

HOSPICE AND PALLIATIVE CARE IN PRISONS

Special Issues in Corrections

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Background: The Hospice Movement

The nationwide hospice movement addresses the special needs of the terminally ill. Focusing on managing pain rather than curing illness, hospice programs emphasize humane care designed to provide the best quality of life for the terminally ill. The commitment of hospice programs is to make the patient comfortable; to provide "palliative care" rather than to cure the underlying disease.¹

According to the National Prison Hospice Association, hospice "is an interdisciplinary comfort-oriented care that allows seriously ill and dying patients to die with dignity and humanity with as little pain as possible in an environment where they have mental and spiritual preparation for the natural process of dying."

Hospice programs provide a wide array of services, including pain management, spiritual support, and psychological counseling, as well as grief counseling for bereaved families.

Over the past decade, hospice programs have become increasingly common in communities around the country. The movement is also slowly gaining a foothold among state, federal, and municipal prison administrations.

1. The Palliative Care Council of South Australia defines palliative care as care which relieves pain and distress, given when treatment to cure an illness is no longer effective. The goal of palliative care is to achieve the best quality of life for terminally ill patients. See <http://www.pallcare.asn.au/dwd.htm>.
2. National Prison Hospice Association, 1998. See <http://www.npha.org>.

Prison administrators develop formal hospice programs primarily to enhance the quality of care given to dying inmates. According to Elizabeth Craig of the National Prison Hospice Association, "Hospice care is known to be effective in providing a compassionate environment for dying persons and their families. In general, the cost of hospice care is less than that of traditional treatment."

In addition, a growing number of inmates are dying in prisons. Two primary factors are behind this increase: the prevalence of HIV infection in prison populations, and the imposition of longer prison sentences as a result of tougher sentencing laws.

Project Method

A 1997 NIC Information Center study provided an initial look at care for terminally ill inmates. (See "Prison Medical Care: Special Needs Populations and Cost Control.") This follow-up report further explores the topic, with particular attention to the implementation of a formal hospice program within secure facilities. Each study was undertaken at the request of the NIC Prisons Division.

Information for this report was provided via written surveys completed by 53 correctional jurisdictions: corrections departments (DOCs) in 47 states and the District of Columbia; the U.S. Bureau of Prisons and the Correctional Service of Canada; the Philadelphia

3. Elizabeth Craig, National Prison Hospice Association Newsletter, 1998. See <http://www.npha.org/execdir.html>.

Prison System; and the correctional systems in Guam and the Virgin Islands. In most instances, surveys were completed by either central office personnel or institution-based medical staff. Telephone follow-up contacts were made with medical or other staff in several agencies.

The 1997 Information Center study identified 24 DOCs as providing hospice care to terminally ill inmates. The present study, predicated on a definition of a "formal" hospice program as one that is governed by specific policies and procedures, identified hospice programs in only 12 agencies. Project staff contacted several agencies to confirm that most discrepancies in the two studies' findings are due to the present study's distinction between "formal" hospice programs and the informal, ad hoc provision of hospice-like services. One state-level and one large urban DOC that reported use of a hospice model in 1997 did not respond to the 1998 survey.

Numbers of Terminally Ill Inmates in Prison

The present study found that most DOCs do not keep complete data on the placement of terminally ill inmates. Available information indicates that most inmates identified in 1997 with terminal illnesses were receiving care in non-hospice settings:

- Nationally, 824 terminally ill inmates were placed in regular DOC infirmaries or prison hospitals.
- 152 terminally ill inmates were placed in formal hospice settings within the correctional system.
- At least 96 inmates were released from prison on parole or another form of compassionate release. A few states, including some of those that also have formal hospice programs, tend to emphasize the release of terminally ill inmates under compassionate parole or other arrangements.

Availability of Hospice Care in Prisons

Hospice care provided within prison settings can be described along a continuum from a formal hospice program to no program. Table 1, page 3, depicts

DOCs' current involvement in providing or planning for hospice programs.

