ORIGINAL RESEARCH

End-of-Life Care Behind Bars: A Systematic Review

Among the caregiver groups studied, inmates are starting to assume a central role.

From 1995 to 2010, U.S. prisons saw a 282% rise in the number of older inmates (ages 55 and older), and between 2001 and 2007, nearly 8,500 prisoners ages 55 and older died while incarcerated.[1] Faced with an increasingly graying prison population and the rising number of deaths behind bars, a number of prisons throughout the country introduced hospice programs.[2] Owing in part to the important work of the Guiding Responsive Action in Corrections at End of Life (GRACE) project[3] and, more recently, publication of the *Quality Guidelines for Hospice and End-of-Life Care in Correctional Settings* by the National Hospice and Palliative Care Organization[4]—end-of-life (EOL) care for prisoners has improved.

To determine the current state of the science regarding EOL care for prisoners and suggest implications for nursing practice and areas for future research, we conducted a systematic review of relevant published research literature. Stone and colleagues had previously conducted an integrative review of empirical and nonempirical literature published between 2000 and 2011 on EOL care of prisoners as practiced in the United States and United Kingdom.[5] Maschi and colleagues conducted a more recent content analysis of 49 studies published between 1991 and 2013 that focused on palliative and EOL care in prison.[6] Our systematic review, however, identifies studies that were omitted from the review by Stone and colleagues as well as new studies published since both reviews were completed. The unique contributions of our systematic review include its exclusive focus on published research, in-depth analysis of study methods and quality, and synthesis of study findings.

The research questions posed to frame this review were as follows:

1. How is prison EOL care described in the research literature?
2. What are important considerations when engaging inmates in the provision of EOL care?
3. What contributions do inmates make to the care of their dying peers?
4. How do stakeholders view EOL care for those dying in prison?
5. What facilitates or impedes delivery of humane EOL care to prisoners?
6. What are the EOL treatment preferences of inmates?

METHODS

In conducting this review, we applied the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.[7] To increase intercoder reliability,[8] both researchers were involved in data extraction. We determined the strength of the studies prior to analysis.

Search strategy. In our literature search, we used the following databases from the time of their inception through June 2014: CINAHL, Criminal Justice Abstracts, the National Criminal Justice Reference Service, PsycINFO, PubMed, and Sociological Abstracts. Within each database, we used the same combination of search terms: *hospice* AND *prison*, *end of life* AND *prison*, and *palliative* AND *prison*.

ABSTRACT

Objective: To conduct a systematic review of the published research literature on end-of-life (EOL) care in prisons in order to determine the current state of the science and suggest implications for nursing practice and areas for future research.

Methods: Applying the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, we performed a comprehensive search of the literature using the following databases: CINAHL, Criminal Justice Abstracts, the National Criminal Justice Reference Service, PsycINFO, PubMed, and Sociological Abstracts. All databases were searched from the time of their inception through June 2014. All English-language articles that reported on original quantitative and qualitative research involving EOL or palliative care delivered to prisoners were included. We abstracted data, using the matrix method, and independently reviewed and graded the evidence on its level of strength and quality in accordance with the Johns Hopkins Nursing Evidence-Based Practice rating scales.

Results: Nineteen articles, all published between 2002 and 2014, met the inclusion criteria. Of these, 53% were published between 2009 and 2014, and 58% reported findings from qualitative research. One article reported on research conducted in the United Kingdom; the remaining 18 reported on research conducted in the United States. Capacity (that is, the number of prisoners requiring EOL care and the ability of the prison to accommodate them) and the site of EOL care delivery varied across studies, as did the criteria for admission to EOL or hospice services. Care was provided by prison health care staff, which variously included numerous professional disciplines, corrections officers, and inmate caregivers. The inmate caregivers, in particular, provided a wide array of services and were viewed positively by both EOL patients and health care staff. There are insufficient data to characterize the patients' and inmate caregivers' perceptions of the EOL care staff and the quality of care they provided. The screening criteria applied to inmate caregivers and the training they received varied widely among care programs. Inmates providing EOL care viewed caregiving as a transformational experience. Likewise, prison administrators and health care staff viewed inmate participation positively.

Conclusions: This literature review reveals the challenges of providing EOL care to prisoners and may inspire nurses to consider steps they can take individually or within nursing organizations to improve this care and address the unique challenges faced by dying inmates. By being aware of these issues and advocating for best practices, nurses can help inmates at the end of life to have a dignified death.

Keywords: end-of-life care, hospice, inmate caregiver, palliative care, prison

We then reviewed the reference lists of all identified articles to discover any research that may have been missed and used Google Scholar to search for additional articles that cited this literature.

Inclusion criteria. We included all English-language articles that reported on original quantitative and qualitative research involving EOL or palliative care delivered to prisoners.

Search results. The database search yielded a total of 374 articles; through the reference list search, we identified an additional five. After we removed duplicates, 238 articles remained. Through a review of titles and abstracts, we eliminated 152 articles that did not meet inclusion criteria. We performed a full article review of the remaining 86 titles, eliminating 67 articles that did not meet inclusion criteria (see Figure 1). For this review, we abstracted and synthesized information from the remaining 19 articles, using the matrix method described by Garrard[9] and in accordance with PRISMA guidelines.[7] We reviewed all evidence based on the Johns Hopkins Nursing Evidence-Based Practice (JHNEBP) rating scales.[10] (See Table 1 for the JHNEBP evidence levels and quality ratings.) After we rated all the evidence, we compared our results. Our evidence reviews were identical with regard to strength and quality in all but three cases. After a discussion and critique of these three articles, we came to an agreement as to how evidence should be graded and included all 19 articles in our review. See Table 2[11-29] at http://links.lww.com/AJN/A70 for a summary and rating of the evidence presented in the studies and Table 3 for information on the studies' key characteristics.

