthcare organizations and published by the *Journal of the American Geriatrics Society*, in an Institute of Medicine report, and in an article by leading ethicists, Emanuel and Emanuel (see table 2).

These and other experts¹⁹ have come to similar conclusions: advance planning and end-of-life care is important; patients desire control of physical and emotional symptoms; dying persons wish to have their autonomy and spiritual needs respected; patients and families expect quality care from providers; and dying persons find their social relationships and support essential. As valuable as these reports have been, they have focused on the needs of people who are like the individuals who serve on these panels — people with homes, families, and health insurance. These reports rarely address the end-of-life needs of those whose daily lives are tenuous and for whom the end of life is most uncertain.

Other studies have examined end-of-life care from patients' perspectives. Singer and colleagues analyzed data from interviews with three groups of Canadians,²⁰ and Steinhauer and colleagues analyzed transcripts from focus groups of health professionals, patients, and recently bereaved family members at a Veterans Administration hospital.²¹ The issues that were identified by patients as essential to good end-of-life care and a good death were similar to those issues identified by experts: receiving adequate pain and symptom management; avoiding inappropriate prolongation of dying; achieving a sense of control; relieving burden; strengthening relationships; clear decision making; preparation for death; and affirmation of the whole person.

Table 2
Domains of Quality End-of-Life Care

<i>Journal of the American Geriatrics Society</i> ¹	Institute of Medicine ²	Emanuel and Emanuel ³
Physical and emotional symptoms	Overall quality of life	Physical symptoms
Support of function and autonomy	Physical well-being and functioning	Psychosocial and cognitive symptoms
Advance-care planning	Psychosocial well-being and functioning	Social relationship and support
Aggressive care near death	Spiritual well-being	Economic and caregiver needs
Patient and family satisfaction	Patient perception of care	Hopes and expectations
Global quality of life	Family well-being and perceptions	Spiritual and existential beliefs
Family burden	Survival time	Provider continuity, skill

Adapted from P.A. Singer, D.K. Martin, and M. Kelner, "Quality End-of-Life Care: Patients' Perspectives," *Journal of the American Medical Association* 28, no. 2 (13 January 1999): 163-8, which cited: "Measuring Quality of Care at the End of Life: A Statement of Principles," *Journal of the American Geriatrics Society* 45 (1997): 526-7; M.J. Field and C.K. Cassel, ed., for the Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academy Press, 1997); and E.J. Emanuel and L.L. Emanuel, "The Promise of a Good Death," *Lancet* 35, suppl. 2 (1998): 21-9.

Another common theme found in empirical work is a preference among most people to die and receive end-of-life care at home. This preference has been cited in studies of patients after they were released from an intensive care unit, in those receiving home care, and among individuals with cancer.²² Widespread preference for dying at home was also confirmed in a 1996 Gallup poll.²³

Poverty and disadvantage have not been completely ignored in the search for good end-of-life care. Researchers, for example, have found associations between higher levels of education, socioeconomic status, and insurance status and greater completion rates of advance directives.²⁴ The few investigations that have addressed the effects of poverty on the quality of end-of-life care usually come to grim conclusions. For example, a study conducted in 1999 among people dying with HIV found that those most impoverished were more likely to die in the hospital and in pain.²⁵ Commentators have noted that uninsured persons probably do not have access to many of the services needed for a good death, while others have speculated that poorer individuals might opt more frequently for life-terminating measures because of financial concerns.

However, even these studies make fundamental assumptions about desirable end-of-life care and the conception of a good death. Given the very personal nature these concerns, and the effects that extreme poverty, alienation, fear, and exposure can have on a person's view of life, it is necessary to hear the actual voices and concerns of people experiencing this condition.

