

HEALING HANDS



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HCH Clinicians Can Help Homeless People Die with Dignity

Death is ever present among homeless people and the providers who treat them. People who are homeless may die unexpectedly—often violently—or they may be seriously ill but not have access to sophisticated hospice and palliative care programs. Some innovative programs provide compassionate end-of-life care to homeless and other underserved people, however, and there are some simple things that HCH providers can do to help their clients think about their preferences for end-of-life treatment. These and other topics related to end-of-life care are explored in the articles that follow.

People who have homes, family, and resources may be able to have a ‘good death,’” says **John Song, MD**, Assistant Professor in the Center for Bioethics and the Department of Medicine at the University of Minnesota. Dr. Song has a National Institutes of Health (NIH) grant to study end-of-life care issues for homeless people. Death can be an especially frightening, lonely, sudden, and/or painful experience for people without a home or family support. Barriers to good end-of-life care for homeless people are explored in this article.

LIVING IN THE SHADOW OF DEATH Homeless people have high mortality rates and tend to die at an early age, some from conditions that are easily treated in people with stable housing, such as pneumonia and influenza. HIV infection, liver disease, renal disease, cold-related injury, and cardiac arrhythmias place homeless people at especially high risk of death.¹ Though the average life expectancy in the United States has increased from 47.3 in 1900 to 77.2 in 2001,² homeless people are dying at a younger age than even their 19th century forebears (see table).

MORTALITY STATISTICS FOR HOMELESS ADULTS

City	Average age at death
Atlanta	44 ³
San Francisco	41 ³
Philadelphia	34 ⁴
Boston	47 ³

SUDDEN, UNEXPECTED DEATHS Contrary to popular belief, most homeless people do not die on the streets, nor do most street dwellers die from exposure. In a study of deaths among homeless adults in Boston, investigators found that death most often occurred in a hospital or residential dwelling; exposure to cold caused only 4 of 606 deaths.⁴ However, living on the streets can increase the risk of sudden and unexpected death.

“Cold puts a huge stress on people who have underlying medical problems,” says **Jim O’Connell, MD**, President of the Boston Health Care for the Homeless Program. Frequently, he says, homeless people who die on the streets die from trauma, seizures, overdoses, and from medical problems that are exacerbated by cold, exertion, and alcohol.

Despite their high risk of death, investigators found that 27 percent of homeless people who died in Boston had no outpatient visits, emergency department visits, or hospitalizations, except those during which death occurred.¹ Barriers to health care include lack of financial resources, health insurance, transportation, or an established source of primary care.

BARRIERS TO HOSPICE AND PALLIATIVE CARE

Homeless people who die in hospitals or nursing homes are spared the indignity of dying on the streets, but many may not receive the most advanced end-of-life treatments and services because they lack health insurance, and even those programs funded by insurance are

rare. About half of all deaths occur in hospitals, but less than 60 percent of the hospitals in any given State offer specialized end-of-life services.⁵ Seventy percent of nursing facilities have no patients receiving Medicare's hospice benefit, and Medicaid spent only slightly more than two-tenths of one percent of its Federal and State spending on hospice care in 2001.^{6,7}

Hospice. In-home hospice care, the more well-known end-of-life service, is largely funded by Medicare and Medicaid. Homeless people face numerous barriers to hospice care, including lack of insurance to pay for it, lack of a fixed residence in which hospice care can be provided, and lack of a primary caregiver to oversee hospice care. In addition, a physician must certify that the patient has 6 months or less to live; this can be difficult for a doctor to determine and for a patient to accept.⁶ Also, those who want to take advantage of Medicare or Medicaid-funded hospice services must agree to forgo any curative treatment.

Though many clinicians believe that, beyond a certain point, life-saving treatment may not be in the best interests of the patient, this can be a difficult decision for doctors and patients to make. Homeless people express a great deal of fear about inappropriate or prolonged intervention, according to Dr. Song, but in the absence of any advance directives that specify their wishes to the contrary, this often is what happens when homeless people are admitted as medical emergencies.

"I wish I could tell you how horrible it is to see people's bodies kept alive in intensive care units," says **Carla Alexander, MD**, Assistant Professor of Medicine at the University of Maryland School of Medicine and Director of Palliative Care for the University of Maryland Medical Center. Dr. Alexander was principal investigator for a grant from the Health Resources and Services Administration (HRSA) to provide end-of-life care for an inner city population in Baltimore. She believes that advance directives are critical for homeless people (see box).

