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Who Wants to Die in Here? Perspectives of Prisoners with Chronic Conditions

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As with the rest of society, the U.S. prison population is aging. Human Rights Watch¹ estimates the number of sentenced federal and state prisoners age 65 or older grew 94 times faster than the total sentenced prisoner population between 2007 and 2010. More than three decades of tough on crime policies such as mandatory minimum sentences and three strikes laws² has resulted in the number of life sentences without parole increasing by 600% in the U.S. from 1972 to 2009.³ With 1 in 10 state prisoners serving a life sentence,¹ the greying of the prison population is expected to grow, especially since Iowa, Illinois, Louisiana, Maine, South Dakota, and Pennsylvania have policies of a life sentence excluding the option for parole.⁴ Taken together, these sentencing and release policies help to explain the increasing numbers of older people living and dying in US prisons.

Many prisoners with life sentences will grow old and die after many decades in prison, while others enter prison with such poor health that they will die long before any opportunity for parole would be considered. In fact, 89% of prisoner deaths in US state prisons are attributed to chronic medical conditions.⁵ The 1976 case of *Estelle v. Gamble*

ensured prisoners' access to care by health care professionals.⁶ Just eight years later, the Sentencing Reform Act of 1984 allowed for compassionate release of prisoners for extraordinary and compelling circumstances,⁷ such as terminal illness if they were deemed both medically eligible and approvable based upon correctional and legal evidence.⁸ There is a possibility of compassionate release for federal prisoners, as well as state prisoners in most states⁸; however, only a tiny fraction are freed.⁸ Providing high quality healthcare to people who are dying in prison is an ethical imperative.⁹

Background

Many prisoners face a solitary death without the supports afforded to people in the free world.¹⁰ Trailblazing U.S. prison hospice programs began to emerge in the decade following *Estelle v. Gamble* and continue to serve as exemplars of humane end-of-life (EOL) care in prisons that balance the competing demands for prisoner confinement and public safety¹¹ with compassionate care. The early prison hospices are in Vacaville, California,¹² Springfield, Missouri,¹³ and Angola, Louisiana.¹⁴ In 2002, an estimated 85% of the 5000+ prisoners at Angola were expected to die while incarcerated, which presents the challenge of providing comfort and care to an increasingly older and sicker prison population as they approach EOL.¹⁵ Unfortunately, the integration of hospice services into other prison systems remains limited.¹⁶

A critical component of successful prison hospice services is the involvement of prisoners as caregivers.¹⁶ Other principal components are the utilization of interdisciplinary teams, the provision of comfort care (e.g., counseling, special privileges), and the delivery of effective EOL care.¹⁷ In addition, the perceptions of prisoners are critical to understanding their needs and experiences regarding health related issues in prison settings.¹⁸ Prisoners and community-living people alike often worry that hospice referrals result in health care providers withdrawing care; however, prisoners' concerns are amplified by the fact that the providers are part of the prison.¹⁵

Previous research on EOL issues in the prison system have shown that prisoners would prefer hospice to be an available option that includes individualized treatment plans for pain management and emotional support.¹⁷ However, much like in the free world, prisoners vary in their opinions and levels of knowledge surrounding hospice services, EOL care, and treatment options.¹⁹ To date, no published research using prisoner patients' perceptions of EOL care in prison could be located in common databases; therefore, giving voice to prisoners with advanced chronic conditions and nearing EOL holds the potential to build our understanding of EOL care within state correctional institutions (SCIs) and to provide critical insights into service delivery. The purpose of this study was to examine the values, beliefs, and perceptions held by current and potential future consumers of EOL care in prisons in order to highlight the facilitators and barriers to providing this essential service.

