

Dying Well in Corrections: Why Should We Care

Journal of Correctional Health Care, 2002

**Ira R. Byock, M.D.
Research Professor of Philosophy
Director, Promoting Excellence in End of Life Care
University of Montana, Missoula**

ABSTRACT

Why should anyone care how convicts die? For some, humane treatment is the right thing to do, but others feel criminals deserve whatever happens. American courts have affirmed society's responsibility to provide a community level of care for prisoners. Many challenges confronting corrections in delivering excellent end-of-life care are similar to those facing the nation's health care system. Chronically ill and infirm elderly patients often feel imprisoned by their disease, disability and confinement within medical institutions. Prison hospices represent a constructive development. The staff and inmate volunteers that work in them have important lessons to teach our contemporary society.

Why Should We Care?

Dying in prison is what inmates dread most. They fear spending their last hours in agony, alone, separated from family outside and from friends within prison walls. Yet those worst dreams can come true for over 2,500 prisoners a year, who die manacled in hospitals or in prison infirmaries.

Why should we care where and how inmates die? This question is implicit whenever prison hospice or compassionate release is discussed in the media and with politicians. Many people would respond that we should care simply because prisoners are human beings and humane treatment is simply the right thing to do. Many Americans, however, feel that convicted murderers, rapists, child molesters, and drug dealers deserve whatever they get. If they die suffering, in pain and alone, so be it.

But turning a blind eye is not an option. American courts have forcefully distinguished punishment from brutality and have repeatedly affirmed society's responsibility to provide a community level of care for prisoners, most notably in *Estelle v. Gamble*. ("Estelle v. Gamble," 1976) The correctional discipline has incorporated this stance in guidelines and policy statements. The American Correctional Association's 1996 Task Force on Health Care in Corrections stated:

Correctional jurisdictions must utilize a comprehensive, holistic approach to providing health and mental health care services which are sensitive to the cultural, subcultural, age, and gender-specific needs of a growing and diverse population. All services provided must be consistent with contemporary health standards. (American Correctional Association, 1996)

Under the constant scrutiny of prisoners and advocate groups, federal and state institutions, which fail to honor their responsibility to provide adequate care, risk legal peril and fiscal liability. Consequently, excellent medical care in corrections is well aligned with society's (read taxpayers') best interests.

Why should we care how prisoners die? A more considered response is that we should care because all of us, even those of us who are well-to-do and strictly law-abiding, are at risk of winding up in similar circumstances as we approach life's end. There are striking similarities between being given a long prison sentence and receiving the diagnosis of a debilitating or terminal illness. More striking still are the similarities between imprisonment and the forced confinement of a stroke, multiple sclerosis, ALS, or the disability of an advanced illness (loss of function, independence, etc.).

In her book Refuge, Terry Tempest Williams (1991) writes of her mother's illness and death.

"I want you to read 'God Sees the Truth, but Waits,'" said Mother. "Tolstoy writes about a man, wrongly accused of a murder, who spends the rest of his life in a prison camp. Twenty-six years later, as a convict in Siberia, he meets the true murderer and has an opportunity to free himself, but chooses not to. His longing for home leaves him and he dies."

I ask Mother why this story matters to her.

"Each of us must face our own Siberia," she says. "We must come to peace within our own isolation. No one can rescue us. My cancer is my Siberia." (Williams, 1991)

When it comes to health care, dying prisoners are one category of a group we might call "the least among us." All of us, and every person we love, are at risk of entering that unfortunate group. Death has been called "the great equalizer"; so too are its cousins: illness, dementia, physical debility, and advanced age. From a sociologic perspective dying prisoners are more similar to other groups of people – such as those with Alzheimer's disease or advanced Parkinson's disease, or Huntington's disease, or serious head injury or paralysis – than different. People with such unenviable conditions are devalued by our culture. They are not viewed as useful to society in any practical sense and thus may be seen merely as a drain on society's resources. People who are most frail and elderly can be made to feel guilty by society, and at times even by their own families, for the crime of being seriously ill or debilitated and not dying quickly enough.

