

Characteristics of Hospice and Palliative Care Programs in US Prisons: An Update and 5-Year Reflection

American Journal of Hospice & Palliative Medicine®
2020, Vol. 37(7) 514-520
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/1049909119893090
journals.sagepub.com/home/ajh



Stephanie Grace Prost, PhD, MSW¹ , Margaret M. Holland, MSW²,
Heath C. Hoffmann, PhD³, and George E. Dickinson, PhD³

Abstract

Individuals with terminal illness are dying behind bars and many state prison administrators have incorporated on-site hospice and palliative care services. Little is known, however, about these programs since a 2010 study of prison hospice characteristics. We provide an updated description and reflection of current hospice and palliative care programs in state prisons serving incarcerated persons with terminal illness. A cross-sectional survey was sent to representatives of all known prisons offering hospice and palliative care programs and services (N = 113). Questions were drawn from an earlier iteration regarding interdisciplinary team (IDT) membership, training length and topics, peer caregivers, visitation policies, bereavement services, perceived stakeholder support, and pain management strategies. Additional questions were added such as estimated operational costs, peer caregiver input in patient care, and the strengths and weaknesses of such programs. Frequency distributions were calculated for all study variables. Responding representatives (n = 33) indicated IDTs remain integral to care, peer caregivers continue to support dying patients, and perceived public support for these programs remains low. Reduced enthusiasm for the programs may negatively influence administrative decision-making and program resources. Further, peer caregiver roles appear to be changing with caregivers charged with fewer of the identified tasks, compared with the 2010 study.

Keywords

prison hospice, prison palliative care, peer caregivers, terminal illness, pain management

Introduction

Older adults face greater physical health concerns than their younger counterparts, but these health concerns are further exacerbated when older adults are incarcerated.¹ Older adults in state prisons have an average of nearly 4 chronic conditions, indicating elevated levels of multimorbidity such as high blood pressure (73%), arthritis (53%), mobility issues (48%), and heart disease (35%). Mental health problems are also common among the incarcerated population,² particularly among older adults.³ Schizophrenia, major depressive disorder, and dementia are the most widely diagnosed mental illnesses among older adults, and concerns regarding comorbidity are also on the rise.^{1,4} Deaths among incarcerated older adults are also increasing,⁵ and the vast majority are linked to chronic and terminal illness. Aging and dying impose a “double burden” on older adults in the correctional system.⁶

Many facilities are exploring strategies to support the needs of these persons at the end of life (EOL). Off-site options, including compassionate release, have yet to gain traction in state Departments of Correction (DOCs).⁷⁻⁹ Thus, the majority of persons with terminal illness in these settings will die behind bars. However, we know little regarding the programs and services for those needing EOL care in prisons.

The proportion of incarcerated persons requiring EOL care has been cited as higher than comparable rates found in the general population.¹⁰ This is likely driven by accelerated aging among the incarcerated population^{11,12}—those who are imprisoned experience negative preincarceration factors that increase risk of physical and mental health problems (eg, little preventative health care, food deserts, racial discrimination) that are often exacerbated by the carceral setting (eg, overcrowding, stress, violence). As a result, national statistics for 44 of 45 responding state DOCs reported some use of palliative and EOL care in prisons as of 2011.¹³ The majority of states provided such care on-site only (n = 35), though 9 states provided services both on-site and off-site.

¹ Raymond A. Kent School of Social Work, University of Louisville, Louisville, KY, USA

² College of Social Work, Florida State University, Tallahassee, FL, USA

³ Department of Sociology and Anthropology, College of Charleston, Charleston, SC, USA

Corresponding Author:

Stephanie Grace Prost, PhD, MSW, Raymond A. Kent School of Social Work, Julius John Oppenheimer Hall, 22175 3 ST, Louisville, KY 40292, USA.
Email: stephanie.prost@louisville.edu

Earlier work indicates the first prison hospice began operations in 1987 and as of 2010, 69 were known to exist across state and federal jurisdictions. These hospice programs have parallel goals and program ingredients found in community-based hospices.¹⁴ A systematic review of published research on prison hospices reveals significant variability in patient capacity, site delivery, and admission criteria.¹⁵ However, the literature reveals a common attribute—care is most often provided by interdisciplinary teams (IDTs) consisting of both medical and correctional professionals and peer carers (ie, caregivers who are also incarcerated). Eligibility criteria for peer caregiving vary across prison systems, but training is typically described as comprehensive (such as more than 30 hours).¹⁵ These carers support individuals with life-limiting illness with activities of daily living (ADLs) and in psychosocial capacities contributing to what has been called a “transformative” experience.^{15,16}