Methods

This qualitative descriptive study was conducted with prisoners from four state prisons in a mid-Atlantic state. Qualitative description was chosen to examine the perspectives of the

prisoners about their experiences and in their own words.²⁰ This study is part of a larger NIH/NINR funded study to infuse enhanced EOL care into state prisons.^{21, 22}

Sample and Setting

Approvals for the involvement of human subjects in the study were obtained from a University Institutional Review Board, the Department of Corrections (DOC) Research Review Committee, and the Office for Human Research Protections, U.S. Department of Health and Human Services (required for engaging prisoners in research). Participants were recruited from four SCIs of varying security levels in a mid-Atlantic state. Although some of the study sites provided EOL services such as prison volunteers who provided supportive care, none had a licensed hospice. Therefore, alternative strategies for determining current and future consumers were devised.

Preliminary qualitative research examining the contextual features of the provision of health care in prisons was used to frame sampling criteria. As inmates progressed into advanced illness, assistive care measures were implemented on the cell-blocks to support chronic care. As debilitation progressed, inmates were transferred to the infirmary for 24 hour care. Since infirmary beds are limited in number and largely used for those with more episodic conditions, permanent residence in the infirmary is reserved for those who are no longer able to be maintained on a general prison housing unit due to advanced functional decline induced by life-limiting conditions. Researchers and insiders judged permanent residence in the infirmary as an appropriate proxy for determining those receiving EOL care (i.e., current consumers). The proxies for identifying potential future consumers of EOL included: participation in a chronic clinic; a history of progressive life-limiting illness with increased debilitation; assignment to a general housing unit; and length of sentence (i.e., length of incarceration anticipated to exceed life expectancy). In addition to these criteria for segmentation of the sample, inclusion criteria included English-speaking prisoners, and aged 18 years or older. Those who were diagnosed with dementia or other cognitive impairments or who were housed in restrictive housing units were excluded from the study.

Recruitment proceeded as the Correctional Health Care Administrator (CHCA) at each of the four SCIs prepared a list of prisoners meeting the inclusion criteria for each segment of the sample. This list of prisoners was used by the Superintendent's Assistant for the distribution of a study flier, which stated, "the purpose of the study is to better understand your values and beliefs regarding care of inmates with chronic health conditions and care for inmates through end of life within a state prison setting." Interested inmates were directed to respond to the Superintendent's Assistant to set an appointment to meet with the researchers.

At the individual appointments, PIs read the description of the study aloud and reviewed the informed consent document. Reinforcing intent, the informed consent form indicated the researchers' goal to "develop strategies to better care for inmates with advanced chronic illness through the end of life" along with explicit descriptions of targeted segments of the sample; including "inmates who are nearing end-of-life" and "inmates with chronic conditions who are potential future consumers of end-of-life care." Potential participants were informed verbally and in writing that their identity would be kept strictly confidential except under the following conditions, if they expressed: (1) intent to harm self, (2) intent to

harm others, or (3) plans to escape. Participants were given the opportunity to raise questions (which were answered under principles of full disclosure).

Procedures

Twenty-two male prisoners agreed to participate in the study; however, one prisoner was soon excluded due to a diagnosis of dementia being revealed with the first discussion question (see Table 1 for discussion guides). The final sample included 21 participants who were designated as current consumers and potential future consumers of EOL care (see Table 2 for a description of participants).

Data were collected during individual interviews in a private setting. Prison staff members were not present during the interviews. All interviews were conducted by two collaborating senior researchers using a semi-structured discussion guide (see Table 1) in order to promote reliability and dependability.²³ Since audio recording of prisoners is prohibited by the DOC, alternative methods were used. Hand-written field notes of the participants' responses were generated while on prison property. Field notes and researcher observations were dictated into a digital recorder upon leaving prison grounds. Data were transcribed verbatim and verified (i.e., confirmed for accuracy by comparing audio files to transcript) and de-identified prior to analysis.

Analytic techniques included content and thematic analyses.²⁴ Content analysis was used to develop a categorical schema of participants' perceptions of EOL care in prison. Thematic analysis was used to uncover patterns or conceptual threads that interpret meaning. A team approach to analysis was employed. Three members of the research team (a PI and two research assistants) completed first level coding of the interview transcripts. All authors (i.e., the team) reviewed the transcripts and the preliminary coding schema, subsequently collapsing categories and refining the codebook. Through a series of collaborative team meetings, six interrelated themes that best reflected participants' responses were identified. Analysis was an iterative process, co-occurring with data collection. Recruitment was closed when data became redundant.