RESULTS

Nineteen articles, all published between 2002 and 2014, met the inclusion criteria. Of these, 53% were published between 2009 and 2014, and 58% reported findings from qualitative research. One article reported on research conducted in the United Kingdom[24]; the remaining 18 reported on research conducted in the United States.

Question 1. How is prison EOL care described in the research literature? *Availability of services.*

An elderly inmate receives compassionate end-of-life care in a prison hospice. Photo by Ackerman + Gruber.

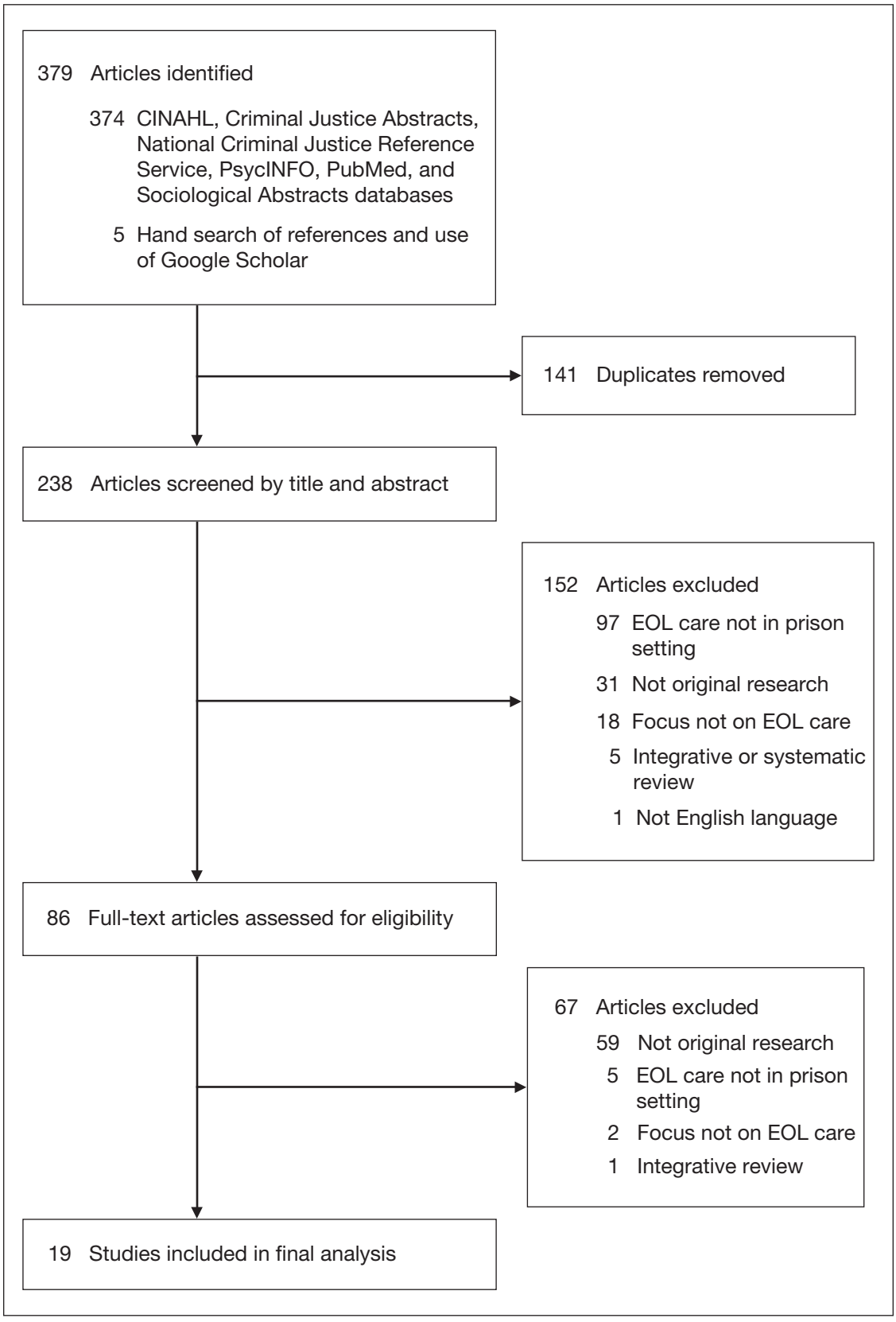
Reviere and Young reported that more than half of the 65 federal and state women's prison infirmaries in their sample offered hospice services.[14] Penrod and colleagues noted that the availability of hospice services varied across prisons within the same state, with variations attributed to perceived need (a considerably larger number of older inmates or prisoners with life sentences, for example); attitudes held by "security personnel, health care staff, other prison staff, and the public," which influenced prioritization; and "prison culture" (that is, how prison leadership sees an institution's mission).[27] The numbers of designated hospice beds in prisons varied from a low of one to three beds to a high cited by nine programs of "unlimited" beds, though most facilities can care for no more than nine hospice patients at any given time, and a significant number can house no more than one, two, or three hospice patients simultaneously.[22] Hospice or EOL care was sometimes offered in a separate area of the infirmary,[29] in housing units,[26] or in day programs outside of prison.[24] Hoffman and Dickinson addressed the availability problem caused by the variation in the daily census of U.S. prison hospices, which ranged from zero to 14 patients per program, with a mean of 2.43 patients per program.[22]