Our major finding in this study was how willing and eager homeless persons were to speak about end-of-life issues. The discussion with homeless individuals was involved, vigorous, and emotional. Discussants often spoke above one another, and each spoke at length. As can be seen by the results, the discussants had either experienced the issues around the end of life firsthand, or through a friend or relative, and/or had thought about the issue at length. Many of their statements were well-developed and demonstrated past reflection. Recruitment to the study was aided by the compensation provided, but the ease of recruiting subjects also reflected, in our opinion, their interest in the subject and/or experience. The amount of personal experience with death; the depth of previous consideration of death, dying, and end-of-life issues; and the passion and interest demonstrated by the participants were surprising and unexpected from a population that is often characterized as focused on daily survival and wary of scrutiny. Even with this small exploratory sample, it is clear that homeless persons desire to discuss death, dying, and end-of-life care.

Another new finding was the identification of several domains of concern regarding dying that have not been described in previous studies of those in more comfortable and secure situations. Even in this preliminary investigation, participants voiced concerns that have not been previously reported. There was, for example, an often-repeated concern about the fate of their physical body — whether anyone would view and witness their passing; whether their body would be respected; and what would actually happen to their body should no one claim it. This is a chilling, but logical, concern that would be raised among those who are so alienated and disenfranchised from close personal relationships and society. It's assumed by most individuals that one's body will be respected and cared for after death, and the authors — all with experience in end-of-life care — were surprised that they had not considered this to be a concern in their previous work and experience.

There was also the view that death was a sudden and ubiquitous part of life, and not the result of prolonged illness — it is something for which one doesn't plan, but one that is sudden and inevitable, yet still unexpected. One could, as the participant said, be "walking down the street and, all of a sudden, lights out." This kind of death requires a very different approach to advance-care planning than the deaths most of us anticipate. Given these and other concerns in this pilot investigation, we believe that further exploration of death and dying issues in this population will yield more concerns that are not yet reported in the end-of-life literature, or, perhaps more importantly, have not been considered by those who deliver care at the end of life.

The major limitation of our work is that it is preliminary and only speaks for the experiences and concerns of a very small sample of homeless persons, who were men. The circumstances of homelessness and the people who experience it are as unique and as varied as the experiences of people who have homes. It would be illogical, incorrect, and a disservice to assume that the experiences and concerns that we have

explored are common to all people living without a home. The number of participants was small, and any conclusions cannot be generalized — all findings are exploratory.

Another limitation is that our subjects represented a convenience sample of individuals who accessed particular service organizations. There is evidence that homeless persons who access service organizations have different demographics than those who do not, and may have different levels of trust in institutions and the healthcare system; as a result, our findings may not be applicable to homeless persons who do interact with institutions. The views of those alienated from institutions may be very different, and this also needs further exploration.

However, despite these limitations and the preliminary nature of this work, our study strongly suggests further follow-up work and even some interventions to improve the end of life in this population. This work needs to be validated in larger groups of people experiencing homelessness, with greater representation of all groups who constitute the "homeless population"; for example, women, parents, elderly, and various racial and ethnic subgroups. Also, this work may need to be replicated in different locales, as the experience of living without secure shelter as well as the local culture differs greatly from place to place — living without a home in frosty Minnesota is a different experience than in Phoenix, for example, and may influence how one thinks of death. Finally, larger-scale survey studies would be needed to generalize and further validate any findings.

Despite the need for further investigation and the preliminary nature of our findings, several interventions to improve dying and death for homeless individuals are suggested from this work. Educational initiatives directed both toward providers and homeless clients may be extremely beneficial. These educational interventions would be directed toward social service providers, who need to understand the end-of-life concerns of their clients, and toward hospice and other end-of-life providers who need to understand the special concerns and needs of homeless individuals. Another possible intervention suggested by our work is the identification of proxies not only for medical decision making — as traditionally identified — but also for the witnessing and care of the body after death. As it was reported that death is sudden and often occurs in out-of-the-way places (for example, under bridges, on the street), having some form of identification card with simple directives or contacts may also serve to preserve the dignity and autonomy of homeless persons at the end of life. It is worth observing that many of the interventions that are suggested by this work are simple ones, perhaps reflecting that — as in life — in death, the initial needs of homeless persons are basic.

