

James J. O'Connell, "Raging Against the Night: Dying Homeless and Alone," *The Journal of Clinical Ethics* 16, no. 3 (Fall 2005): 262-6.

## Raging Against the Night: Dying Homeless and Alone

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On the first Friday of March, we gathered in the basement of St. Anthony's Shrine in the heart of downtown Boston to remember a 49-year-old Air Force veteran and high school hockey star whose stubborn charm enchanted and exasperated us during his two decades on the streets of our city. Three days after Christmas, in frigid and snowy weather, he was found on a cement bench two blocks from Massachusetts General Hospital (MGH) with a core body temperature of 78°. The cause of death remains uncertain; he likely suffered a myocardial infarction or a seizure in the hours before he was found. Heroic measures to "warm" him in the emergency room with heated saline and bilateral chest tubes failed to restore a heart rhythm.

The subterranean ceremony was evocative and profound: songs sung to piano, guitar, and trumpet; poems of loss and hope; readings from the Old Testament; tears punctuated by peals of laughter as the many assembled shared stories. The wide circle of caregivers surprised all of us and included emergency room nurses and social workers, outreach street workers, therapists from the mental health community, and our own street team who provided his primary medical care. This ebullient man had logged legendary numbers of visits to the MGH emergency department, earning a virtually permanent gurney in the hallway while blowing kisses to nurses, never refusing meals, and never failing to offer profound thanks to each one who cared for him. He was one of the most frequent and outspoken utilizers of the emergency service team of the Department of Mental Health. The staff of Andrew House lamented the loss of a man who had tried literally hundreds of detoxifications in this dual diagnosis unit, but never managed to achieve more than a few weeks of sober time. We couldn't help but share a single observation: how surprised he would be to see how many persons remembered and cared for him.

His past was shrouded in mystery, although he once admitted he had been married and had lost contact with his two children. No family members have been located since his death, and his hulking body remains unclaimed in the city morgue.

The findings in the evocative study by Song and colleagues in this issue of *The Journal of Clinical Ethics* resonate dramatically for clinicians engaged in the care of homeless individuals and families. The experience of illness and suffering for persons living without homes in urban and rural America is complex and poorly understood. The literature is bereft of studies on palliative and end-of-life care for homeless

persons, even though our best practices firmly place the home and family at the center of care for the dying. Our patient's story is a familiar one; most inner-city physicians and other clinicians have witnessed the lonely, desperate, and often painful deaths of homeless men and women in our hospitals. Song and his colleagues urge us to no longer ignore this hidden burden of human suffering and tragedy.

Death is commonplace on the streets and in the shelters, a constant — albeit erratic — companion for persons living in shelters and on the streets. Studies from Philadelphia, Boston, and Atlanta have found mortality rates in homeless adults to be three to four times greater than in their housed counterparts.<sup>1</sup> A study of homeless women in Toronto found a 10-fold increase in mortality when compared to other women in that city.<sup>2</sup>

The risk of dying increases dramatically for persons wandering the streets. The Boston Health Care for the Homeless Program (BHCHP) has followed a cohort of 119 persons living on the streets since 2000. Most have been homeless for more than a decade, and many for more than 20 years. The mean and median age is 47, with a range from 32 to 82 years. The demographics do not differ from the overall homeless population in Boston. Surprisingly, 80 percent are disabled and have health insurance. In the five years from 2000 through 2004, 33 (28 percent) died and another six (5 percent) are now in nursing homes. The causes of death were primarily chronic diseases such as cancer, cirrhosis, obstructive lung disease, and heart failure; only two persons died of hypothermia and exposure. Such morbidity and mortality is alarming and often preventable; such outcomes in any disadvantaged population represent astonishing healthcare disparities that constitute a public health emergency.

Behind the numbing statistics are the stories: people struggling against the oppressive odds of persistent poverty and homelessness. Stunning glimpses of these lives emerge in the interviews in Song's study. Fears candidly voiced include dying alone and in the streets, the disposition of one's body after death, and whether anyone will remember them. The ubiquity of death in the journey through homelessness seems to ease any reluctance to discuss dying and spirituality among those interviewed. While the group interviewed is small in number, their responses parallel our experiences during these past 20 years.