About half of the responding agencies reported involvement or interest in the hospice model:

- **Formal prison hospice programs in operation-** Twelve (12) DOCs, including 11 state agencies and the Federal Bureau of Prisons, have instituted a formal prison hospice program at one or more sites.
- **Formal prison hospice programs being developed-** Eight (8) correctional agencies are now developing formal hospice programs. These include four state DOCs initiating their first prison hospice programs, two state DOCs developing additional hospices, one municipal prison system, and the Correctional Service of Canada.
- **Hospice care being considered-** Twelve (12) DOCs are considering the development of a formal hospice program. These agencies include 11 that have no current formal hospice program and one DOC (Louisiana) that is considering the creation of a third formal hospice, this one in a women's prison.
- **Other palliative care being provided-** At least nine DOCs are offering some form of palliative care outside a formal hospice setting. (Because the survey did not specifically request information on informal hospice/palliative services, there may be more DOCs that provide such services.) Most of these agencies also have a formal hospice program operating at another site, are actively developing a formal program, or are considering development of a formal hospice program.
- **No hospice services-** Nineteen (19) DOCs do not have a hospice program or other form of palliative care and did not report any plans for either.

Formal Prison Hospice Programs

Eleven state DOCs and the Federal Bureau of Prisons have established formal prison hospice programs. States include California, Colorado, Illinois, Louisiana, Maryland, Missouri, New York, North Carolina, Pennsylvania, South Carolina, and Texas.

Table 1. Agencies' Level of Involvement in Provision of Formal Hospice Care

	Formal Hospice Program in Place	Formal Hospice Program Being Developed	Formal Hospice Program Being Considered	Other Palliative Care Being Provided	No Hospice Services
Alabama					✓
Alaska					✓
Arizona					✓
Arkansas					✓
California	✓				
Colorado	✓				
Connecticut					✓
Delaware				✓	
D.C.		✓			
Florida				✓	
Georgia			✓	✓	
Hawaii			✓		
Idaho					✓
Illinois	✓				
Indiana			✓		
Iowa					✓
Kansas		✓		✓	
Kentucky				✓	
Louisiana	✓	✓	✓		
Maine					✓
Maryland	✓				
Massachusetts			✓		
Michigan				✓	
Minnesota					✓
Mississippi					✓
Missouri	✓				
Montana			✓		
Nebraska				✓	
Nevada					✓
New Hampshire					✓
New Jersey		✓			
New Mexico			✓		
New York	✓			✓	
North Carolina	✓				
North Dakota					✓
Ohio	No information available				
Oklahoma			✓		
Oregon		✓			
Pennsylvania	✓				
Rhode Island					✓
South Carolina	✓				
South Dakota					✓
Tennessee				✓	
Texas	✓				
Utah			✓		
Vermont			✓		
Virginia	No information available				
Washington			✓		
West Virginia					✓
Wisconsin			✓		
Wyoming					✓
U.S. BOP	✓				
Canada		✓			
Guam					
U.S. Virgin Islands					
Philadelphia Prison System		✓			

Table 2, below, indicates the locations of 28 formal hospice programs in operation in U.S. prisons and identifies the types of housing used for terminally ill inmates.

- In five state DOCs and the Federal Bureau of Prisons, regionally located facilities provide the hospice programs. Formal hospice care in the

Federal Bureau of Prisons is delivered in six regional medical referral centers.

- In six state DOCs, formal hospice care is provided at a single facility.

Inmates receiving hospice care are housed in both single-cell and multiple-bed settings, as determined by a variety of factors.