Although one recent systematic review¹⁵ provides an updated framework for understanding the state of the literature regarding hospices and palliative care programs behind bars, these findings do not represent firsthand information from program representatives. And although in-depth analyses of individual prison hospices are common,¹⁷ it is unclear how the characteristics of such programs have changed since the first effort to characterize US prison hospice programs in 2011.¹⁴

For the purposes of the current study, we sought to provide an updated description of current hospice and palliative programs serving incarcerated persons with terminal illness in state prisons. Our exploration includes areas related to managing patient care, IDTs, peer caregivers, visitation policies, bereavement services, and perceived stakeholder support. This allows us to identify and reflect upon changes in program characteristics between the publication of Hoffmann and Dickinson’s¹⁴ seminal work and prison hospices today. We also aimed to describe several new facets of care for persons with terminal illness in these settings, including operational costs, the role of peer caregiver insights in patient care, and program representative perspectives regarding the strengths and barriers of these programs.

Methods

This study was approved by the institutional review board of College of Charleston prior to data collection. We began with a list compiled in 2010 that included 75 known hospice and palliative care programs.¹⁴ This list was supplemented with additional facilities ($n = 73$) identified by contacting all state DOCs by phone.

We then called each of the 148 facilities to ascertain the appropriate representative of the EOL care program and their contact information, as well as their preferred method of survey completion (electronic or hardcopy). One facility on the list had closed since the first study and 22 facilities indicated they did not have programs when contacted. Over the course of 6 months, several facilities did not return our calls or our calls did not lead to obtaining a representative’s contact information

($n = 12$). In total, representatives for 113 facilities were sent the survey either electronically or in hardcopy. E-mail and phone call follow-ups were made at 1- and 2-week intervals. Of the 113 surveys distributed, 33 completed surveys were received (10 hardcopy, 23 electronic; response rate = 29.2%). It is important to note that 2 completed surveys reflected responses from across several programs as the representative supervised EOL care services at more than 1 facility. Data are available by request from the first author.

Results

Of the responding representatives ($n = 33$), the average number of patients in surveyed EOL care programs ranged from 0 to 22 (mean = 5.31; standard deviation = 6.60). Of all the facilities, over half reported service for 5 or more patients daily. Twenty-four facilities reported that they served men, 5 facilities served women, and 3 facilities served both men and women. No programs reported being run by a for-profit medical corporation.

Most facilities ($n = 16$) reported being a hospice program, while 14 indicated being other types of EOL care programs. Fourteen facilities were not accredited. Only 1 program was accredited (ie, National Commission on Correctional Healthcare) and another reported their state’s Department of Health provided accreditation—another 9 reported being accredited by the Joint Commission for the Accreditation of Health Care Organizations.

We asked for estimates on annual program costs. Nine reported that they were unsure of the operating costs and 6 reported costs to be 0. The highest reported cost was US\$180 per patient per day. When asked whether annual costs of health care for patients were impacted by the program, 13 representatives reported no change, 10 were unsure, and 3 noted that costs had been reduced.

In terms of housing, most ($n = 13$) patients reside in a separate unit within the infirmary, whereas 8 representatives reported patients are housed in the infirmary. Ten representatives reported other housing situations such as single- or double-bed cells in the general population or in off-site community-based hospice program. If space was unavailable, only 2 facilities had waiting lists. The remainder had never run out of space or had contingency plans if such were to occur (eg, make accommodations in the infirmary until a separate room could be arranged).

Regarding admission criteria, 13 programs required that patients forgo life-prolonging treatments and 25 required a prognosis of 12 months. One-third of programs require a signed do-not-resuscitate (DNR) order and 6 had additional requirements. The most common admission diagnosis was cancer ($n = 22$), followed by Alzheimer or related dementias ($n = 2$) and liver disease ($n = 2$). Patients were most often admitted between the ages of 41 and 79 years.

Interdisciplinary teams in these settings are composed of many different professions that assist in the continuum of care. Most programs had a medical doctor ($n = 24$), nurses ($n = 22$), and medical directors ($n = 20$). Interestingly, many also reported IDT membership included correctional officers ($n = 20$). Interdisciplinary teams met as often as daily ($n = 1$) and as

Table 1. Training Topics Covered for Interdisciplinary Teams in Prison Hospice and Palliative Care Programs (Number of Programs).