Certain ethnic groups that are disproportionately represented among the homeless population may have a particularly difficult time with the concept of in-home hospice care. Though about 85 percent of whites say they wish to die at home, about a third of both Latinos and African Americans say they do not want to die at home.⁸ Reasons given for preferring to die in the hospital were that better care and medical equipment are available.

The issue of hospice care or advance directives may be especially troubling to ethnic groups, such as African Americans, who may feel they have not received the most advanced care during their illness, according to **Mary Ellen Foti, MD**, Area Medical Director for the Massachusetts Department of Mental Health and Associate Professor of Psychiatry at the University of Massachusetts Medical School. Dr. Foti was principal investigator for a Robert Wood Johnson Foundation grant to integrate mental health care with hospice/palliative care.⁹

Helping Homeless People Plan for the End of Life

Advance directives help people retain control of health care decisions at the end of their life. At its most basic, an advance directive involves selection of a health care proxy or agent to make decisions for a person who can not communicate his or her wishes directly. Homeless people who are estranged from family and who have problems trusting others will have a hard time choosing a health care agent, clinicians report. Here are some ways HCH clinicians can help:

- Begin such discussions before a person is ill. "No one is too young or too healthy to talk about death when they are living on the streets," says Dr. John Song.
- Have more than one conversation about advance care planning. If it makes the person more comfortable, talk about a scenario that involves someone else's medical crisis, Dr. Mary Ellen Foti suggests.
- "Don't assume that because someone has a serious mental illness, he or she is unable to make this type of decision," Dr. Foti says. There may be better times than others to have these discussions.
- In the absence of a formal advance directive, have conversations with patients about their wishes and record these in their chart, Dr. F. Amos Bailey suggests.
- Advance care planning can be as simple as having a homeless person give his or her provider an emergency contact number, Dr. Song points out.
- Be clear about how you will use the information and how it will help, Dr. Foti says. Respect a person's cultural attitudes about death and dying.

Palliative Care. Palliative or "comfort" care is the broader umbrella under which hospice services fall; unlike hospice, patients may receive palliative care when they are still undergoing curative treatment. "Palliative care is integrated into good medical care; it's not an either/or option," says **F. Amos Bailey, MD**, founder of the Balm of Gilead palliative care unit at Cooper Green Hospital in Birmingham, Alabama, and Director of Palliative Care at the Birmingham VA Medical Center.

Palliative care typically is offered in an inpatient facility for life-threatening illnesses that have the potential to end in death without a specific time frame, and it focuses on symptom management, decision-making, and goal clarification, explains **Beth Miller Kraybill, RN**, a member of the Pain Research Department at Swedish Medical Center in Seattle and project manager for an NIH-funded end-of-life care grant. However, palliative care may be difficult to find. On average, only 33 U.S. physicians for every 10,000 people are certified in palliative care, and most hospital-based palliative care programs are

located in the Northeast.⁵ Programs that offer hospice and palliative care to underserved individuals are profiled in this issue.

MANAGING PAIN Managing pain at the end of life is a critical component of both hospice and palliative care programs, but homeless people may not have access to the most sophisticated pain management techniques. “Homeless people fear their pain won’t be taken seriously and that their behavior will be seen as drug-seeking,” says Dr. Song. HCH patients in Minneapolis participated in one of Dr. Song’s focus groups.

Research findings indicate that racial and ethnic minorities lack access to treatment for pain.¹⁰ Reasons include patients’ and doctors’ fears of addiction, the high cost of pain medication, and the reluctance of pharmacies in neighborhoods with a majority of non-white residents to carry opioids.⁸ When Dr. Bailey treats pain in people who remain homeless, he emphasizes that he will continue to work with them unless he finds out they are abusing or selling the drugs.

SPIRITUALITY Spiritual issues may be important to the dying person, and this is one area where homeless people may have an advantage. Her discussions with homeless people revealed to Dr. Alexander that “homeless people have a strong dependence on spirituality and God. Their faith and belief in God carries them through despite lack of family and friends.” In his pilot study focus groups, Dr. Song found that religion is a source of strength for homeless people, even more so, he believes, than it would be among a cross-section of other populations.