Jail is not the only place a person can be imprisoned. Even if one has never broken a law, a person who is seriously ill or physically dependent may end up feeling defenseless in an uncaring environment. Most Americans would like to be at home, surrounded by loved ones as they die. (Tyler, 1997) Yet fully 80% of Americans die in hospitals and nursing homes. When Goodlin and her associates examined the records of 104 patients who died in an academic medical center and an affiliated Veterans Affairs hospital, they found that 18% were in physical restraints within 48 hours of their death. (Goodlin, Winzelberg, Teno, Whedon, & Lynn, 1998)

Anna Mae Halgrim was one person who felt imprisoned by her age, disability, and her clinical environment. In an article published posthumously in Newsweek, Halgrim poignantly describes her life in a nursing home "from the inside."

I tried once or twice to make my feelings known. I even shouted once. That gained me a reputation of being "crotchety"... After I've asked for help more than a dozen times and receive nothing more than a dozen condescending smiles and a "Yes, deary, I'm working on it," something begins to break. That time I wanted to be taken to the bathroom.

I'd love to go for a meal, to travel again. I'd love to go to my own church, sing with my own choir. I'd love to visit my friends....

Something else I've learned to accept is loss of privacy. Quite often I'll close my door when my roommate – imagine having a roommate at my age – is in the TV room. I do appreciate some time to myself and I believe that I have earned at least that courtesy. As I sit thinking or writing, one of the aides invariably opens the door unannounced and walks in as if I'm not there. Sometimes she even opens my drawers and begins rummaging around. Am I invisible? Have I lost my right to respect and dignity? I am still a human being. I would like to be treated as one.

Did you ever sit in a wheelchair over an extended period of time? It's not comfortable. The seat squeezes you into the middle and applies constant pressure on your hips. The armrests are too narrow and my arms slip off. I am luckier than some. Others are strapped into their chairs and abandoned in front of the TV. Captive prisoners of daytime television....

The afternoon drags into early evening. This used to be my favorite time of the day. Things would wind down. I would kick off my shoes. Put my feet on the coffee table. Pop open a bottle of Chablis and enjoy the fruits of my day's labor with my husband. He's gone. So is my health. This is my world. (Halgrim, June 27, 1994)

Since at the end of life we are far more alike than different from one another, how we care for others may well determine how we are cared for ourselves.

Of course, ensuring a high quality of care for inmates as they die is easier said than done. Social trends have contributed to rising numbers of incarcerated people. The reasons are well known. Rising crime rates, the "war on drugs," more effective policing and prosecution, harsher sentences, "three-strikes-you're-out" laws, and other mandatory sentencing laws have put more people behind bars for longer times.

Chronic illness, psychiatric illness, developmental delay, and seizure disorders have historically been prevalent in prison. Now, swelling and aging inmate populations with high rates of drug abuse, hepatitis, HIV, cancer, heart and lung disease—even tuberculosis—are straining budgets to the breaking point.

Several factors complicate attempts to provide care and contribute to the suffering of dying inmates. Prisons are rife with personality disorders, racism, and gangs. Aggressiveness is an adaptive asset. Isolation and anger abound, and hostility finds fertile ground. Seeds of compassion among security personnel and inmates find little soil in which to take root. As illness-related disability progresses, an inmate becomes vulnerable in this environment. Isolation cuts patients off from family outside, and even from "family" and friends inside. Security rules, including precautions to curtail diversion of medications, may result in limited access to narcotic analgesics on which hospice and palliative care rely. Inmate distrust of corrections causes tension between inmates and providers.

Correctional physicians' expertise in palliating symptoms and counseling individuals confronting life's end also may be limited. Continuity of care is not easy to achieve. Plans of care may not be followed; what worked the last few days may be changed by the doctor coming on shift who wants to do it his way.

The situation confronting correctional end-of-life (EOL) care is more critical, but the obstacles are not fundamentally different from many pervasive barriers encountered in striving to provide excellent health care for dying Americans. The Institute of Medicine's 1997 report, Approaching Death, points to serious deficiencies in medical education, in health systems financing, and in attitudes and culture, and cites extensive errors of omission and commission in clinical practice. (Field & Cassell, 1997) Physical pain, for all our medical prowess, remains poorly treated, even in prestigious medical institutions, as a series of studies, including the widely referenced SUPPORT study, make clear. (SUPPORT Principal Investigators, 1995) Another study, looking at pain treatment in the nation's nursing homes, concluded that 42% of the 4,000 studied were seriously undertreated, either receiving no pain medication (26%) or as little as one dose a day of acetaminophen or aspirin (16%). (Bernabei et al., 1998) Studies in outpatient cancer clinics and HIV clinics have yielded similar results. In each, around 40_50% of patients were found to be undertreated. (Breitbart et al., 1996; Cleeland et al., 1994) The aging of the baby boomers, the increase in prolonged chronic illnesses, and the shrinking pool of caregivers threaten to make today's crisis much worse.

