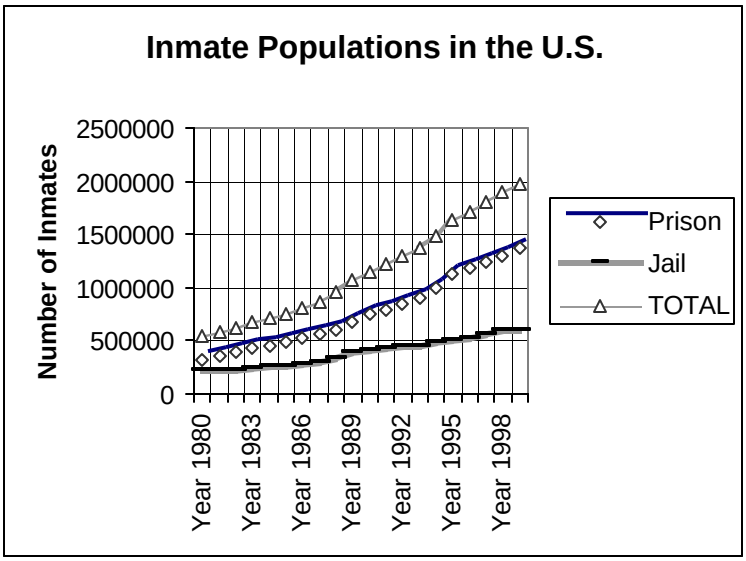
Incarceration of the Terminally Ill:
Current Practices in the United States

As the United States continues to experience steady growth in inmate populations at the local, state and federal level, changes in the characteristics of inmates pose new challenges.

Overall Inmate Population Growth

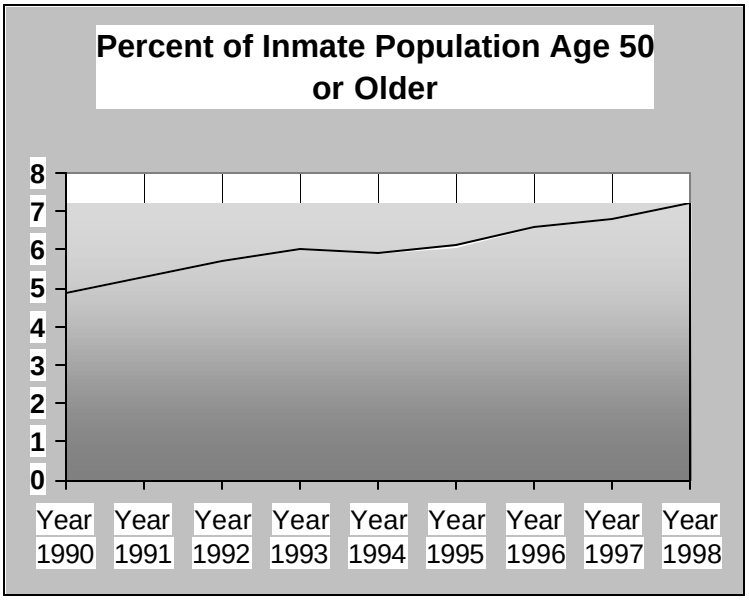
The total inmate population in the United States increased nearly four-fold in the past two decades, from a total of 540,036 in 1980 to 1,972,664 in 1999.



Jail populations have grown at a lower rate (275% since 1980) compared to a 427% increase in state and federal prison populations. State and federal inmates comprised nearly 70% of the total inmate population in 1999, held in approximately 1,400 adult correctional facilities operated by states, territories, and the Federal Bureau of Prisons. Although the jail population is about half the size of the prison population, jail inmates are housed in approximately 3,300 adult local detention facilities operated by counties and cities. While 500,000 persons are admitted and released from state and federal prisons annually, twenty times that amount—over *eleven million*—persons are admitted and released from jails annually. And the majority of all jail inmates come from, and return to, the local community. This volume of activity has drawn the attention of public health professionals, including those who are concerned about the seriously ill inmates who frequent our jails.

The Inmate Population Is Aging

As the overall inmate population soars, the *proportion* of prison inmates who are age 50 or older has slowly, but steadily, increased in recent years.



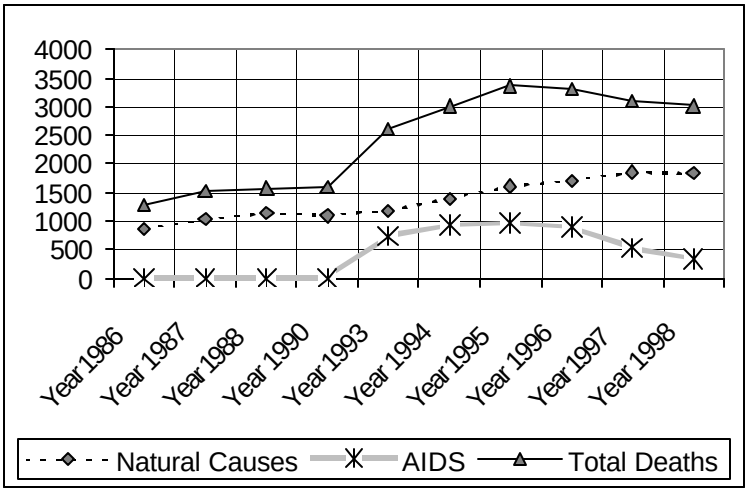
The Ohio Department of Rehabilitation and Correction recently predicted that inmates age fifty or older will account for *twenty-five percent* of the state's prison population by the year 2025—nearly four times the proportion of older inmates currently housed in the state's prisons (Ohio Dept of Rehabilitation and Correction, 1999).