Criteria for receiving EOL services. All of the studies addressing the criteria for receiving EOL care indicated that the patient must be terminally ill.[12, 13, 21, 22, 24, 26, 29] Requisite prognoses for EOL care varied substantially. One study reported that in 57% of the 43 prisons surveyed only prisoners with a life expectancy of no more than six months were eligible.[22] Other prison hospice programs admitted prisoners with life expectancies of up to one year or set no life expectancy requirements.[12, 22] In contrast to community hospice programs, only 48% of prison hospices required termination of curative treatment as a prerequisite for hospice care.[22] Some, but not all, required prisoners to have do-not-resuscitate orders in place before program entry.[12, 22] One study reported that some programs required inmates to be made aware of their prognoses and to provide consent for admission.[22]

EOL care providers. EOL care in the prison setting was provided by both health care staff and inmates. The studies using national samples of prison hospice providers described hospice teams as being multidisciplinary, variously including numerous professional disciplines, which in some cases exceeded National Hospice and Palliative Care Organization (NHPCO) and National Commission on Correctional Health Care (NCCHC) recommendations (see *Professional Disciplines on Prison End-of-Life Care Teams*[4, 12, 17, 18, 22, 30]).

In one prison, social workers served as advocates for compassionate release and counseled inmates whose release was denied.[18] Dieticians not

Figure 1. PRISMA Flow Diagram of Included Studies



only monitored patients' nutritional status, making dietary and supplement recommendations, but ensured that the kitchen was stocked with hospice patients' preferred foods. Corrections staff transported inmate caregivers to the hospice section of the prison.[18] Chaplains often made funeral arrangements.[18] Some programs sent inmates' surviving family members cards or letters of condolence and made referrals to community-based grief counseling services.[22] Some prison hospices offered services that are not available in many community hospices.

EOL care delivery was typically described as hands-on, service-based, coordinated care. Hospice care teams generally developed and revised care plans in meetings, which sometimes included family members.[18, 22, 24]

Care of the dying inmate ranged from addressing psychosocial and emotional needs to providing health care interventions. Psychological and spiritual counseling services were reported occasionally to assist inmates in coping with the prospect of death and dying.[12, 13, 18] Several studies reported that prison EOL programs contacted inmates' families and arranged family visits.[12, 18, 22] As in community EOL care, pain management was a primary focus.[13, 18, 22] Hoffman and Dickinson reported that most of the 43 prison hospice programs they surveyed offered sustained-release opioid pain medications; about 18% used patient-controlled analgesia pumps, and about a quarter used short-acting pain medications or behavioral management interventions.[22] Wright and Bronstein reported that physicians were responsible for EOL medical treatment plans and symptom management.[18]

Question 2. What are important considerations when engaging inmates in the provision of EOL care? *Screening and selection of inmate EOL caregivers.* The prison hospice programs studied differed in terms of whether inmate caregivers were paid or unpaid volunteers.[12, 25, 26, 29] The screening process for potential inmate caregivers varied among the programs, but eligibility relied heavily on inmate behavior and past offenses, typically requiring that inmate caregivers have no sex offenses and no rules infractions over the past one to two years.[12, 22, 29] Some programs required medical and mental health clearance and no prior convictions of abuse of any kind.[12, 22] After initial screening, potential inmate caregivers were interviewed and selected by the hospice team, including current inmate caregivers, and prison officials.[12, 29]

Age and time commitment of inmate EOL caregivers. In one state program, examined by two studies, inmate caregivers ranged in age from 27 to 71 years, with a mean age of 48.[25, 29] Similarly, a third study reported the age of inmate caregivers as ranging from 35 to 74 years, with a mean age of 49.[26] Two survey studies that included a total of 53 prison hospice programs indicated that the weekly hours of inmate caregivers varied according to patient acuity, increasing when patients were close to death.[12, 22] Caregivers' weekly hours were reported as ranging from one to 21 or more in one survey[22] and from two to nine in addition to their regular work hours in another.[12] Some facilities considered hospice service a "full-time job" and inmate caregivers worked in the hospice 40 to 48 hours per week.[12] Weekly hours worked and level of experience needed to become

Table 1. Johns Hopkins Nursing Evidence-Based Practice Evidence Levels and Quality Guides

Evidence Levels	Quality Guides
Level I Experimental study, randomized controlled trial (RCT) Systematic review of RCTs, with or without meta-analysis **Level II** Quasiexperimental study Systematic review of a combination of RCTs and quasiexperimental, or quasiexperimental studies only, with or without meta-analysis **Level III** Nonexperimental study Systematic review of a combination of RCTs, quasiexperimental and nonexperimental studies, or nonexperimental studies only, with or without meta-analysis Qualitative study or systematic review with or without a meta-synthesis	**A** High quality: Consistent, generalizable results; sufficient sample size for the study design; adequate control; definitive conclusions; consistent recommendations based on comprehensive literature review that includes thorough reference to scientific evidence **B** Good quality: Reasonably consistent results; sufficient sample size for the study design; some control, fairly definitive conclusions; reasonably consistent recommendations based on fairly comprehensive literature review that includes some reference to scientific evidence **C** Low quality or major flaws: Little evidence with inconsistent results; insufficient sample size for the study design; conclusions cannot be drawn