All this casts a bright light on the need for creative, bold new approaches—a shift in our cultural orientation towards life's end. How we care for the most disadvantaged, frail, elderly, and ill among us is the central social and moral challenge confronting our generation. To build solutions, it is important to consider what success would look like: in a patient's life, in our clinical practice, and in our careers as corrections professionals.

Success in EOL care would look a lot like palliative care. Hospice and palliative care are often used as synonyms. As I define them, palliative care is a discipline of practice; hospice is a way of delivering that discipline. The elements of palliative care are encompassed in hospice standards (National Hospice Organization Standards and Accreditation Committee, 1997) and the Last Acts Task Force's "Precepts of Palliative Care." (Last Acts Task Force, 1998) Palliative care:

- involves respect for patient autonomy and the role of family and legal surrogates in making decisions for patients when they cannot.
- involves an interdisciplinary team approach.
- cares for the individual who is dying with his or her family and close friends.
- focuses and depends on effective and, when necessary, intensive symptom management. No modality is withheld in service of comfort and quality of life.
- is distinguished from the best of general medicine in understanding that dying is a time of life, part of the human life cycle. Improving quality of life is therefore a primary goal.
- recognizes that a patient's inner life often comes to the fore as death comes near, and extends support for this realm of the person's experience.
- extends to bereavement support for families and understands the importance of funerals and memorials. (It is gratifying that bereavement programs are a prominent part of prison hospices around the country.)

Sometimes palliative care is equated with symptom management, but they are different. Symptom management is the first priority for palliative care; until clinicians get some control of symptoms, patients often are not able to attend to anything else. Their symptoms command attention; managing them can be difficult, requiring intensive care. But while pain management is the first priority, it is not the ultimate goal. Palliative care recognizes that dying is more than a set of medical problems to be solved. Dying is personal; it is experiential. Care for people who are dying helps them to say and do the things that matter most to them.

The period of living we call “dying” holds important opportunities for communication, for completing relationships, even reconciling strained relationships between family members, former spouses, or close friends. Beyond this, there is a chance to tell one’s stories and review one’s life, to make a unique contribution to the family legacy, and for those around the dying person to listen and receive, to affirm for the person departing the value of their being and their story. And there is a chance to explore soulful and spiritual aspects of life, those deeper questions of meaning and connection inherent in the human condition. (Byock, 1996, 1997)

“Family” in this circumstance is not defined by marriage or bloodline alone, but by the phrase “for whom it matters.” Family needs are simple to define in palliative care. Families need to know their loved ones received the best care possible: life-prolonging care, palliation of symptoms, and care for quality of life. Families need to know that their loved ones’ preferences for care were honored and that they were treated in a dignified manner, that they had the chance to say and do the things that mattered most to them. And families need to feel that their loved ones were not only cared for in a competent medical way, but in a way that honored and even celebrated them. Finally, families usually need time to grieve together.

We know what real excellence in EOL care looks like. It’s part of the culture; it is conveyed by the phrase, tender loving care.

Mark Wilson, serving a life sentence at Oregon State Penitentiary, has written about his experience as a hospice volunteer for a fellow inmate dying of muscle cancer.

I knew that Benito’s death would be very painful for me if I allowed myself to get close to him. But keeping my distance or imposing boundaries on our relationship were never options for me. I wanted and needed to open my heart completely, to be there for him unconditionally, no matter how painful it might be for me in the end.

When Benito was overcome by fear of pain, I stayed through the night when I could. Sometimes we talked all night; sometimes I spent the night supporting his head with a pillow as he tried to nap in a wheelchair, the least painful position for him. Sometimes I massaged knots out of tight, pain-ravaged muscles, and sometimes I just sat quietly next to him so he wouldn’t be alone.

Benito’s trust in me grew and our bond deepened as we spent countless hours talking about the things that mattered most: family, love, memories, fears, regrets, spiritual questions, pain, cancer and death.

He gave me a gift that I will treasure until the day I die when he said, “A month ago I didn’t know you existed, but now you are my family.”

