

The Needs and Resources for Hospice Care in the Connecticut Prison System: A Feasibility Study

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Higher morbidity rates and aging populations are trends in our nation's prisons. In 1997 and 1998, correctional staff members and inmates were interviewed to assess their understanding of end-of-life care and the need for hospice in Connecticut state prisons. Community resources were identified for future partnerships in developing such services.

This study is based on a feasibility analysis of the needs and resources of hospice care in the Connecticut prison system. During 1997 and 1998, interviews were conducted with nurses, doctors, counselors, chaplains,

This essay is edited from presentations given at a conference held on 1 May 1998 to present and discuss the findings of the project "Hospice Care for State Correctional Facilities: A Feasibility Study in Connecticut." The conference, titled "Finding Common Ground for Hospice Care in Connecticut Prisons," lasted a full day and included several other presentations of importance, but only the remarks of Nealy Zimmermann, Florence S. Wald, and A. Siobhan Thompson specifically addressed material from the feasibility study. The authors edited the essays again in December 2001. The authors hope that these essays will focus interest on what they consider a vital issue in the Connecticut prison system, yet one that has an easy solution if all can agree on the common remedy of some type of hospice care inside or outside the correctional institutions for those facing the prospect of dying in prison. The authors would like to acknowledge the following individuals and agencies that helped make this project possible: The Center on Crime, Communities and Culture and the Project on Death in America; ConnectiCare, Inc.; the Albert Schweitzer Institute for the Humanities; Choate Rosemary Hall School; the Virginia Henderson Research Fund at the Yale University School of Nursing; Jeffrey Green of Community Partners in Action

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educators, correction officers, prison administrators, hospice professionals, people involved in various community support agencies, and various others outside the prison system. A separate part of the study was an inmate questionnaire, which addressed the specific concerns of the incarcerated.

Our first impression was that prisons and hospices are two living, breathing organizations. Both are labor intensive, and both are regulated by legislation and limited funds. Further investigations with a health administrator of the University of Connecticut Correctional Health Care Program confirmed for us that it was as if prisons and hospices were two foreign countries, each with idiosyncratic purposes, values, and problems but for which through working together, a common language and customs could be formed.

Clearly, our society has two parts: the open society and the closed society consisting of those who do not abide by the rules. Once people are incarcerated, open society loses interest in them, preferring protection from those it does not trust and advocating retribution and segregation rather than looking for the causes of errancy. This was found to be the dominant mode. On the other hand, we found individuals and services already working together, both in the community and the prisons, in the restoration and restitution of inmates, as well as many others wanting to get involved.

The scope of inmate services covers many areas. Focusing on hospice care helped us see the potential already there for networking and collaboration. The purpose of this study is to explain these impressions, to clarify misconceptions, to explore possibilities, and to suggest avenues for linking the prison community—which includes prisoners, caregivers,

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security officers, administrators, and those who set policy and shape it—with the community at large. This is not to deny the high-stress environment in which caregivers and inmates live but rather to look beyond it for understanding and possible change.

An important question that came up for us is whether society is aware of the health issues and the cost of health care in prisons. In conversation with Dr. Curtis Prout, M.D., who had been involved in a prison project in Massachusetts in the 1970s, he said that “the public has simple ideas of an enormous problem” and that “we as a nation know very little about inmates as people.” Furthermore, he added, “the cost to society is incalculable and is a public problem.” The central paradox pointed out in Prout and Ross’s (1988) book *Care and Punishment* is the inherent difficulty of giving the same institution responsibility for both the care and the punishment of its inmates.

HOSPICE CARE

Modern hospice care has been thirty-one years in the making, beginning at St. Christopher’s Hospice in London, England. It began treating patients with life-threatening illnesses (especially progressive malignancies) as an alternative when cure and remission were no longer effective. Hospice care is palliative in that it relieves pain, whether from swelling, tumor, fracture, abscess, or pressure on nerves. One usually thinks of physical pain first, but pain is only one form of suffering. Helplessness, weakness, loneliness, and isolation are the more common discomforts.

During those thirty-one years, the medical, pharmacological, and psychological control of pain has become better understood and managed, so that in most instances pain is relievable. While we witness or hear about death and dying, whether sickness or violence is the cause, it is still true that most people do not know what dying entails. For example, the sons of one patient had lost their mother the previous year, and now their father was dying. The home-care nurse noticed that if the father was upstairs in the house, the boys were down. If the father was down, they were up. She realized that the boys could not face what was coming next, so the father came into the hospice and the social worker helped the three sons with their fears and feelings so they could remain a family through the second loss and be able to plan for their futures. As a London policeman with Lou Gehrig’s disease once said to Dame Saunders when she asked him what to tell an American audience about his illness, “Tell them it is a ‘bringing-together’ illness.”

Letting go is a balancing act. When caregivers invest themselves, as they do in all stages of end-of-life events, they too need support. The

institution must recognize when it has a depletion of staff morale and provide relief. Resuming the natural flow of life allows this to happen.

An interdisciplinary team working in unison, each with a specific role, can keep the family from being the lone helper. Facing death can stimulate growth in all involved, growth that is personal, social, and spiritual. Letting go is usually easier when a life has been fruitful and meaningful and a family unit or circle of friends has lived harmoniously. It takes time and energy to heal a broken relationship, disentangle conflicts, resolve its disagreements, and reach for forgiveness.

Given all the above difficulties with end-of-life events, it is easy to understand that hospice care for the prisoner is a greater challenge than for the ordinary person. Long separation from family and friends and a lifestyle that has been deemed unacceptable are added burdens. More time and skill are needed to restore communication and mend the image of oneself, which wrongdoing, blame, punishment, and isolation have battered.

WHO ARE THE PRISONERS?

For every 100,000 Connecticut residents, 310 are incarcerated. The national rate is 433 per 100,000 citizens. Forty-five percent of Connecticut inmates are black, 27 percent are Hispanic, 27 percent are white, and 1 percent are other. Ninety-three percent are male, and 7 percent are female. The population of inmates in Connecticut has increased significantly over the past ten years, from 6,810 in 1987 to 15,588 in 1997. The average sentence is 26.7 months. Sale of drugs and possession of drugs are the first and third top offences, respectively, and account for 22 percent of all offenses, while murder represents 5 percent. Many of the other offenses are drug related. The drug theme was also prominent in our interviews.