Professional Disciplines on Prison End-of-Life Care Teams

Disciplines included in the studies reviewed[12, 17, 18, 22]	Recommendations for inclusion by the NHPCO[4]	Recommendations for inclusion by the NCCHC[30]
• Nurses • Social workers • Physicians • Chaplains • Psychologists • Corrections officers • Dieticians • Pharmacists • Physical and occupational therapists • Medical records staff • Case managers • Respiratory therapists • Physician assistants • Medical technicians • Personnel from transitional services • Community volunteers • Bereavement coordinators • Institutional activity coordinators • Volunteer coordinators	• Physicians, NPs, or physician assistants • Qualified RNs • Qualified LPNs or aides • Qualified mental health professionals • Qualified chaplain or spiritual advisor • Security officer • Inmate volunteers	• Medical staff • Mental health staff • Custody staff • Clergy • Inmate workers or volunteers

NCCHC = National Commission on Correctional Health Care; NHPCO = National Hospice and Palliative Care Organization.

an EOL caregiver varied with the facility and prison system.

Oversight and training of inmate caregivers. Training was usually overseen by members of the hospice team.[12, 29] Depending on the specific program, social workers, chaplains, nurses, health administrators, or corrections officers monitored and coordinated the EOL program; supervision of inmate caregivers tended to fall to the nurses.[18, 26] The inmate caregivers participated in considerable training, ranging from a low of one to 10 hours (reported by seven of 35 programs in one study)[22] to a high of four weeks (reported by one program in another study),[29] with most programs reporting more than 30 hours.[12, 22, 26, 29] Areas encompassed by inmate training ranged from basic aspects of EOL care to the more abstract philosophy of hospice. Some training topics were equivalent to those covered in certified nursing assistant programs, including infection control and universal precautions, feeding, making a bed that's occupied, transferring patients, and providing postmortem care.[22, 26, 29] Other training topics included the philosophy of palliative care, patient communication, stress management, the spiritual aspects of dying, dealing with grief and bereavement, and setting boundaries.[22, 29]

Question 3. What contributions do inmates make to the care of their dying peers? Inmate caregiver responsibilities extended from day-to-day supportive care to death vigils and postmortem care (see Table 4[12, 18, 22, 25, 26, 28, 29]). Assistance with activities of daily living, such as bathing and toileting, and support with instrumental activities of daily living, such as letter writing and transport of patients within the prison, were two key contributions of inmate caregivers. In addition, they provided companionship and religious support, while protecting their charges from predatory abuse (they watched over patients' commissary provisions, for example).[26, 29] Their housekeeping responsibilities ranged from general cleaning to body fluid management. More medically complex duties included assessing symptoms and notifying health care staff of changes in patient status.

Question 4. How do stakeholders view EOL care for those dying in prison? *Views of administrators and frontline EOL care staff.* The caregiving experience was perceived by hospice coordinators as transformative for inmate caregivers, increasing inmates' compassion and consideration for others, self-esteem, self-worth, and sense of empowerment.[17-19] Hospice coordinators also reported that inmate caregivers

Table 3. Key Characteristics of the 19 Studies Reviewed

Characteristics	No. (%) of Studies
Journal type[a]	
Palliative/EOL	12 (63)
Criminology	3 (16)
Gerontology	2 (11)
Nursing specialty (not focused on EOL)	2 (11)
Study design	
Qualitative	11 (58)
Mixed methods	4 (21)
Quantitative	4 (21)
Settings	
Single site/single state	8 (42)
National sample	6 (32)
Multiple locations within single state	3 (16)
Five Southern U.S. states	1 (5)
Multiple locations in two counties in the United Kingdom	1 (5)

EOL = end of life.
[a] Percentages do not sum to 100% because of rounding.

promoted dignity and respect for dying patients, making such deep connections with them that administrators saw the caregivers as surrogate family.[17] In a qualitative, descriptive study, central administrators in one state's department of corrections universally endorsed grief support for inmate caregivers, emphasizing the notion that prison becomes home for prisoners with long or lifetime sentences who age and die in the system.[27]

Hospice workers perceived prison EOL care as having the support of many groups within the prison, including inmates, pastoral staff, nurses, physicians, and administrators.[22] Prison EOL care was not, however, supported by all prison staff, with the most notable resistance and lack of support coming from corrections officers.[17, 22] This resistance was attributed to concerns about security and to the view held by some that EOL care undermines the punitive aspect of prison, a resistance that was particularly evident if the crime of the dying inmate was considered heinous.[17] Corrections officers with substantial exposure to hospice were seen as more supportive than those with little or none.[17, 19]

Hospice coordinators perceived prison hospice care to be on par with that of hospices in the community,[17] and a study of prison health care and community hospice workers reflected a belief that the two should be of equal quality.[24] Within prisons with hospice programs, there were many positive environmental effects.[17, 18] For example, hospice coordinators felt that EOL care had a positive impact on the general prison population as well as on dying prisoners because it promoted compassion and presented an alternative to the view of the prison system as entirely punitive—showing it to be more humane and caring, supportive of the dignity of the dying patient, and encouraging of trust between prison staff and inmates.[18]

Views of inmate EOL caregivers. Overall, inmate caregivers felt that prison hospice was helpful both to themselves and to the dying inmates. Hospice care was described by inmate caregivers as attending to the physical, emotional, and spiritual needs of dying patients.[25] This care promoted quality of life and was viewed as a moral and social responsibility.[25] Inmate caregivers noted that, prior to the inception of prison hospice, dying inmates had a lonely and painful death. Hospice helped dying inmates have a "good death," but required considerable emotional, physical, and spiritual commitment from inmate caregivers.[29]