In summary, this preliminary exploration supports our hypothesis that homeless people have a desire and interest in talking about end-of-life care, dying, and death. Interviews with homeless individuals and their service providers revealed a number of end-of-life concerns not described in the literature. Further investigation is needed to validate these findings and discover new concerns with a larger and broader sample of people experiencing homelessness. Homeless populations are extremely diverse and complex, and further research is needed to differentiate among those different subpopulations who live without safety and security. Finally, exploration is needed to identify possible interventions to improve the final days of those who live such desperate and difficult lives.

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NOTES

1. E.J. Emanuel and L.L. Emanuel, "The Promise of a Good Death," *Lancet* 35, suppl. 2 (1998): 21-9; M.J. Field and C.K. Cassel, ed., for the Institute of Medicine *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academy Press, 1997).

2. Ibid.

3. Ibid.

4. M.R. Burt, "Homelessness: Definitions and Counts," in *Homelessness in America*, ed. J. Baumohl (Phoenix, Ariz.: Oryx Press, 1996), 15-23; D.A. Webb et al., "Prevalence of Episodic Homelessness among Adult Childbearing Women in Philadelphia, Pa.," *American Journal of Public Health* 93, no. 11 (November 2003): 1895-6; S. Metraux et al., "Assessing Homeless Population Size Through the Use of Emergency and Transitional Shelter Services in 1998: Results from the Analysis of Administrative Data from Nine US Jurisdictions," *Public Health Reports* 116, no. 4 (July-August 2001): 344-52.

5. U.S. Conference of Mayors, "2001 Hunger and Homelessness Survey," http://www.usmayors.org/uscm/news/press_releases/documents/hunger_121101.asp.

6. W.H. Martens, "A Review of Physical and Mental Health in Homeless Persons," *Public Health Reviews* 29, no. 1 (2001): 13-33; M.L. Reardon et al., "Alcohol Use and Other Psychiatric Disorders in the Formerly Homeless and Never Homeless: Prevalence, Age of Onset, Comorbidity, Temporal Sequencing, and Service Utilization," *Substance Use and Misuse* 38, nos. 3-6 (February-May 2003): 601-44; L.C. Kleinman et al., "Homing In on the Homeless: Assessing the Physical Health of Homeless Adults in Los Angeles County Using an Original Method to Obtain Physical Examination Data in a Survey," *Health Services Research* 31, no. 5 (December 1996): 533-49; W.R. Breakey, P.J. Fischer, and M. Kramer, "Health and Mental Problems of Homeless Men and Women in Baltimore," *Journal of the American Medical Association* 262(1989): 1352-7.

7. Ibid.; L. Wojtusik and M.C. White, "Health Status, Needs, and Health Care Barriers among the Homeless," *Journal of Health Care for the Poor and Underserved* 9, no. 2 (May 1998): 140-52; M. McMurray-Avila, *Organizing Health Services for Homeless People: A Practical Guide* (Nashville, Tenn.: National Health Care for the Homeless Council, 1997).

8. A.M. Cheung and S.W. Hwang, "Risk of Death among Homeless Women: A Cohort Study and Review of the Literature," *Canadian Medical Association Journal* 170, no. 8 (13 April 2004): 1243-7; J.R. Hibbs and L. Benner, "Mortality in a Cohort of Homeless Adults in Philadelphia," *New England Journal of Medicine* 331 (1994): 304-9; S.W. Hwang et al., "Causes of Death in Homeless Adults in Boston," *Annals of Internal Medicine* 126 (1996): 625-8.

9. S.W. Hwang et al., "Health Care Utilization among Homeless Adults Prior to Death," *Journal of Health Care for the Poor and Underserved* 12, no. 1 (February 2001): 50-8; McMurray-Avila, see note 7 above; L. Gelberg and L. Thompson, "Competing Priorities as a Barrier to Medical Care among Homeless Adults in Los Angeles," *American Journal of Public Health* 87 (1997): 217-20.

10. Ibid.; Y.W. Lim et al., "How Accessible is Medical Care for Homeless Women?" *Medical Care* 40, no. 6 (June 2002): 510-20; K.B. Kushel, E. Vittinghoff, and J.S. Haas, "Factors Associated with the Health Care Utilization of Homeless Persons," *Journal of the American Medical Association* 285, no. 2 (January 2001): 200-6.