Many explanations are offered for this trend, such as "truth in sentencing" laws, determinant sentencing, and anti-drug initiatives; but, regardless of the causes, the effect on the operation of adult institutions is being felt, primarily at the state and federal level.

Number of Inmate Deaths Eased in Recent Years

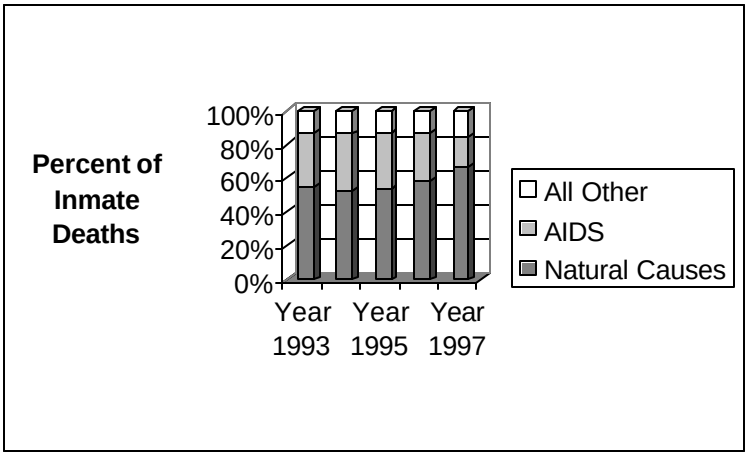
Although the number of inmates confined in United States jails and prisons increased steadily, the number of inmate deaths has declined in recent years and appears to have leveled off in the past year.

Number of Prison Inmate Deaths 1988-1998



The decline in the number of prison inmate deaths is largely due to the 65 percent drop in the number of AIDS deaths from its peak in 1995. Yet, over the last decade deaths from other natural causes has more than doubled.

Causes of Jail Inmate Deaths 1993-1997



While the death rate among *jail* inmates fell between 1983 and 1993, the rate of death from illness, including AIDS, remained relatively constant over the period.

Not Enough Is Known About Causes of Death

As the preceding charts suggest, "natural causes" continues to be the largest category of inmate deaths. Unfortunately, data that further describe natural causes are not collected nationally at this time, and are even difficult to secure at the state level.

This lack of data characterizes current local, state and federal data collection and analysis practices. In 1991 the National Institute of Corrections (NIC) found that:

> Almost without exception, national incidence and prevalence data were lacking. More importantly--at least in terms of its potential impact on specific DOCs -- good data often were not available at the state level either. In the absence of specific information on the extent and level of current needs, it is impossible to plan for what many believe to be the coming crisis in corrections. (Moore, 1991)

When NIC explored the hospice and palliative care in prisons in 1998 it found that "most DOCs do not keep complete data on the placement of terminally ill inmates." (National Institute of Corrections, 1998)

An examination of the experience of the Oregon State Penitentiary, one of the sites that maintains data about cause of death, reveals some interesting findings for the past seven years (Oregon Department of Corrections, 2001). For example, nearly half of the inmates who died from natural causes were *under* age 55 (excludes inmates who died of AIDS).

Characteristics of Inmate Deaths
Oregon State Penitentiary 1994-2000

CAUSE OF DEATH	Age: Under 35	Age: 35-54	Age: 54 & over	**TOTAL**
SUICIDE	8	5	0	**13**
EXECUTION	0	1	1	**2**
CAUSED BY ANOTHER	0	1	1	**2**
OVERDOSE	1	0	1	**2**
AIDS	3	5	0	**8**
NATURAL CAUSES:	?	?	?	**66**
Cancer	2	9	9	
Cardiac Event	1	9	15	
Liver Disease/Failure	0	7	3	
Congestive Heart Failure	0	0	2	
All Other Natural Causes	1	3	5	**93**
TOTAL	**16**	**40**	**37**	

New data on the causes of death are expected in the future. Last year Congress passed the *Deaths in Custody Act of 2000* and allocated funds to allow the Bureau of Justice Statistics (U.S. Department of Justice) to begin collecting data from prisons, jails, police lockups, and police departments.

Responses to the Needs of Terminally Ill Inmates Are Accelerating

Current practices can be described under two broad categories: *release* and *services for inmates*.

