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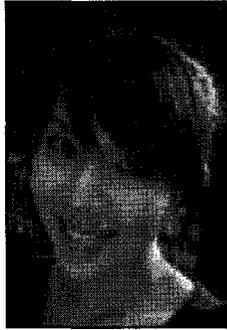
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## Volunteer Prisoners Provide Hospice to Dying Inmates

Janice A. Cichowlas\*  
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### I. INTRODUCTION



A hospice program is a supportive service provided for terminally ill patients and their family members, in either a home setting or a community-based inpatient site. The primary difference between a hospice and a hospital is that the hospice program addresses a broader range of comfort, psychological and rehabilitation needs of the dying patients and their family members.<sup>1</sup> Just as the older adult population in the United States is growing, the number of elderly and infirm inmates in state prison systems has also increased considerably. The National Institution of Corrections indicates that state and federal inmates age fifty and older has grown 172.6% between 1992 and 2001.<sup>2</sup> There is a need to promote better prison hospice programs, especially when data have shown that prisoners tend to age more

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1. Barry Lunt, & Cherie Neale, *A comparison of hospice and hospital: care goals by staff*, 1 PALLIATIVE MED. 136-148 (1987).

2. B. JAYE ANNO ET AL., DOJ – NAT'L INST. OF CORR. CORRECTIONAL HEALTH CARE: ADDRESSING THE NEEDS OF ELDERLY, CHRONICALLY ILL, AND TERMINALLY ILL INMATES (2004), available at <http://www.nicic.org/pubs/2004/018735.pdf>.

rapidly than their counterparts, and are at more risk to contract communicative disease leading to terminal illness.<sup>3</sup>

Unlike traditional person-centered community hospice programs, a prison's hospice program needs to be institution-centered, due to the dying inmates' sentences to complete their criminal justice penalty. For instance, family involvement will be limited under the prison's regulated visiting hours, and desirable food might not necessarily be provided within a hospice program in a correctional setting. Nevertheless, a quality hospice program is a still need and a must, in order to comply with ethical imperatives within a criminal justice system. After all, "courts have generally affirmed that incarceration itself, not substandard health care, is the intended punishment for criminal acts"<sup>4</sup>

#### A. Background

The American Bar Association concludes that uniform and consistent legislation on medical parole and compassionate release has never been implemented to address "both the humanitarian concerns associated with dying inmates and the concerns of prison officials dealing with the overcrowding and healthcare problems plaguing the prison system."<sup>5</sup> In order to accommodate the social concern of releasing prisoners into the community, and humanitarian treatment for terminally ill prisoners, it is important to recognize the need for hospice programs within correctional settings.

According to a 2004 national survey by the National Institute of Corrections (NIC), twenty-three states, including Illinois, owned a hospice unit in their correctional system.<sup>6</sup> However, Illinois was one of the five states that did not provide compassionate release for dying inmates.<sup>7</sup> Several legislative attempts to promote medical parole or compassionate release for terminally ill inmates have failed to pass in Illinois. For instance, SB1829 in the Ninety-Fifth General Assembly did not foster sufficient general assembly votes to become law. On the other hand, strong victim advocacy groups, such as the National Center for Victims of Crime ([www.ncvc.org](http://www.ncvc.org)), oppose possible prisoner release in any form. With a lack of alternative means to provide quality medical care for dying inmates in Illinois, state correctional centers must advocate for better hospice programs

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3. Svetlana Yampolskaya & Norma Winston, *Hospice care in prison: General principles and outcomes*, 20 AM. J. HOSPICE & PALLIATIVE CARE. 290-96, 290 (2003).

4. John F. Linder & Frederick J. Meyers, *Palliative Care for Prison Inmates: "Don't Let Me Die in Prison,"* 298 JAMA.894-901, 896 (2007).

5. Fleet Maull, *The Prison Hospice Movement*, 1 EXPLORE 477-79, 478 (2005).

6. Anno, *supra* note 2, at 79.

7. *Id.* at 80-81.

in prison.

Unlike Medicaid/Medicare reimbursed community-based hospice programs, there are no specific legislative regulations for hospice programs in correctional settings. The National Hospice and Palliative Care Organization (NHPCO) has developed “quality guidelines for hospice and end-of-life care in correctional settings”, to ensure dying patients’ humanitarian needs are met. There are ten components listed in the guideline, including: 1) inmate patient and family centered care; 2) ethical behavior and inmate patient rights; 3) clinical excellence and safety; 4) inclusion and access; 5) organizational excellence and accountability; 6) workforce excellence; 7) quality guidelines (utilizing NHPCO’s guidelines for developing and implementing hospice in corrections in concert with the American Correctional Association and National Commission on Correctional Health Care accreditation standards); 8) compliance with laws and regulations; 9) stewardship and accountability; and 10) performance improvement.<sup>8</sup>

By weighing terminally ill inmates’ medical and emotional needs and society’s concern for public safety of compassionate release, correctional centers will be able to implement institutional-centered, if not completely patient-centered, hospice programs to provide necessary support for these terminal inmates who desperately need medical and emotional support.

## II. DIXON CORRECTIONAL CENTER

Researchers have developed a list of five general principal components of prison hospice programs based on different service categories and actual program elements provided.<sup>9</sup> The list includes: 1) hospice program in prison; 2) multidisciplinary team; 3) inmate volunteer involvement; 4) comfort care; and 5) end-of-life care.<sup>10</sup> The following section will discuss each component based on this model developed by Yampolskaya and Winston (2003), within the context of a hospice program at the Dixon Correctional Center in the state of Illinois.

