

EDITORIALS

Dying on the Streets

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Andrew Jackson once commented that the health of a society can best be measured not by how those at the top are doing, but by the welfare of those at the bottom. The United States is among the wealthiest nations in the world; those at the top of society are doing well. But the gap between the “haves” and “have-nots” in the United States is growing, and no one has less than the homeless. For healthcare professionals and students wondering why they should get involved in politics and health care policy, there are few better examples of the impact of policy on society and on individuals than the plight of the homeless. In 1963, Congress passed, and John Kennedy signed, the Community Mental Health Act. This well-intended act was designed to create and expand community mental health centers to provide community-based care as an alternative to institutionalization. Many states took advantage of the opportunity to close expensive state mental health facilities and released institutionalized patients into communities without the facilities or expertise to treat them. The consequence was an upsurge in the rate of homeless not seen in the United States since the Great Depression.

In this issue of the *Journal of General Internal Medicine*, Dr. Song and colleagues contribute to a growing literature on end-of-life care for the homeless. Facing one's own mortality is difficult, no matter what the circumstances. Yet, the homeless at the end of life face particularly difficult challenges. Where do they go for medical care and how do they get there? Where do they keep their medications, particularly narcotics or other pain medications? Where do they store their advance directives or other medical documents? Who do they appoint as their surrogate for medical decision-making in the event they are unable to speak for themselves? Where do they go and who cares for them if they cannot care for themselves on the street while they are dying?

It is not surprising that the wishes of the homeless mirror those found in other studies on end-of-life care: the importance of spirituality, a desire for death with dignity and freedom from pain, a wish to avoid being a burden to others, and a desire for advance-care planning.¹ However, as Dr. Song's research makes clear, the homeless have several unique perspectives. First, they have an astonishingly high rate of exposure to loss, both early in life and while living on

the streets. Consequently, they live with a daily fear that death is lurking just around the corner. Given reported rates of morality from 2 to 30 times that of age-matched populations, that fear may be justified.^{2–4} Another unique characteristic is that the homeless worry deeply about dying alone and anonymously on the streets. Furthermore, while most studies of the dying find that they desire to be surrounded by loved ones, many of the homeless are estranged from their families and want no contact with them.

Adding to the already complex nature of end-of-life care among the homeless is their history of difficult interactions with medical professionals and their resulting distrust of the health care system. Dr. Song's research reports that the homeless feel that they are not treated with respect and that there is a palpable bias among health professionals that the homeless are not deserving of basic health care. Patients sick enough to merit hospitalization can generally expect good care while in the hospital, but even the most basic posthospitalization care, such as follow-up appointments and obtaining outpatient medications, is problematic in this population. Most patients at the time of hospital discharge are not healthy enough to go to their own homes alone, much less directly to the streets. Most homeless patients are ostensibly discharged to shelters, although the “dirty little secret” is that most just wind up back out on the streets, particularly because many shelters are open only at night.

Outpatient health utilization among the homeless is high, constituting over half of all emergency department visits.⁵ For most homeless, the majority of their health care is through emergency departments.⁶ The health needs of the homeless will grow because, like the general population, it is an aging population.⁷ Of course, emergency departments were never designed to provide comprehensive, longitudinal care. Although very troubling, the poor communication and level of distrust that has developed within this fractured, broken system is not surprising.

So what is the way forward? The modern causes of homelessness are complex. The U.S. Conference of Mayors identified the main causes as lack of affordable housing, low-paying jobs, substance abuse and mental disorders coupled with a lack of needed services, and domestic violence.⁸ Clearly, the treatment of substance abuse and mental disorders falls within the domain of physicians. Yet, a comprehensive plan to reduce homelessness is clearly beyond the purview of health professionals. Improving access to empathic ambulatory care professionals, knowledgeable about the needs of this population, would be an important first step in improving health care among the homeless and reversing their distrust of the system. While a comprehensive national insurance program would be

an important step towards improving access to health care for all Americans, up to half of the homeless have health insurance, so shifting care from the emergency department to clinics would require something more. Even when the homeless achieve housing through public assistance programs, the pattern of heavy emergency department rather than ambulatory clinic utilization continues.⁹

Clinicians engaged in the care of the homeless can learn from the growing disparities literature to be aware of and sensitive to the cultural context of their patients' lives. Openly acknowledging the homeless person's situation and tailoring the interaction around their circumstances could help reduce homeless patients' distrust of the health care system. Dr. Kushel provides a number of helpful questions for a needs assessment of homeless patients in her 2006 article on end-of-life care for the homeless.¹⁰ The principles of shared decision making and good patient–doctor communication apply to interactions with the homeless as they would to any patient. A comprehensive, widely disseminated, and broadly accessible electronic medical record could also help, particularly one that allows the storage of such documentation as advance directives. There are examples of a few cities that have developed such medical record systems, accessible by many local health providers, such as Indianapolis.¹¹ Several other cities, as well as states, are working on developing better systems of creating and linking health records. Portable electronic media, such as “smart cards” that resemble credit cards, can be kept in patients' wallets and used to store electronic medical records or advance directives. The U.S. military uses such a system for keeping medical information on soldiers in hectic battlefields with the individual rather than on separate “paper” charts.¹²

Research, such as the articles in this month's *Journal of General Internal Medicine*, that illuminates the unique attitudes and challenges of the homeless can help those of us who care for these patients to understand and empathize more deeply with them and, ultimately, provide better care. This is one of the unique contributions that qualitative research can make. Quantitative research has been the basis for the astonishing, breathtaking progress of science over the last few decades, but as powerful as it is, quantitative research often misses the human element. Qualitative research can illuminate the soul; it can delve deeply into what makes us uniquely human. By highlighting the unique challenges that these patients face, qualitative research, such as Dr. Song's article, allows us to help our patients on a broader scale—to

ponder global solutions to the problems they face and to engage more effectively in advocacy for political and social change on their behalf. With these steps, we can help improve the plight of some of the most vulnerable in our society: the homeless at the end of life.

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