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# Care and companionship in an isolating environment: Inmates attending to dying peers

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## Abstract

The purpose of this study was to examine the values, beliefs, and perceptions of end-of-life (EOL) care held by inmates caring for peers approaching end of life. The study is part of a broader participatory action research project to infuse enhanced EOL care into state prisons. Face-to-face interviews using a semi-structured discussion guide were conducted with 17 male prisoners who were providing care for peers with advanced chronic illness and approaching end of life. Qualitative data were analyzed using content and thematic analyses. Key themes were: *getting involved; living the role*; and *transforming self through caring for others*. As well, contextual features at the organizational, peer, and personal levels were identified that either facilitated or impeded inmate caregiving. Provision of enhanced EOL care by inmate peers shows promise for improving prison community relations and morale, reducing suffering, and demonstrating care and compassion within the harsh prison environment. This study provides clear evidence that providing compassionate care for dying peers may result in transformative experiences for inmate

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caregivers. Implications for correctional nursing practice include providing training for inmate caregivers, including them in team meetings, and implementing grief support programs. Also, upholding nursing's code of ethics and watching for predatory behavior are critical.

> "Prisons in the United States contain an ever growing number of aging men and women who…are incontinent, forgetful, suffering chronic illnesses, extremely ill, and dying" (Human Rights Watch, 2012, p. 4)

The US prison population is aging, and the aged population is growing at a brisk rate. Between 1995 and 2010, the number of inmates ages 55 and older increased by 282%, while the overall prison population increased by 43% (Human Rights Watch [HRW], 2012). Factors contributing to this demographic shift are: aging of the US population (Aday, 2005–2006); longer sentences, including more life sentences due to state and federal sentencing statutes; limited opportunities for early release (Kerbs & Jolley, 2009); and parole revocation policies (HRW, 2012). This considerable increase in older prisoners has brought end-of-life (EOL) issues to the fore (Granse, 2003); growing numbers of prisoners will age and die while incarcerated.

## Vulnerability of Older and Chronically Ill Inmates

Of concern to correctional nurses are factors such as the "particular risk of medical neglect given the complexities associated with chronic health conditions and aging" (Kerbs & Jolley, 2009, p. 121). Also, inmate patients often have difficulty separating the therapeutic roles from the security roles of health care workers (Feron, Tan, Pestiaux, & Lorant, 2008), since the care given to prisoners is described as administration-centered rather than patient-centered (Mezey, Dubler, Mitty, & Brody, 2002). Finally, the risk of psychological and economic victimization of older inmates by their peers is a documented reality (Kerbs & Jolley, 2007) that contributes to the vulnerability of patients in the prison setting. As chronic health conditions worsen and EOL approaches, the cumulative effects of feelings such as lack of trust, neglect, and vulnerability compound the stressors faced by inmate patients.

## Care for Those Dying in Prison

Providing security and care for older, sicker inmates requires considerable resources; therefore, creating a strain on both state and federal budgets (Gorman, 2008). Compassionate caregiving may be a key to addressing the "prospect of dying in a foreign place in a dependent and undignified state" (Aday, 2005–2006, p. 201). The National Commission on Correctional Health Care's (NCCHC) standard of care for the terminally ill (those with less than one year life expectancy) in prison points to a need for the following: pain management; potential care in a community setting; staff training; and, if a hospice program is present—informed choice by the inmate about hospice participation. The overarching goal is the achievement of a "good death" (NCCHC, 2008, p. 110) with adequate pain control, dignity, and a supportive community of family/friends. This standard is designated as "important," but not "essential" (NCCHC, 2008, p. 109). A recent integrative review of hospice care in prison by Stone and colleagues (2011) concludes that, "the limited available literature on prison hospices may suggest an attitude of less value being placed on EOL care for incarcerated individuals" (p. 2). Taken together, these factors indicate that there is room for growth both in policy and research related to end-of-life care for those who will spend their final days behind bars.