Almost 30 percent of Connecticut prison admissions are readmissions. The recidivism rate is high throughout the country, with an average for the nation of 32.6 percent. Discharge violation is the second top offence, reflecting the prevalence of probation violators who failed a drug test. This raises the question, Has society invested in a system to control drugs that does not work? The predominance of drug selling and usage both in and out of prison underscores a drug policy that is ineffective and even counterproductive. This is a group of people who have been living in a drug-trade environment and are fully engaged in risky living with little experience or knowledge of health and illness.

A number of inmates are HIV positive or have AIDS. A research study by the Yale School of Medicine and its Department of Public Health to follow the course of prisoners with AIDS who were given protease

inhibitors had been in effect for several years before our study. The number of deaths from AIDS-related diseases has diminished. In addition, the ongoing treatment of patients with AIDS was ensured as a result of a class-action lawsuit that mandated the Department of Corrections (DOC) to include this in its health care protocols.

Care for the older prisoners has become a concern nationwide. Longer sentences dictated by federal law have increased this population over a ten-year period. Chronic disease rates are higher, and it has been found that inmates age faster than the free population. For these reasons, older inmates need to be quartered separately from the younger, more physically aggressive population. At Osborn Correctional Institution, the LOFT is an area where prisoners older than fifty live, and others are on a waiting list to get in. It is located right above the infirmary, thus allowing the chronically ill more access to personal health care.

Until a few years ago, no one died in prison. As one administrator said, "It was the Department of Correction's duty to get the patient out under any circumstances. Many were sent to hospital emergency rooms and went through all kinds of tests." When the population mushroomed, a new role was created specifically for health services. Now there are at least seven infirmaries in the system, and death is a part of the program.

Mental illness in correctional facilities has increased significantly over the past thirty years since large state psychiatric hospitals closed nationwide. Community health clinics are inadequate in correcting behavior that society is unwilling to countenance. Isolation increases the stress of psychiatric patients, and prison staff lacks the appropriate training. It is evident that the inappropriateness of the prison setting to address mental illness makes it difficult for both prisoners and staff.

In speaking with prison health care workers, they noted that "the mortality rate is climbing," "sicker people are entering the system," "the age of inmates is increasing," "there are a lot more duo diagnoses," "the population is getting sicker," "a number of inmates are not old chronologically, but, due to their life styles, their bodies are old," and "we see more inmates with drug addictions."

THE PRISON INFRASTRUCTURE

To accommodate the large increase in the Connecticut inmate population, huge building projects were initiated in the early 1990s. Currently, there are nineteen facilities being used to house almost sixteen thousand inmates. Of these nineteen facilities, ten were built in the 1990s, the most publicized being the "Super-Max" (Level 5) Northern Correctional Institution, which was built in 1995. Two percent of the inmates are housed at this facility. This means isolation for twenty-three hours, with one hour

each day to be out of the cell for exercise in a secured area. Forty-nine percent are in maximum-security facilities (Level 4), and the rest are in medium- and low-security facilities.

There are 1,158 women housed in one location that has a higher and a lower security section. The men are scattered in the other eighteen facilities, of which three are called jails and one is called both a jail and a prison. For the men, the jails have their own atmosphere. We were told that "the pre-sentenced population is harder to control. They don't know what is going to happen to them nor how long they will be incarcerated, and they are more recently in the system." The words used to describe them were "stressed," "detoxing," "angry," and "in and out."

Due to the building expansion, the exteriors of most buildings appear new and well constructed. Inside, the buildings and their furnishings are clean and well kept. However, facilities such as libraries and greenhouses are often unused since operational funds are limited for such activities.

WHAT ARE THE COSTS?

With regard to costs involving incarceration, in 1986-87, the general fund expenditure for the Connecticut DOC was \$105,531,000. Ten years later, in 1996-97, the general fund expenditure was \$400,834,000. This expenditure includes the cost only of the incarcerated individuals and those on conditional release, a population representing only about one quarter of the sentenced or arrested population in the state. Other offenders are in an alternative incarceration program, on probation, or part of the juvenile sector. The number of probationers and parolees currently under active supervision, which is patently less costly than incarceration, is 54,507.

All of these increases in the number of inmates and costs are a reflection of what is happening around the country. Governor Roy Romer of Colorado was quoted in the *Boston Globe* in January 1998 as saying that "the cost of building and running prisons in Colorado is ballooning out of control and threatens to undermine the state's education and social service systems." He also observed that "this is an issue that every governor in the United States is going to face" (Hal Clifford, "Colo. Governor Says Prison Costs Threaten Other Programs," *Boston Globe*, 25 January 1998, A4).

INMATE PORTRAITS

Against this statistical background, the comments, impressions, and thoughts of the people interviewed in this study were significant. What kind of portrait of the inmates emerged from talking to people about

them? First, there were some general comments about the incarcerated women in the Connecticut system.

Because of the high level of addiction, these women burn bridges and when they are at the end stage, they have no place to go, also they have stronger separation issues with their children, so many losses, it is like a war zone, with trauma involved.

While most prisoners come from one of the state's seven urban centers, the correctional facilities are mostly located in rural areas. Having visitors from the city requires a private car and driver. We were told, however, that "visits and mail decline as the years go by" and that "many have burned bridges with family and friends." This was mentioned several times, as illustrated by one comment: "How prevalent is it for an inmate to have family visitations? About a third of the time." Also mentioned was the difficulty of families' being able to visit due to the location of the facilities. For inmates, having spent many years in prison, the open community is a foreign land and their incarcerated peers have become their family.

What about behavior? Manipulation is a common theme and a common trait. "The manipulative nature of patients here is an issue, but is workable. Some are master manipulators. Others do it for a while. It is a street skill." Manipulation is related to addiction. Many were forced to learn the subtleties of surviving in a noncaring environment. Also, they were trying to beat the system and "they know when you are lying."

"The biggest problem is drug addiction," noted another person.

The issue continues to be addiction, not HIV. HIV will not kill you, drugs will. It is harder to deal with than AIDS. All but a few have a history of drug addiction. Keeping free of drugs when released is a challenge. Unfortunately, they go back to the same environment they came from, and back to drugs.

Also, "a lot of them have no coping skills." How about the relationship between addiction and the manipulation of drugs for pain control? The tolerance level might be higher for an addict, and therefore there may be a need for higher doses of pain control. Would an inmate try to become a hospice patient to get drugs? One person responded that you have to know them to figure out if they are being manipulative or not.