Findings

Key Themes

Responses from current and potential future consumers of EOL care in four distinct SCIs centered around six themes: *seeking human interaction*; *accessing material resources*; *obtaining compassionate care*; *seeking equitable care*; *addressing physiological needs*; and *facing death*.

Seeking human interaction—“[I’ll] walk up and down the unit looking for opportunities to interact.”—*Seeking human interaction* focuses on interpersonal relationships, including non-clinical interactions with others inside the walls of prison and with people from the free world community. While visitors are often restricted from the infirmary, some participants highlighted the significance of permitting family to visit in the infirmary. One potential future consumer of EOL care shared “...they have let family visit [in the infirmary]. There was an inmate who had AIDs and they let his mother come in to

visit.” A current consumer of EOL care was similarly positive: “I get to interact with others. Everyone knows I’m a joker. I’m a lifer. I found God here...My brother and his wife come here...Also, the lady minister or chaplain comes here to see me...” Socializing with “the dudes in the infirmary area” also was cited as important.

While most participants appreciated interactions with others, some potential future consumers of EOL care expressed a desire for solitude.

Insights about prison practices that either served as facilitators or barriers to *seeking human interaction* were reported. For example, one current consumer shared, “they’re [staff] good about calling families and about letting families come and stay with the inmates.” Another participant who was a current consumer suggested that the staff of the DOC “try and keep us guys a little closer [to home] because seeing your family is important...A video conference would even be appreciated. It’s really tough on me and my brother...”

Even when living with a terminal condition, some prisoners strategized to spend time with others. For those who were able, programming was one option: “I go to GED classes and I’m doing pretty good at them. I get to be with other inmates from different blocks; some who can’t do much...” Others described interactions with prisoner-workers, “...there are people [other prisoners] who come in and clean up, sometimes they...help fill out forms, sit and write letters. [I] used to do this for other inmates until [my] health got worse.” For the most impaired, interacting with fellow infirmary patients was a strategy: “I spend time with [another prisoner] who can only move one hand and his head. We play cards and I give him encouragement...”

Accessing material resources—“...they bring in pillows and blankets...they lack equipment but still make it work”—*Accessing material resources* encompassed descriptions of tangible items or lack of such items that would directly impact the care of prisoners with advanced chronic conditions and approaching EOL. A variety of references to material resources were highlighted, including: “the beds themselves don’t work”; “we have no...medical kind of stuff in the library”; and “I can’t even go outside because I’m tied to the electric [oxygen] concentrator...we really need a portable tank.” Despite reported challenges to accessing material resources, it was noted that “the rooms were clean” and “they treat you well...the medical staff do what they can and they do what they have to do to get the job done with their limited resources.”

While this theme was dominant in the current consumer group, considerations of access to material resources were evident in the potential future consumer group as well. For example, age-segregated exercise was cited as a facilitator to accessing material resources in “the old-timer’s exercise...they have weights, treadmills,...mostly, though, I just ride the bike, but there are other activities available...I like that it’s just the guys 50 and older.” In contrast, challenges were expressed by another potential future consumer “...there is a PT [physical therapy] room, but no equipment to help amputees or stroke victims...”

Obtaining compassionate care—“They got nurses with a little bit of guard in them. They need guards with a little bit of nurse in them”—Descriptions of care or

lack of care demonstrated toward chronically ill and dying prisoners revealed the theme of *obtaining compassionate care*. Compassionate care focused on perceptions of caring attitudes and behaviors. Reports of receiving compassionate care were many and included: “being allowed to go to the VA once a month, which is helpful”; “the basic attitude among medical [is] they take their jobs really seriously”; “inmate workers promote good care”; “there is somebody always there”; “I’m...only a few steps from the infirmary and that is good”; “they check me regular and they check to see if you have any problems”; “they’re good about calling families and about letting families come and stay with inmates...they actually go the extra mile in terms of providing care”; and “they push the inmates to contact their families.”