Training Topics	Peer Caregivers		Correctional Officers		Classification Officers		Community Volunteers		Infirmiry Staff	
	n	%	n	%	n	%	n	%	n	%
The philosophy of hospice and palliative care	19	58	4	12	3	9	1	3	11	33
Patient bereavement	20	61	3	9	2	6	0	0	10	30
Grief and bereavement for loved ones	19	58	3	9	2	6	0	0	10	30
Infection control	18	55	7	21	6	18	0	0	15	45
Physical aspects of the dying process	19	58	3	9	3	9	0	0	12	36
Psychosocial aspects of the dying process	18	55	2	6	2	6	0	0	12	36
Confidentiality	19	58	6	18	6	18	4	12	15	45
Communication with patients	19	58	3	9	2	6	1	3	12	36
Communication with patients' family members	13	39	3	9	2	6	0	0	11	33
Stress management and self-care	20	61	5	15	3	9	1	3	13	39

infrequently as monthly ($n = 7$) to discuss patient care, though weekly and biweekly meetings were also common. Training for members of the IDT who were not medical professionals was highly variable, but peer caregivers often received more than 16 hours of training ($n = 15$). Community volunteers and correctional and classification officers received no training, and infirmiry staff received between 1 and 10 hours of training. Training content was also widely variable (see Table 1), with peer caregivers receiving the greatest breadth of topics compared to other members of the IDT. Seventeen representatives reported collaborating with a community hospice or EOL care provider, and of these, 10 received training from that community organization. Other programs provided their own training.

Peer Caregivers

Most representatives indicated their respective programs used peer caregivers for service delivery ($n = 31$ of 33) and the majority noted these carers were unpaid ($n = 23$; see Table 2). Some prisons required peer caregivers to have no more than 1 year remaining on their sentence ($n = 9$). In other programs, potential carers were prohibited from working in these settings if they had prior convictions for sexual offenses against children ($n = 13$) or adults ($n = 18$), or if they had disciplinary infractions during the past 2 years ($n = 25$).

Program representatives most often indicated that peer caregivers received 16 or more hours of training ($n = 15$). Nineteen programs reported that peer caregivers must sign a confidentiality waiver to protect patient rights. Three programs reported having circumstances when peer caregivers took advantage of patients and 2 of these indicated the peer caregiver had benefitted financially or materially. Peer caregivers performed a range of duties (see Table 3) relating to both ADLs and instrumental ADLs. Thirteen programs affirmed that peer caregivers provide information to the IDT through patient progress notes, verbal communication, or log books. Of those programs that use peer caregiver insights to guide care, most reported using this information only moderately.

Table 2. Selection Criteria, Training, and Work-Related Characteristics of Peer Caregivers in Prison Hospice and Palliative Care Programs.

Criteria	n	%
Eligibility criteria (minimum time remaining to serve) ($n = 33$)		
No minimum requirement	7	21
6 months	4	12
1 year	5	15
2 years	2	6
3 years	4	12
Exclusionary criteria ($n = 33$)		
Sex offense against child	13	39
Sex offense against adult	18	55
Prior drug conviction past year	1	3
Drug/alcohol infraction past year	15	45
Drug/alcohol infraction past 2 years	6	18
Disciplinary infraction past year	20	61
Disciplinary infraction past 2 years	5	15
Reading and/writing comprehension standards	3	9
Maximum security classification	2	6
HIV/AIDS, hepatitis B, or hepatitis C	1	3
Training length (hours)		
0	2	8
1-5	3	12
6-10	4	15
11-15	2	8
16+	15	58
Caregiving hours per week ($n = 28$)		
1-5	14	50
6-10	1	4
11-15	2	7
16-20	5	18
21-25	1	4
30+	3	11

Peer caregivers worked between 1 and 5 hours per week ($n = 13$), though 3 programs indicated peer carers worked in excess of 30 hours per week. Representatives also noted that most peer carers were assigned only 1 patient ($n = 12$), though 9 reported assigning carers to 2 or 3 patients, and 3 other representatives reported assigning caregivers to 4 or more

Table 3. Duties Performed Regularly by Peer Caregivers in Prison Hospice and Palliative Care Programs (%; n = 31).