Table 2. Provision of Formal Prison Hospice Care

	Facility Name and City	Location of Program Within Facility	Patient Housing
California	California Medical Facility, Vacaville	Separate unit in general population of medical facility	Single and double cells
Colorado	Colorado Territorial Facility, Cañon City	Non-separate housing in infirmary	Single and double cells
Illinois	Dixon Correctional Center, Dixon	Non-separate housing in infirmary or general population	Double cells
Louisiana	Louisiana State Prison, Angola	Non-separate housing in infirmary	Single and double cells; single for maximum security inmates or those requiring medical isolation
Maryland	Maryland Correctional Institution for Women, Jessup	Separate housing in infirmary	Double cells
	Baltimore City Correctional Center, Baltimore		
Missouri	Moberly Correctional Center, Vandalia	Variety of settings	Single cells when possible, or double cells
	Potosi Correctional Center, Mineral Point		
New York	Greene Correctional Facility, Coxsackie	Separate housing in regional medical unit	Single cells or double hospital room
North Carolina	Central Prison Hospital, Raleigh	Separate housing in infirmary	Double cells
	McCain Hospital, McCain		
Pennsylvania	State Correctional Institution–Waymart	Non-separate housing in infirmary	Single and double cells
South Carolina	Allendale Correctional Institution, Fairfax	Variety of settings; at Kirkland, in infirmary only	Single and double cells
	Broad River Correctional Institution, Columbia		
	Kirkland Correctional Institution, Columbia		
	Lee Correctional Institution, Bishopville		
	Lieber Correctional Institution, Ridgeville		
	Perry Correctional Institution, Pelzer		
Women’s Correctional Institution, Columbia			
Texas	Michael Unit, Tennessee Colony	Separate 20-bed facility	Single cells
	Stiles Unit, Beaumont	Non-separate housing in infirmary	
	Clements Unit, Amarillo		
U.S. Bureau of Prisons	Federal Medical Center, Ft. Devens, Mass.	Private medical units in regional medical referral centers	Single cells
	Federal Medical Center, Rochester, Minn.		
	Federal Medical Center–Carswell, Fort Worth, Tex.		
	Federal Medical Center, Lexington, Ken.		
	Federal Medical Center, Fort Worth, Tex.		
	U.S. Medical Center for Federal Prisoners, Springfield, Mo.		

Licensure. Two state DOCs' hospice programs are licensed by state agencies, and licensure will soon be sought in a third state.

- In Colorado, the Department of Health licenses the DOC's hospice program, and in California the Department of Health Services, Licensing, and Certification grants the license.
- The hospice program run by the Louisiana DOC is not licensed but is structured under the standards of the National Hospice Organization, and officials are planning to apply for a state license.
- In New York State, where the DOC hospice program is closely affiliated with a community hospice, the program is not state-licensed, but Medicaid and Medicare authorize payment for hospice services to inmates.

Policies. All 12 formal hospice programs are governed by specific policies and procedures; the Missouri DOC's policy is currently in draft form. Policies address criteria for admission, special privileges for terminally ill inmates, requirements for housing in hospice settings, and "do not resuscitate" orders, among other issues. Copies of some of these policies were provided by survey respondents and are available from the NIC Information Center.

- **Admission procedures-**The decision to admit an inmate to a prison hospice program is, in about half the states, made jointly by medical and security staff or by medical staff and the hospice coordinator. In the remaining programs, the decision is made by medical staff only or through physician referral to the hospice team. Admission to a prison hospice program generally requires a doctor's certification that the patient has a terminal condition with an approximate life expectancy of 6 months or less if the illness runs its usual course. Participants are required to sign informed consent statements, whose provisions vary by location.
- **Special privileges for terminally ill inmates-**All DOC hospices grant terminally ill inmates special privileges intended to make them more comfortable and to provide emotional support. The most common of these privileges is a relaxed visitation

policy. In the Louisiana DOC, for example, "family" is defined by the inmate and may include "persons within or without the prison who are not related to the patient by blood." Hospice residents often can keep additional personal property, are provided special diets, and may make special food requests. Privileges in some DOCs include smoking rights and the services of clergy and social workers, as well as the opportunity to participate in planning their memorial services.

- **Housing options-**Ten (10) agencies allow inmates who have signed up for the hospice program to remain in the general population as long as their conditions allow. However, policies in the Louisiana DOC and the Federal Bureau of Prisons require hospice participants to move, on acceptance into the program, to the central or regional site at which hospice care is provided. In the South Carolina prison system, which operates seven hospices, an effort is made to place terminally ill inmates in the hospice closest to their families.
- **"Do not resuscitate" orders-**Half the DOC hospice programs currently require participating inmates to sign "do not resuscitate" orders as a condition of their participation in the hospice program. The Illinois program is considering eliminating this requirement. Participants in the six other DOCs (in California, Missouri, New York, North Carolina, South Carolina, and the Federal Bureau of Prisons) are not required to sign such a document-although the New York respondent noted that many inmates choose to do so.

Operational issues. Prison hospices commonly emphasize an interdisciplinary team approach and the use of inmate volunteers to provide care.