11. See note 6 above; M.J. Robertson, C. Zlotnick, and A. Westerfelt, "Drug Use Disorders and Treatment Contact among Homeless Adults in Alameda County, California," *American Journal of Public Health* 87 (1997): 221-8.

12. P. Compton and P. Athanasos, "Chronic Pain, Substance Abuse and Addiction," *Nursing Clinics of North America* 38, no. 3 (September 2003): 525-37; W. Wiebel et al., "Risk of HIV Infection among Homeless IV Drug Users in Chicago," In *Abstracts International Conference on AIDS*, abstract no. M.A.P.50; S. Daneault and J. Labadie, "Terminal HIV Disease and Extreme Poverty: A Review of 307 Home Care Files," *Journal of Palliative Care* 15 (1999): 6-12.

13. See note 6 above; C.S. North et al., "Are Rates of Psychiatric Disorders in the Homeless Population Changing?" *American Journal of Public Health* 94, no. 1 (January 2004): 103-8; E. Susser, E.L. Stuenkel, and S. Conover, "Psychiatric Problems in Homeless Men," *Archives of General Psychiatry* 46 (1989): 845-50.

14. *Stewart B. McKinney Homeless Assistance Act*, 42 U.S.C. 11431 et seq.

15. R.A. Krueger and M.A. Casey, *Focus Groups: A Practical Guide for Applied Research* (Thousand Oaks, Calif.: Sage, 2000).

16. H.R. Bernard, *Research Methods in Cultural Anthropology* (Beverly Hills, Calif.: Sage Publications, 1988).

17. Ibid.; A. Strauss and J. Corbin, *Basics of Qualitative Research: Grounded Theory Procedures and Techniques* (Thousand Oaks, Calif.: Sage Publications, 1990).

18. P.A. Singer, D.K. Martin, and M. Kelner, "Quality End of Life Care: Patients' Perspectives," *Journal of the American Medical Association* 281 (1999): 163-8.

19. AARP Research Center, "End-of-Life Care in Managed Care Organizations 1999," http://research.aarp.org/health/9908_end.html; American Medical Association Council on Scientific Affairs, "Good Care of the Dying Patient," *Journal of the American Medical Association* 275 (1996): 474-5; M.J. Field and C.K. Cassel, ed. for the Institute of Medicine, *Approaching Death: Improving Care at the End of Life* (Washington, D.C.: National Academy Press, 1997); World Health Organization (Report of an Expert Committee), "Cancer Pain Relief and Palliative Care 1990, pp. 52-3.

20. E.K. Vig and R.A. Pearlman, "Quality of Life While Dying: A Qualitative Study of Terminally Ill Older Men," *Journal of the American Geriatrics Society* 51, no. 11 (November 2003): 1595-601; see note 18 above.

21. K.E. Steinhauser and C.C. Clipp, "In Search of a Good Death: Observations of Patients, Families, and Providers," *Annals of Internal Medicine* 132 (2000): 825-31.

22. The SUPPORT Investigators, "A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)," *Journal of the American Medical Association* 274 (1995): 1591-8; E.R. Ratner, L. Norlander, and K. McSteen, "Death at Home Following a Targeted Advance Care Planning Process in the Home Setting: The Kitchen Table Discussion," *Journal of the American Geriatrics Society* 49, no. 6 (2001): 778-81; C.M. Monpour and L. Polissar, "Factors Affecting Place of Death of Hospice and Non-Hospice Cancer Patients," *American Journal of Public Health* 79 (1989): 1549-51.

23. The Gallup Organization, *National Hospice Organization survey, Knowledge and Attitudes Related to Hospice Care* (Princeton, N.J.: Gallup Organization, September 1996).

24. D.E. Meier, B.R. Fuss, and D. O'Rourke, "Marked Improvement in Recognition and Completion of Health Care Proxies," *Archives of Internal Medicine* 156 (1996): 1227-32; L.C. Hanson and E. Rodgman, "The Use of Living Wills at the End of Life," *Archives of Internal Medicine* 156 (1996): 1018-22.

25. Daneault and Labadie, see note 12 above.