On the other hand, one administrator told us that she has "seen camaraderie among sick male inmates but has also seen cruelty, whereas women in general come to each other's assistance more." Another person mentioned an inmate whose job was to work in the infirmary cleaning, picking up garbage, and so forth. This inmate ended up talking to the patients and felt like he was doing something useful.

At one prison, a group of inmates has developed a program to prepare their peers for resettling in the community. They call it "The Lost and Found School of Thought." With the help of a prison social worker, it offers a twelve-week course for those whose sentences are ending. By the time of release, the prisoners will have thought through the issues of resettlement and have a peer group for support in place.

The comments indicate that providing hospice care for an inmate presents certain challenges that might not be true on the outside. The average hospice patient deals with end-of-life issues, such as forgiveness and life review. For the most part, they can say they had a pretty good life. But for the inmate population, they have obviously made some terrible choices. As one interviewee put it, "We all have some guilt, but these inmates have made horrific choices. You can't just bury those feelings of guilt." A medical worker told us that "if they have been forgiven, they fare much better. Working out these issues is complex and takes a long time." Andi Rierden's (1997) book *The Farm* is an in-depth portrayal of life in the Connecticut women's prison where these issues are vividly portrayed.

THE STAFF

Prison employment in Connecticut has increased from 2,775 in 1987 to 6,971 in 1997, reflecting the increase in the prison population. This has resulted in many changes in the system. Furthermore, the commissioners, deputy commissioners, wardens, and other prison officials all change or move around at different times and have different styles that affect the system. One nurse supervisor said that she has "worked with seven different administrators with seven different styles." An administrator told us "the environment is always changing. It never quite gets set, but at least it is never boring."

What are the needs and thoughts of prison staff? Here are some typical comments: "There is a big need for support for the medical staff"; "There is never time to address staff support"; "There is a lack of staff resources, the work is strenuous"; "There is a shortage of doctors and nursing staff"; "There is no replacement when sick or on vacation"; "There is no time to take care of a dying person's needs—we're too busy"; "There are no staff to help sick patients get up and walk"; "Nurses don't have death and dying training"; "Everyone, not just inmates, has issues to deal with"; "Staffing is a problem, we are overwhelmed with the work load and bogged down in paperwork, we don't have time to listen [to the patient], in a rush; but don't get us wrong, we like our jobs but we need training." At one location, however, someone said, "We finally have enough staff and they are all great," and at another location,

"The staffing has improved lately." These responses reflect the fact that each facility is run differently and has different dynamics.

Other staff comments follow: "It is difficult to be a nurse in this setting because you are in this conflict between security and compassion for this individual; you are not permitted to touch anyone"; "The staff people have not taken courses on death and dying and yet they are dealing with it so they just get through it." A common theme mentioned was that often because of broken family ties the medical staff and other prisoners end up being family for a sick inmate.

What about the question of hospice care in prison? "For many, dying in prison is the worst, yet some have no home to go to," "Do the patients want to be out of prison before they die? Some of them do and some don't. For some, prison is their only 'home'." Another point mentioned was that "inmates perceive a move out of the general population into the infirmary as punitive and more restrictive." Another possibility is compassionate release, discussed later in this essay.

REACHING IN AND REACHING OUT

Let us now consider the many health care and social agencies, services, and individuals in Connecticut's open community that are already engaged in similar care or would like to be.

The state of Connecticut is rich in community resources. The Directory of Contracted Community Services illustrates the many agencies the DOC already works with: thirty-two residential programs and twenty-eight nonresidential ones.

Transitional Linkage to the Community, one of many programs administered by Connecticut Partners in Action, provides continuity of care for released prisoners with AIDS. It connects prisoners, families, and health agencies in the community to ensure that care is continued in the home. There is a hard-working group of case managers whose expenses come from Ryan White money.

Although there are 660 halfway houses in the state, only a few, such as Mercy Housing & Shelter and Trinity Hill, have beds and well-prepared staff for terminal care. The DOC contracts with some of them, and the Alternative Incarceration Program has contracts with them also.

Connecticut's alternative incarceration program is under the auspices of adult probation and contracts services through private nonprofit organizations. It was created because of the crowded conditions under which prisons swelled to unmanageable and illegal proportions. Most of the program's facilities are treatment centers for first-time offenders. Being under the judicial branch rather than the executive branch, as the prison system is, the program allows state legislative involvement of the judiciary committee in approvals and budgeting. The DOC is in the

executive branch, which is more restrictive to change and appropriating funds.

Intensive end-of-life care is possible at four different centers in Connecticut: Leeway in New Haven (for patients with AIDS), the Connecticut Hospice in Branford, Middlesex Hospital Hospice in Middletown, and Hartford Hospital in Hartford. These four in-service units have a full interdisciplinary care team and are equipped to deal with complicated symptom management.

Hospice home care is spread throughout the state. There are twenty-nine services scattered like stars covering all five regions of the state. A council that also includes the Connecticut Hospice and its home-care programs links them. There are 137 nurses in Connecticut certified by the Hospice Nurse Association, and there are also four hospice physicians.

In Groton, there is a double-sized mobile home called "Sacred Place." It is the home of an ex-inmate from the women's prison who provides housing for other such ex-inmates. Everyone shares the household chores. House rules ban drugs. Residents may stay until they feel ready to go out on their own. A few residents have stayed through the end of their lives. Local health and welfare services give professional help when needed. Here again is an example of ex-offenders helping each other.

COMPASSIONATE RELEASE

When we asked about medical parole or compassionate release, the answer was, "It used to happen more frequently, but it is rare now." Multiple agencies are involved: the Board of Parole, the commissioner of the DOC, the warden, and the prison physician.

We looked at state statutes, the DOC administrative directives, and *Connecticut Prisoner's Rights* (Stern 1997). Students in the Jerome N. Frank Legal Services Organization at the Yale Law School published the latter in 1997 in conjunction with the Connecticut Civil Liberties Union Foundation to educate themselves and others. Chapters include "Due Process and Discipline," "Prison Conditions," and "Medical Care." In the chapter titled "Getting out Early," the document describes terminal illness furloughs and medical parole as determined by the board of parole.

There appears to be a discrepancy between DOC practices and the Connecticut statutes and DOC directives. Why are they used so infrequently? It could be explained that public fear of criminals, drug sellers and users, child molesters, and violence make the governor of the state and the commissioner of corrections reluctant to release any prisoner under virtually any circumstances.

An added difficulty is in predicting how long a patient will live. A prediction of six months is nearly impossible; three months is a little more certain. But by the time the permissions, the arrangements with community agencies, and entitlements are in place, it is likely that the patient may have died. Sluggish communications in a large bureaucracy add to the delay.