The call from the Medical Examiner's office to help identify a John or Jane Doe comes often. The fear of dying alone on the streets is prominent and palpable among homeless persons, and not without good reason. Many individuals in the city morgue remain unknown; more commonly, as with our patient above, we are able to identify the body but cannot find any next of kin. Unless we are able to find a generous funeral home director and a donated cemetery plot, those unfortunate individuals are cremated and buried in a paupers' field after six months. A 35-year-old man died of AIDS several years ago after months of suffering through repeated bouts of pneumonia and a profound wasting syndrome. He absconded from innumerable hospitals and nursing homes seeking independence on the streets, soon to be found gravely ill and brought to local emergency rooms. As happens frequently with our patients, we learned upon his death that the name he gave us was an alias. Despite caring for him intensively for over a decade, we never learned his true identity and have no idea whether any family members exist. A kind funeral director arranged a wake for him, a Mass was said in an inner-city church where he often slept in the alcove, and he was buried in a plot alongside thousands of indigent citizens of our city. His grave is marked by a small bronze medallion with a number; the name associated with the number is kept in a ledger at Boston City Hall.

The loss of autonomy and the fear of losing control at the time of death are concerns with substantial validation. A patient of ours was apprehended for several misdemeanors and imprisoned in the county jail for several months. This 45-year-old man, combative and vituperative, won my begrudging respect for his fearlessness and noble insistence on being the protector of older folks on the streets. His approach to the world was explosive and confrontational, raging openly about the "lousy hand" he had been dealt in life. He belittled most of us in healthcare for "never listening," even though he frequently presented with a plethora of somatic complaints that resulted in exhaustive and futile evaluations. He wrote several letters from jail imploring our intercession, as his complaints of severe back pain were being ignored. I finally visited and found a pale, cachectic man unable to get out of the chair without severe pain. His complaints had gone unheeded, even though a chest x-ray upon incarceration four months earlier showed a suspicious lung mass

and several collapsed vertebrae. After an immediate transfer to our hospital for treatment, he requested that "everything" possible be done. However, his condition rapidly deteriorated, and we began a nightly vigil in his room. An armed guard was constantly at his door, and his leg shackles remained in place because he was a prisoner of the county. He fought furiously for life, sitting up through the night gasping for breath while refusing oxygen. On the day before his death, he pleaded for the dignity of dying without the shackles on his legs. After many hours of calls and with the help of the hospital lawyers, we found a judge willing to release him to our custody. Once the shackles were removed, his anger and will to live both dissipated, and he died within hours.

The lack of stable housing exposes a critical shortcoming in the continuum of care offered by our country's healthcare system and raises substantial ethical and pragmatic issues, especially for palliative and end-of-life care. In 1985, to bridge this gap, Health Care for the Homeless programs in Boston and Washington, D.C., with funding from the Robert Wood Johnson Foundation, developed and implemented the concept of "respite care." Medical care and a safe place to heal were offered to homeless persons who have short-term illnesses, infections, and injuries, who would otherwise require prolonged hospitalizations or risk considerable harm on the streets.

In the interim, seismic changes in our healthcare system have shifted the focus of care from hospital to home for many critical services. Drastic reductions in hospital lengths of stay, the astonishing evolution of anesthesia and minimally invasive day surgery, and the shift in specialty services from hospital to outpatient clinic (for example, chemotherapy) have resulted in a dramatic increase not only in the demand for respite beds, but also in the acuity and the complexity of the medical needs of persons referred for respite care. In 1993, BHCHP moved its original respite care program of 25 beds, initially nestled in a local shelter, to the Barbara McInnis House, a free-standing former nursing home that has 90 beds with 24-hour medical and nursing care. This program offers acute, subacute, pre- and post-operative, recuperative, rehabilitative, palliative, and end-of-life care to homeless persons throughout Boston and the Commonwealth of Massachusetts. Referrals come from emergency departments, hospital in-patient units, primary care and specialty clinics, and directly from BHCHP staff in shelters and on the streets. The demand remains intense and overwhelming; the census at McInnis House has seldom fallen below 95 percent.

