

Palliative Care Volunteers: *A Program of Compassion*

By Art Beeler

Author's Note: *The views expressed in this article are those of the author and do not necessarily represent the views of the Department of Justice or the Federal Bureau of Prisons.*

When the Federal Medical Center in Butner, N.C., opened in 2000, staff knew one of the facility's missions was to treat cancer patients. However, it is doubtful that many patients gave thought to the significant number of deaths that accompany oncology treatment. Since beginning oncology treatment in 2002, the Federal Medical Center has provided almost 28,000 treatments to more than 2,100 patients. During fiscal year 2005 (Oct. 1, 2004, to Sept. 30, 2005), there were 765 patients treated with radiation and/or chemotherapy oncology. During calendar year 2005, the center experienced 110 deaths, with 77 (70 percent) attributed to cancer. There is no doubt this high number of deaths has had an impact upon the psyche of this prison hospital. Many different work groups have been formed to provide ways for coping with death and dying with dignity in the prison environment. No matter the suggestion, the issue of providing reconciliation and dignity for the inmates rises to the top, along with affording compassion to staff.

Although not extensive, literature on prison hospice and palliative care universally suggests similar things when dealing with deaths of inmates and using inmate volunteers to assist. Linder et al. indicate that inmate volunteers must identify and enhance their interpersonal communication skills to include listening, increasing tolerance for various beliefs without judgment, developing the ability to empathize with those who are dying and managing appropriate self-care.¹ This may not be particularly earth-shattering in a community hospital or hospice setting, but in a prison environment, it may be.

Shortly after opening in 2000, the Butner medical center developed an interdisciplinary group comprising nursing, religious services, correctional services and psychology services to determine if and how to develop inmate volunteers to assist with those who were dying. Since staff had not yet experienced a death during this time, and given the immediacy of day-to-day activities, it was very difficult to get them to view the development of a program to deal with death and dying as a priority. However, staff were fortunate to have had a psychologist, primarily assigned to the medical unit, and an assistant director of nursing, as well as a supervisory chaplain who understood the

significance of the dying process. Without the foresight of these champions, it is doubtful the medical center would have an effective program or the ability to adapt to meet new and challenging needs. With time, custody staff agreed with the need of having a palliative care program but continued to be skeptical of the process.

Inmate Involvement

Eventually, a group of palliative care inmate volunteers was established. This group of inmates is trained in the needs of dying patients, in developing empathy, in understanding boundaries and in assisting with reconciliation. There is also a great deal of discussion about self-care and the need for supportive therapy for inmate workers. Setting boundaries is the single most important distinction between a hospice activity in the community and in prison. As staff are teaching this pro-social activity to those who volunteer, they must always be on the lookout for the inmate who desires to become a part of the process just to take advantage of the inmate who is dying. Although staff have experienced boundary violations, they found the best remedy is quick and certain accountability. When staff

suspect and find an inmate who, for example, charges canteen for letter writing or for assisting in some other activity, they terminate the palliative care volunteer immediately. Because the Butner medical center is an administrative facility housing all classifications of offenders, outsiders tend to think those who are penitentiary inmates would be the most manipulative; however, staff have found those who have cause problems are typically low-custody offenders.

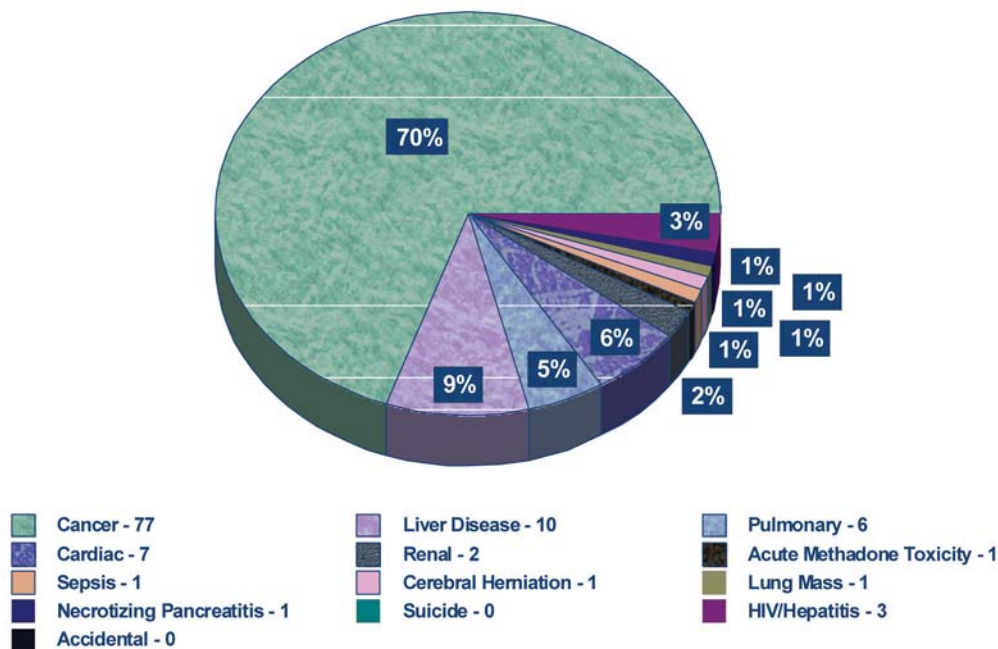
Developing reconciliation has been perhaps one of the most rewarding parts of the palliative care program. Inmate workers have assisted the patients in bridging communications with estranged family members, allowing for a realization of acceptance before dying. In some cases, it is the palliative care volunteer who, through correspondence, becomes the link between the family and the dying inmate. Quite often, the inmate patient becomes too weak to write and the palliative care volunteer writes to the family. This is in addition to staff updating the family when an inmate illness warrants end-of-life discussions. One of the most poignant examples of this came from the family member of an inmate who was released on compassionate release and died nine days later. His palliative care worker shared a letter from his wife who indicated that the family was grateful he was released, but was equally grateful that there was someone there with him during the time he was in the