The Maryland Division of Corrections set up a medical parole program in their state. Candidates' diagnosis, prognosis, and function levels are determined. Social evaluations and aftercare plans are made by a social worker. A correctional case management team makes security evaluations. The recommendations are then sent to the commissioner of corrections and the Maryland parole commissioner, who either approves or rejects them. Twenty-three working days is the time frame. In 230 instances, 52 percent of the prisoners were released and 23 percent were denied parole. Twelve percent died during evaluation. In a four-year period, 3 percent were reincarcerated (four persons: two had dementia and could not be handled at a chronic care facility, one committed armed robbery, and one violated parole regulations). The interdisciplinary team members developed a process that was acceptable in the realm of both care and security.

Both the American Bar Association and the American Civil Liberties Union have written resolutions on the issue of compassionate release legislation and consider pertinent to the issue the question of the adequacy of care in prison facilities and its cost. By 1996, it reported that twenty-six states and the District of Columbia had at least one form of compassionate release program specifically addressing terminal illness.

In one meeting with Randy Braren, parole supervisor, Connecticut Board of Parole, and another with Representative Mike Lawlor, judiciary committee chair, Connecticut General Assembly, it was agreed that reviewing the relevant statutes, and rewriting them if needed, would be a reasonable "do-able" procedure.

INMATES' COMMENTS

What did the inmates think about a prison hospice program? One male inmate who was to be released soon for medical reasons said that "anything is better than here." He did not want his family to see him there. There was a sense of the stigma of being incarcerated. When a few inmates were asked if they had thought about dying in prison, they gave the following responses:

Yes, I have thought about dying in jail, but if I had to I would want my family or someone close by my side.

I feel as if the prison hospice program would be very instrumental in the development and growth of sensitivity and individual concern for their fellow human beings.

My little brother committed suicide December 29 and I was very depressed. I thought about taking my own life but I did a lot of thinking. I realize that my being here was probably for the better and with me being able to get through that kind of thing, maybe I can help someone who is also thinking about taking their own life.

I would like to help anyone who is dying alone; I know how it feels to lose someone and I don't believe anyone should die alone.

I have thought about death quite frequently because I am positive. It is part of my daily concern. By being in prison I feel very scared because I do not want to die while here. I would prefer to die with my family and friends. People who care for and about me.

It is one of my worst fears. I would hate to have to die without family or friends. It would be a great help to me to have someone to help me during that rough time in life so any help you can give us would be greatly appreciated. Thank you.

IMPLICATIONS

It is crucial that society be better informed about health issues and the cost of health care in prisons. Beginning with the case of the terminally ill inmate, the question of how much punishment is enough must be addressed. When a sentence of so many years is meted out, we must ask, Was death considered as a part of it?

This study of needs and resources for individuals in a closed society followed a study twenty-five years earlier of creating hospice care in the small state of Connecticut. Now hospices are spread throughout the state as are the prisons, and they are within easy reach of each other. While the number of prison deaths is small, the health of inmates is compromised by years of risky behavior, little health care, and years of confinement. A disproportionate number of patients are black and Hispanic, and most are disadvantaged, unlike those in hospice care at large.

Within the DOC, two philosophies are at work. One is to punish the criminal and to confine him or her as a protection to society. The other is to correct by understanding cause and opening avenues to solutions. These two approaches are found in the DOC officers and staff as well as in the population at large. Public and private community agencies in the nation and state contribute in a variety of ways so that there are many avenues available for entrance and assimilation of programs providing care.

Although working toward freeing more dying prisoners through compassionate release is a long-term and worthwhile option, the study

concludes a hospice in prison supported by hospice training for inmates as caregivers would be beneficial in several ways: patients would not die alone (fellow volunteer inmates would be there for him or her), it provides an opportunity for inmates to render a service, it would give outside hospice caregivers a glimpse of a different population, and it would provide education to prison health care staff about end-of-life care. In fact, DOC nurses favor carrying their patients through the end of life but welcome learning palliative skills and having support from experienced hospice experts. Community hospices go into nursing homes to take that role. Can they extend that to DOC infirmaries? Certainly, Yale physician Dr. Richard Altice and his team were successful in bringing treatment and education to HIV/AIDS prisoners.

After these papers were presented in 1998, work began to start the first prison hospice program in Connecticut. In February of 2001, nineteen inmate volunteers graduated from a six-week hospice training program and immediately began to work with their fellow dying inmates.

ANALYSIS OF THE DATA

This article will examine information collected from inmates while they were incarcerated. The reader should keep in mind that some data still has yet to be fully analyzed, so this essay is basically an introduction to some of the data collected in 1997 and the winter of 1998.

We would like to acknowledge the invaluable assistance we received from the University of Connecticut Correctional Managed Health Care Program and the Connecticut Department of Correction in assisting us in this research. This research was made possible by the correctional staff, University of Connecticut managed care professionals, and inmates in the seven facilities in which the research was conducted.

OBJECTIVES

The objectives of the inmate interview survey component of our project are the following:

- to examine the descriptive profiles of inmates, their families, and relationships;
- to assess the knowledge and attitudes for hospice care among inmates in the Connecticut correctional system; and
- to determine the demographic and clinical characteristics associated with knowledge of hospice among incarcerated inmates.

Last, when all our analysis is complete, we hope to accomplish one clear objective:

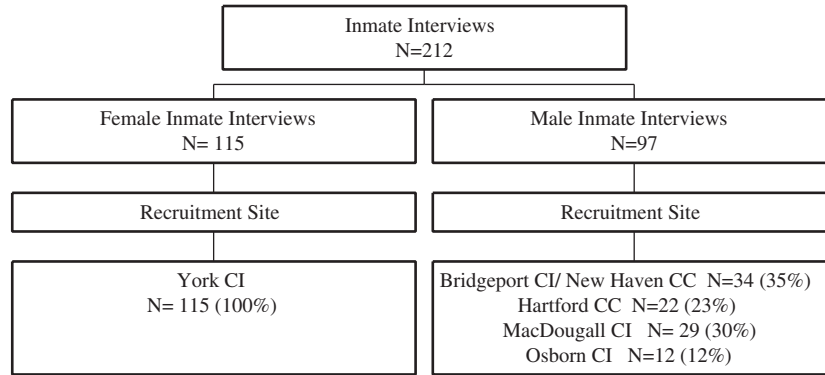


FIGURE 1 Hospice Feasibility Study in Connecticut State Correctional Facilities, 1997-98

NOTE: CI = correctional institute; CC = correctional center.