Variations in the degree of compassionate care reportedly depended upon who was working at a particular time, what the staffing was like on a given shift or day, and at which SCI the prisoner was detained. Cited examples of variation among specific staff roles included nurses (“...some of the nurses are pretty good, if get the right nurse, you’ll get good care...”); physicians (“...it really depends on the doctor”); and corrections officers [CO] (“there’s inconsistency...some of the COs will let you visit a very sick inmate who’s in the infirmary and some of them won’t”). Staffing patterns shifted the perception of compassionate care. One prisoner summarized, “...there are some good folks that I’m happy to say are here, and there are others who do nothing but bring misery with them”). Staffing also had an impact on direct care, as reported by another prisoner, “there are days when they have more people here and the service is excellent...other days when they’re short staffed...you can’t get a toothbrush.” Institutional variation was commonly reported, as reflected in this participant’s report: “...the care was better [at different SCI]...they let [me] pick up trash and do things like that...it’s very difficult to occupy your time in the infirmary here because they won’t let you get up or move around and do things.” Accounts were shared of how services changed over time within one SCI. “We had a nice set of porters...they came in and talked to you, cleaned your locker. Now we only get courtesy calls...they mainly work day shift...only one guy on the other shifts.”

Opportunities for greater compassion and care for the seriously ill and dying included services, attitudes, and staffing. One service issue raised was in regard to call bells as noted in the following quote: “another thing is the timeliness in answering call bells. Sometimes it takes 20 minutes to have someone respond.” Another area for improvement was medication delivery: “the pill line here is very slow...stand in the pill line and then...miss a meal.” Features of the care setting also were cited as impacting the quality of care; for example, “the sleeping arrangements are really bad here; the mattresses are too hard.” Attitudinal issues were cited as an area for improvement: “when an inmate’s health goes downhill, the attitude is, ‘well, it’s another one gone that we don’t have to put up with no more.” Opportunities for improvement in compassionate care related to staffing were offered. “...They really needed to get...a more diverse workforce that is more reflective, or looks more like the inmate population...” Another recommended consideration for training and staffing was: “guards need to be trained...sometimes guards from the hole [solitary confinement area of the prison where prisoners with disciplinary issues are held] will come in and substitute in the medical unit...that’s been a problem.”

Seeking equitable care—“quality of care depends on whether anyone on the outside is showing any love and concern”—Equitable care referred to the perception of being treated fairly and equally. Inequalities were often cited as comparative exemplars highlighting the quest for equitable care. For example, differences in care or treatment based on affiliation with particular prisoner groups versus no affiliation and comparisons of treatment in the free world versus prison were described.

Variations in the equity of EOL care or treatment across different prisoners or prisoner groups was most evident in the words of a current consumer, “when you come in here, they give you a jacket and you have to wear that jacket your whole life.” The metaphorical jacket that he was referring to was the outward mark of being a drug addict. Even though this participant reportedly had not done drugs in 23 years, he feels as if he is treated as if he’s still seeking illicit drugs. He went on to share, “we shouldn’t have to suffer; we shouldn’t have to prove that you’re messed up in order to have adequate pain control.” Other participants shared similar sentiments such as “...lots of folks are in pain but they have a policy where they don’t want folks to get addicted to narcotics...they try things like extra strength Tylenol or Ultram...they’re [dying prisoners] really suffering and really in pain.” Likewise, a current consumer from a different SCI offered similar experiences when he spoke of a time where he “had a lot of pain” and went on to state that it was “not adequately dealt with...staff are worried about pain medications...” He even reported that he had threatened suicide due to his pain. In sharp contrast, a prisoner from the same SCI reported that he “feels like the pain management here is good.”

Another perceived inequity arose for those who had fewer financial resources: “it’s five dollars to see medical and five dollars for a prescription so a guy with a lump on his neck may not have it checked out because he couldn’t afford the co-pay.” A future consumer reported:

quality of care depends on whether anyone on the outside is showing any love and concern. If no one is calling about you; calling in here crying about you, if no one on the outside cares about you, you don’t get as good of care and you just seem to fade away...

