“People Don’t Understand What goes on in Here”: A Consensual Qualitative Research Analysis of Inmate-Caregiver Perspectives on Prison-Based End-of-Life Care

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Abstract

Background: The age demographic of the incarcerated is quickly shifting from young to old. Correctional facilities are responsible for navigating inmate access to healthcare; currently there is no standardization for access to end-of-life care. There is growing research support for prison-based end-of-life care programs that incorporate inmate peer-caregivers as a way to meet the needs of the elderly and dying who are incarcerated.

Aim: This project aims to: a) describe a prison-based end-of-life program utilizing inmate peer-caregivers, b) identify inmate-caregiver motivations for participation, and c) analyze the role of building trust and meaningful relationships within the correctional end-of-life care setting.

Design: Twenty-two semi-structured interviews were conducted with inmate-caregivers. Data were analyzed using Consensual Qualitative Research methodology.

Setting/Participants: All inmate-caregivers currently participating in the end-of-life peer-care program at Briarcliff Correctional Facility (pseudonym) were given the opportunity to participate. All participants were male, over the age of 18, and also incarcerated at Briarcliff Correctional Facility, a maximum security, state-level correctional facility.

Results: In total five over-arching and distinct domains emerged; this manuscript focuses on the following three: a) Program Description, b) Motivation, and c) Connections with Others.

Conclusions: Findings suggest that inmate-caregivers believe they provide a unique and necessary adaptation to prison-based end-of-life care resulting in multilevel benefits. These additional perceived benefits go beyond a marginalized group gaining access to patient-centered end-of-life care and include potential inmate-caregiver rehabilitation, correctional medical staff feeling supported, and correctional facilities meeting end-of-life care mandates. Additional research is imperative to work towards greater standardization of and access to end-of-life care for the incarcerated.

Keywords: Prisons; Hospice Care; Qualitative Research; Health Care Quality, Access, and Evaluation

Key Messages:

Already known about topic:

-Elderly inmates are the fastest growing incarcerated population.

Providing healthcare for chronically ill and/or dying inmates poses challenges both within the correctional environment and upon release to community-based facilities. -There is a lack of standardization of palliative care for people who are incarcerated and a lack of consensus about how to adapt hospice and palliative care philosophy to the correctional environment.
What this paper adds:

- This paper evaluates a prison-based end-of-life peer-care program and contributes significantly to the growing support for the peer-care model.

- This research suggests that this program may adapt the community palliative care model to better fit the correctional environment as well as provide benefits beyond the care received by inmates.

Implications for practice, theory or policy:

- The inmate-caregiver model demonstrates promise towards reconciling hospice and palliative care models with the prison environment.

- This type of program could help a marginalized group of people gain access to end-of-life care and may provide secondary benefits to the inmate-caregivers, correctional medical staff, the correctional system, and society as a whole.

- Continued research should evaluate this model in order to build towards a standardized model of end-of-life care for those who are incarcerated.
**Introduction**

“Approaches to death and dying reveal much of the attitude of society as a whole to the individuals who compose it.” – Dame Cicely Saunders\(^1\) (p49)

Substantial research examines the urgency to address the challenges and needs of aging inmates\(^2\)–\(^6\) as well as the provision of care for chronically ill and dying-inmates\(^7\)–\(^10\).

Demographics are shifting from young to old\(^11\),\(^12\) and correctional facilities are facing the difficult task of meeting the needs of aging and dying inmates\(^3\),\(^13\). According to the Bureau of Justice Statistics, “from 2001 to 2013, the majority (9 in 10 deaths) of prisoner deaths were due to illness-related causes.”\(^14\)(p1) With research identifying the needs of aging and/or dying-inmates, exploration of models of care to meet these needs should be a priority.

Standards of care for the incarcerated in the United States are usually determined by governing legislative and judiciary bodies; however, facilities are responsible for interpreting and carrying out these standards\(^15\). “The courts have mandated sweeping reforms. Incremental change, however, has required corrections based medical services to secure the funding, resources and community support to begin reflecting the standards of care that exist outside of correctional institutions.”\(^15\)(p50) Prison-based end-of-life care often depends on collaborations between correctional facilities and outside agencies or hospitals, although in rare cases, facilities develop their own programs.\(^16\) Despite considerable news and media coverage on the topic of prison end-of-life care there has been limited scientific inquiry. The need for research into prison-based end-of-life care was noted as one of the most salient issues at a summit on criminal justice healthcare.\(^17\) Additionally, it was noted that inmates 55 and older account for four times the healthcare costs compared to younger and healthier inmates; this was attributed to the sudden increase in elderly inmates and lack of palliative care, particularly early intervention and planning.\(^18\) Although the need for palliative and supportive medicine continues to grow
exponentially, the question remains: how can correctional facilities optimize end-of-life care for inmates?