- to apply information derived from this study toward the development of hospice programs in Connecticut correctional systems.

The data from the inmate survey has been broken down by gender. As can be seen in Figure 1, female inmates were recruited from Connecticut's sole intake correctional facility for women, York Correctional Institute, where we interviewed 115 female inmates.

For male inmates, a total of ninety-seven interviews were conducted in five facilities. Three large jail jurisdictions—Bridgeport, New Haven, and Hartford (58 percent in total)—and two state correctional facilities—MacDougall (30 percent) and Osborn (12 percent)—helped in the effort. The time line for the project was eighteen months; we started in January of 1997.

These seven facilities were selected because they all have an infirmary located on prison grounds. It was concluded that prisons with on-site infirmaries are the best place to start in terms of exploring the possibility for hospice care in Connecticut's prisons. The resources and programs in these facilities triage and provide care to thousands of inmates every year.

STUDY DESIGN

An anonymous survey was conducted among male and female inmates incarcerated in Connecticut correctional facilities. Voluntary participation included inmates who were randomly selected off the prison's daily roster or selected from group meetings. Surveys were self-

TABLE 1 Age, Race, and Education of Inmate Participants

	<i>Total</i> (N = 212)		<i>Female</i> <i>Inmates</i> (n = 115)		<i>Male</i> <i>Inmates</i> (n = 97)		p
	n	%	n	%	n	%	
Race							.012
Black	79	38	32	28	47	50	
Hispanic	33	16	22	19	11	12	
White	82	39	52	46	30	32	
Other	14	7	8	7	6	6	
Education							.017
Less than high school	66	32	47	41	19	20	
High school graduate/GED	85	41	38	33	47	50	
Some college/trade school	49	24	26	23	23	24	
College graduate	9	4	3	3	6	6	
Mean age (years)	34.2		34.0		34.4		

administered and devoid of any inmate identifiers. Statistical analysis was performed in Statistical Analysis Software.

SELECTED DEMOGRAPHICS OF INMATE PARTICIPANTS

Tables 1 through 4 contain demographic information about the inmates who were interviewed. The first column represents the total group of 212 inmates, the second column represents the 115 female inmates, and the last column contains the 97 male inmates.

The data need to be qualified by the knowledge that this was a voluntary survey. Inmates could discontinue at any time and were not required to answer every question. That means that not every inmate is represented in every question. The analysis corrects for those disparities, so the easiest way to view the data is to focus on the percentages located inside the parentheses for every question.

The *p* value on the far right in the tables indicates the statistical significance. *p* values are used to assess the probability that two or more groups are different on some frequency or mean value. The smaller the *p* value, the less likely they are the same. Any *p* value less than .05 indicates statistical significance.

As can be seen in Table 1, there is no difference in the mean age of the inmates. They were in their mid-30s, with a mean age overall of 34.2 years. Connecticut reports their inmates to be on average 29.7 years on

TABLE 2 Selected Family Demographics of Inmate Participants

	<i>Total</i>		<i>Female</i>		<i>Male</i>		<i>p</i>
	<i>(N = 212)</i>		<i>Inmates</i>		<i>Inmates</i>		
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
Family							.037
Single	110	52	61	53	49	51	
Married	32	15	12	10	20	21	
Divorced/separated/ widowed	50	24	32	28	18	19	
Common law partner (opposite sex)	15	7	6	5	9	9	
Common law partner (same sex)	4	2	4	4	0	0	
Ever lost custody	45	30	33	38	12	20	.016
Mean children born		2.93		2.90		2.97	
Mean children living		2.73		2.67		2.82	.001

admission. National rates estimate that 68 percent of inmates are younger than 35 years of age.

The ethnicity in our survey population is somewhat comparable to national averages; however, slightly more whites and slightly less blacks are represented in our Connecticut survey. National averages in 1991 were the following: 39 percent white, 45 percent black, 17 percent Hispanic, and 2 percent other.

Among the inmates, the survey team interviewed more male prisoners belonging to racial minorities. There were almost twice as many black men (50 percent) in comparison to black women (28 percent).

With regard to education, 69 percent of the inmates had a high school education or above, and 4 percent were college graduates. This is about 10 percent higher than the national rate of inmates with a high school education.

When comparing female inmates to male inmates, men tended to have achieved a higher educational status. Only 20 percent of the men had less than a high school education, whereas 41 percent of the women reported not having completed high school.

As for relationship status, presented in Table 2, most inmates were single and never married (52 percent). These percentages are comparable to national averages, in which more than half of inmates report themselves to be single. In terms of gender, twice as many men (21 percent) were currently married as compared to women (10 percent).

TABLE 3 Employment, Health Insurance, and Public Assistance Histories

	<i>Total</i>		<i>Female</i>		<i>Male</i>		<i>p</i>
	<i>(N = 212)</i>		<i>Inmates</i>		<i>Inmates</i>		
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
Ever held a legal, steady job	152	72	92	80	60	62	.003
Ever had private health insurance	101	48	53	46	48	48	
Ever received public assistance	146	72	103	90	43	48	.001
Mean number of entitlements		2.1		2.4		1.3	.001
Mean time last received (years)		2.2		1.6		4.0	.03

There are few reported differences in the mean number of children born to the prisoners. The inmates who had children reported an average of 3 children, with an average of 2.7 still living at the time of the interview. As can be seen in Table 2, 30 percent of the female inmates reported having lost custody of their children at some point in their lives. More women than men reported custody loss, and this is probably related to women being more likely than men to have lived with their children and to have been family caregivers.

Table 3 indicates that more than 70 percent of the inmates reported having had a legal steady job at some point in their lifetime. Although women (80 percent) reported having been steadily employed at a higher rate than men (62 percent), women reported marginally less private health insurance coverage.

Close to three-fourths of all inmates reported having received some form of public assistance in the past. Significantly more women claimed to have been recipients of public assistance.

Female inmates reported having received almost twice as many entitlements (2.4 per woman) than men and reported having received entitlements on average up to a year and a half prior to their arrest.

Table 4 presents the living circumstances of inmates before their arrest. These numbers suggest that close to 50 percent of the inmates did not have a place to live that they could call their own. When combining the last two numbers in the column of the table, 10 percent of all inmates in the sample reported living in a shelter or on the streets prior to their arrest.

