

End of Life Care for Incarcerated Individuals: The Louisiana State Penitentiary Hospice Care Program

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What is considered End of Life Care?

- ❑ End-of-life care is the term used to describe the support and medical care given during the time surrounding death.
- ❑ This care does not mean just the care in a person's' very last moments, but rather the care required for people in the days, weeks, or months leading up to death.
- ❑ Hospice care includes palliative and supportive services that provide physical, psychological, social, and spiritual care for dying persons and their families (Jones and Strahan, 1997).

End of Life Care (EOLC) for Incarcerated Individuals

- ❑ Attitude of correctional facilities toward implementing end of life care for incarcerated individuals.
- ❑ Factors that motivate and deter correctional facility participation in end of life care, specifically in the U.S prison system.
- ❑ Provide insight for administrators attempting to improve or impact end of life care for the aging prison population.

Literature Review Criteria

- ❑ Attitudes and experiences of inmate volunteer caregivers, administrative perspectives, and policy changes regarding end of life care while incarcerated.
- ❑ A content analysis of the existing peer-reviewed literature on palliative and end of life care in prison was performed.
- ❑ Current, not older than 10-20 years, and focused solely on the United States.
- ❑ 39 articles, some of which were actual research studies and others that were descriptive articles or summaries.
- ❑ 9 articles were ultimately chosen for review.
- ❑ Studies used both quantitative and qualitative methods, utilizing surveys that included short-answer questions or interviews with between 12-20 offenders which represented the qualitative aspect of the studies

(Cloyes et al., 2014, Sanders et al., 2018, Zimmerman et al., 2002)

The Aging Prison Population

- ❑ Due to an increase in the U.S. prison population and average inmate age, correctional facilities have been inundated with caring for chronically and terminally ill incarcerated persons.

Prison by the Numbers

- ❑ “The aging prison population has more than tripled since the early 1990s, representing one of the most dramatic changes in the American correctional system” (Phillips, Allen, Salekin, & Cavanaugh, 2009, p.620).

85%

- ❑ **“One of every 23 inmates in prison today is age 55 or older, an 85% increase in the past 10 years” (Phillips, Allen, Salekin, & Cavanaugh, 2009, p.620).**

127,000

- “A 2004 report by the Sentencing Project found an 83% increase in the number of inmates serving a life sentence since 1992, yielding a total of 127,000 lifers” (Mauer, King, & Young, 2004).

75

- **“There are approximately 75 hospice programs in prisons in the country. There are six programs in the Federal Bureau of Prisons. Of the existing programs, about one-half use inmates as hospice volunteers” (NHPCO, p.1, n.d.).**

Potential Barriers to Program Participation

“These include but are not limited to:

- (1) prison rules and regulations,
- (2) distance of the inmates' family members to the prison,
- (3) the physical prison environment,
- (4) mutual suspicion between inmates and staff,
- (5) barriers to communication and affection that exist in the punitive correctional environment and
- (6) racism” (Granse, 2003, p. 362).

Potential Barriers to Program Participation

Other issues specific to end of life care in prison include:

- ❑ care standards
- ❑ inmate-physician relationships
- ❑ confidentiality
- ❑ lack of interdisciplinary team care
- ❑ the complexities of do-not-resuscitate orders
- ❑ potential inability to deliver adequate pain relief.

Misconceptions in Literature

Included:

- ❑ a belief that criminals do not deserve to die with dignity
- ❑ concerns about risks to prison security
- ❑ prejudice against use of inmate volunteers
- ❑ ethical concerns
- ❑ and budget concerns

(Tillman, 2000, p. 521).

Cost

State Departments of Corrections are given a flat per diem for each inmate. There are no increases or adjustments in the rate due to age or health status. Prisons are mandated to provide “community standard” health care.

- ❑ Thus, correctional facilities are financially strained by the cost of care for aging and dying inmates” (NHPCO, p.1, n.d.).

“This difference is believed to have developed due to inmates’ excessive drug and alcohol use, poor nutrition and eating habits, stressful life experiences, and lower socioeconomic status in comparison with non-offenders” (Phillips et al., p.621).