McInnis House has been the venue for the deaths of several of our patients, a difficult but enlightening body of experience that confirms much of what has been voiced by the cohort in Song's study. Several years ago we diagnosed an undocumented 42-year-old man from Central America with a leiomyosarcoma. A tireless worker at a local thoroughbred racetrack, he lived in a barn on the backstretch and sent half of his meager wages to his impoverished family. With no place to go, he was admitted to McInnis House after his initial surgery and remained while he underwent monthly chemotherapy that left him frail and fatigued. His response to treatment was disappointingly brief, and his medical and nursing care became intense as he weakened, and we initiated a referral to a skilled nursing facility for hospice care. This taciturn man tearfully pleaded to stay in the place he felt safe and accepted. The staff of doctors and nurses had become family as well as caregivers, a situation we had not anticipated. Virtually everyone volunteered to take turns sitting with him at night to monitor pain, ease his fears of being alone, and help him to the commode. Hospice nurses came to McInnis House to assist with his care and to educate us in end-of-life care. He died peacefully and with minimal pain two months later.

The time spent and intensity of these efforts were exhausting and created considerable tension within an already beleaguered staff. Yet all were grateful for the opportunity. Perhaps most profoundly, the fears of our other patients were allayed with the realization that they also would not be abandoned at the time of death.

Each death has posed new challenges and unearthed new obstacles. A 50-year-old Vietnam veteran who spent 20 years living in Boston Commons developed head and neck cancer soon after celebrating a year of sobriety. His medical odyssey included a sequence of progressively more radical surgical procedures after he failed to respond to weeks of radiation therapy and two courses of chemotherapy. He eventually lost most of his mandible and his tongue. Time outside the hospital was spent in our respite care program, where he stubbornly managed his own tracheostomy care while still smoking in the courtyard. His deepening depres-

sion, explosive outbursts over innocuous comments by other patients, and an escalating dependency on opiates for pain control became contentious and frightening, and he was eventually transferred to a nursing home for the last three months of his life. We would visit him regularly, although we endured venomous wrath if we missed a day or failed to bring cigarettes. Unable to muster even a nod of thanks through his disfigured face, he left a poem of hope and gratitude in his bedside drawer to be read at his funeral.

Respite care programs for homeless persons now exist in over 30 cities throughout the country. Studies are critically necessary to determine clinical outcomes, cost-effectiveness, and the ability of such programs to divert emergency department visits, avoid acute care hospitalizations, and shorten hospital lengths of stay. Respite care programs offer a stable venue for palliative and end-of-life care and the hope of a good death.

Homeless persons in this small study echo a familiar desire to be remembered after death. To mark the deaths of homeless persons and to stave off fears of oblivion on the part of the living, annual memorial services are conducted in most large cities across the country, often sponsored by the National Health Care for the Homeless Council, the National Coalition for the Homeless, the National Alliance to End Homelessness, and local advocacy or religious groups. These public gatherings are attended by large numbers of homeless persons, and the litany of those who die each year is read aloud. Some cities have public memorials prominently displayed throughout the year. Jim Withers, MD, and Operation Safety Net, who have provided care for street persons in Pittsburgh for over a decade, engrave small bronze plaques with the names of each deceased person and mount them on the abutment wall of a bridge. This breathtakingly simple monument is located in a busy downtown area well-traversed by the homeless community.

Palliative and end-of-life care in our society must continue to improve throughout our healthcare system, and this important article by Song and his colleagues begs us to not forget or ignore our homeless poor who die alone and forgotten in the long shadows cast by our hospitals and healthcare institutions.

## NOTES

1. J.R. Hobbs et al., "Mortality in a Cohort of Homeless Adults in Philadelphia," *New England Journal of Medicine* 5, no. 331 (4 August 1994): 304-9; S.W. Hwang et al., "Causes of Death in Homeless Adults in Boston," *Annals of Internal Medicine* 8, no. 126 (15 April 1997): 625-8; "Deaths Among the Homeless — Atlanta, Georgia," *MMWR* 36, no. 19 (22 May 1987): 297-9.

2. 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.