TABLE 4 Housing and Homelessness Prior to Incarceration

	<i>Total</i>		<i>Female</i>		<i>Male</i>		p
	<i>(N = 212)</i>		<i>Inmates</i>		<i>Inmates</i>		
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
Residence prior to arrest							
Own/partner's place	106	51	49	43	57	61	
Relative/friend	79	38	48	42	31	33	
Rooming house/shelter	7	3	6	5	1	1	
On the streets	14	7	10	9	4	4	
Ever homeless	88	42	62	54	26	27	.001

Close to half of all inmates considered themselves to have been homeless at some point in their lives. More than 50 percent of the women, or twice as many in comparison to the men, reported some prior homelessness. This finding is somewhat startling and has important implications for correctional policies on compassionate release for the terminally ill.

FAMILY RELATIONSHIPS OF INMATE PARTICIPANTS

As Table 5 indicates, 18 percent of the total population reported that their mother was deceased and close to 40 percent reported that their father had passed away prior to the interview. The mean age of their father's death was slightly younger (22 years) than their mother's (23.5 years).

The lower portion of Table 5 explores the perceived relationship status, or, in other words, how close inmates felt to their parents while growing up. There is an almost threefold difference in inmates reporting not having grown up with their father (28 percent) as compared to those reporting not having grown up with their mother (10 percent). This suggests that many inmates grew up in a single-parent household. National estimates report that 43 percent of state inmates grew up in a single-parent household and 14 percent had lived in households with neither parent. As the chart indicates, very close maternal relationships were reported by more than 50 percent of all inmates, with significantly more men (62 percent) than women (41 percent) reporting a very close relationship with their mothers.

Paternal relationships appear to be less close, with fewer than one-third of all inmates reporting a very close relationship with their father

TABLE 5 Family Relationships of Inmate Participants

	<i>Total</i>		<i>Female</i>		<i>Male</i>		<i>p</i>
	<i>(N = 212)</i>		<i>Inmates</i>		<i>Inmates</i>		
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	
Mother deceased	37	18	23	20	14	14	
Father deceased	75	37	40	36	35	37	
Relationship growing up with mother							.036
Did not grow up with mother	21	10	14	12	7	7	
Not close	16	8	10	9	6	6	
Somewhat close	66	30	43	38	23	24	
Very close	107	51	47	41	60	62	
Relationship growing up with father							.002
Did not grow up with father	58	28	39	35	19	20	
Not close	29	14	9	8	20	22	
Somewhat close	58	28	26	23	32	34	
Very close	61	30	39	35	22	24	
Mean age at parent's death							
Mother		23.6		23.2		24.5	
Father		21.9		23.0		20.5	

while growing up. More women (35 percent) reported having a closer relationship with their fathers than did the men (24 percent).

Table 6 further explores inmates' relationships. Overall, inmates reported an average of three brothers or half brothers and two sisters or half sisters.

What is interesting to note is that close to 60 percent of the inmates surveyed reported that a direct family member (mother, father, sister, or brother) had also spent time incarcerated. This is more than one and one-half times greater than the national rate, in which 37 percent of inmates reported an immediate family member had served time.

The survey also examined visitation by family members and by friends among inmates to get a sense of how much support inmates get while serving time in prison. Overall, 64 percent reported that they did have visitations by family members. While it is not shown in any of these accompanying tables, the data reveal that of all the visitors, inmates considered their mothers to be the visitor they most looked forward to seeing, followed by their children. There is a significant difference in visitation between male inmates and female inmates.

TABLE 6 Selected Family Characteristics and Prison Visitation

	<i>Total</i> (N = 212)		<i>Female</i> <i>Inmates</i> (n = 115)		<i>Male</i> <i>Inmates</i> (n = 97)		p
	n	%	n	%	n	%	
Other family members ever in prison	121	58	71	62	50	52	
Ever visited by family while incarcerated	127	64	56	52	71	77	.001
Ever visited by friends while incarcerated	71	35	32	29	39	42	.05
Mean number of brothers/ half brothers	2.8	2.2	2.7				
Mean number of sisters/ half sisters	2.4	2.2	2.6				

At the bottom of Table 6, the reader can see that slightly more than one-third of all inmates reported that their friends come to see them while they are in prison. Again, more men than women reported visitations by their friends.

Some other information collected tried to explore barriers to prison visitation by family members. Some of the top barriers reported centered on distance and transportation issues, with a number of inmates reporting that family members found it too difficult to visit them in prison. Inmates also reported that some visitors they would have liked to see did not come because they were either in prison or had criminal records and were not granted visitation privileges.

CAUSES OF DEATHS IN THE FAMILY

As part of exploring family dynamics, the survey team asked inmates about how their family members had died. This broaches the delicate subject of the high mortality rate among siblings of inmates. We have yet to explore comparable statistics on sibling deaths; nevertheless, the information presented in Figure 2 is startling.

In the total sample, 25 percent, or one in four inmates, reported that at least one of their siblings had died. Furthermore, 6 percent reported that two or more of their siblings were dead.

In Figure 2, the first set of columns looks at the causes of death among mothers, the second set looks at fathers, and the third set looks at siblings.

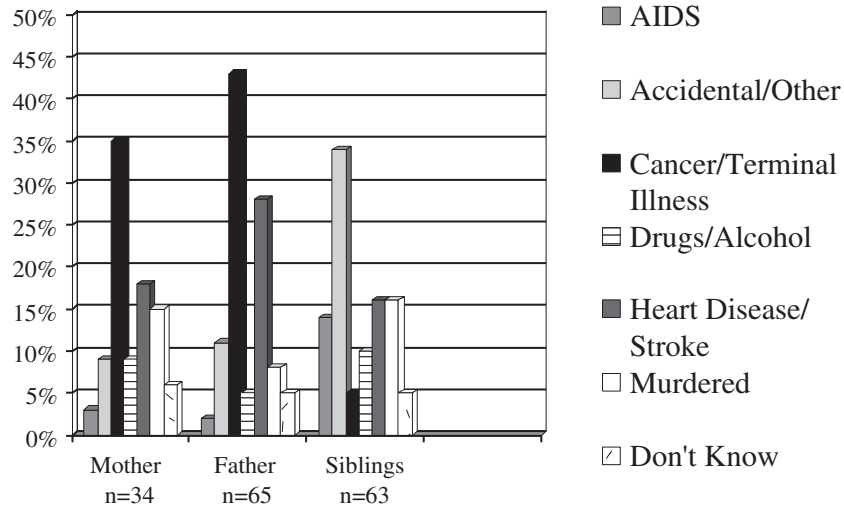


FIGURE 2 Reported Causes of Death among Family Members of Inmates

Among mothers, the leading cause of death, at 35 percent, is cancer or some other terminal disease. Heart disease ranks second, at 18 percent. It is astonishing that murder ranks third, at 15 percent. Three percent of the mothers purportedly died of AIDS.