Despite reports by some of perceived inequities across prisoners, one potential future consumer shared a resource in his SCI that leveled the playing field for those who are Hispanic.

They have the inmate volunteer program...that’s a really good thing. They don’t get paid but they like doing it and there is one inmate volunteer who speaks Spanish and is able to help translate and speak to some of the inmates who are Spanish speakers.

Two current consumers shared the importance of communication skills and information to their quest for equity. One man said, “if you communicate properly with the medical staff... you will get proper treatment.” The second man asserted, “if you don’t do anything for yourself, you can’t expect to get a lot of help. Some want to be catered to and it doesn’t work well, but if you help yourself, others will help you...” A potential future consumer shared a tip from the Medical Director at his SCI, “to get the best care...you need to learn

everything that you can about the system...no one can take care of you like you can...[I] started writing national organizations to learn everything...and get...free reputable information...[I've] been treated very well..."

Finally, one current consumer reflected on lack of responsiveness in the prison infirmary and contrasted that with care received at a hospital. "They [prison staff] would draw labs and [I'd] hear nothing about the results." He recalled feeling "tired all the time" and "couldn't even stand." Eventually, he was sent to a hospital where he received three units of blood.

Addressing physiological needs—"I'm just miserable from trying to breath."

The theme of *addressing physiological needs* includes participants' descriptions of basic necessities, such as cleanliness, physical environment, safety, pain and symptom control, nutrition and hydration, and elimination issues. Physiological needs for oxygen, nutrition, a suitable environment (i.e., hygienic and temperature controlled), and pain management were described. In regard to oxygen, a current consumer reported, "Last week the electric went out so my concentrator didn't work. I was panicking. They did not find me a tank for over 20 minutes." A positive report concerning nutrition came from a potential future consumer who asked dying friends about "things they needed and typically it was stuff like ice cream or potato chips. I would go and get permission and bring them these special foods since they were dying and the nurses were okay with that." A negative statement about nutrition in prison from one current consumer was, "there's a heavy emphasis on carbs...patients with diabetes are not able to get their dietary needs met. They need more protein." Another current consumer stated:

I have been in this jail now for about 8 years and the food is always the same so I don't try it anymore. It is a waste of my time to go to the cold day room to lift the lid on the tray and get disappointed yet again... I do like the vanilla and strawberry ice cream. We had ice cream the other day and I missed it because of [treatment].

The need for a suitable environment included reports calling for improved hygienic practices and temperature control. The issue of hygiene is noted in the following quote regarding insanitary smells, "...you have guys with dirty diapers. Instead of putting all the dirty diapers in a diaper pail, they put them in a general garbage and it smells so bad you can hardly get your breath..." Temperature control was the focus of a current consumer: "...rooms in the infirmary are really not adequate...there's no heat in there...[I] had to sleep under three blankets..."

Both positive and negative reports regarding pain and symptom management in prison were shared by participants, variations appeared to be patient dependent (i.e., there were variations in impressions within SCIs). One current consumer told of a fellow inmate, "He hurt really bad...they never gave him any pain meds or they didn't give him enough or often enough, and so he suffered badly...he didn't deserve to suffer the way that he did." Another current consumer from a different SCI reflected on his own pain experience when he shared that he "has had a lot of pain... and feels like [his] pain is not adequately dealt with...staff are worried about pain medications..." Conversely, two other participants, both of whom are also current consumers, reflected positively about their pain management. The first asserted

that he “feels like the pain management here is good”, and the second shared “Now I don’t get much pain at all. I feel some pain but it’s tolerable and the nurses would get me a pain pill if I needed something.”

Facing death—“...give me my meds and let me die easy.”—Long sentences permit ample time for experiencing the death of others and these experiences shape the anticipation of one’s own death. Analysis of the participants’ reports of experiences with death, including fellow prisoners dying, and acknowledgments of their own eventual deaths resulted in a theme entitled, *facing death*. This theme captures the beliefs and perceptions of death among prisoners who will likely die while incarcerated.