Inmate caregivers cited many motivations for their role. A common theme was redemption—providing a way to give back and right past wrongs.[25, 26] Some reported that the caregiving role was something they were meant to do.[25] Others mentioned a desire to provide care to those who needed it most,[25] perhaps because they too would need EOL care while incarcerated.[26] Providing EOL care was viewed as honoring dying inmates.[25] The experience of seeing inmates die in prison or having an inmate caregiver as a role model motivated some inmates to become EOL caregivers.[26]

Similar to reports by administrators and staff, inmate caregivers viewed their experiences in providing EOL care to dying peers as transformative. They felt that helping others helped them to become better people.[25, 26] Redemption acted as both a motivator and an outcome. Providing EOL care was a way to show others that they were compassionate people.[25] Finally, they were able to form close connections with others, feel like a family, and garner respect from the prison staff.[25, 26]

Despite the considerable positive effects of caregiving, many inmates experienced grief after a care recipient's death.[29] Some coped by establishing boundaries in the knowledge that the patients for whom they were caring would soon die. Most inmate caregivers, however, reported getting close to the care recipient and feeling grief after the patient's death. Talking with peers or members of the hospice team often helped them to cope.[29]

Views of inmates who are not EOL caregivers. Fear and anxiety about dying in prison is a common stressor for inmates. According to Aday, more than 50% of inmates who identified as in poor health

thought about dying in prison on a regular basis.[15] Deaton and colleagues reported that inmates who had witnessed a death in prison or knew of someone dying in prison had many emotions related to anticipating their own death.[20] Higher death anxiety while in prison was significantly related to poor health, poor perceived mental status or outlook, feeling unsafe, and depression. The stigma of dying in prison was a concern, especially in terms of how it might negatively affect family members.[15, 20]

Some inmates avoided thinking about it.[15] Many did not fear death itself but rather the process of dying in prison.[20, 28] Some feared not having their medical needs met while incarcerated if faced with a major catastrophic event, such as a heart attack.[20] Some perceived pain control to be substandard.[28] Inmates feared dying in the prison setting for such reasons as leaving loved ones behind, dying without loved ones present, and dying without dignity.[15]

Many inmates dealt with the reality of dying in prison by turning to their faith, attending religious services, or talking with peers or chaplains about the prospect of dying in prison. Some inmates were accepting of the "escape" that death would bring, perceiving it as an end to their suffering, pain, loneliness, and diminished social status.[15, 20] Being able to interact with others inside and outside of prison (through family visits, for example) was seen as important.[28]

Question 5. What facilitates or impedes delivery of humane EOL care to prisoners? Facilitators and barriers to humane EOL care in prison were often opposite sides of the same coin (see Table 5[12, 13, 17-19, 22, 24-29]). They included such communication and caregiving factors as collaboration versus disputes among multidisciplinary team members and presence versus absence of compassionate care from prison infirmary staff. Inmate caregivers noted such environmental facilitators as the ability of dying patients to receive preferred foods and such environmental barriers as poor temperature control and the smell of dirty adult diapers in the infirmary. In addition, there were such individual factors as motivated staff with experience in EOL care versus lack of compassion from staff; institutional factors related to prison culture (as manifested in the values, attitudes, and beliefs of prison administrators); and external factors, such as support or lack of support from community-based hospices.

Question 6. What are the EOL treatment preferences of inmates? In 1997 and 1998, a feasibility study of the Connecticut prison system's hospice needs and resources found that nearly half the inmates sampled (47%) had "ever heard of hospice" care, and 81% would use prison hospice if eligible, though almost three-quarters (74%) would prefer to be transferred to a medical facility outside of prison for EOL care should they become terminally ill.[11] More recent studies have found that, when faced with terminal illness, a prisoner's parole status, severity of

Table 4. End-of-Life (EOL) Care Provided to Prison Hospice Patients by Inmate Caregivers

Activities of daily living
• Bathing, feeding, grooming, dressing, and toileting[12, 22, 25, 26, 29]
• Mobility assistance[12, 22, 25, 26, 29]
Instrumental activities of daily living
• Letter writing[12, 18, 26]
• Ordering, delivering, and storing items from the commissary[26]
• Finding television or radio stations for patients[26]
• Helping with patient transport[26]
• Helping patients prepare for family visits[26]
Emotional and social support
• Providing companionship[12, 18, 25, 26, 29]
• Reading to patients[18, 22, 26]
• Providing spiritual or religious support[22, 26, 29]
• Singing to patients[18]
• Providing lay counseling[12, 22]
Housekeeping
• Cleaning and maintaining patients' bedside area[25, 26]
• Assisting with diaper and linen changes[26]
• Cleaning and disposing of blood and body fluids[26]
Advocacy or protection
• Acting as patient advocate[25]
• Safeguarding patients' belongings[26]
• Protecting patients from abuse from other inmates[26]
• Functioning as intermediary between patients and security or health care staff[26]
More medically complex
• Assessing symptoms and providing nonpharmacologic symptom management (such as repositioning or massage)[25, 29]
• Writing patient progress notes[12, 22, 25]
• Protecting patients' privacy and confidentiality[26]
• Notifying health care staff of patients' status[25, 26]
Care prior to and after death
• Holding 24-hour vigil at patients' bedside[18, 25, 26, 29]
• Providing comfort care[28]
• Providing postmortem care[25, 26, 29]
Hands-off duties
• Helping train new inmate caregivers[22, 25, 26]
• Helping vet new inmate caregivers[25]
• Fundraising for prison hospice[25]
• Providing administrative support for health care staff[22]
• Providing bereavement support for inmates[22, 25]
• Educating peers on the hospice program[22, 25]
Nonspecific care
• Providing nonskilled EOL care, both physical and psychosocial[29]