The top three leading causes of death for fathers are the same as those for the mothers. Cancer and terminal disease at 43 percent are first, heart disease at 28 percent ranks second, and murder is third at 8 percent. Two percent of the fathers purportedly died of AIDS.

Acts of fate, such as car accidents, drowning, or fire, were the leading causes of death among siblings, while murder and heart disease were tied for second at 16 percent. AIDS was fourth at 14 percent.

Across the board, approximately 5 percent of all inmates reported that they did not know from what or how their parents or siblings had died.

The message behind these data is that inmates have indeed suffered losses in their lives, with a significant number of them losing a family member to violent or accidental deaths as well as chronic diseases.

RELIGIOUS BELIEFS AND SPIRITUALITY

The survey team was also interested in exploring support mechanisms for inmates through religious beliefs and spirituality. Table 7 quantifies responses to the questions we selected. While the majority of inmates did not consider themselves to be very religious (20 percent) or

TABLE 7 Religious Beliefs and Spirituality

	<i>Total</i>		<i>Female</i>		<i>Male</i>	
	<i>(N = 212)</i>		<i>Inmates</i>		<i>Inmates</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>
Religious						
Not at all	19	9	5	4	9	10
Little/somewhat	113	64	80	70	53	60
Very religious	42	20	1	18	21	23
Spiritual						
Not at all	14	7	7	6	7	8
Little/somewhat	104	50	66	57	38	41
Very spiritual	75	36	35	30	40	43
Spirituality as source of strength						
Never	12	6	8	7	4	4
Rarely/sometimes	74	36	42	37	32	34
Often/always	122	59	63	56	59	62
Music, art, or dance to heighten spirituality						
Never	19	9	7	6	12	13
Rarely/sometimes	66	33	35	31	31	34
Often/always	117	58	70	63	47	52

very spiritual (36 percent), they identified with spirituality when questions were redirected through more tangible concepts, such as spirituality as a source of strength or a sensation heightened by a stimulus such as music, art, or dance. Almost 60 percent of all inmates reported that their spirituality very often or always gave them strength. On a lighter note, close to 60 percent of all inmates reported that a stimulus such as music, art, or dance often or always heightened their spirituality.

SELF-REPORTED ILLNESSES

Table 8 shows the frequency of self-reported illnesses and therefore may actually be an underestimation of the true burden of disease in the sample. Most notable are the rates for HIV and AIDS, both many times higher than national rates. In both cases, female inmates had a significantly greater frequency of having the HIV disease. Female inmates also reported more than three times the rate of psychiatric disorders than male inmates did. Overall, 35 percent of all inmates reported having at least one major illness.

TABLE 8 Self-Reported Illness among Inmate Participants

	<i>Total</i> (N = 212)		<i>Female</i> <i>Inmates</i> (n = 115)		<i>Male</i> <i>Inmates</i> (n = 97)		
	n	%	n	%	n	%	
Cancer	8	5	7	6	1	1	
Diabetes	9	5	2	2	7	9	
Heart disease	18	10	10	9	8	11	
Tuberculosis	7	4	3	3	4	5	
HIV	38	20	30	27	8	11	.007
AIDS	16	8	11	10	5	6	
Psychiatric disorder	22	13	19	17	3	5	.07
Any one illness	58	35	42	37	24	25	.065

INCARCERATION HISTORIES

Tables 9 and 10 present the incarceration histories of the inmates we surveyed. The mean reported age at first incarceration was just younger than twenty-three years, and there was no significant difference between the male and female inmates. Women had significantly more incarcerations than male inmates did, even though they were older at the time of their first incarceration. This is in part explained by the fact that male inmates reported a greater than twofold increase in the mean time served without release. In addition, the types of offenses for which women are more commonly arrested, such as commercial sex work, drug offenses, fraud, and larceny, carry shorter sentences than the offenses men are more likely to be serving time for, such as robbery, assault, and burglary. Male inmates also reported a significant threefold greater mean duration of current sentence relative to female inmates.

INCARCERATION HISTORIES AND DRUG USE

As seen in Table 10, the vast majority of inmates (92 percent) reported having used illicit drugs at least once in their life. Female inmates reported more frequent drug use than male inmates as well as a higher rate of arrests for drug-related charges. There was no significant difference between male and female inmates on the frequency of drug-related charges when broken down by race. Whites were significantly older than both blacks and Hispanics at the mean age of first arrest for drug use. There were no significant differences in the mean number of incarcerations, however, nor in the total time spent incarcerated.

TABLE 9 Incarceration Histories of Inmate Participants

	Total (N = 212)	Female Inmates (n = 115)	Male Inmates (n = 97)	p
Mean age first incarceration (years)	22.8	23.8	21.7	
Mean number of incarcerations	3.9	4.6	3.2	.01
Mean total time incarcerated (years)	6.6	3.7	9.8	.05
Mean time served without release (years)	2.9	1.7	4.4	.005
Mean duration of current sentence (years)	4.7	2.9	7.6	.001

TABLE 10 Incarceration Histories and Reported Drug Use of Inmate Participants

	Total (N = 212)		Female Inmates (n = 115)		Male Inmates (n = 97)		p
	n	%	n	%	n	%	
	Ever used drugs	151	92	101	95	50	
Ever arrested on drug charges	105	64	74	70	31	53	.037
Race							
Black	36	64	20	67	16	62	
Hispanic	19	79	17	85	2	50	
White	43	62	34	71	9	43	
			<i>Black</i>	<i>Hispanic</i>	<i>White</i>		
Age first in prison (years)	21.5		21.5		26.0		.002
Mean number of incarcerations	4.0		3.3		3.9		
Total time incarcerated (years)	9.8		4.2		4.4		

TERMINAL CARE PREFERENCES

The data presented in Table 11 should be interpreted with the understanding that no matter what the circumstance, inmates will likely prefer to receive health care by professionals that are not officially connected to prison life, and whenever possible, anywhere outside a prison setting. As to be expected, for most inmates (74 percent), transfer to a hospital, nursing home, or medical facility was the first choice for terminal care. In the first-choice category, note that only 3 percent preferred to receive terminal care from correction's medical staff.

