Inmate-Facilitated End-of-Life Care: Unique Perspectives on Confronting Death and Living a Meaningful Life in Prison

Rachel M Depner, MS1, Pei C Grant, PhD1, David Byrwa1, Jennifer M Breier, MS Ed, MS1, Jennifer Lodi-Smith, PhD2, Christopher W Kerr, MD, PhD1
1Center for Hospice and Palliative Care, Cheektowaga NY, 14227; 2Canisius College, Department of Psychology, Buffalo NY, 14208

Introduction

- With longer sentences and stricter rules on parole, the age demographic of inmates is quickly shifting from young to old1. It is not surprising that an increasing number of inmates spend the remainder of their lives incarcerated and require some form of end-of-life care.
- A growing number of correctional facilities have employed inmate-facilitated hospice care programs (IFHPs) in order to meet the rising demand and mandates for end-of-life care in the correctional setting2. In spite of the large penal population there are only 69 known IFHPs in the country3.
- The Center for Hospice and Palliative Care (CHPC) located in Erie County, New York, along with a maximum-security state correctional facility in Western New York, has successfully run an IFHP for a decade.
- In this program counselors, chaplains, and nurses from CHPC train selected inmates in hospice philosophy, techniques, and care. Trained inmates readily offer companionship, practical care assistance and a caring presence for the dying.
- There is limited research on this topic and no in-depth analyses have explored the lived-experience of inmate caregivers. Due to the lack of research in this area and the resounding call for more knowledge on inmate end-of-life care, the goal of this study is to better define and enhance understanding of inmate-facilitated hospice care, as well as explore the complex experiences of the inmate-caregivers who choose to be a part of it.

Study Purpose and Aims

1-Explore inmate attitudes, perspectives, and motivation for participation in IFHP
2-Capture the phenomenological perspective of inmates participating in the program with regard to meaning and purpose in life, attitudes on death and dying, and program personal impact
3-To highlight a unique inmate-facilitated hospice program model

Barriers to Hospice Care for Inmates

- Program oversights by correctional staff
- Inmates rigorously screened & interviewed prior to participation
- Zero Tolerance Policy
- Inmate caregivers trained by CHPC
- Work jointly with & supported by correctional facility medical staff
- Ongoing training/support from CHPC & facility

Methods

Participants
- 22 Male Inmate Caregivers interviewed by CHPC researchers
- Incarcerated at a maximum-security state correctional facility in WNY
- Active Caregivers involved in the IFHP at the time of interview
- To protect participant anonymity demographic information was not collected

Procedure
- Semi-structured interviews (11 questions + probes as needed)
- Interviews were audio recorded, transcribed, and deidentified
- Currently being analyzed using Consensual Qualitative Research Methodology4

Question Topics:
- Program duties/tasks, motivation for participation, meaning and purpose in life, attitudes towards death and dying, experience of caring for the dying, coping with death, what the inmate wants others to know about program, hopes for program, perceived personal impact of participation

Consensus Domain List of Emergent Themes*

Connect with Others: relationships with beings outside the self- other inmates, facility staff, families, friends, society and/or a higher power
- You are connecting with a person that may have lived his life totally different from what you lived and been able to understand and say that connection is really amazing. - Hospice Aide
- Confronting Death and Dying: inmate insight into death/dying, coping with death, impact on personal mortality, change in perception/awareness of death.
- I am sitting here worrying about my little problem and the(dying inmate) having on their death bed. It makes you look at things in a different way. That humbles you a lot. - Hospice Aide

Program Description: examines the structures, duties, and tasks associated with the program
- The program is very beneficial. It shows the humanity in places like this. From prison you don't expect good things like this. The program is one of those things that shows we still have integrity and it shows that people care for people. - Hospice Aide

Motivation: exploration of reasoning or incentive for program participation
- For me experiencing Hospice showed me another side. There is so much you can learn from the dying. The dying teaches the living. - Hospice Aide

Personal Growth and Transformation: reviews changes or a desire to change in beliefs, worldview, character, behavior, and/or thinking due to program participation
- So you go in there and just do what you can. Just be understanding and you have to have patience. Have a lot of patience. Be patient and open-minded. That is something I had to learn. - Hospice Aide

References


*Analyses for this project are currently incomplete and only preliminary analyses are being reported in this paper.

Preliminary Findings*

- Preliminary findings about the IFHP suggest that the inmate-caregivers provide multifaceted care including:
  - Physical Needs: feeding, helping to the bathroom, putting lotion on, reducing noise or bright lights, helping dying inmate get into a more comfortable position, helping with mobility
  - Psychological Needs: providing a comforting and non-judgmental presence, helping the inmate feel dignified, and building a connection with the dying inmate
  - Spiritual/Existential needs: reading the Bible or Koran to the dying inmate, helping the dying inmate make sense of death through open discussion, aiding with unfinished business, or being present during the moment of death so that the inmate does not have to die alone

- Additional findings suggest that participating in the IFHP may impact the inmate caregiver as well with regard to death awareness and education, building meaningful relationships with others, challenging personal worldview/assumptions, and living a life with intention.

- Many of the caregivers explicitly stated that participating in the program has shaped who they are today.

Future Directions

- Due to the nature of this population and continuous barriers to end-of-life care, on-going research is essential in order to understand and operationalize the program as well as potential impact of participation.
- Future endeavors should seek to focus on pre/post measures of inmate-caregivers from a rehabilitative perspective, the dying inmate’s perspective, medical and correctional staff perspectives, as well as a comparison group from the general inmate population. Female inmate-caregiving experiences and attitudes should be explored as well.
- In addition, in order to address one of the largest barriers to this program, funding and implementation, research looking at the financial components and sources are essential.