Table 5. Barriers to and Facilitators of End-of-Life (EOL) Care in Prison

	Barriers	Facilitators
Communication	• Difference between dying inmates' perceived EOL needs and those of prison staff[13] • Disputes among members of the interdisciplinary hospice teams[17] • Late identification of prisoners needing hospice care[17] • Lack of meetings to debrief inmate caregivers about their charges[26]	• Collaboration through interdisciplinary teams[17, 18] • Informal reporting on sick inmates by inmate caregivers to other inmate caregivers[26]
Caregiving	• EOL decision making is physician driven without interdisciplinary team input[18] • Effectively using pain medications on inmates with a substance abuse history[22, 24, 28] • Physicians and pharmacists not always available immediately[24] • Perceived lack of compassionate, quality care from prison health care providers[28] • Issues related to processes such as timeliness of answering call bells or wait times to receive medications[28] • Lack of continued training and education for inmate caregivers[26]	• Transformative effect on inmate EOL caregivers[12, 17, 19] • Care provided by inmate EOL caregivers[17, 19, 28] • Inmate volunteers focusing on patient needs and providing companionship to dying patients[25] • Inmate caregivers establishing boundaries with patients to avoid burnout[29] • Compassion and quality care from prison health care providers[28] • Adequate control of pain[28] • Opportunities to remember the deceased[26] • Support of inmate caregivers by their inmate peers who are also caregivers[26]
Environmental	• Needed medications not always available[24] • Mobility issues for the dying patient in older buildings with poor disability access[24] • Lack of needed resources and equipment[26, 28] • Poor temperature control and the smell of dirty adult diapers in the infirmary[28] • Lack of a comforting environment[26] • Negative attitude of noncaregiver inmates[26]	• Dying inmates able to receive favorable foods[28]
Individual factors	• Negative attitudes and lack of compassion from corrections staff[17, 18, 26] • Corrections officers not trained in hospice substituting in the infirmary[28]	• Support of the prison warden and corrections staff[17] • Support of inmate caregivers by health care staff[26] • Inmate caregivers prepared to deal with health challenges of patients with a criminal history[26] • Knowledgeable, motivated staff[27]
Institutional factors	• Competing responsibilities of health care staff and corrections staff[24, 27] • Inmates in hospice care sent to solitary confinement for rule infractions[25] • Need to maintain security[26] • Moving staff around to cover hospice care[27] • Inconsistent application of centralized policies among individual institutions[27] • Prisons with high-risk security inmates require a greater focus on security[27] • Lack of corrections staff prepared to care for inmates with dementia[26] • Memorials not permitted[26]	• Perception of hospice as a cost-effective alternative to receiving care outside of prison[12, 27] • Perception that prison can be a caring environment[19] • Prisoner perception that hospice staff are there for them should they ever need hospice care[17, 19] • Culture (value, attitudes, beliefs) of the prison and how centralized policies were applied[27]
External factors	• Insufficient support by community and national hospice groups[17] • Negative public perception of providing EOL care in prison[27]	• Support of community hospices and other free-world organizations[17, 18] • Family visits to inmates at the end of life[28]

disease, and race influenced her or his desire for active treatment.[21, 23] Inmates who were not serving life sentences, were members of racial minority groups, or had high levels of death anxiety were most likely to express the desire for feeding tube placement if it was needed to prolong life.[21] Prisoners who were serving life sentences or were white were more likely to express the desire for palliative care interventions at the end of life.[21] Parole status did not affect white prisoners' expressed preference to forgo life-prolonging treatment if they developed cancer with pain or emphysema, though if they developed Alzheimer's disease, they indicated a desire to receive related treatment if they had a chance for parole.[23] Conversely, inmates who were members of racial minorities felt they would want active treatment for emphysema, cancer with pain, and Alzheimer's disease if they were going to be paroled. Minorities who did not anticipate parole did not believe they would want nonpalliative or life-prolonging treatment for cancer with pain. Inmates were more likely to want life-prolonging treatment if they had a greater fear of death, fewer negative effects of illness, and a greater mistrust of the prison health care system.[23]

DISCUSSION AND IMPLICATIONS FOR NURSING PRACTICE

This discussion considers key findings related to our six research questions in the context of the two previous reviews on the topic by Maschi and colleagues[6] and Stone and colleagues,[5] other relevant literature, and guidelines on caring for dying prisoners from the NCCHC,[30] the NHPCO,[4] and the United Nations Office on Drugs and Crime (UNODC).[31]

Eligibility for EOL care. According to the Centers for Medicare and Medicaid Services, nonincarcerated Medicare enrollees are eligible for hospice if they have a terminal illness with a life expectancy of six months or less, pursue palliative or supportive care rather than curative treatment, and sign a statement acknowledging that they choose to receive hospice care rather than other treatments covered by Medicare.[32] The one criterion that was consistent in all seven studies that addressed this issue[12, 13, 21, 22, 24, 26, 29] was that inmate patients must be terminally ill to receive prison EOL services. With regard to life expectancy, Hoffman and Dickinson found that 57% of the 43 prison EOL programs they surveyed had equivalent life expectancy requirements for eligibility, and 48% required EOL patients to relinquish curative care.[22]