Ecclesia Ministries, a street-based church without walls, comes to the Barbara McInnis House respite program at Boston Health Care for the Homeless every week. “We always ask patients if they want to see a chaplain, and it’s unusual for them to say, ‘no,’ says Director **Sarah Ciambrone, MS**. “Even if they doubt, they think, ‘I’ll cover all my bases.’”

CULTURAL TRADITIONS Health Care for the Homeless clinicians understand that attitudes towards health and illness are influenced by a person’s cultural heritage. Cultural traditions also are important in the rituals of death and dying, because “we die the way we live,” says **Walter B. Forman, MD, FACP, CMD**, Professor in the University of New Mexico’s Program in Palliative Care and Principal Investigator for a Robert Wood Johnson Foundation grant to build a hospice network for several diverse, multicultural communities in New Mexico. He discovered, for example, that the Navajo Indians don’t want to be told how to provide end-of-life care, but they do want to know about symptom management so they can modify selected techniques to fit their culture.

In Alaska, many Native elders were being flown to hospitals and nursing homes hundreds of miles away to die. The Robert Wood Johnson Foundation-funded Helping Hands Program changed that, by offering a blend of traditional medicine and modern health care to provide pain and symptom management for people who wanted to

die at home.¹¹ A storybook translated into English and Yup’ik, the Native language of many tribal elders, advises visitors to remove their shoes at the door, sit down to have tea and talk, and examine the patient in the presence of family and friends.

“The ultimate disgrace is when modern medicine applies what it believes to be its best and finest treatment to everyone in the same way,” says **Christine A. DeCourtney, MPA**, Cancer Program Planning and Development Manager for the Alaska Native Tribal Health Consortium. “People need what is comfortable and what they know to pass away in peace.”

ACHIEVING CLOSURE Death is often a time for reconciliation with loved ones, but for homeless people estranged from their families, closure may be difficult to achieve. Many homeless people don’t want their families involved in their final days because they fear becoming a burden, according to Dr. Song. Still, some level of resolution is possible. When this happens, says Ciambrone, “It’s evident how much loss and regret there is on both sides.”

SUPPORT FOR STAFF Despite the fact that HCH clinicians deal with death on a regular basis, projects may not have specific programs in place to help staff grieve. “Death can be so devastating, there’s no easy way to support people, but you have to recognize the challenge,” Dr. O’Connell says. **Pam Stein, LCSW-C**, a therapist/case manager at Baltimore HCH, took time off after she lost nine clients in several months. “I did art work and wrote a life story for each person who died,” Stein says. “By the time I finished, I felt I had done what I needed to do.”

The very act of providing comfort to a dying person can be therapeutic, according to Ciambrone. “It’s always difficult when one of our patients dies, but it’s helpful for staff to know they’ve given a person a supportive, nurturing, and dignified way to die,” she says. “If the person died alone in a hospital, he or she would be just another patient.” Often, staff who work with homeless people at the end of life become surrogate family members for their patients. However, they may be excluded from the rites of death by the patient’s real family members, who show up to make funeral arrangements.¹² This makes it more difficult for staff to grieve.

A PROFOUND AND MOVING EXPERIENCE Service providers who help people at the end of life find it anything but depressing. “Becoming involved in the process of dying can be a profound and moving experience,” Dr. O’Connell says. The skills HCH clinicians employ to help homeless people live better lives are the same skills needed to help their clients die well: education, patience, persistence, and establishing trust. “For many, terminal illness is a time of growth, reconciliation, spiritual circumspection, transcendence, and discerning meaning for a brief interval of physical existence,” writes Paul Rousseau, MD. “Shouldn’t the homeless have the same opportunity?”³ ■

Innovative Programs Provide Comfort to Homeless People

There is a balm in Gilead to make the wounded whole; There is a balm in Gilead to heal the sin-sick soul.

African American spiritual, based on Jeremiah 8:22

EASING SUFFERING IN BIRMINGHAM, ALABAMA The Balm of Gilead at Cooper Green Hospital in Birmingham, Alabama, is “a safety net within a safety net,” says founder Dr. F. Amos Bailey. Built in an abandoned wing of the county hospital, the Balm of Gilead is a 10-bed palliative care unit, the only inpatient unit providing end-of-life care in Birmingham, a city of 1 million people. Seventy percent of its patients are African American, and many are homeless.