**Inmate Peer-Care Programs**

Some facilities are beginning to address end-of-life needs by employing inmates as caregivers for dying inmates. While inmate-caregivers were identified as one of the five elements of an effective prison-based end-of-life program, more research is needed within criminal justice healthcare. Priorities should include an evidence-based curriculum for inmate-peer care programs and meeting the needs of aging and dying inmates through the provision of palliative care when appropriate. Programs should be evaluated from a myriad of perspectives, including those of the dying inmates, their caregivers, correctional staff, and medical personnel. The need for appropriate care for dying inmates is not limited to the United States. Recent research has emerged from Switzerland, Ireland, the United Kingdom, Canada, and other countries. Although correctional regulations vary from country to country, the experience of dying while incarcerated has universal elements that could be addressed by synthesizing or cross-evaluating the research that has emerged globally.

Prior research focuses on psychosocial aspects of inmate-caregiving, such as the grief experience and the potential for transformation or positive growth of inmate-caregivers. In spite of increasing support, as of 2009, there were only 69 facility-based end-of-life inmate peer-care programs within the U.S. 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 and elucidate this unique and potentially helpful model of end-of-life care delivery within the correctional setting. Some previous research focused on other perspectives
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than the inmate-caregivers or employed less precise group evaluation methods such as focus groups. In order to build upon this foundation the authors chose to focus on the inmate-caregiver perspective to increase understanding of the inmate-caregiver role, experiential knowledge of what it is like to be incarcerated and care for someone who is chronically ill and/or dying, as well as how the addition of the inmate-caregiver component to prison-based care may extend beyond the individual level.

The Inmate-Caregiver’s Perspective

A model that relies on inmate-caregivers requires exploration of the caregiver perspective. Loeb and colleagues (2013) noted that after interviewing all other frontline staff (superintendents, deputies, correctional healthcare administrators, business office personnel, etc.) within the correctional setting about prison-based EOL care, it became clear that there was a gap in knowledge and understanding. “It became evident that we must clarify, first hand, the perspectives of inmates. For this reason, the study was expanded to include a focus on the values, beliefs, and perceptions of inmate-caregivers.” The current study also focuses on inmate peer caregivers’ experiences, although with a different focus. This is essential not only because there is limited research on inmate-caregivers in general but also because the inmate-perspective has been marginalized and undervalued due to lack of social status and vulnerability, both historically and in modern times. Additionally, the inmate-caregivers may have personal insights into inmate-related health concerns, as compared to outside observers who may not fully comprehend the unique experience of health/illness while incarcerated.

Study Purpose

This study explores a prison-based end-of-life care program from the perspective of the inmates who directly provide care. This study specifically aims to a) describe a program utilizing
Methods

Study Design

This is a qualitative study of 22 inmate-caregivers from a single correctional facility in New York State. Data were collected across two days in September of 2014.

Participants

Inmate-caregivers. All 22 participants were male, at least 18 years old, and participating in the Briarcliff Inmate-Facilitated End-of-life Care Program* (*pseudonym) as inmate-caregivers. Due to the risk of participant identification, researchers did not collect additional demographic information beyond inclusion criteria.

Briarcliff Correctional Facility*. Briarcliff is a maximum-security male correctional facility with a regional medical unit. Briarcliff and the Center for Hospice and Palliative Care (CHPC) (Erie County, NY) created the program in 2004 to train healthy inmates to care for dying-inmates under the supervision of facility medical and correctional staff. CHPC provides ongoing training and support about the physical, social, and existential aspects of end-of-life care.

Researchers. As part of the Consensual Qualitative Research (CQR) process personal biases and expectations were discussed, recorded, and revisited throughout analysis (see additional material for full report). It is the authors’ views that end-of-life care should be accessible for all people, even marginalized people such as inmates.

Procedure
**Project Approval.** This project was approved by the State University of NY at Buffalo Social and Behavioral Research Institutional Review Board (FWA00008824) on 5/27/2014, as well as Briarcliff Correctional Facility, and the New York State Department of Corrections and Community Supervision on 8/19/2014 (No.0403). An NIH Certificate of Confidentiality provided additional security with regard to data and privacy of inmate-caregivers approved on 6/28/2014.

**Recruitment.** All individuals meeting the inclusion criteria were given the opportunity to meet individually with researchers who read aloud the project consent form and answered any questions. Meetings occurred in private rooms where correctional officers waited outside a closed door. Inmates-caregivers were informed that participation had no impact on their incarceration status or participation in the end-of-life peer-care program.

**Interviews.** Semi-structured interviews were conducted (table 1) with allowance for follow-up probes and clarifiers. All interviews were audio-recorded and transcribed verbatim. Transcripts were maintained in Microsoft Word format. Names and other identifying information were changed to protect the interviewees. On average, interviews lasted between twenty and fifty minutes.