Release of Terminally Ill Inmates

Thirty-three states and the Federal Bureau of Prisons have procedures for granting "compassionate" release to dying prisoners; the remaining states have at least one general mechanism that patients at end of life can use to seek release. These procedures vary widely and include commutation of sentence through the DOC, executive clemency and/or commutation, reduction of sentence through the courts, administrative leave or furlough, and parole. Formal requests for medical release ask judges, correctional administrators, governors, and/or parole boards to "weigh the needs of dying or desperately ill inmates against society's desire for retribution, deterrence, and protection." (Wolfson, 2000)

While all correctional systems have some mechanism for releasing terminally ill inmates, very few medically appropriate patients are actually released before dying. California, with a prison population of some 150,000, grants an average of 28 compassionate releases of 78 applications received annually. (Dubler and Heyman, 1998) New York's 1992 Medical Parole Law resulted in a total of 215 releases in the seven years ending in 1998. (Beck, 1999)

The American Bar Association's *Section of Individual Rights and Responsibilities* lamented in 1996 that plea-bargaining restrictions and mandatory minimum sentencing guidelines in many jurisdictions tie the hands of prosecutors and judges who would like to consider alternatives to prison for non-violent, terminally ill defendants. According to the ABA report, "even when the judge and prosecutor consider the sentence to be inappropriate, especially for non-violent and terminally ill inmates, they still have no choice but to incarcerate them." The report concluded that adoption of uniform legislation in the areas of compassionate release and alternative sentencing "should go a long way toward addressing both the humanitarian concerns associated with dying inmates and the concerns of prison officials dealing with the over-crowding and health care problems plaguing the prison system." But such uniform legislation has not yet been implemented.

Services for Inmates

The majority of terminally ill inmates will not receive compassionate releases before they die. For these, innovative services are being developed by the Federal Bureau of Prisons, by most states, and even by some jails.

A first-of-its-kind national survey on hospice and palliative care in prisons conducted by the NIC (1998) identified the range and extent of end-of-life programs in adult correctional facilities found that:

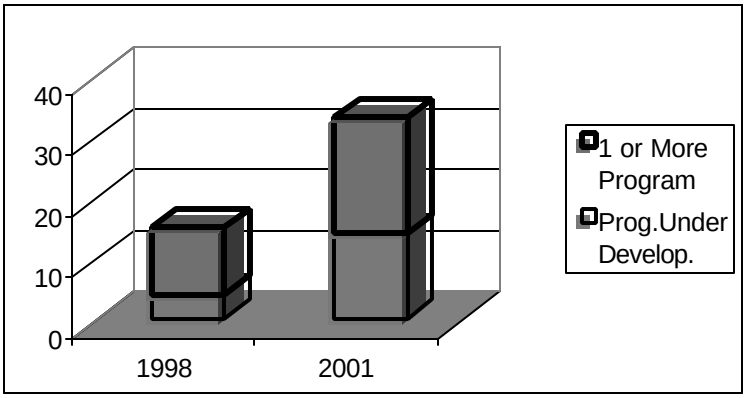
- Eleven states and the U.S. Bureau of Prisons operated "formal" prison hospice programs at one or more sites within their correctional systems
- Four states, one municipal prison system, and the Correctional Service of Canada were developing their first formal hospice program
- Eleven states were considering development of their first formal hospice program
- Nine states reported offering some sort of palliative care outside of the formal hospice setting

The GRACE (Guiding Responsive Action in Corrections at End-of-life) Project, a Robert Wood Johnson Foundation *Promoting Excellence in End-of-Life Care* program also began in 1998. Led by Volunteers of America, a national non-profit human service organization, this collaborative project collected information on end-of-life care programs in the Federal Bureau of Prisons and 14 state departments of corrections. It also compiled a profile of program components that constitute best practices, including (1) involvement of inmates as hospice volunteers; (2) increased visitation for families, including inmate family; (3) Interdisciplinary Team, including physician, nurse, chaplain and social work, at a minimum; (4) comprehensive Plan of Care; (6) advance care planning; (7) training in pain and symptom management; (8) bereavement Services; and (9) adaptation of the Environment for “comfort.” (Ratcliff, 2000)

In March 2001—30 months after the NIC survey—the GRACE Project conducted a new inventory of correctional hospice and palliative care programs. A remarkable growth in activity was found; the number of states with end-of- life care programs in place or under development has more than doubled. The number of states with at least one formal end-of life care program has grown from 11 (1998) to 19 (2001).

And, the number of states with an end-of-life care program under development has grown from 4 (1998) to 14 (2001). Additionally, 9 states that have a program in place have additional programs under development.

Number of Formal End-of-Life Care Programs In Place and Under Development



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Statistics in this report were compiled from the annual issues of C. J. Camp and G. M. Camp, *The Corrections Yearbook* (Middletown, CT: Criminal Justice Institute) for the years 1994 – 1998; and from various reports of the Bureau of Justice Statistics (Washington, DC: U.S. Department of Justice) for the years 1980 – 1998.

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