The program, which was begun by the county and received support from the Robert Wood Johnson Foundation, also expands the county’s hospice program, allowing people without resources to be seen at home (even if home is under a bridge), in the hospital, and in nursing homes. Though it was never intended for people to stay at Balm of Gilead, one-third to 40 percent of the patients have died there. “Truly homeless people live at Balm of Gilead until they die unless another placement can be made,” Dr. Bailey says.

The Balm of Gilead works on the “suffering paradigm,” which presupposes that people who are ill have physical, emotional, social, and spiritual needs,” Dr. Bailey says. For each patient, medical staff rate 10 symptoms, including pain, on a scale from 0 to 5 and make a plan to manage them. At Balm of Gilead, pain is considered the “fifth vital sign,” after pulse, blood pressure, respiration, and temperature. When physical symptoms are under control, staff evaluate emotional, social, and spiritual needs and connect patients to appropriate support.

The Balm of Gilead isn’t just a humane way for people without resources to receive end-of-life care, it’s a cost-effective one. Dr. Bailey reports that a day at the Balm of Gilead costs from \$500 to \$700, compared to daily costs of \$2,000 a day for a regular hospital bed and \$5,000 for a bed in the intensive care unit.¹³

HELPING BOSTON HCH PATIENTS DIE WITH “FAMILY” The Barbara McGinnis House at Boston Health Care for

the Homeless began as a 25-bed, shelter-based respite program for people who needed to elevate a fractured leg or rest with the flu. However, with managed care dictating shorter hospital stays, patients at McGinnis House—which is now a 90-bed inpatient facility with 140 staff—“are more ill than they used to be,” says Director Sarah Ciabrone. Many are receiving outpatient chemotherapy and radiation; they have to be driven to these appointments and cared for when they return.

“There’s a lot to be said for the dignity this environment provides. This is an ideal place to be at the end of life, among people who care about you.”

—Sarah Ciabrone, Director, Barbara McGinnis House, Boston

Patients who have insurance typically are referred to hospice or palliative care programs at the end of life, Ciabrone says. But for people who have no other options, including undocumented immigrants, or for those who refuse to leave, McGinnis House is their home until they die. Six people have died at McGinnis House in the past 5 years.

Dr. Jim O’Connell remembers the first person to die at McGinnis House. “He begged us to stay because we were his family,” Dr. O’Connell says. Nurses volunteered their time to stay with him around the clock, and a local hospice program provided support.

Having someone die at McGinnis House absorbs a huge amount of staff time and emotional resources, Ciabrone acknowledges. Also, the medical respite program can’t provide pain management as sophisticated as that provided in a hospice or palliative care program. Still, Ciabrone says, “There’s a lot to be said for the dignity this environment provides. This is an ideal place to be at the end of life, among people who care about you.”

SERVING PEOPLE ON A CONTINUUM IN NEW YORK CITY The Supportive Care Program at St. Vincent’s Hospital in New York City, part of St. Vincent’s Catholic Medical Centers, serves “people who fall through the cracks,” says program Manager Eileen Hanley, RN, MBA. The program is supported by an endowment and fundraising and accepts no Medicare or Medicaid payments. “Because we’re not dictated by reimbursement, we can see people on a continuum,” Hanley says. “We maintain contact with the patient wherever he or she is receiving treatment.”

The Supportive Care Program was founded 25 years ago based on the hospice model, but with flexibility to provide services to people who may have more than 6 months to live. All of the program’s patients have serious and progressive illnesses that ultimately will result in death; most remain with the program for 8 months to a year. A team of nurses, social workers, and a chaplain provide psychosocial and spiritual support and limited clinical services.

Homeless people who are sheltered, ideally in a place they can remain for 24 hours a day, receive services from the program team. “What we provide homeless people is paying attention and caring,” Hanley says. “So often they’re invisible in our society.” She notes that people frequently want someone to talk to at the end of life, and speaking with a nonjudgmental stranger can be beneficial.

Because all of their patients eventually will die, the Supportive Care Program offers extensive support for staff. Every 6 weeks, an outside facilitator runs a support group for clinical staff. Staff also have informal potluck lunches, and they meet weekly to discuss new cases and concerns. Hanley says that recruitment and retention is not an issue; a year ago, the program hired its first new person in 8 years. “You get immediate gratification from helping a person through some very difficult issues,” she says.¹⁴ ■

Remembering Those Who Have Died

D'Ann Davis hasn't seen Dr. John Song's pilot study results, which indicate that homeless people fear dying in anonymity, but she's already doing something to alleviate that fear. Davis has been homeless for 2 years, and she is active in the Women in Black program sponsored by WHEEL (Women's Housing, Equality, and Enhancement League) and the Church of Mary Magdalene in downtown Seattle.