**Data Analysis Procedure**

**CQR Analysis.** Data were analyzed in accordance with CQR methodology. CQR adheres to a mixed research paradigm merging elements of constructivism with aspects of post-positivism. This process is data-driven, uses a team consensus approach, and results in a list of representative themes and sub-themes. The process includes: a) sorting data into domains or over-arching themes, b) conversion of raw data into core ideas (table 2), and c) cross-analysis, which evaluates within each domain for emergent categories or sub-themes. Data are reviewed
across all cases for representativeness based on standard levels of frequency (noted in tables 3, 4, 5). This qualitative analysis was employed to explore an inmate end-of-life peer-care program from an experiential perspective. All storage, coding, sorting, and cross-checking procedures were done via Microsoft Word.

Consensus Process. Team members individually reviewed each stage of the CQR process, then review and reach agreement about the current task before moving on. At each stage external auditors review and give feedback, which is incorporated at the discretion of the core team.

Stability. A check for stability was established by withholding a portion of transcripts during initial coding, (5/22). The addition of the withheld transcripts did not significantly impact themes or sub-themes.

Standards for Reporting Qualitative Research. This manuscript was prepared in accordance with the Standards of Reporting Qualitative Research.36

Results

Domains

During the Consensual Qualitative Research process 5 distinct domains emerged. Two domains, Confronting Death and Dying and Personal Transformation and Growth are published in a separate manuscript because their content was thematically different from those discussed here.21 The current manuscript focuses on three over-arching domains: 1) Program Description, 2) Motivation, and 3) Connections with Others. Program Description was defined as any discussion of structure, duties, or tasks, including how individuals defined the program, what inmate-caregivers wanted others to know about the program, hopes for the program, and personal perceptions about the program. Motivation was defined as the reasoning or incentive for participation. Finally, the Connections with Others domain was described as any discussion of
relationships with entities outside the self (other inmates, staff, family, etc.). This manuscript will explore sub-themes within each domain, which are italicized within the text (tables 3, 4, 5).

**Domain 1: Program Description**

**Program Perceptions and Observations.** All participants discussed perceptions and observations of the end-of-life peer-care program. Goals as a peer-caregiver included: a) provide companionship and comfort, b) help the dying person have a peaceful transition, and c) provide individualized care. One participant named Cooper* (*pseudonym) summed up the program by saying, “Hospice is different for everyone…It is making a person as comfortable as you can, understanding that they are about to pass away.” Some interviewees spoke about personal expectations or hopes for participating and the importance of focusing instead on what the dying-inmate needs/wants. One inmate-caregiver named Murphy* stated, “You’re not going in to be a savior, you’re not going in to do things your way, you’re making this person comfortable.” Others shared day to day tasks of caring for the dying, and approaches used to facilitate a comfortable and peaceful transition to death; “It could be the littlest thing – fetching a cup of water, changing the sheet or even rotating a person from their side to their back. The littlest thing and it doesn’t take nothing out of us, you know, to do these little things,” said an inmate-cargiver named Tom*.

**Advocating for the Program.** Inmate-caregivers advocated for the program and discussed its value. Many shared that they try to promote the program to others because it is good/beneficial for all. They noted the program is a win-win situation that can positively impact all involved, because it changes/rehabilitates people for the better and is better than other programs in prison at facilitating rehabilitation. Another participant named Romilly* shared, “This program, if we allow it, for those of us who are going home I believe that if we openly embrace this program
and live this program, it is going to help us make that transition from a convict to a productive member of society. It teaches us to be nurturers.”

Interviewees expressed that contrary to stereotypes and the negative environment of the correctional system, good things are happening in prison. One inmate-caregiver named Doyle* noted “Wouldn’t you rather have them [inmates] go home with a sense of humanity, with a sense of justice, with a sense of caring and helping others?” Some shared their sense of urgency to spread the word about the positive programming occurring within the Briarcliff program and the importance of dispelling stereotypes about the incarcerated. Inmate-caregivers also hoped other correctional facilities implement the program and hope the program continues, as inmates expressed concern that the program could be cut if no one knows about the benefits it provides. One inmate-caregiver named Alec* pleaded, “People don’t understand what goes on in here. So any chance we have to let the world know what is going on inside. And we doing something good, something positive come out of it.”