TABLE 11 Terminal Care Preferences among Incarcerated Inmates in Connecticut

	<i>First Choice</i> (n = 195)		<i>Second Choice</i> (n = 152)	
	n	%	n	%
Transfer to a hospital, nursing home, or medical facility	144	74	31	21
Receive care in prison from hospice medical staff	35	18	99	65
Receive care in prison from corrections medical staff	6	3	14	9
I would not want care from anyone	10	5	7	5

NOTE: Sixty-five percent of all inmates surveyed reported that they had received care (other than routine medical care) while incarcerated.

As far as second choices, 65 percent chose to receive care in prison from hospice medical staff as opposed to correctional professionals trained in hospice care (9 percent). Five percent reported for their first and second choice that they would not want care from anyone.

Qualitative analysis of the data captured in this table examined inmates' reluctance to receive correctional-based terminal care. Because the overwhelming majority of first and second terminal care preferences among inmates reveal unlikely options (being moved to an outside facility, receiving care from hospice providers) for the incarcerated, we explored the extent to which their choices may have been influenced by having had negative experiences with prison health systems and/or providers in the past. Of the 65 percent who reported having had more than routine care provided to them by correctional health professionals, the majority (73 percent) reported that the care they received was satisfactory or more than satisfactory (data not shown). This suggests that their preferences were not a function of past negative experiences or perceived ineptitude of correctional medical staff but rather may reflect their frustration with their incarcerated status and their resentment or dislike of correctional systems in general.

HOSPICE KNOWLEDGE

Table 12 explores the extent to which inmates had any knowledge of hospice prior to the interview. Overall, nearly 50 percent of the inmates reported having heard of hospice previously. Women were significantly more likely than men to have heard of hospice and were also significantly more likely to report that they would use hospice in prison if they

TABLE 12 Hospice Knowledge

	<i>Total</i>		<i>Female</i>		<i>Male</i>		p
	<i>(N = 212)</i>		<i>Inmates</i>		<i>Inmates</i>		
	n	%	n	%	n	%	
Ever heard of hospice	95	47	66	59	29	33	.001
Would use hospice in prison if eligible	165	81	100	88	63	72	.016
Don't know	36	18	13	11	23	26	
Prefer hospice staff	180	91	95	84	76	89	
Prefer correction's staff trained in hospice care	16	8	7	6	9	11	
Would become hospice peer volunteer	176	87	103	91	73	81	
Don't know	21	10	8	7	13	14	
Would want support from peer volunteer	155	77	95	84	60	67	.021
Don't know	42	21	16	14	26	29	

were eligible. As noted previously, the vast majority of the inmates preferred outside hospice staff over corrections medical services, with no difference in preference between men and women.

Many inmates (87 percent) reported wanting to become hospice volunteers, and there was no difference in their willingness by gender. Seventy-seven percent overall also reported they would want support from other inmate volunteers, and the women were significantly more likely than men to express this desire.

CHARACTERISTICS OF INMATES AND KNOWLEDGE OF HOSPICE

Table 13 shows a number of self-explanatory characteristics associated with prior knowledge of hospice in the survey sample in terms of age, gender, and education. As expected, inmates who were acquainted with someone who had received hospice care in the past were more likely to have heard of hospice, and inmates who knew someone else who had HIV/AIDS were also more likely to have heard of hospice.

Table 14 shows some of the characteristics of the inmates who had no prior knowledge of hospice. Some of these findings are surprising. Inmates who had deceased family members, HIV infection, a diagnosis of AIDS, or a diagnosis of cancer were no more likely to have heard of

TABLE 13 Characteristics Associated with Having Prior Knowledge of Hospice among Inmates

The older the inmate, the more likely they are to have heard of hospice.
Female inmates are more likely than male inmates to have heard of hospice.
Inmates with a high school education or above are more likely to have heard of hospice.
Inmates who know someone who received hospice care in the past are more likely to have heard of hospice.
Inmates who know someone else who has HIV/AIDS are more likely to have heard of hospice.

TABLE 14 Characteristics Not Associated with Having Prior Knowledge of Hospice among Inmates

Marital status
Spirituality
Having cared for someone who was terminally ill
Deceased family members (parent, sibling, or child)
Psychiatric disorder
HIV infection
Diagnosis of AIDS
Diagnosis of cancer

hospice than those inmates who did not have these characteristics in their case histories.

Further analysis will look into these findings. However, given the small sample size and the complexity of the life circumstances faced by inmates, it may be difficult to fully explore their lack of knowledge.

WHAT IS HOSPICE TO A PRISONER?

We realize that inmates have many competing needs for services, but we think that hospice is one of many programs that can respond to a wide range of their service needs. Here, for example, are some definitions of hospice from the mouths of inmates. They show the kind of service that the incarcerated men and women think they would receive if they were able to participate in a hospice program.

- a means by which a human being is allowed to die with dignity
- a way to die with dignity and sense of peace with oneself and your surroundings

- to be able to die with dignity at home close to a loved one and to spend the time remaining in peace
- final care for terminally ill patients to ease their transition from life
- learning to live with health problems and teaching others about disease means the world to others
- medical, emotional, and physical care by people who choose to care for me
- emotional support for people who need medical care, naturally sharing love for self with others
- support for people who are going to die or for those who are going to lose someone
- making your last days more comfortable and less scary
- support who sticks by you when you can't survive without the help of others
- a place where terminal people go to die by caring people that treat you medically, spiritually, and religiously
- security and comfort with proper medical attention for the terminally ill and family relief
- bringing the benefit of goodwill to hospital people minus the charge for professional services
- it means a lot to me because it is a wonderful thing to have someone to care about you
- listening to us women and caring enough to make a change
- a lot of people go to hospice for care they don't get anywhere else, such as a last resort for AIDS
- hospice helped my sister at the time of my mother's death because I was in prison
- a friend to talk to and a shoulder to lean on in a time of need
- one day I might go to hospice in my last days of life
- a place that offers help to terminally ill prisoners
- a better place to die

CONCLUSION

Some of the significant conclusions that can be deduced from the above information are the following:

- There is a significant lack of knowledge among prison inmates about hospice.
- Prison systems should be a reliable resource for educating inmates about hospice care.
- When given information about hospice, inmates express an interest in both receiving and participating in hospice programs.
- The high prevalence of morbidity among prison populations validates the need for connecting inmates to hospice services.

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