Developing reconciliation has been perhaps one of the most rewarding parts of the palliative care program.

inpatient unit. For those who do die in prison, one of the most frequently asked questions from family members is, "Did he die alone?" The palliative care worker who sits with the dying inmate during his illness is often the person who is with the patient when he passes. It did not take staff long to acknowledge the significance of providing the comfort to the family by having someone with their loved one.

The palliative care workers are now buttressed by hospice volunteers from the community, and while staff certainly appreciate the service they provide to the dying offender, they do not visit around the clock, at 3 a.m. or on Sunday afternoons. This comfort is provided by those inmates trained in palliative care. An aspect often overlooked is the emphasis not only on the inmate who is dying, but the caregiver himself. Anyone who has served as a caregiver knows the toll such activities take. Additionally, for many inmates providing palliative care, this is the first time he has been involved in such a pro-social activity. The coping mechanisms for handling personal stress are taught during regular debriefing sessions. A psychologist spends a significant amount of time making sure debriefs are constructed in a meaningful manner. Not only do staff endeavor to validate the dying inmate's emotions, they endeavor to validate the palliative caregiver's emotions.² This helps to enhance the end-of-life care they attempt to provide. Staff

Causes of Death at FCC Butner Jan. 1, 2005 - Dec. 31, 2005



have even seen palliative care workers reconcile with their families while working with others.

Lessons Learned

This article has concentrated on what the inmate volunteers do in palliative care activities because they are the success of the program, which could not be provided without them. However, as much as these inmates and the staff who provide oversight have done, palliative care workers have also learned much. One such lesson is to emphasize advanced directives, which are documents signed by an inmate entering inpatient status, expressing his wishes for treatment. Often, advanced directives become do-not-resuscitate and do-not-intubate orders that are given at the end of life. As the prison population ages, all correctional agencies will need to re-examine policies on advanced directives. A second lesson learned is that space should have been devoted to a true hospice area, rather than providing palliative care within the inpatient environment. A multidisciplinary group is in the process of determining if the facility can segregate those who need "true" hospice care. Staff will continue palliative care for others, no matter their housing arrangement. Another lesson is the essential nature of keeping everyone not only involved in the process, but informed of issues no matter how trivial. As anyone who works in a prison knows, there are no secrets, but misinformation runs rampant. The need to communicate, especially with correctional staff when any aspect of the program or a caregiver becomes suspect, is essential to maintaining credibility. The communication need not be with the captains, but with the line officers as they are the employees supervising the process on a day-to-day basis.

Why do staff at the Federal Medical Center in Butner, N.C., care about providing palliative care to dying inmates? Simply put, it is the right thing to do. In a more philosophical context, is this not what anyone would want for his or her family member if he or she was dying in prison? According to Jonathon Turley who is a law professor at Georgetown University and the founder of Project for Older Prisoners, an advocacy group supporting the needs of geriatric offenders, corrections will experience an increase in inmate deaths. He relates that in the past 20 years, the population of older

Sample Training Schedule for Inmate Palliative Care Volunteers

First Day	
8:30 a.m.	Introduction/Curriculum Review/History of Palliative Care
9:30	Compassionate Release Program
10:30	End-of-Life Issues/Communicating With the Terminally Ill
11:30	Lunch
12:30 p.m.	Nutrition Issues With Chronic/Terminal Patients
1:00	Pain Management/Course of Medical Illness/Comfort Measures
1:30	Correctional Issues/Rules and Regulations/Logistics
2:00	Universal Precautions
2:30	Nursing Care With Chronic/Terminal Patients
3:00	Spiritual Care of the Terminally Ill/Grief and Bereavement
3:30	End of Day 1 Training/Return to Units
Second Day	
11:30 a.m.	Presentations by Current Palliative Care Volunteers/Role Playing
1:30 p.m.	Presentations/Role-Playing Continued Questions and Answers
3:00	Closing Remarks/Issuance of Certificates
3:30	End of Training/Recall

The affirmation of life given by providing comfort and dignity to those who are dying not only is the right thing to do, it is the only thing to do.

inmates has grown 750 percent, with no end in sight.³ The Butner palliative care volunteers provide comfort to inmates who are dying, often serve to bridge reconciliation with family members and learn about themselves in the process. The affirmation of life given by providing comfort and dignity to those who are dying not only is the right thing to do, it is the only thing to do.

REFERENCES

- ¹Linder, J., J. Blais, S. Enders, S. Melberg and F. Meyers. 1999. Palliative education: A didactic and experiential approach to teaching end-of-life care. *Journal of Cancer Education*, 14(3):154-160.
- ²Taylor, S. 1988. A thoughtful word, A healing touch. *Modern Maturity*. p.11-13. (December 1988-January 1989).
- ³Gutierrez, K. 2005. Aging out of crime: Geriatric facilities in the United States. *Fortune News*, XLI (11): 14.

Warden Art Beeler, MGA, works at the Federal Medical Center in Butner, N.C. He is responsible for overseeing medical and mental health care provided at the facility. He can be contacted at abeeler@bop.gov.