Program Practicalities and Realities. All discussed Program Practicalities and Realities, ranging from physical aspects of care, to how the program differs from hospice in free-society. Although interviewees often focused on psychosocial or spiritual aspects of care, they also described physical duties and tasks (getting water, changing sheets, repositioning), which help ease suffering. According to the interviewees, shift duties and details varied based on the dying-inmate’s disease progression and number of patients enrolled. More care is provided as an inmate approaches death, including “death watch,” a round-the-clock vigil during which the dying-inmate is never left alone. This practice is an example of another sub-theme which emerged exploring differences/limitations of hospice in a correctional facility. The vigil is not regularly practiced by clinical-caregivers outside of the correctional system.
Some inmate-caregivers acknowledged the controversial nature of a prison-based end-of-life program, noting that *not all correctional staff like/agree with the program*. As in free-society, some people do not understand end-of-life care or see the need within a correctional setting. Suggested reasons included a lack understanding of the program and the belief that inmates do not deserve a peaceful death. Many inmate-caregivers felt that misconceptions were inherent to caring for fellow dying-inmates, so it did not deter them from participating. One of the inmate-caregivers named Mark* pondered, “It is just something that I know I have had to deal with…I guess they don’t understand or like what we do. Maybe they feel that as a prisoner or something that we are not supposed to have a peaceful end.”

**Domain 2: Motivation**

All participants explored their personal motivations, and most inmate-caregivers shared multiple or complex reasoning. Inmates discussed personal motivation as a fluid process, noting initial reasons, current motivation, and ongoing reasons for participation. The most common were a) *the program is an avenue to help others*, b) *a way to give back/make amends*, and c) *it gives meaning and purpose to life*. Some shared how their motivation, and initial reluctance, changed as they became more involved. One inmate-caregiver named Olly* shared, “So I’m like man, I don’t know about this [becoming a peer-caregiver]. But then I realized that if a person can’t help himself, why can’t I help him? So it was more of if I could help someone, why not help him.”

Participating in the program was a way *to give back or make amends*. Interviewees shared that caring for dying-inmates felt like a way to compensate for missing opportunities to care for their own loved-ones. One participant named Jamal* noted, “So I decided that because I can’t be there for him [relative with terminal illness] that I would give back and try to be there
for somebody else.” Some inmate-caregivers sought involvement because of family triumphs over illness; absenteeism during a loved-one’s illness or death, or missing out on caring for their children. Others were motivated by the idea of using one’s time in a positive way, as it gives meaning and purpose to life. This theme was noted when a participant named Lee* stated,

> At the end of the day that [sharing compassion and love] just makes me say I had a good day. I accomplished something because I helped somebody… Again, it gives me a sense of purpose. It is a meaningful purpose.

Secondary motivations included: a sense of duty and responsibility, positive feelings from caregiving, and making the best use of one’s time. One inmate-caregiver named Clive* shared, “It doesn’t matter who they are, what they did, why they are in prison. It doesn’t matter at that point…I have a responsibility and I do it to my fullness no matter what.” Many shared that being alone is the hardest aspect of dying and expressed a sense of responsibility to ensure that no inmate dies alone. One inmate-caregiver named Trevor* painfully recalled, “I don’t feel that no one should die alone. I [knew someone] who passed away here and his family didn’t come and pick his body up. Ever since then I took it. I took the program.”

**Domain 3: Connecting with Others**

One of the most comprehensive domains was Connecting with Others. Three main categories explored the different realms of connection: a) connection with the dying-inmate, b) connections/relationships outside prison, and c) reflections on impact of caregiving experience (connecting with self). One inmate-caregiver named Ricky* exemplified this domain by saying, “It is about that human connection. You are connecting with a person that may have lived his life totally different from what you lived and being able to understand and getting that connection it is really amazing.”
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Connection with the dying-inmate. Participants reported that it was important for the caregiver and dying-inmate to get to know each other/figure out preferences. Many participants described the importance of gathering information and noting preferences early on in caregiving, as communication may become more difficult as illness progresses.

Another prevalent theme was bonding with the dying-inmate; more specifically developing an authentic bond and developing a familial bond. Authentic bonds emerged as connections between dying-inmates and caregivers through building trust, openness, active listening, and remaining non-judgmental. One inmate-caregiver named Barrett* stated, “It’s they trust factor too. Because they have been around doing things on their own for so long…You will see it [a bond forming] because they start talking about their family. Things they never talk about.” Many shared that the caregiving relationship was enhanced as time went on, and often the dying-inmates changed during the caregiving relationship once a bond had formed. This was noted by an inmate-caregiver named Pete* who shared, “When you first meet somebody you meet their representative and what I mean is you know they putting on the camouflage but as you get to know them you see who they really are.”

Developing a familial bond described connections which mirrored relationships between family members. Many noted the isolating nature of dying while incarcerated with limited access to family, and that the inmate-caregiver bond made them feel like family. One of the inmate-caregivers named Charlie* passionately stated, “You want people to understand how serious it is. How serious it is for people who…had to die at the hands of people who were not their family, who were not close enough, were not anything to them but became family through a bond of not just suffering but love.”