### *A. Dixon Hospice Care*

Hospice in Illinois began as a social movement to reform care for dying patients, and stayed as a volunteer-based program until relevant legislation was proposed in 1980’s to regulate the industry. Ms. Cheryl Price, LCSW, the coordinator of the Dixon Hospice program, obtained her master of social work degree in 1980. Ms. Price started working as a medical social

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8. National Hospice and Palliative Care Organization, Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings, [www.nhpc.org](http://www.nhpc.org).

9. Yampolskaya, *supra* note 3, at 292.

10. *Id.*

worker at a local hospital. When the first discussion of hospice in prison was coordinated by the John Howard Association and Lutheran Social Services in 1994, Ms. Price was a part-time director of the “Sauk Valley Hospice,” a community hospice program. Driven by her passion about end-of-life care, when contacted by the Dixon Correctional Center in 1995, Ms. Price decided to help develop a prison hospice in Dixon with other local leaders.

Dixon hospice has two programs: 1) hospice program that tries to follow community standards, and 2) adult care program that takes care of any inmates with mental or physical frailness. These programs are both run by full-time prison staff with additional duties assigned to the hospice program. The Inmate Benefit Fund appears to be the primary funding source for the program, providing equipment and occasional items for the services provided, such as videos for training purposes, luncheons and t-shirts for inmate volunteers. Ms. Price was hired as program coordinator in 1997 and has enhanced transformative experiences for the dying inmates and the inmate volunteers. The Dixon Hospice program has successfully modified community hospice standards in order to thrive in the correctional setting.

#### *B. Multidisciplinary Team*

Similar to other prison hospice programs in the country, Dixon Hospice has a multidisciplinary team including nurses, physicians, psychologist, psychiatrist, social workers, chaplains and security officials. Ms. Price discussed the difficulty of convening interdisciplinary team meetings. Strategies have been used at Dixon to address this issue, including flexible dates and times.

#### *C. Inmate Volunteer Involvement*

Dixon Hospice adopts a comprehensive selection process for identifying suitable inmate volunteers for the program. At the initial stage, prisoners voluntarily express their interest; the Program Coordinator and Associate Coordinator review inmates’ master files to evaluate types of crimes committed, and eliminate anyone who has been in segregation during the past year. Sex offenders are automatically excluded from the list. Based on the prison classification system, qualified inmate volunteers have to have a low risk level and at least eighteen months left on their sentence. A thorough screening process is performed in Dixon, where Coordinators call inmates’ housing units and job sites to test responsibility level. Trust and integrity are the central elements for selected volunteers. After the “vote sheet process” of internal review, the warden makes the final decision as to whom will be accepted into the five-month training process for hospice

volunteers. Overall, Dixon Hospice admits eight to ten inmate volunteers among the approximately fifty applications received annually.

Training sessions for volunteer inmates are offered, with quality matching that of the community standard. The current training program consists of at least fifteen modules for two-hour sessions on a weekly basis. In Dixon, inmate involvement with hospice care is an unpaid work in addition to their regular prison job assignments. Volunteers do not participate in regular staff meetings, however their input and suggestions are included from their own volunteer conference. Volunteer involvement and participation in Dixon Hospice appear to be highly positive.

#### *D. Comfort Care*

In Dixon, counseling services are offered by professional social workers and psychologists for dying inmates. Although special privileges are not allowed in Dixon, end-of-life inmates generally can get their needs fulfilled to the maximum degree. For instance, their family members are contacted and their visiting hours are adjusted to best accommodate dying inmates' needs. It is crucial to acknowledge that Dixon Hospice adopts an adjusted definition of family, which can include other inmates with whom the dying inmates are close. Inmate volunteers are often given release time from their regular job duties in order to be with the dying inmate when exiting life. Inmate volunteers expressed how significant it is for them to be with the dying inmate during this round-the-clock "Vigil." After the inmate exits life, the Coordinators will have a discussion with the inmate volunteer to discuss any necessary issues, including suggestions to improve the overall quality of the program. An annual luncheon is held for the inmate volunteers, which can be viewed as a periodical memorial service for the prisoners who passed away during the past year.

#### *E. End-of-Life Care*

In terms of Do Not Resuscitate (DNR) orders, Dixon Hospice encourages but does not require this of dying inmates. Both their family members and the prisoners are asked at intake. If the prisoner's medical condition worsens, the professionals will raise the question again and remind the clients of their rights. Dixon Hospice tries to follow the six-month prognosis community standard when admitting patients into their end-of-life care program, however, relatively flexible criteria are adopted. The prognosis period is more delayed in Dixon Hospice, where prisoners are often admitted to the Adult Care Program first.

#### *F. Funding and Volunteer Benefits*

There is little line-item funding for the Hospice program in the Dixon

Hospice. There is an “Inmate Benefit Fund” which is used for equipment (i.e., videos for training purposes), appreciation luncheon and t-shirts for the inmate volunteers. There is no line item for salaries and routine supplies.

Volunteer prisoners were interviewed by the authors. The prisoners expressed that the volunteer experience for them was “life-changing,” it gave them a way to “give back” to the community. For some, it was a “healing” experience and a source of pride to be able to contribute within the prison walls. This work was an additional assignment for the volunteers, but through a highly selective and competitive selection process. Eight to ten volunteers are selected from a pool of about fifty applicants based on such variables as interest, low risk, trust and integrity as exemplified in their prison housing and job recommendations.

### III. CONCLUSION: A NEW DIRECTION

The basic concept of hospice is that every individual should die with dignity and respect. It is appropriate to provide hospice services even in the prison setting. Inmate volunteers benefit from the opportunity to give back in a humanitarian way to the prison community.

In Illinois, the Dwight Correctional Center is exploring the initiation of a hospice program for women offenders. More research is needed to determine if there are specific needs for women offenders that differ from that of the male offenders.