The number of deaths encountered within the prison setting was remarkable to one potential future consumer who estimated that he’d “experienced about two deaths a month” since he had been in the SCI. He reflected that he has “...witnessed more deaths here than ...in [his] 1 ½ year tour in Southeast Asia, during the Vietnam War.” Another participant spoke of his buddy who died of pancreatic cancer and stated, “...the most important thing for these patients is that they do not suffer.” As segregated communities, prison deaths are often personal. A potential future consumer of EOL care shared a story about a young prisoner:

He wanted to get his GED...[I] was going to be working with him to help him to pass his GED but never had the opportunity because the young man died...[of] end stage renal disease...he was scared to death of dying...what can you do? I just try to talk to them...If I allowed my guard to be down, they might have to put me on a psychotropic drug.

The place of death played significantly in the experience, “...the older inmates...get them out to a nursing home...Who wants to die in here?”

Shifting to a more personal perspective, one current consumer of EOL care reflected, “if I can’t get myself closer to home, I want to make things as best I can while I’m here. I ain’t never getting out. This is it.” His perspective was not unique as evidenced in the words of another participant who knew that eventually he’s going to die in prison. Although he didn’t “care so much about dying” he did worry about “having to suffer.” Another current consumer stated, “I...have cancer...and it is spreading. I’m fighting the cancer. I actually canceled my advance directive recently. I’m a believer in fighting to the end.”

Limitations

This study was conducted exclusively in state prisons housing men in a single state, limiting generalizability of findings. As well, none of the four prisons in this study had a licensed hospice. Therefore, future studies of EOL care in correctional settings are needed to examine jail and federal prison populations, women prisoners, prisons in geographic regions beyond the Mid-Atlantic region, and institutions with licensed hospices. Advance directives and advance care planning are other emergent concerns in corrections research that warrant further research.

Discussion and Implications

Current and potential future consumers of prison EOL care have clear perceptions of facilitators and barriers to compassionate care for themselves and their peers. Both groups cited examples of facilitators which promoted meeting their needs for *human interactions*: staff communicating with family members and encouraging prisoners to contact their families; administrative and staff receptivity to visitation in the infirmary by family and fellow prisoners (for those who desired such visitors); opportunities for prisoners to still contribute, even when living with a terminal condition (i.e., work or tutor others); and provision of support and companionship from prisoner volunteers and porters. Barriers to visitation included family living too far away to allow for visitation of the prisoner when nearing EOL. One way to address this barrier would be to expand the use of videoconferencing or free services such as Skype, which can achieve the same goal when family members could access computer technology at their local public library or place of worship. Providing access to videoconferencing can benefit staff as well by easing suspicion and the adversarial mentality between prisoner patients and the health care professionals charged with their care.¹⁴ However, soliciting and maintaining an up-to-date list of desired visitors from prisoner patients nearing EOL is indicated to prevent unwelcome visitation by outside of prison family and/or prisoner peers. Finally, providing opportunities for recreation and making contributions through work or volunteerism should be afforded as long as desired, feasible, and safe. Such initiatives on behalf of dying prisoners rest on whether prison systems feel that providing EOL care is part of their mission. Interviews with state level leaders (in a related arm of the parent study) revealed that delivery of EOL related services is impacted by the culture of a particular institution—particularly conflictive values and beliefs related to the rival priorities of treatment versus security.²²

Lessons learned through the Angola Hospice Program could be applied in other prisons in order to address the numerous *material resource* needs that were perceived as unmet. For example, durable medical equipment was donated by community agencies to Angola's hospice, an equipment repair shop was developed within the prison (providing jobs and a needed resource), and plans were underway for donations of needed equipment across prisons.¹⁴

Opportunities to remain active through the designated exercise times for older prisoners was an offering in at least one SCI that could be implemented in other prisons as suggested by prior research with older prisoners.^{18, 25} The proposed changes in practice may foster prisoners' perceptions of health care staff getting the job done as best they can despite limited resources.