Although inmates have limited access to the outside world, one of the categories which emerged was connections/relationships outside prison. Particularly, connecting with family
and/or loved-ones emerged as well as connecting with spirituality and/or a higher power. One inmate-caregiver named Len* shared, “Seeing that it [life] is not over ‘til it is over and knowing that you have so much to live for, even if it is behind these walls, or out there [beyond prison] have the faith.” It is evident that inmates attempted to link themselves with others both within and outside of their everyday, isolating environment.

Reflections on impact of the caregiving experience. Sub-categories focused on the inmate-caregiver relationship with self or the contemplation of personal caregiving experiences. Most had a desire to pursue a healthcare vocation/continue to use caregiving skills upon release, citing experience, exposure, and knowledge about caregiving. Most were aware, however, that caring for the dying while incarcerated would likely be their only opportunity due to their criminal record, although many planned to care for family/loved-ones in the future. Some also discussed what it felt like to be part of the care team and that although their primary goal was to provide support to the dying-inmate it also appeared to help the medical staff. One inmate-caregiver named Arthur* stated,

“Like for example nurses…they might not feel comfortable doing certain things, especially in this environment. You got some people in here for crazy crimes and certain nurses might be afraid of them. So to know that, you know, you’re able to go in there and calm them down [dying-inmate], talk to them, you give the nurse a break so she feel comfortable coming in and administering her medicine.”

Additionally, inmate-caregivers discussed positive feelings from connecting with the dying-inmate, allowing them to build and experience positive relationships.

Discussion

Main Findings
This study explores a prison-based end-of-life care program from inmate-caregiver perspectives. The findings suggest that incorporating inmate-caregivers into a prison-based end-of-life program may be beneficial in addressing the needs and unique concerns associated with caring for this marginalized population. 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, which are often issues within this population. Additionally, the findings suggest the program may have additional benefits beyond providing end-of-life care for a marginalized population such as inmate-caregiver rehabilitation and relieving care-burden of correctional medical staff. This research may also be of interest beyond the US because the US mainly provides end-of-life care within correctional facilities whereas international prison systems, such as in the UK, focus more on external end-of-life care. This information may help international prison systems supplement their current approach to providing end-of-life care for inmates.

What this Study Adds

Positive Aspects of Program

The typical endorsement by inmate-caregivers that the program was good and/or beneficial for all (figure 1) is a strong, unique finding because of ideological and logistical challenges of incorporating end-of-life healthcare into the correctional environment. A significant portion of research focuses on pathological aspects of correctional healthcare such as lack of access, increasing age, illness demographics, and overwhelming need for end-of-life healthcare. However, the current data suggest that training inmate-caregivers to supplement current medical services may be a valuable and viable option. Additional research
also supports inmate-caregiver models.\textsuperscript{6,29} Moving forward, it is essential to continue exploring the role of inmate-caregivers.

\textit{Dying-Inmate Benefits}

Facilitating a comfortable and peaceful death was reported as an important role for caregivers. Loeb, Hollenbeak, and Penrod et al. (2013) noted that inmate-caregivers had the potential to reduce suffering and provide comfort for dying inmates.\textsuperscript{25} These findings are congruent with hospice and palliative care models in free-society which value the reduction of suffering, and dignity of the dying.\textsuperscript{38} Although population characteristics and setting may impact end-of-life care programs, the goals of reducing suffering and facilitating dignified death are universal.

Inmate-caregivers serving as surrogate family for the dying was also a unique finding. Building an authentic and/or familial bond was viewed as an essential aspect of providing end-of-life care within the correctional setting, as there are both institutional and geographic barriers to families/loved-ones being present for extended periods of time. Inmate-caregivers assigned great importance to becoming like family, with perceived benefits for inmate-caregivers, dying-inmates, and their loved-ones.

\textit{Benefits to Inmate-Caregivers}

Inmate-caregivers reported that being a caregiver provided meaning and purpose in their lives. Meaning in life has been linked to many facets of health and well-being\textsuperscript{39-41} and is how people make sense of life and cope with difficult challenges.\textsuperscript{42} The capacity for meaning-making amongst the incarcerated was noted to follow a similar pattern to non-incarcerated individuals.\textsuperscript{43} Future research is needed to evaluate the impact of meaning-making on inmate end-of-life caregivers and how it may help facilitate rehabilitation.
Inmate-caregiver motivations included giving back, being an avenue to help others, and a sense of personal meaning. Caring for fellow dying-inmates may be a transformative process in which inmate-caregivers begin to demonstrate rehabilitative benefits such as prosocial behavior. The transformative impact of caring for the dying while incarcerated has been documented, and suggests that participating as a caregiver may impact and help facilitate the rehabilitation process.