- **Use of inmate volunteers-**Many prison hospice programs rely heavily on inmate volunteers to provide hospice services; in only two DOCs are inmate volunteers not involved in hospice care. Inmates are trained in health care and the hospice philosophy and take the place of family or community members who provide hospice care in the community setting. The use of inmate volunteers enables prisons to care for terminally ill inmates without hiring additional staff. In addition, the

inmate volunteers also benefit from their participation. According to one survey respondent, for example, "Inmate volunteers state this is an enriching experience for them. They state that they receive more than they give."

- **Interdisciplinary approach-**All DOC survey respondents indicated that their hospice programs operate under an interdisciplinary team management approach. Most teams include administrative or security staff, chaplains, and mental health staff in addition to medical personnel. Some teams also include social workers, dietitians, recreation staff, pharmacists, and inmate or community volunteers.
- **Links with outside hospice programs-**Six of the formal hospice programs operated by DOCs are linked to some degree with community hospices. These programs are located in California, Louisiana, Maryland, Missouri, New York, and North Carolina. In each of these programs, community hospices provide training to DOC staff on hospice issues; the California DOC's staff training is provided under contract with the University of California-Davis hospice program. Other services provided through partnerships with community programs are inmate counseling (in one DOC), consultation on pain management and symptom control (one DOC); and the provision of general information, such as brochures (one DOC).

The New York DOC's hospice program is closely linked to a community hospice. Terminally ill inmates are placed in a hospice setting at the Greene Correctional Facility, a regional medical unit in Coxsackie. A designated team of staff from the Community Hospice of Columbia works collaboratively with DOC staff to provide the services. Services provided to the prison hospice program include access to medical personnel, staff training, family support services, an active donation program, and religious and hospice volunteers.

- **Services to families-**Prison hospice programs provide a variety of services to families of terminally ill inmates. Ten of these programs provide family members counseling on issues of death and dying; in North Carolina, the counseling is provided by a statewide religious organization. Four agencies

provide transportation to the hospice setting for families of inmates, and three offer families assistance with lodging. Other services to families include referrals to community resources and assistance with funeral services.

- **Training-**All corrections departments with formal hospice programs have a commitment to providing special training on hospice issues to those who will be involved in the program. Survey respondents from all 12 agencies indicated that they provide such training to custody staff, medical staff, program staff, and, where applicable, to community and inmate volunteers.
- **Case closure-**In 10 of the 12 DOCs with formal hospice programs, the hospice team meets formally for consultation and review after the death of a hospice patient. Agencies may also hold memorial services for the benefit of families, staff, and inmates.

Other Approaches to Palliative Care in Prisons

The survey did not ask specifically about "informal hospice services," but respondents from nine DOCs indicated that their agencies provide palliative care to terminally ill inmates outside a formal hospice setting. These informal hospice services are not governed by uniform policies and procedures, but are provided on an ad hoc basis and depending on individual needs. Care is typically provided informally at one or more prisons in the state system or is provided through the efforts of community volunteers

Among these nine agencies:

- Delaware tries to provide a "hospice-like" environment in the prison. Care in each instance is tailored to the need of the inmate and family and to the facility. These services are provided informally to terminally ill inmates at the four major facilities across the state.
- The Tennessee DOC does not have a formal hospice program, but the chaplain has organized volunteers and a local area HIV/AIDS support group to provide inmate counseling and support.

- Two facilities in Nebraska provide informal hospice care within their infirmaries.
- In addition to its formal program at the Greene medical facility in Coxsackie, the New York DOC has an informal supportive care program, staffed by inmate volunteers, for terminally ill female inmates at the Bedford Hills Correctional Facility.
- Kentucky's DOC offers informal hospice services at a nursing facility in one institution in the system.
- Michigan's statewide prison hospital offers hospice services to individual patients in cooperation with community volunteers.

Advantages of the Hospice Approach in the Prison Environment

Survey respondents cited many benefits that formal hospice programs can bring to prisons:

- **Improved quality of life/experience of death-**

"The hospice care program provides terminally ill inmates a dignified and compassionate death."

"Compassionate program in a difficult setting."

"It has created a humane, caring setting for those who must die in the prison setting."

"Quality of life at the end of life has improved."

"Extra care provided to patient to assist in process of illness and dying."

"Death with dignity."

"Ill inmates appreciate the advocacy and attention."

"Special meals to promote comfort."