There were a number of reports of *compassionate care* by participants which collectively fostered a perception that the system had the capacity to provide compassionate EOL care; however, some areas were in need of improvement. Staff attitudes demonstrating a lack of care or compassion may be linked to the observation by some participants that the prison workforce did not look like the prison population. Such concerns are not restricted to the prisoner population, but rather are parallel to concerns expressed by community-living African American focus group participants (i.e., low visibility of African American staff and

distrust of the healthcare system).²⁶ Providing culturally competent care is an essential consideration for prisoner patients, as well as their community-living counterparts. Professional development efforts could help educate prison staff about care for the dying and who would be better than hospice professionals to deliver the programming? Maull (1998) reported that the training of prison staff and prisoner volunteers in some of the early prison hospice programs was done by hospice professionals.¹³ Partnering with a local agency for training and on site consultation is one possibility, while another avenue is through telehospice.²⁷ Increasing sensitivity and compassion and advancing prison employees' knowledge about dying and death were needs emphasized by study participants. Partnering with local colleges or accessing computer based training modules²² could provide educational resources on culturally competent communications surrounding EOL care.²⁸ Finally, learning opportunities can arm staff with the tools needed to handle unsettling situations, to enrich their work, and to aid them in coping with non-work-related deaths.²⁹

Providing prisoners with opportunities to expand their health knowledge so that they may better communicate with health care professionals is one way to promote *equitable care* for chronically ill and dying prisoners. In order to better position chronically ill prisoners to best partner with healthcare providers to promote their health and facilitate a good death, they should be provided with health planning and decision making education and resources.²⁵ Having these tools and training is equally beneficial to those preparing for release from prison.²⁵ Prison systems can serve as conduits of information. For example, by reaching out to longstanding prison hospices in the U.S. approaches to successfully managing the pain of dying prisoners can be shared, which is especially important because many of their prisoner patients would similarly have histories of narcotic addiction.

Improvements in meeting dying prisoners' *physiological* needs can be achieved in low cost, yet highly effective ways. Provision of comforting foods to dying prisoners could be a community project for general population prisoners—funds could be donated to purchase desired items for those approaching EOL through the prison commissary. As well, community organizations could be enlisted to sponsor the purchase of desired foodstuff and institution approved comfort items including pillows and blankets. Management of garbage that contains human waste in a manner that both controls offensive odor and prevents environmental contamination is important.

A belief within the *facing death* theme was to get dying prisoners out of prison to a nursing home to die. Although technically possible,⁷ the probability of a dying prisoner being granted compassionate release is fairly low due to the combination of clinically flawed medical eligibility criteria (i.e., challenges to achieving accurate prognostication) and procedural barriers.⁸ Public attitudes of *not in my community*³⁰ (i.e., opposition to services being offered to prisoners in close proximity) can get in the way of nursing homes accepting parolees as residents. Alternatively, corrections professionals and prisoner peers may provide humane care and compassion within the environment which has become home to many.²⁹ Therefore, continued growth and development of prison EOL care programming⁸ must be a priority. Simultaneously well-planned efforts to convey to the public that if prisoners nearing EOL were to be released from prison via compassionate release they are

carefully vetted in advance to ensure that they pose little risk to public safety and may actually result in cost savings to the tax-paying public if prisoners' family members are willing and able to provide community-based care. In addition, public fears could be lessened by application of ankle monitoring bracelets, as suggested by Maschi and colleagues²⁵ for early release of elderly prisoners. Finally, since prisoners may not be viewed by some as deserving health care investments³¹, communicating that the program facilitates humane care for the dying rather than coddles criminals may promote public tolerance.¹⁴ Alternately, if humane care for the dying is not sufficient incentive to motivate expansion of EOL care in prison settings, perhaps the potential for cost savings or cost avoidance (as noted earlier in regard to early release) could be compelling. Specifically, caring for prisoners inside of prison, rather than transferring them to hospitals for care could result in cost savings as evidenced in The Louisiana State Penitentiary at Angola, which has a long-standing hospice program that meets the National Hospice and Palliative Care Organization's standards and delivers these services at no additional cost to the penitentiary. At Angola, EOL care delivery is accomplished through a combination of existing prison staff along with inmate volunteers¹⁵—a model that could be adopted in other institutions.