**Staff and Facility Benefits**

Traditional end-of-life care practices are often at odds with security protocols and procedures, requiring prison-based end-of-life programs to adapt to the environment, leading to location-specific practices which differ from standard community-based care models. The *Program Practicalities and Realities* category was also supported in a recent systematic review which found that prison-based end-of-life programs offered different services than community based programs. Facilities are faced with shrinking economic resources, increased age and illness of inmates, and a lack of public support, making it difficult to meet end-of-life care mandates. The use of inmate-caregivers may help adapt models to the correctional environment, and help correctional facilities meet care mandates. Continued research is essential for future standardization and sustainability of end-of-life care for the incarcerated, as well as to evaluate benefits of such programs from patient and facility staff perspectives.

Bonding played an essential role in adapting the care model to a correctional environment. Stone, Papadopoulos, and Kelly (2011) identified trust as one of the challenges for integrating adequate end-of-life care within the correctional setting. Training healthy inmates may help build the relationship and level of trust necessary to meet end-of-life needs. The peer-care model reflects a level of mutual understanding that evolves from shared experiences.
Finally, using inmate-caregivers to improve support may also reduce workload, stress and burnout for medical staff, which are realities within the correctional system. Further research is needed to determine the extent of these benefits.

**Societal Benefits**

Inmate-caregiver models help a marginalized group gain access to end-of-life care which can positively impact society through equalizing privilege and reducing discrepancies based on group characteristics. Healthcare for the incarcerated is often interpreted in congruence with the Equivalence Model of care. Based on interpretation of the US Supreme Court’s Eighth Amendment, if a person is imprisoned and incapable of accessing healthcare autonomously, the agency incarcerating that person is responsible to provide adequate healthcare to the imprisoned individual. This end-of-life care model may create a societal shift to help bridge the gap between end-of-life care for the privileged and end-of-life care for all.

**Limitations of Study and Next Steps**

The current study omits demographic data to protect the privacy of participants. Future research should find a way to examine individual and group characteristics of inmate-caregivers. Additionally, data was collected over the span of only two days. Future research should evaluate inmate-caregivers and dying-inmates longitudinally to gain a deeper understanding of the role of bonding, dynamic motivations, and delivery of prison-based end-of-life care. Research should also include multiple correctional facilities reflecting the varying levels of facilities. Evaluation of the financial structure (e.g. costs, funding sources, and where money for the program comes from) of inmate peer-care programs merits exploration. Additionally, potential societal and community impact such as a comparative analysis of the cost to release inmates to the community for end-of-life care compared to providing services within facility. Other research
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should evaluate the potential impact of being an inmate-caregiver on recidivism as this may give important information about inmate rehabilitation. Finally, research should explore how these programs may be implemented and received in countries beyond the United States where peer-care programs are less common.

Conclusions

Although providing end-of-life care to the incarcerated is a complex task, the current research, amalgamated with the previous decades of research, suggest that prison-based peer care programs are a way to simplify this task. Utilizing healthy inmates to supplement and adapt care may ameliorate previously documented barriers for inmate access to end-of-life care. Ultimately, prison-based peer care programs are a viable alternative to providing end-of-life care to the incarcerated and may be better able to address bidirectional issues of trust that have traditionally been a challenge to incorporating end-of-life care in a penal setting. This type of program may also provide additional benefits beyond helping a marginalized group of people access patient-centered end-of-life care, so that the inmate-caregivers experience rehabilitation, correctional medical staff are supported, and correctional facilities are able to meet their care mandates.

Moving forward it is essential that in addition to continued research and development of prison-based peer care programs, correctional administrators make a concerted effort to implement prison-based peer care programs both domestically and internationally.

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Declaration of Conflicting Interests and Authorship

The authors have no conflicts of interest to disclose with regard to this manuscript. All listed authors have contributed significantly to the conceptualization, execution, and/or drafting of this project and manuscript.

Data Availability and Sharing

In accordance with the State University of NY at Buffalo Social and Behavioral Research Institutional Review Board and New York State Department of Corrections and Community Supervision approval of this project all audio recordings and transcripts are to be kept secure, private, and not to be shared.
References


Table 1, Interview Questions

1. Tell me about the Hospice program.
2. What made you interested in joining the Hospice Program?
3. What does it mean to you to be a part of the Hospice Program?
4. With your experience as a hospice-caregiver, would you consider seeking a similar position after release or as a health care worker?
5. What gives your life meaning and/or purpose? What brings joy to your life?
6. What are your thoughts and feelings about death and dying? Have they changed since you started the Hospice Program?
7. What has it been like for you to care for people who are dying?
8. How do you find the strength to keep going after someone you have been taking care of dies?
9. What is one thing that you wish you could tell others and/or want others to know about your experience as a Hospice caregiver?
10. How do you think caring for someone who is dying has shaped who you are today?
Table 2, Core Idea Conversion Examples