We would argue that nurses should advocate for more lenient eligibility requirements for prisoners seeking EOL care, as it's been reported that inmates often view prison health care professionals with suspicion[33] and feel they are unresponsive to their health-related needs.[34] Concerns about inadequate care or pain control could cause inmates to view a requirement to relinquish curative care as a reason to reject EOL care. In fact, current NCCHC guidelines support more lenient eligibility requirements, defining a terminally ill inmate as "one whose physical condition has deteriorated to the point where the prognosis is less than a year to live" and emphasizing that inmates should not be placed in hospice if "reasonable therapeutic options" exist or for the sake of convenience.[30] Rather, they recommend that the determination of hospice eligibility should be made by a physician who has no direct involvement with the inmate patient's care, based on patient examination, record review, and patient preferences.[30]

Disciplinary diversity on EOL care teams. The fact that three of the reviewed studies[12, 18, 22] described multidisciplinary EOL care teams that included many varied professional disciplines, often exceeding NCCHC and NHPCO recommendations, provides a wide array of potential team members to consider when developing a prison EOL care team. The value of team diversity is recognized by the UNODC, which holds that effective, individualized care of terminally ill prisoners requires a multidisciplinary team that includes, at minimum, a physician, nurse, and psychologist.[31]

Characteristics of EOL team members. In *Correctional Nursing: Scope and Standards of Practice*, the American Nurses Association specifies that an RN's "primary duties in the correctional setting are the prevention of illness, health promotion, health education, and restoration and maintenance of the health of patients in a spirit of compassion, concern, and professionalism."[35] In accordance with that principle, other crucial characteristics of EOL care team members would include a compassionate attitude toward dying inmates and knowledge of the best EOL care practices. Notably, the lack of compassion for dying inmates and negative attitudes toward inmates expressed by corrections staff and prison health care providers were identified as barriers to quality EOL care in three studies[17, 26, 28] we rated as "good quality" (evidence grade IIIB) based on the JHNEBP rating scale.[10]

The importance of inmate caregivers figured prominently in this review and was reflected in the previous integrative review by Stone and colleagues, the content analysis by Maschi and colleagues, the NHPCO guidelines, and the NCCHC standards.[4-6, 30] A key point made by the NCCHC is that inmate workers "are not a substitute for professional health care staff . . . [and need to be properly] screened . . . [and] trained in the tasks they are expected to perform, and supervised by a qualified health care professional."[30] The amount of training received by inmate caregivers in our review varied widely—with the lower end of the range (one to 10 hours reported by seven of 35 programs in one study[22]) quite concerning. As nurses train and supervise inmate caregivers, it's essential they provide ongoing

assessment and feedback on care delivery to promote the caregivers' continued growth and ensure quality EOL care in prison.

Supervision, selection, and screening of inmate caregivers. Our review findings contrasted with the NCCHC standard in that the supervision of inmate caregivers was not limited to health care professionals but also included chaplains, social workers, and corrections officers. Broadening the array of disciplines from which professionals can fill this supervisory role allows those with the most suitable demeanor and personal characteristics to be put in positions of training and supervising inmate caregivers.

In addition to appropriate supervision, it's essential to apply the right selection and screening criteria when engaging inmate caregivers. In their review, Stone and colleagues discussed two strategies for selecting inmate caregivers that were not evident in ours: targeting inmates who already held responsible positions and focusing on inmates with low security classifications.[5] Nor did our review find evidence that two of the screening criteria specified by the NCCHC were consistently employed: emotional stability and intellectual capability.[30] Both are logical prerequisites for caregivers, since inmate caregivers engage in fairly complex activities, including symptom assessment, writing progress notes, and notifying staff of patients' health status.

Age and weekly time commitment of inmate caregivers. Our review revealed that many inmate caregivers are in their middle years, which is appropriate in terms of both maturity and their likelihood of being in Erikson's developmental stage of "generativity," which is focused on the virtue of care.[36] Weekly hours inmates spent working in EOL care varied from a low of one hour in one study[22] to a high of 48 hours in another.[12] In prisons where deaths occur less frequently and EOL care is not needed on a routine basis, it's important for nurses to engage inmate caregivers in alternative but related caring activities, such as assisting in the care of peers with disabilities or dementia, in order to sharpen their skills and maintain their involvement. Although some responsibilities are common to caring for both dying patients and those with dementia, additional training in managing behaviors of inmates with dementia and engaging them in appropriate activities is necessary—and nurses are well prepared to provide that training. Aday and Krabill have outlined the basics of the structured dementia program at the Fishkill Regional Medical Unit in Fishkill, New York.[37]

Site of EOL care. As in the broader community, in which hospice care is delivered in varied settings, so EOL care is delivered in various locations in prisons, as four articles in this review reported.[22, 24, 26, 29] Sites included designated hospice beds in the prison infirmary, a separate area of the overall health care treatment area, in inmate housing units, and in a day program outside of the prison setting. This finding is congruent with the NHPCO guideline stating that "palliative care is available to inmate patients in as wide a range of housing settings as health care and security can accommodate."[4]

Services provided by inmate caregivers. The many clusters of services provided by the inmate caregivers extend well beyond what would be expected from nonincarcerated volunteer caregivers in the community. For example, acting as advocate, safeguarding belongings, acting as a go-between with security staff, and protecting the dying inmate from abuse by fellow inmates would not be expected outside of prison. In addition, two studies we rated as having "good quality" evidence reported services unique to inmate caregivers: providing administrative support to health care staff,[22] and vetting potential inmate caregivers and fund-raising.[25]

Differing perspectives on EOL care. This review captured the following perspectives on EOL care in prison from three groups of stakeholders: prison administrators and frontline EOL care providers, EOL care recipients, and current and potential future consumers of EOL care.