Hospice and palliative care nurses have a unique opportunity to share their expertise and knowledge with colleagues with whom they normally might not interact on a regular basis: correctional health care professionals. Examples of opportunities to impact EOL care in prisons include, but are not limited to: donating lightly used equipment, excess supplies, or resource materials; delivering staff development programming; providing videoconference consultations for challenging cases (a form of *telehospice*); and acting as advocates for enhancing EOL care in prisons. By reaching out to correctional facilities in their geographic regions, nurses with proficiency in EOL care can partner to ensure that humanity and compassion for the dying does not end at prison gates.

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Table 1**Discussion Guides****Current Consumers of End-of-Life (EOL) Care**

- 1 Could you tell us about your health?
- 2 Can you tell us about how comfortable you are? [If needed: prompt to touch on things such as pain control, N&V, mouth care, access to nutritional items and fluids, environmental issues (room temperature; dry, clean linens and pillows; and general surroundings)]
- 3 Please tell us about opportunities that you have to interact with other people while staying here in the infirmary. [If needed: prompt them to consider staff (specify), fellow inmates, & family (if any)]
- 4 What kinds of things do you do to pass the time each day?
- 5 Can you tell us about the care you have received since staying in the infirmary here at SCI_____?
- 6 What kinds of things, if any, support good care for patients such as yourself here at SCI_____? [If needed: prompt that we are looking for facilitators for good EOL care.]
- 7 What kinds of things get in the way of good care for inmates such as yourself here at SCI_____? [If needed: prompt that we are looking for barriers to good EOL care.]
- 8 What are some things you think that SCI_____does well in regard to your care and the care of others?
- 9 Can you tell me about some area(s) where there is room for improvement in regard to the care provided?
- 10 Before we close is there anything else that you would like to share with us?

Potential Future Consumers of EOL Care

- 1 Could you tell us about your health and the care you receive for your health here at SCI_____?
- 2 Have you had any inmate friends that have passed away since you have been here at SCI_____?
- 3 Can you tell me a specific story about care provided for them in their final months, weeks, and days? [If needed: prompt that we are seeking things they observed when a fellow inmate was nearing end of his life.]
- 4 How would you describe the care that they received? [If needed follow up with whether or not they considered their death to have been a good death? (if so how so, if not why not?)]
- 5 How did that experience affect you?
- 6 What kinds of things, if any, support good care for men who are approaching their end-of-life here at SCI_____? [If needed: prompt that we are looking for facilitators for good EOL care]
- 7 What kinds of things, if any, get in the way of good care for men who are approaching their end-of-life here at SCI_____? [If needed: prompt that we are looking for barriers to good EOL care]
- 8 What are some things you think that SCI_____does well in regard to care for people who are nearing their end-of-life?

Table 2

Description of Participants

Participants	Frequency (Percent)
Current Consumers	14 (66.7%)
Potential Future Consumers	7(33.3%)
Age	Frequency (Percent)
40–49	1(4.8%)
50–59	5(23.8%)
60–69	10(47.6%)
70–79	1 (4.8%)
Not reported	4(19.0%)
Major Health Problem Self-reported	Frequency (Percent)
Heart Disease	4(19.0%)
Chronic Obstructive Pulmonary Disease (COPD)	3(14.3%)
End Stage Renal Disease (ESRD)	3(14.3%)
Cancers (lung; lymphoma, throat and prostate)	3(14.2%)
Stroke with Seizures	2(9.5%)
Advanced Diabetes with Leg Amputation	2(9.5%)
Liver Disease	1(4.8%)
Ulcerative Colitis	1(4.8%)
Parkinson's Disease	1(4.8%)
Partial Paralysis and Degenerative Arthritis (frailty)	1(4.8%)