"Spiritual support through services, Bible Study volunteers, family meetings."

"Opportunity for the inmate to talk about his death."

"Improved morale of patient."

- **Improved quality of medical care-**

"More focused care is provided."

"Improved continuity of care."

"The program has assisted in handling difficult medical management problems that occur with terminally ill inmates."

"Better pain control/comfort care."

- **Benefits to staff and inmates-**

"Has provided the opportunity for inmate volunteer activities."

"Inmate volunteers say this is an enriching experience."

"Pride in program and care."

"Has improved non-hospice inmates' outlook and behavior about their health issues and their attitude toward other inmates who are actively dying."

"Nursing staff seem to appreciate the program."

"Improved offender and staff morale."

"Better institutional acceptance."

"Ability to draw staff out on death and dying issues."

"Improved inmate morale concerning health care."

"Many sectors of the inmate population have gotten involved with the program by providing financial support through clubs and through personal, individual participation."

- **Benefits to inmates' families and friends-**

"Reunites family with inmate."

"Improved relationships with family members (both staff and offenders)."

"The families appreciate timely updates."

- **Cost benefits-**

"Cuts down on trips to outside hospital."

"The program has been cost effective because it has been implemented without increase in staff or funding and has decreased in-hospital patient days."

"Decreased expenses of community placement."

- **Other issues-**

"Decreased custodial problems."

"Correctional officers have responded well to movement of inmate volunteers."

"Good public relations."

"Team management concept has improved overall cooperation and communication between participating categories of staff."

"Terminally ill inmates are sometimes hard to place when given compassionate release; this program is an alternative."

“Ability to use counseling resources and hospice network to find family members and assist with parole procurement.”

“Multidisciplinary teams.”

Difficulties Encountered with Prison Hospice Programs

Respondents cited the following difficulties with their hospice programs:

• **Inmate trust-**

“Inmates not wanting to accept terminal diagnosis, distrustful of staff.”

“Getting inmates to trust the system enough to sign living wills and ‘do not resuscitate’ orders.”

“Initial difficulty in communicating the purpose of hospice to inmates because of mistrust of staff.”

“Inmates have refused to enter unit-the ‘death room.’”

• **Management factors-**

“The early perception was that the hospice program could not be initiated within a maximum security facility while still maintaining the standard of the National Hospice Organization. However, staff have now proven that it can be done.”

“Staffing requirements and expensive FTEs.”

“Need better links to community hospice program.”

• **Staff factors-**

“Misperceptions by security staff of the mission and value of hospice in a prison setting.”

“Staff turnover necessitates retraining.”

“Obstacles erected by security staff who believe the inmate is not deserving of a dignified death.”

“Physicians are slow to accept the program, while nurses make the transition easily.”

“Training of staff, especially security.”

“Establishing the team.”

• **Other issues-**

“Security issues sometimes override hospice management issues.”

“Pain control.”

“Referrals.”

“Family members fail to keep scheduled appointments; usually the second visit works.”

The Outlook for Prison Hospice Programs

Findings of this study suggest that the trend toward providing hospice care for terminally ill persons is gaining ground in corrections agencies. Among the eight DOCs that are now developing formal hospice programs, several are already offering informal palliative care and two already operate formal programs in one or more institutions.

- South Carolina DOC, now with seven formal hospices in operation, is planning to add two more hospice locations. The Louisiana DOC is developing a second hospice and considering establishment of a third.
- The Oregon DOC has already written the policies that will govern a hospice program being implemented at the Oregon State Penitentiary.
- The Correctional Service of Canada has established a National Palliative Care Committee to assess issues related to palliative care services for federally incarcerated offenders and to implement policy in this area. The committee is exploring end-of-life issues; legal and ethical issues; symptom control; and palliative care training for clinicians. Regional prison hospitals will offer the hospice program.
- The Kansas DOC has included in an RFP for medical services a request for the provision of a formal hospice program. Care now provided by the agency depends on the interest of staff in each unit and on individual inmates' circumstances.
- Until its planned hospice program becomes operational, the District of Columbia DOC will continue to emphasize medical parole for geriatric, permanently disabled, and terminally ill inmates. Most terminally ill inmates are now transferred to private nursing homes or hospice centers identified by DOC case managers. ■

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