Women in Black began in 1988 when Israeli and Palestinian women stood together for peace. The group Davis is involved with stands, dressed in black, from noon to 1 p.m. on Wednesdays in front of the Public Safety Building. "We don't stand for every homeless person who dies, or we'd be standing every week," Davis says. "We stand for those who died outside, because they might still be alive if they had a better place to go. We do it to remember their lives and to call attention to the need for shelter."

BURIAL PRACTICES The Women in Black were present December 4, 2003, when King County paused to remember 200 homeless and impoverished men and women whose cremated remains were buried the day before at the Mount Olivet Cemetery in Renton. They were interred in a single vault, but each urn was labeled with the person's name and a number matching a file kept in the Medical Examiner's Office, in case family members turn up.

In contrast, people who die without family or resources in Birmingham are placed in a body bag and buried in a pauper's grave, according to Dr. F. Amos Bailey. Residents of the Balm of Gilead are buried with the Afghans made for them by members of local churches, and a garden club provides flowers and mourners. HCH clinicians advise their colleagues to form relationships with local churches, charities, and funeral homes, which may be able to donate reduced-price funerals, burial plots, and other services to help ensure a dignified service and burial for homeless people.

MEMORIALS AND REMEMBRANCES Many HCH projects have regular memorial services for their clients who have died, and

staff also participate in city or statewide remembrances, often held at the winter solstice as part of the National Homeless Persons' Memorial Day sponsored by the National Coalition for the Homeless.

Candles and Conversation. The Baltimore HCH project holds two in-house memorial services a year that feature a blend of religious traditions, says **Jan Caughlan, LCSW-C**, Coordinator of Mental Health and Case Management Services. "In Quaker style, we talk about each person, remembering what he or she was like and why we cared about them," Caughlan says. After the Jewish tradition of the Yahrzeit candle, which is burned for 24 hours on the anniversary of a person's death, each staff person takes home one of the candles that was burned for each of the individuals who died.

Photo by Abby Hale



A small but sturdy tree, planted to commemorate homeless people who have died in Burlington, Vermont, hangs onto some of its leaves on a cold winter day. The plaque in front is inscribed with a poem by an anonymous author:

"The strongest oak tree of the forest is not the one that is protected by the storm and hidden from the sun. It's the one that stands in the open, where it is compelled to struggle for its existence against the winds and rains and the scorching sun."

A Memorial Tree. In Burlington, Vermont, the Homeless Healthcare Project planted a tree on the library lawn, with a plaque commemorating homeless people who have died (see photo). "The plaque is inscribed with a beautiful poem given to us by a homeless person," notes **Abby Hale, PA-C**, Medical Coordinator at the Safe Harbor Clinic in Burlington.

A Silent March. Minnesota holds an annual statewide Homeless Memorial Service in Minneapolis, where HCH staff participate. In 2002, at the 18th annual service, some 150 people marched in silence carrying signs stating the name, age, and city of the people who died; the service itself is at a local church followed by a free community

meal. The 2002 service commemorated 95 people from around the State who had died, according to **Christine M. Reller, MSN, RN**, HCH Project Manager. The youngest was a 6-week-old girl and the oldest an 82-year-old man.

For more information on National Homeless Persons' Memorial Day, see the National Health Care for the Homeless Council's *Mobilizer* of December 9, 2003, at www.nhchc.org/mobilizer.htm or visit the National Coalition for the Homeless Web site at www.nationalhomeless.org/memorial96.html. ■

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- Balm of Gilead was the fourth in a four-part PBS series titled "On Our Own Terms" with Bill Moyers. For information on the series, visit www.pbs.org/wnet/onourown/terms/about/index.html. Video tapes of the series may be ordered by calling Films of the Humanities at (800) 257-5126.
- For more information about the Supportive Care Program, contact Eileen Hanley at ehanley@svcmcnyc.org. She also recommends the following Web sites for more information on end-of-life care: www.lastacts.org, www.growthhouse.org, and www.nhpc.org.

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