Care Duties	n	%
Provide companionship to patients	25	81
Read to patients	23	74
Change bed linens	22	71
Feed patients	19	61
Provide spiritual support for patients	17	55
Write letters to family for patients	15	48
Help to train new peer caregivers	13	42
Dress patients	13	42
Keep logbook of patient's condition	12	39
Educate general inmate population about the program	11	35
Bathe patients	11	35
Administrative duties for program staff	3	10
Provide lay counseling to patients	3	10
Make telephone calls to family for patients	3	10
Help to train new community volunteers	2	6

patients. To support peer caregivers, 12 programs held bereavement or grief-related meetings as needed, 8 weekly, and 1 program did so daily. However, 3 representatives reported their program never provided bereavement services to caregivers.

Services

Data were collected on the types of pain management strategies used in programs (nonexclusive). Twenty-two used sustained-release opioid analgesic pain medication and 21 reported treating pain with psychosocial or behavioral interventions. Seven others reported various approaches, including patient-controlled analgesia pumps, pastoral care, recreational therapy, subcutaneous buttons, short-acting opiates, and nonopioid pain medication. Eight programs also reported using pet therapy.

Most programs allowed nonincarcerated family members (n = 26) and nonincarcerated friends (n = 18) to visit patients. However, only 19 allowed incarcerated family members within the same facility to visit. Seventeen programs provided vigils where peer caregivers could provide around-the-clock support and companionship to the dying patient; 1 allowed community volunteers, and 6 allowed family members to do the same. Family members were also allowed to be present at the bedside of patients during regular visitation hours in 7 facilities. One program even allowed patients to record videotaped messages for family members who could not visit.

Just over half of programs offered bereavement services for families (n = 17) and slightly fewer offered telephone calls to nonincarcerated family members (n = 15), but only a few provided condolence cards (n = 5), letters from peer caregivers (n = 2), and counseling referrals (n = 3). Four programs provided additional services to patients, such as weekly funds at the canteen, funds for additional phone calls to family members and friends, family reunification services, birthday and holiday celebrations, and recreational therapy.

Most programs (n = 21) had not experienced any legal problems, yet a minor of programs reported having experienced

problems with the legal competency of patients (n = 2), guardianship (n = 2), and DNR orders (n = 3). All facilities reported engaging in prerelease planning to initiate/reinstate the patient's Medicare and/or Medicaid benefits for patients who were soon-to-be-released. The majority (96%) of prisons also reported that they planned for patients' care in the community when preparing for release.

Institutional and Public Support

Representatives were asked to rate the extent to which different groups demonstrated support for their respective programs. The instructions note that "by support, we are referring to verbal, material, and/or the exercise of time and labor to support the . . . program." Respondents were asked to rate perceived support from 0% (no support) to 100% (complete or total support). Average perceived support was highest for the facility's medical doctors (94%), followed closely by nurses (93%), pastoral staff (92%), and prison administrators (91%). Support from the general incarcerated population and corrections officers was near 84%. The lowest support was noted for the general public (50%).

Greatest Strengths and Barriers

Program staff identified many strengths of their programs. Sixteen representatives identified peer caregivers as the greatest strength of their programs. Peer caregivers were reported to "express that they are 'giving back' to others in need," as well as develop family-like connections and empathy for others. Other representatives stated that patients had usually been in the prison for extended periods of time and have developed friendships with peer caregivers that make, as one program staff member indicated, their "transition to death less burdensome and scary." Other facilities noted that the multidisciplinary team (n = 6) and pastoral care (n = 2) were their program's greatest strengths.

Although peer caregivers were identified by most programs as their biggest strength, some representatives reported having difficulty recruiting and maintaining peer caregivers (n = 5). Lack of administrative and correctional staff support (n = 7; eg, not allowing a peer caregiver to go to the when under lockdown or during irregular times for vigils) and improper physical environments (n = 5; eg, needing more beds, better equipment, and a more therapeutic environment) were also areas of growth identified by representatives.