One group of stakeholders was glaringly absent—inmates' family members, an absence that was similarly noted in the content analysis by Maschi and colleagues.[6]

Several findings from our review provide an argument for instituting an inmate caregiver program in prisons:

- Inmate caregivers make important contributions to EOL care in prison.
- Providing care for peers in prison can be a transformative experience for inmates.
- Mistrust of prison health care staff, which is often a problem among inmates, may be alleviated.

Our review further suggests that prisons could benefit from greater attention and resources directed toward grief support.

Major challenges. Stone and colleagues identified two major challenges faced by prison EOL programs: the inability to deliver adequate pain relief and the inability to secure inmate trust.[5] This systematic review, like the content analysis by Maschi and colleagues,[6] identifies a wider array of difficulties ("barriers") that contribute to these challenges. Ways to overcome barriers ("facilitators") noted by Maschi and colleagues were also identified in this review, most in the areas of communication and environment.

Takeaway points for nurses. Nurses can play a vital role in promoting awareness of and accurate information about EOL or hospice services among inmates, who may be unaware of these programs. Nurses should also be aware that inmate EOL treatment preferences vary, sometimes reflecting the outlook of a particular demographic, though an inmate's

preferences should always be explored. Nurses are best positioned to initiate conversations with inmate patients about their treatment wishes. Although the related literature doesn't clearly delineate any best approach to such discussions, one approach is to initiate a conversation about advance directives and EOL care wishes as part of all annual physicals. This proactive, efficient approach can ensure that inmates receive care they desire and avoid unwanted care.

EOL care for inmates is not solely a concern of nurses working within the prison setting. Nurses in many different settings may have the opportunity to provide care to dying inmates. Being aware of both the physical and psychosocial concerns of dying inmates sent back to prison after hospitalization can help nurses develop an appropriate plan of care and ease the discharge process. Not all orders and nursing interventions specified in the discharge plan will be carried out because of insufficient resources or security concerns. It's important to consider whether the receiving prison has a hospice program or whether the inmate is being discharged to regular infirmary care. By being aware of the issues dying inmates face within the walls of prison and advocating for best practices, nurses can help inmates at the end of life to have a dignified death.

RESEARCH IMPLICATIONS

In this systematic review, nonexperimental quantitative and qualitative studies (Level III on the JHNEBP strength of evidence scale) constituted 95% of the research literature on EOL care in prisons. Although there were no intervention studies, we evaluated 63% of this research—all published between 2009 and 2014—as being of "good quality" (Grade B on the JHNEBP quality of evidence scale).[10] The studies we rated as lower quality were the six published between 2002 and 2006[11-16] as well as one study published in 2011.[24] Maschi and colleagues reported that most of the nonempirical articles in their review were published in 2002 or earlier.[6] From these findings, we can reasonably infer that the quality of published articles in peer-reviewed journals on prison EOL care has improved in strength over the past two decades.

This descriptive work, however, points to important contributions that could be made by high-quality quasiexperimental and experimental studies that rigorously test EOL interventions in the prison setting and evaluate outcomes for inmates, inmate caregivers, prison staff, inmates' family members, and the prison environment. Perspectives of inmates' family members were not reflected in the literature reviewed here. In addition, some studies reported on inmates' lack of trust in health care professionals, though the research did not directly address the role of nurses and other health care providers in the EOL care of inmates. These findings point to a need for future research focused on health care providers' approach to EOL care and to the quality of EOL care delivered by nurses and other health care professionals in prison settings as perceived by EOL patients, external hospice providers, and prison administrators. Other potential areas of exploration might address the experience of nurses and health care providers delivering EOL care to prisoners—for example, whether they, like inmate caregivers, have found it personally transformative; whether it has affected their perceptions of prisoners or of the prison system. Foundational descriptive work with inmates' families and nurses in correctional settings is needed to reveal important information about the perceived adequacy of

- visitation allowance.
- communication with prison staff about the condition of EOL patients.

Nurses should advocate for more lenient eligibility requirements for prisoners seeking EOL care.

Limitations. One limitation of this review is that the body of literature reviewed contained little research that directly addressed the role of nurses and other health care professionals in the assessment and care of prisoner patients. Another important limitation is that three of the studies reviewed were conducted by the same authors[17-19] and report findings from the same 14 prison hospice programs, with considerable overlap. Three articles reported on different aspects of a global study,[26-28] and two articles shared researchers and focused on inmate hospice volunteers within the same state program.[25,29]

One of us (SJL) was a principal investigator for three of the included studies.[26-28] To address this limitation, each of us individually rated all the evidence, compared and contrasted our results, and stated in the evidence table each study's strengths, limitations, and evidence grade. Finally, one inclusion criterion required that articles be written in English, which may be why only one article reported on findings outside the United States.

- emotional support provided to EOL patients as well as their families, inmate peers, and caregivers.
- follow-up with inmates' families after their death.

Finally, because only one of the 19 articles reported on research outside the United States, future research should include sites beyond U.S. borders, which similarly contain prisons in which a growing number of aging and ill prisoners reside.[31] This should include studies conducted in the United Kingdom, where physician Dame Cicely Saunders pioneered the hospice movement when she established the first modern hospice, St. Christopher's, in a London suburb.[5, 38] ▼

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