## Prisoners as Caregivers for Dying Peers

Prisoner caregivers may be one important resource for enhancing EOL care for dying peers (Stone, Papadopoulos, & Kelly, 2011). Although the phenomenon of prisoners serving as

caregivers has received national media attention (Belluck, 2012; Streeter, 2011), empirical studies regarding inmates providing EOL care in prisons are few. Yampolskaya and Winston's (2003) study of prison hospice providers revealed that inmate caregivers were in place in all of the 10 prisons, which were settings for their study and 70% of the prisons included inmate caregivers in interdisciplinary hospice team meetings. Wright and Bronstein's (2007a; 2007b) survey of 14 prison hospice coordinators found that inmate volunteers forged critical relationships with both dying peers and staff. In addition, inmate caregivers improved the quality of care that was provided to dying inmates. Nurses often supervised inmate volunteers, with few reportedly feeling this responsibility added to their workload. Similarly, a study of 43 prison hospices indicated that all but three programs had inmate caregivers, and nurses were nearly universally supportive of using inmate caregivers. Prison hospices were more discerning in selecting volunteers and required more training and longer work hours than community-based hospice programs. Most (79%) offered stress management training for inmate caregivers (Hoffman & Dickinson, 2011). In order for correctional nurses to successfully guide inmate caregivers there is a need to understand the experiences of inmate caregivers in doing their critical work. Our purpose was to examine the values, beliefs, and perceptions of EOL care reported by prison inmates caring for peers in advanced stages of chronic illness and approaching end of life.

## Study Design, Sample, and Setting

This qualitative descriptive study (Sandelowski, 2000) was part of a larger participatory action research (PAR) project to infuse enhanced EOL care into prisons. Qualitative description produces "a comprehensive summary of events in the everyday terms of those events" (Sandelowski, 2000, p. 334). In the broader National Institutes of Health/National Institute of Nursing Research funded parent study (Grant # 1R01NR011874-01), the research team explored the feasibility and effectiveness of using PAR to facilitate change. This method is well suited for promoting the systems change needed for infusing generalist end-of-life (EOL) strategies into the complex context of corrections health (Loeb, Penrod, Hollenbeak, & Smith, 2011). The research team originally proposed that key insights could be gleaned from the perspectives of front line staff (e.g., nurses, physicians, corrections officers, counselors, unit managers, social workers, psychology support staff, and chaplains); hence, inmates were not included as participants in the initial study. Through interviews with Department of Corrections central office administrators, as well as both administrative (e.g., superintendents and their deputies, correctional health care administrators, and business office personnel) and front line staff from six State Correctional Institutions (SCIs), it became evident that we must clarify first-hand, the perspectives of inmates. For this reason the study was expanded to include a focus on the values, beliefs, and perceptions of inmate caregivers.

Participants for this arm of the study were recruited from four male population SCIs of varying security levels in a mid-Atlantic state. Inclusion criteria were English-speaking prisoners, age 18 or older, who were either inmate workers (prisoners whose paid work detail was providing assistance to peers in advanced stages of chronic illness) or volunteers (prisoners who were not compensated for their caregiving role and typically completed this work in addition to a paid prison work detail) caring for their peers with advanced stages of chronic illness. Exclusion criteria included: diagnosis of dementia or housed in the restricted housing unit—either of which would have precluded inmates from functioning as caregivers. An advertisement flyer was distributed through the prison mail system to inmates meeting the study's inclusion and exclusion criteria. The flyer advised inmates of the opportunity to participate in the study and inquired whether or not they were willing to meet with an investigator to consider participation. To express interest, the flyer instructed the prisoners to complete the bottom portion, tear it off, and return it to the Superintendent's

Assistant in order to schedule an appointment with the researchers and learn more about the study. Human subjects review and approval for the study were obtained from both the University Institutional Review Board and the Department of Corrections Research Review Committee. Authorization to engage prison inmates as participants was obtained from the Office for Human Research Protections.