A hospice vigil began for Benito [when] it was believed that he was within 48 hours of death. His family was escorted to the infirmary where they joined Benito and me. We were with him around the clock, comforting him by placing cool washcloths on his forehead, fluffing his pillows, holding his hand and doing anything else we thought might ease his suffering.

I attempted to stay in the background as the family shared their intimate stories, laughter and love, tears and pain. But as the four of them were saying their good-byes, Benito called for me. Without hesitation, his family opened their hearts and allowed me to share in this profoundly intimate moment. We hugged and cried as each of us told Benito how special he was to us and how much we were going to miss him.

Gradually he slipped into a coma-like state. We were all aware that he was about to die. Yet there was a deep sense of peace and resolve among us. We wanted him to know that we were all still with him. None of us wanted to leave his side. It was a rare moment that we all weren't touching him. Benito passed away at 9:20. (Wilson, 2000)

In contrast to the vision that inmates have of dying inside, the process of dying amidst love can liberate people, creating a space of freedom inside as they die. That's what success looks like.

How do we get there from where we are? Having professional standards helps. Formal standards claim the high ground, giving us guidelines for building programs. The 1996 American Correctional Association Task Force Report called for the establishment of hospice services for terminally ill offenders supported by a compassionate release program for those who qualify. Each correctional jurisdiction shall have written policies and defined procedures in support of a program to provide for the treatment and disposition of offenders with terminal illnesses. (American Correctional Association, 1996)

This need is emphasized by the GRACE Project standards (GRACE Project, 2000), and in the March 2001 Health Resources and Services Administration funded task force report on Improving Palliative Care Practice in Jails and Prisons (Dubler & Post, 2001) and the National Commission on Correctional Health Care Draft Standards (National Commission on Correctional Health Care, In Draft). Statements such as the Last Acts "Precepts of Palliative Care" (Last Acts Task Force, 1998) and the American Geriatrics Society 1997 statement "Measuring Quality of Care at the End of Life" (American Geriatrics Society, 1997) offer basic outlines and domains of quality for protocols and for education of clinicians, security personnel, and administration, as well as of the public and legislators.

As we integrate professional and institutional standards into our programs, we need to encourage collaboration. However, while we work together, we must also keep our roles distinct. Prison chaplains do not perform well as jailers, and security personnel cannot provide clinical care.

We need to discern domains of quality and not only measure conformity with standards, but also distinguish excellent care from merely mediocre care. Measurement tools can be embedded in institutional quality improvement programs. Dynamic corrections requires continual improvement, and measurement allows us to

use data to increase program effectiveness and improve our discipline. Measurement also helps fiscal accountability.

DOC administrators and managers will find hospice programs positive and cost-effective. By providing high quality care that measurably conforms to community standards, the correctional system also will earn some protection from legal allegations of deficient care.

The prospect of dying inmates actually receiving not only medically competent but genuinely compassionate, loving care seems implausible. Yet thirty-five or more programs currently exist or are in development, most experiencing real success. Courageous but also cautious wardens and leaders within departments of corrections have supported them without sacrificing the priorities of detention, safety, and security. Hospice leaders have reached out to correctional staff, sharing expertise and resources. Clinicians caring for inmates have exhibited true professionalism in adapting hospice to their environments. But most credit belongs to the inmate volunteers, whose efforts and commitment are extraordinary.

Visiting with prison hospice volunteers and correctional staff has reminded me of William Golding's classic novel, Lord of the Flies. In this story about adolescents stranded on a remote island and stripped of the usual constraints of civilized life, cooperation gradually gives way to competition, conflict, and aggression. Penitentiaries are islands within our society, where isolation, anger, and hostility abound. Choices between cooperation and conflict are made daily. Yet prison hospices are the opposite of Golding's chaotic island.

Inmate volunteers attest the remarkable transformative effect of hospice work:

I have learned that life is precious and so is what I do with it. Life is a beautiful gift and without the men who showed me death, I might never have learned to live.... Hospice work has opened my heart. It has given new vision. It has changed part of my nature.... I care more for people now.

I volunteered for hospice because I saw it as an opportunity to do something positive for someone else which in turn allows me to feel better about who I am. My motivation now comes from what I see in a patient's eyes as I enter the room. I know that if I'm of no value to anyone else, I am of value to him.

There are evil people in the world, and many inmates we meet have been guilty of vicious acts. No amount of good deeds can exonerate an inmate or make up for murder or other crimes of violence. But recognizing the presence of evil, I also recognize where it is not. Whatever they did and however wicked they may have been in the past, the patients and hospice volunteers I have met are far from evil now.