Discussion

Most prison EOL programs were unaccredited hospices that had been operational between 10 and 20 years. Over 75% of responding programs indicated that patients must have less than 12 months to live to be admitted to the program—a practice similar to community hospices despite critiques regarding the accuracy of prognostication in this population.^{18,19} Generally, these programs house 5 or more patients who are most

often admitted with cancer, dementia, or liver disease, significantly more than the average of 2.43 in the 2010 study.¹⁴ Although cancer and dementia are common principal diagnoses in community-dwelling hospice patients, liver disease is less common²⁰—potentially driven by substance use disorders among those who are incarcerated. Patients were most often admitted to EOL care between the ages of 41 and 79 years—far younger than that of community patients—likely reflecting accelerated aging of those who are incarcerated.²⁰

Although most representatives did not know the annual cost of operating the program, those who did know reported that their programs did not add any costs to the facility budget. In fact, those who were aware of health-care costs for patients noted that patient costs decreased with the implementation of EOL programming. Cost is a common concern among DOC administrators,²¹ and the current study provides initial support that operational costs for such programs may be nominal. However, it is possible that program representatives may be less informed regarding the fiscal state of the program when compared with administration—an area for future exploration.

The use of both sustained-release opioid analgesic and psychosocial strategies for pain management was nearly equally common. Sustained-released analgesic pain relievers are well known to manage pain in EOL care settings despite contentions surrounding their use in correctional environments.²² However, combined approaches are often touted as most supportive²³ and the use of psychosocial approaches as supplement to pharmacotherapy is a promising practice due to their low cost and application ease. For instance, embracing a train-the-trainer approach whereby peer carers are empowered to offer guided imagery or similar strategies at bedside may enhance effects of pharmaceutical intervention to manage pain and symptoms.

Prison hospices and palliative care programs often have a care team, including physician, nurses, chaplains, correctional officers, and peer caregivers. Peer caregivers provided care in nearly all of the represented programs. And their roles are generally seen as positive, consistent with earlier work.^{15,16} In 42% of programs, peer caregivers were working between 1 and 5 hours a week (compared to 23% in 2010),¹⁴ 16% were working between 16 and 20 hours a week (compared to 7% in 2010)¹⁴—equating to a part-time job. Further, one-quarter of programs that relied on caregiver insights on patient well-being used this information to a moderate or greater extent in care provision. We found 58% of responding programs reported that peer caregivers received 16 or more hours of training. However, a recent systematic review indicated that peer caregivers often receive more than 30 hours of training.¹⁵ We are unable to identify the reason for this discrepancy, though it is possible that the synthesis of existing literature reflects summary of larger, more established programs in which scholarly inquiry is taking place and these programs may require greater training than what was found in the current study. It is also possible that the length of training has decreased over time.

More recent research has highlighted that peer carers are endowed with a particular skill set when it comes to matching patient self-reports regarding health and quality of life.²⁴ These

caregivers are intimately linked to their patients in ways that are unlike traditional carers as their lived experiences are likely markedly parallel. Carers' ability to walk in their patients' shoes reflects a distinctive role-taking capacity.²⁴ Despite their obvious instrumental role in care, peer carers are represented on only half of IDTs in the current study ($n = 13$). As their relationship is unique (ie, familial-carer) and they serve as the first-line defenders of patient care,²⁵ they should serve as members of IDTs in prison hospice and palliative care programs. With adequate training and ongoing support, privacy can be maintained and the intimate knowledge of peer carers can be harnessed to assure timely and targeted care. We also encourage information provided by peer carers be captured in a systematic way to assure accuracy and to allow for follow-up by other IDT members. This strategy would likely enhance caregiver self-efficacy and self-esteem, as well.

Program representatives identified peer carers as the greatest strength of their programs; however, their bereavement needs are not supported—less than half of responding programs include memorialization services. Bereavement groups or similar strategies are instrumental to facilitating grief work for those who are incarcerated²⁶ and disenfranchised and complicated grief is associated with mental health sequelae. Thus, peer carers (and the larger general population) are being deprived from integral supports necessary for managing grief. It is worth noting that many representatives also indicated that peer caregivers can serve as barriers in hospice and palliative care programs in prisons due to attrition. It is quite plausible that the burdens faced by carers in this challenging role manifest as death anxiety, compassion fatigue, or burnout—driven in part by unmanaged grief.²⁷ Furthermore, incarceration is punctuated by loss: loss of freedom, loss of roles (eg, spouse, parent, sibling), and death (ie, bereavement).²⁸ And yet 9% of programs using peer carers do not offer any services to these men and women to cope with their physically and emotionally challenging roles.

Barriers also related to limited correctional staff support, which may be overcome by adequate training. It is possible that an enhanced understanding of the philosophy of care, as well as death-related processes, and bereavement may serve to increase awareness, empathy, and appreciation for palliative care in the institution. Barriers were also related to improper physical environments. Compassionate, EOL care and corrections are often considered incompatible.²¹ However, limited resources may be linked to little buy-in from upper echelon administration, justice cabinet members, and legislators.