Investigators met with potential participants and read the description of the study aloud. In addition, the informed consent document was reviewed, and an opportunity was provided for potential participants to raise questions and have them answered. None of the investigators had any current or prior relationships with the prisoner participants. All prisoners providing care to peers with advanced chronic conditions and approaching end of life who came to learn about the details of the study agreed to participate, and provided signed informed consent (N=17). Interviews took place in a private space such as an educational room, conference room, or unoccupied staff office. In order to promote confidentiality, no corrections officers or other staff members were present for the interviews. Participants were informed both verbally and in writing, during the informed consent process, that researchers were required to break confidentiality if they indicated the following: (a) intent to harm self; (b) intent to harm others; or (c) plans to escape. Aside from the three aforementioned scenarios, the inmates' identity was to be kept strictly confidential. All participants in group interviews were directed not to reveal to others what individual participants said during the group interview. Each participant took part in one individual (n=2) or group interview (3 groups with 4–6 participants each). The data are stored and secured in a locked file cabinet in the first author's office, in a separate locked file cabinet from the signed informed consent documents. Data analyses commenced after the first day of interviews, emergent themes were confirmed and refined during progressive interviews by the principal investigators (PIs). Interviews were stopped when no new information was reported, thus indicating saturation was achieved.

## Methods

The first author designed a discussion guide (see Table 1) for the interviews. To ensure consistency in data collection, and to promote reliability and dependability, (Cooper & King, 2006) two collaborating Principal Investigators (both of whom are university faculty: a nurse and a health economist) collected all data. All interviews were 90 minutes or less. The opportunity for individual or group interviews were provided to the non-inmate participants in the broader parent study, and the researchers wished to be parallel in their approach with the inmates. This offered some degree of flexibility/responsiveness to institutional/prisoner preferences. Typically group interviews were held with the inmate caregivers, unless a particular inmate wished to have an individual interview or institutional officials requested that inmates be interviewed one at a time for logistical reasons (e.g., due to high security level). The same discussion guide was used for both individual and group interviews. When in a group setting, care was taken to provide everyone the opportunity to have a voice.

Because audio-recording of inmate research participants was prohibited by the Department of Corrections, data were recorded through the investigators' hand written field notes. These notes, which included interview responses as well as any methodological insights, were promptly dictated into a digital recorder upon leaving each state correctional institution (SCI). Audio recordings of the dictated field notes were transcribed verbatim and the accuracy of the transcription was verified by comparing the audio-recording with the transcript word-byword. Transcripts were cleaned of identifiers before the data were analyzed using the techniques of content and thematic analysis (Morse & Field, 1995).

The first author completed the first-level coding of the interview transcripts using content analysis (Morse & Field, 1995) to develop a categorical schema of caring for inmate peers with advanced chronic illness and approaching end of life. Next, during an extended team meeting prior to which team members reviewed the interview transcripts, the preliminary codes were examined by the group and a coherent coding scheme was developed. Through team analysis, the number of categories was collapsed, and key themes were arrived at, which were judged to best reflect what the prisoner caregivers had reported. Goodness of fit between the data and the arrived-upon themes was established. All themes were confirmed to be mutually exclusive (Waltz, Strickland, & Lenz, 2004). In addition, throughout the process there were no negative units of content discarded. The team reached consensus. Contextual features relevant to end-of-life care and caregiving in prison were also revealed and examined.

## Findings

### Characteristics of Participants and State Correctional Institutions

The participants' average age was 49 years (range=35–74) and their racial/ethnic mix of Blacks, Whites, and Hispanics reflected the gro ups most prevalent in prisons in the mid-Atlantic state where the research took place in the order presented from most to least. Nine prisoners reported that they were unpaid volunteer caregivers (7 were trained and 2 provided informal assistance). The other eight were trained, paid workers, and four volunteered additional hours.