Benefits of EOLC

- ❑ Purpose
- ❑ Comfort
- ❑ Autonomy
- ❑ Emotional and spiritual growth
- ❑ Respect
- ❑ Sustainability

Benefits

“Although prison life offers other means for inmates to learn to be responsible or to interact socially in positive ways, for example, through attending school, participating in church groups, or becoming affiliated with inmate clubs, only the hospice experience teaches inmates about respect for life”

(Tillman, 2000, p. 518)

Benefits

Tillman discusses how difficult it is for inmates to have their own autonomy given the contextual setting, even though this is an expected outcome of incarceration.

“One of the most dramatic and significant losses relative to autonomy is that of free choice of one’s healthcare provider and medical facility”
(Tillman, 2000, p.522).

Benefits

“Inmates are strongly encouraged to exercise their autonomy through advance care planning. Making an advance directive at the time of admission for hospice care allows the patient those treatments and or actions he wishes to have withheld” (Tillman, 2000, p. 522).

Benefits

“Many inmates see their participation in the hospice program as a way to prepare for how they themselves will die or as a means of giving back something to others, and a way of repaying their debts”
(Tillman, 2000).

Benefits

“The ability of inmate-caregivers to connect with, understand, and communicate needs of dying inmates is essential to administering patient-centered care and establishing trust” (Depner et al., 2017).

Benefits

Depner et al., (2017) found:

“According to a recent ethnographic review of the largest prison-based hospice program, inmate caregivers contribute to a comprehensive system of care that also allows for program sustainability. Based on these findings, it is important that research continues to explore this unique and potentially helpful model of end of life care delivery within the correctional setting.”

End of Life Care is Justified

Tillman concludes “The program, in many ways, affords inmates and prison staff common ground to stand on. This does not mean that the appropriate distance between the two groups is violated. It is important to emphasize that security is in no way compromised” (2000).

- ❑ End of life care provides a space where humanity can be honored and acknowledged regardless of how the patient lived.



Figure 1: Louisiana State Penitentiary (Prison Mindfulness Institute, 2010).

Findings

- ❑ Care was provided by prison health care staff, which included interdisciplinary teams, corrections officers, and volunteer inmate caregivers.
- ❑ The volunteer inmate caregivers were viewed positively by both end of life care patients and health care staff, for their ability to create a level of trust with patients that is not easily achieved by healthcare staff (Williams et al., 2012).

Findings

- ❑ Repeated themes in two of the studies included inmates providing end of life care viewed caregiving as a transformational experience which provided growth (Depner, 2017).
- ❑ Findings also showed that the amount of training inmate volunteers receive varies widely, with some studies sighting 1 to 10 hours of training, others reporting up to 40.

Findings

- ❑ The importance of good relationships and respect between inmate volunteers, nursing staff, and correctional officers was also found to be a factor that contributed to programs running more smoothly.
- ❑ However, findings also suggest that the screening process for inmate volunteers is much stricter compared to end of life care in the free world.

Implications and Future Research

- ❑ Perform a specific study on the impact mental illness and emotional health have on an inmate's decision when choosing end of life care.
- ❑ Making sure patients understand their options and the outcomes of their choices

Implications and Future Research

- ❑ In Phillips et al., (2012) the authors of the study expressed concern that inmates had to ask for explanations regarding the differences between palliative care and life-sustaining treatment during the interviews.

“From further comments made by the inmates, it is questionable whether they fully understood the ramifications of the treatment preferences they expressed” (p.632).

Implications and Future Research

- ❑ More work with inmates' families and nurses in the prison setting
- ❑ More research is also needed to evaluate the impact of benefits relating to the meaning of the hospice care process on inmate caregivers and how meaning may help further facilitate rehabilitation.

Conclusion

This literature review illustrates the challenges of providing end of life care to prisoners and may inspire prison administrators to consider steps to improve and expand this care to address the challenges dying inmates experience.

By being aware of these issues and practices, prison administrators, healthcare staff, and volunteer caregivers can help inmates at the end of life reclaim dignity in death.

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