<table>
<thead>
<tr>
<th>Domain/Category</th>
<th>Raw Data</th>
<th>Core Idea Conversion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program</td>
<td>“Cause that’s mainly our goal is to make them more comfortable in life well, the remaining time of their life so they can go in peace and not think so much of their ailments and their disease and their pain because they are going through a lot of pain.” –Jeff, Inmate-Cargiver</td>
<td>P states that the program’s main goal is to make patients more comfortable at the end-of-life so patients can go in peace and not think of their ailments, disease, or pain.</td>
</tr>
<tr>
<td>Motivation</td>
<td>“It means I am giving back. I did a lot of wrong in my life and it is like I am helping people out. It is bringing something out of me that was always there that I forgot was there. It is showing compassion. It is showing compassion.” –Troy, Inmate-Cargiver</td>
<td>P feels that P is giving back. P states that P did a lot of wrong in P’s life and by helping DIs in the program; it is bringing something different out of P and showing P’s compassion.</td>
</tr>
<tr>
<td>Connecting with Others</td>
<td>“You might not know this person at first but when you been with them for a while and you start noting their habits like some can’t speak but if he moves a certain way I know what he wants. The nurses might have somebody and like someone with [omitted] disease and they can’t talk but I can understand. If I am in a room with another patient they are going to get me and say can you translate what he is saying?” –Abed, Inmate-Cargiver</td>
<td>P does not always know the DI at first but P starts to note the DI’s habits and P can understand DIs that can’t talk due to disease. If P is with another DI nurses or other staff go get P to translate what the DI needs/wants.</td>
</tr>
</tbody>
</table>

[P=Participant/Interviewee; DI=Dying-inmate]
Table 3, Program Description Domain Cross-Analysis Representativeness

<table>
<thead>
<tr>
<th>Category/Sub-Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Program Perceptions and Observations</td>
<td>General</td>
</tr>
<tr>
<td>Provide companionship and comfort</td>
<td>Typical</td>
</tr>
<tr>
<td>Helps dying person have peaceful transition</td>
<td>Typical</td>
</tr>
<tr>
<td>Provides individualized care for patient</td>
<td>Typical</td>
</tr>
<tr>
<td>It changes/rehabilitates people for the better</td>
<td>Typical</td>
</tr>
<tr>
<td>Provides/is viewed as an opportunity</td>
<td>Typical</td>
</tr>
<tr>
<td>Program is educational</td>
<td>Variant</td>
</tr>
<tr>
<td>It shows humanity/inmates are humans too</td>
<td>Variant</td>
</tr>
<tr>
<td>Program teaches about life</td>
<td>Variant</td>
</tr>
<tr>
<td>Advocating for the Hospice Program</td>
<td>General</td>
</tr>
<tr>
<td>It is a good/beneficial program for all</td>
<td>Typical</td>
</tr>
<tr>
<td>Hope other correctional facilities implement program</td>
<td>Variant</td>
</tr>
<tr>
<td>All others should try being a hospice caregiver</td>
<td>Variant</td>
</tr>
<tr>
<td>It is important to know that good things happen in prison</td>
<td>Variant</td>
</tr>
<tr>
<td>Program is better than other programs in prison</td>
<td>Variant</td>
</tr>
<tr>
<td>Hope the program continues</td>
<td>Variant</td>
</tr>
<tr>
<td>Program Practicalities and Realities</td>
<td>General</td>
</tr>
<tr>
<td>Physical duties and tasks</td>
<td>Typical</td>
</tr>
<tr>
<td>Shift duties and details</td>
<td>Variant</td>
</tr>
<tr>
<td>Team support</td>
<td>Variant</td>
</tr>
<tr>
<td>Difference/limitations of hospice in a correctional facility</td>
<td>Variant</td>
</tr>
<tr>
<td>Not all correctional staff like/agree with program</td>
<td>Variant</td>
</tr>
<tr>
<td>Unaware of/did not think about hospice prior to program</td>
<td>Variant</td>
</tr>
<tr>
<td>Expressed desire to be certified</td>
<td>Rare</td>
</tr>
</tbody>
</table>

Frequency Labels: *General*, theme represented in all or all but one case; *Typical*, occurs in between half and less than all cases; *Variant*, represented in less than half, more than three cases; *Rare*, theme only occurs in 2 or 3 cases.34
### Table 4, Motivation Domain Cross-Analysis Representativeness