Most members of the IDT and institution provide verbal, material, and work-related supports to these programs, as was true in Hoffmann and Dickinson's initial study.¹⁴ Although the query is somewhat limited in the combining of numerous supports (ie, verbal and material), public support remains low for prison hospice and palliative care programs based on program representative perspectives. A recent study regarding prison hospice programs revealed that public sentiment drives administrative decision-making.²¹ This may beget fewer resources, potentially decrease quality care, and increase negative health

outcomes for persons in these settings. As public support was noted as the lowest among all stakeholder groups in the current study, identifying and describing factors shaping reduced public support are critical next steps in future research to supporting persons requiring EOL care in prisons.

It was difficult to contact the appropriate representative in each of the 148 institutions, though such was sought via telephone. Some institutions simply would not respond to our calls. We received a low return rate, yet not too out of line for such “institutional” surveys faced with bureaucratic red tape. Some programs stated they were hospice affiliated, yet others said they were an EOL care program. Most programs were not accredited by the National Commission on Correctional Healthcare, the State Department of Health, or the Joint Commission for the Accreditation of Health Care Organizations; thus, mixed policies and procedures were represented. And due to this lack of standards, practices and policies were likely unregulated, reflecting a hodge-podge distribution. Also, some of the respondents to the query about operating costs were unsure, which points to limitations in program representative knowledge regarding some operations—administrators, in turn, may prove better respondents for this and other queries in future research of program cost-effectiveness or program implementation. Our study was also limited to state prisons, with future research requiring extension beyond state programs (ie, federal prisons, local jails, regional detention centers). And though hospice and palliative care services are often used interchangeably, we recognize that each is unique. Some confusion may also exist regarding the meaning of “program” in this context and some agency contacts may not have self-identified as having a hospice or palliative program as defined in the current study. As noted, our response rate was less than 30%. However, some scholars note that an average response rate for organizations hovers near 36%.²⁹ Prenotification strategies may have likely increased response.³⁰ Although this study has limitations, the findings highlight commonalities among many programs and some changes since 2010. Our findings also showcase pros and cons of hospice-like options within correctional institutions. Findings from this study may be shared with administrators considering potential programs, offering a chance to start above “ground zero” and could be used as a foundation for further examination of the state of hospice and palliative care in carceral settings.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The study was funded in part with support from a Florida State University Undergraduate Research Opportunity (UROP) materials grant.

ORCID iD

Stephanie Grace Prost  <https://orcid.org/0000-0001-5110-7287>

References

1. Prost SG, Golder S, Archuleta A. Co-and multimorbidity among older adults in a state prison system: Prevalence across age cohorts. In-press. Manuscript submitted for publication. *Aging and Mental Health*.
2. James DE, Glaze LE. Mental health problems of prison and jail inmates. 2006. <https://www.bjs.gov/content/pub/pdf/mhppji.pdf>. Updated November 28, 2019. Accessed July 23, 2019.
3. Maschi T, Dasarathy D. Aging with mental disorders in the criminal justice system: a content analysis of the empirical literature. *Int J Offender Ther Comp Criminol*. 2019;63(12):2103-2137.
4. Prost SG, Williams BA, Archuleta A, Golder S. Older adults incarcerated in state prison: health and quality of life disparities between age cohorts. Manuscript in preparation.
5. Bailey M. More prisoners die of old age behind bars. 2016. <https://khn.org/news/more-prisoners-die-of-old-age-behind-bars/>. Updated November 28, 2019. Accessed June 3, 2019.
6. Turner M, Peacock M, Payne S, Fletcher A, Froggatt K. Ageing and dying in the contemporary neoliberal prison system: exploring the ‘double burden’ for older prisoners. *Soc Sci Med*. 2018;212:161-167.
7. Holland MM, Prost SG, Hoffmann HC, Dickinson GE. U.S. Departments of Corrections compassionate release policies: a content analysis and call to action. *Omega*. 2018;6. doi:10.1177/0030222818791708.
8. Kanbergs A, Ahalt C, Cenzer IS, Morrison RS, Williams BA. “No one wants to die alone”: incarcerated patients’ knowledge and attitudes about early medical release. *J Pain Symptom Manag*. 2019;57(4):809-815.
9. Prost SG. Terminal illness in correctional settings. In: Church WT, Springer DW, eds. *Serving the Stigmatized: Working Within the Incarcerated Environment*. New York, NY: Oxford University Press; 2018:351-364.
10. Pazart L, Godard-Marceau A, Chassagne A, et al. Prevalence and characteristics of prisoners requiring end-of-life care: a prospective national survey. *J Palliat Med*. 2018;32(1):6-16.
11. Aday RH, Krabill JJ. Older and geriatric offenders: critical issues for the 21st century. In: Gideon L, ed. *Special Needs Offenders in Correctional Institutions*. Thousand Oaks, CA: Sage; 2013:203-233.
12. Williams BA, Abraldes R. Growing older: challenges of prison and reentry for the aging population. In: Griefinger R, ed. *Public Health Behind Bars: From Prisons to Communities*. New York, NY: Springer, 2007:56-72.
13. Chari KA, Simon AE, DeFrances CJ, Maruschak MA. National survey of prison health care: selected findings. 2016. <https://www.bjs.gov/content/pub/pdf/nsphcsf.pdf>. Updated November 28, 2019. Accessed May 23, 2019.
14. Hoffmann HC, Dickinson GE. Characteristics of prison hospice programs in the United States. *Am J Hosp Palliat Care*. 2011;28(4):245-252.
15. Wion RK, Loeb SJ. End-of-life care behind bars: a systematic review. *Am J Nurse*. 2016;116(3):24-36.