Clinicians do not have to reconcile issues of legal or metaphysical guilt before caring for patients or families. Such considerations are irrelevant to the task of caring. Genuine palliative care entails preserving the capacity of patients and families to grow through the end of life. Prison hospice workers observe personal qualities of openness, honesty, and tenderness in patients and volunteers. Ironically, these are qualities associated with childhood innocence. We do not have to reconcile philosophical or metaphysical issues of guilt and innocence to recognize that real

transformations do happen. Acceptance of this fact is distinct from issues of legal guilt. Acknowledging genuine, positive change in an inmate does not require society to modify his or her sentence. We can recognize people for who they are, today, and respect and encourage their remarkable work.

Sometimes life's most profound lessons come from unexpected places. Prison hospices programs have something important to teach. It is worth examining why, in aggressive and predatory prison environments, inmates are choosing to work together, without recognition or material reward, to care for one another and to build a civil community.

Their compassion and hours of work are evidence of goodness within the human condition where one would least expect to find it. Their commitment to one another is a declaration of value and dignity in every human life and a vow to build a better future right where they live. We all have something to learn from that.

Acknowledgements:

I would like to thank Elizabeth Craig and Robert E. Craig for their extensive assistance in editing this manuscript. This was support in part by Promoting Excellence in End of Life Care, a national program of the Robert Wood Johnson Foundation.

References:

American Correctional Association. (1996). Public policy on correctional health care. Lanham, MD: American Correctional Association.

American Geriatrics Society. (1997). Measuring quality of care at the end of life: A statement of principles. Journal of the American Geriatrics Society, 45, 526-527.

Bernabei, R., Gambassi, G., Lapane, K., Landi, F., Gatsonis, C., Dunlop, R., Lipsitz, L., Steel, K., & Mor, V. (1998). Management of Pain in Elderly Patients with Cancer. Journal of the American Medical Association, 279(23), 1877-1882.

Breitbart, W., Rosenfeld, B. D., Passik, S. D., McDonald, M. V., Thaler, H., & Portenoy, R. K. (1996). The undertreatment of pain in ambulatory AIDS patients. Pain, 65, 243-249.

Byock, I. R. (1996). The nature of suffering and the nature of opportunity at the end of life. Clinics in Geriatric Medicine, 12(2), 237-252.

Byock, I. R. (1997). Dying Well: The prospect for growth at the end of life. New York: Riverhead, Putnam.

Cleeland, C. S., Gonin, R., Hatfield, A. K., Edmonson, J. H., Blum, R. H., Stewart, J. A., & Pandya, K. J. (1994). Pain and its treatment in outpatients with metastatic cancer. New England Journal of Medicine, 330(9), 592-596.

Dubler, N., & Post, L. F. (2001). Improving Palliative Care Practice in Jails and Prisons. Rockville, MD: Health Resources and Services Administration.

Estelle v. Gamble. (1976). US (Vol. 429, pp. 97).

Field, M. J., & Cassell, C. K. (1997). Approaching death: Improving care at the end of life. Washington, DC: National Academy Press.

Goodlin, S., Winzelberg, G. S., Teno, J. M., Whedon, M., & Lynn, J. (1998). Death in the hospital. Archives of Internal Medicine, *158*, 1570-1572.

GRACE Project. (2000). Standards of practice for end-of-life care in correctional setting. Alexandria, VA: Volunteers of America.

Halgrim, A. M. (June 27, 1994). My Turn. Newsweek, 11.

Last Acts Task Force. (1998). Precepts of palliative care. Journal of Palliative Medicine, *1*, 109-112.

National Commission on Correctional Health Care. (In Draft). End of Life Care. In Standards for Health Services in Prison. Chicago, IL.

National Hospice Organization Standards and Accreditation Committee. (1997). A pathway for patients and families facing terminal disease. Arlington, VA: National Hospice Organization.

SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. Journal of the American Medical Association, *274*, 1591-1598.

Tyler, B. A. (1997). The quest to die with dignity: An analysis of Americans' values, opinions and attitudes concerning end-of-life care. Appleton, WI: American Health Decisions.

Williams, T. T. (1991). Refuge: An unnatural history of family and place. New York: Pantheon Books.

Wilson, M. (2000). personal communication.