<table>
<thead>
<tr>
<th>Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>It’s an avenue to help others</td>
<td>Typical</td>
</tr>
<tr>
<td>A way to give back/make amends</td>
<td>Typical</td>
</tr>
<tr>
<td>It gives meaning and purpose to life</td>
<td>Typical</td>
</tr>
<tr>
<td>Sense of duty and responsibility</td>
<td>Variant</td>
</tr>
<tr>
<td>Positive Feelings</td>
<td>Variant</td>
</tr>
<tr>
<td>Make the best of one’s time</td>
<td>Variant</td>
</tr>
<tr>
<td>Experienced Prior Losses</td>
<td>Variant</td>
</tr>
<tr>
<td>Recruited by other hospice aides</td>
<td>Variant</td>
</tr>
<tr>
<td>Gratitude from patients/families</td>
<td>Variant</td>
</tr>
<tr>
<td>To make up for not caring for my loved-ones</td>
<td>Variant</td>
</tr>
<tr>
<td>View as an opportunity for change</td>
<td>Variant</td>
</tr>
<tr>
<td>To learn more about the dying</td>
<td>Variant</td>
</tr>
<tr>
<td>To Serve God</td>
<td>Variant</td>
</tr>
<tr>
<td>Initial Reluctance</td>
<td>Variant</td>
</tr>
<tr>
<td>Positive feedback/judgment from others</td>
<td>Variant</td>
</tr>
<tr>
<td>Participation is a privilege/unique opportunity</td>
<td>Variant</td>
</tr>
<tr>
<td>I saw a change in other hospice aides</td>
<td>Rare</td>
</tr>
<tr>
<td>Past experience as a caretaker</td>
<td>Rare</td>
</tr>
</tbody>
</table>

*Frequency Labels: General, theme represented in all or all but one case; Typical, occurs in between half and less than all cases; Variant, represented in less than half, more than three cases; Rare, theme only occurs in 2 or 3 cases.*

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Inmate caregiver perspectives on end-of-life care
Table 5, Connecting with Others Domain Cross-Analysis Representativeness

<table>
<thead>
<tr>
<th>Category/Sub-Category</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connection with the Dying-inmate</td>
<td>General</td>
</tr>
<tr>
<td>Getting to know each other/figuring out preferences</td>
<td>Typical</td>
</tr>
<tr>
<td>Developing an authentic bond</td>
<td>Typical</td>
</tr>
<tr>
<td>Focusing on helping others</td>
<td>Typical</td>
</tr>
<tr>
<td>Developing a familial bond</td>
<td>Typical</td>
</tr>
<tr>
<td>Dying-inmate changed during caregiving relationship</td>
<td>Typical</td>
</tr>
<tr>
<td>Providing comforting presence/energy</td>
<td>Variant</td>
</tr>
<tr>
<td>Connecting through humor/shared laughter</td>
<td>Variant</td>
</tr>
<tr>
<td>Special/unique bond</td>
<td>Variant</td>
</tr>
<tr>
<td>Connections/ Relationships outside of Prison</td>
<td>General</td>
</tr>
<tr>
<td>Connecting with Family/ Loved-Ones</td>
<td>Typical</td>
</tr>
<tr>
<td>Connecting with Spirituality/ Higher Power</td>
<td>Variant</td>
</tr>
<tr>
<td>Connecting with people outside prison</td>
<td>Variant</td>
</tr>
<tr>
<td>Connecting with Life beyond Prison</td>
<td>Variant</td>
</tr>
<tr>
<td>Connecting with Dying-inmates’ Family</td>
<td>Variant</td>
</tr>
<tr>
<td>Reflections on Impact of Caregiving Experience</td>
<td>General</td>
</tr>
<tr>
<td>Desire to pursue healthcare vocation/use skills upon release</td>
<td>Typical</td>
</tr>
<tr>
<td>Positive Feelings from Connecting with Dying-inmate</td>
<td>Variant</td>
</tr>
<tr>
<td>Performing unexpected tasks outside of comfort zone</td>
<td>Variant</td>
</tr>
<tr>
<td>Caring for the Dying-inmate is painful and/or difficult</td>
<td>Variant</td>
</tr>
<tr>
<td>Being Selfless</td>
<td>Variant</td>
</tr>
<tr>
<td>Being a part of a team</td>
<td>Variant</td>
</tr>
<tr>
<td>Sentiments of humbleness and privilege</td>
<td>Variant</td>
</tr>
<tr>
<td>Imagining how the Dying-Inmate Feels</td>
<td>Rare</td>
</tr>
<tr>
<td>Importance of Setting Example for Children</td>
<td>Rare</td>
</tr>
</tbody>
</table>

*Frequency Labels: General, theme represented in all or all but one case; Typical, occurs in between half and less than all cases; Variant, represented in less than half, more than three cases; Rare, theme only occurs in 2 or 3 cases.*
Figure 1, Primary and Secondary Perceived Benefits of End-of-Life Peer-Care Program

- Primary
  - Dying Inmate Receives Access to EOL Care
  - Inmate-Caregiver Rehabilitation
  - Medical Staff Supported
  - Facility Fulfills EOL Care Mandate

- Secondary
  - Societal Impact