16. Cloyes KG, Rosenkranz SJ, Wold D, Berry PH, Supiano KP. To be truly alive: motivation among prison inmate hospice volunteers and the transformative process of end-of-life peer care service. *Am J Hosp Palliat Care*. 2014;31(7):735-748.
17. Ratcliff M. Dying inside the walls. *J Palliat Med*. 2000;3(4):509-511.
18. Holland MM, Prost SG. The end of life within social work literature: a conceptual review. *Omega*. 2019. doi:10.1177/0030222819835650.
19. Williams BA, Goodwin JS, Baillargeon J, Ahalt C, Walter LC. Addressing the aging crisis in US criminal justice health care. *J Am Geriatr Soc*. 2012;60(6):1150-1156.
20. National Hospice and Palliative Care Organization. NHPCO Facts and Figures. 2018. https://39k5cm1a9u1968hg74aj3x51-wpengine.netdna-ssl.com/wp-content/uploads/2019/07/2018_NHPCO_Facts_Figures.pdf. Updated November 28, 2019. Accessed May 17, 2019.
21. Penrod J, Loeb SJ, Smith CA. Administrators' perspectives on changing practice in end-of-life care in a state prison system. *Public Health Nurs*. 2014;31(2):99-108.
22. Lin JT, Mathew P. Cancer pain management in prisons: a survey of primary care practitioners and inmates. *J Pain Symptom Manage*. 2005;29(5):466-473.
23. Cavalieri TA. Pain management in the elderly. *J Am Osteopath Assoc*. 2002;102(9):481-485.
24. Prost SG, Tripodi S, Lacasse JR. The quality of life perception gap in prison health care settings: rater disparities among incarcerated patients and peer caregivers. *Appl Res Qual Life*. 2019;1-18. doi:10.1007/s11482-019-09732-1.
25. Melamed S. More people than ever are dying in prison. Their caregivers? Other inmates. 2017. <https://www.inquirer.com/philly/living/more-people-than-ever-are-dying-in-prison-their-caregivers-other-inmates-20170927.html>. Updated November 28, 2019. Accessed June 5, 2019.
26. Olson MJ, McEwen MA. Grief counseling groups in a medium security prison. *J Spec Group Work*. 2004;29(2):225-236.
27. Supiano KP, Cloyes KG, Berry PH. The grief experience of prison inmate hospice volunteer caregivers. *J Soc Work End Life Palliat Care*. 2014;10(1):80-94.
28. Hendry C. Incarceration and the tasks of grief: a narrative review. *J Adv Nurs*. 2009;65(2):270-278.
29. Baruch Y, Holtom BC. Survey response rate levels and trends in organizational research. *Hum Relat*. 2008;61(8):1139-1160.
30. Fox RJ, Crask MR, Kim J. Mail survey response rate: a meta-analysis of selected techniques for inducing response. *Public Opin Q*. 1988;52(4):467-491.