There was some degree of variability in roles, responsibilities, and titling of the inmate caregivers across the four SCIs of varying security levels (i.e., Minimum [n=2], Medium [n=1], and Maximum [n=1]). The SCI that inmate caregivers were housed at influenced types of care provided, due to differences in demographic makeup of the prison and level of security. All of the SCIs involved in the study had an infirmary on site. (It is important to note that care in the infirmary is limited to those inmates who require skilled professional care, typically episodic or terminal care.) As noted in Table 2, the comprehensive set of caregiving activities provided by inmate caregivers were not limited to episodic crises or the terminal phases of illness that occurred in the infirmary setting. A number of contextual factors influenced the degree to which inmates were restricted in the location in which they were permitted to perform caregiving role functions. In some institutions care took place inside the housing units (cell blocks), while at others it was exclusively in the prison infirmary. When prisoner caregivers assisted peers inside the general population housing units, they were supervised by corrections officers. In contrast, in settings such as the infirmary, personal care, or skilled care units, supervision was largely provided by nurses. However, corrections officers were also present in the infirmary to ensure security. While discussion of these contextual factors are beyond the scope of this article, it is clear that regardless of the site of care delivery, the values embedded in the process of inmates caring for peers were universal.

Training for the inmate caregivers included such things as blood and body fluids precautions, transfers, making an occupied bed, and feeding. Some SCIs provided an introductory training of 40 hours for inmate volunteers. The prisoners who informally helped their peers inside the general population housing units, did not always report formal training with the exception of prisoners who happened to be on the blood and body fluids clean up team.

### Major Findings

Key themes of caregiving for inmate peers nearing EOL were: *getting involved; living the role*; and *transforming self through caring for others.* Themes are purposefully presented in

this order because *getting involved* was found to be an essential first step for *living the role*, which in turn needed to occur prior to *transforming self through caring for others*. In addition, contextual features were revealed that were significant on three levels: the institutional level, the peer (community) level; and the personal (internal) level. These features influenced the inmate caregiving experience and encompassed both barriers and facilitators.

## Key themes

**Getting involved—"I could be in the same boat"—**Participants recounted a variety of reasons for becoming caregivers. Thought processes, past experiences, and the perceived chance to make up, to some degree, for past wrongs were among the motivations offered for becoming a caregiver for their fellow inmates. Their explanations of *getting involved* clustered around the following subthemes: *reflecting on self; past experience; seeing others die in prison; role models;* and *the opportunity to do something right*.

*Reflecting on self* prompted some participants to get involved because they too would need care one day. One prisoner's comment was most typical, "I could be in the same boat…I'll be in the system until I die and I want someone I know to be around with me when the time comes."

*Past experience* with either informal or formal caregiving inside or outside of prison also contributed to the decision to provide care for their dying peers. Informal experience included: caring for a dying family member; attending to a mentally ill sister; and assisting a brother who suffered from Agent Orange exposure. Formal caregiving experience outside of prison included serving as a medic in the military and working in a nursing home caring for hospice patients.

Observations such as *seeing others die in prison,* were also shared as a motivator. One man recalled, "you used to find people dying alone in their cells" and another recounted "… fellow inmates…got HIV and [I] wasn't able to visit them in the infirmary…[I] really wanted to be there for them so they didn't die alone like some other friends did."

Others noted the impact of caregiver *role models.* One prisoner related the pride he had in his mother who progressed from being a licensed practical nurse to earning a graduate degree in nursing. Another man became a caregiver after witnessing an inmate care for his dying "cellie".

Finally, *the opportunity to do something right* was emphasized as a reason for getting involved. One man succinctly said: "how often do you have a chance to do good in prison?" Another inmate delved a bit deeper: "we all did something not good to get here. Now we can do something right. We can help people."

**Living the role—"It doesn't end because we leave the infirmary…"—***Living the role* represents the inmate caregivers' commitment to their chronically ill and dying peers, valuing of the role and program (if one were in place), and committing to a responsibility that doesn't end at the conclusion of a shift. Caregiving measures that figured most prominently in *living the role* were: *providing companionship and comfort; facilitating others in becoming good caregivers*; and *protecting their charges*. Also these caregivers described dedication, "it doesn't end because we leave the infirmary or our jobs. We are on call 24 hours a day, 7 days a week."

*Providing companionship and comfort* often extended beyond just being present. One caregiver proudly shared the story of his final visit with a man who told him "you're like a grandson to me."

> I…held his hand and said a prayer for him [and said] 'this pain and suffering is about to be over…' I put his hat on him and covered him up with his blankets. He always liked sports so I put the TV on ESPN…I kissed him on the forehead before I left…

See Table 2 for a complete listing of caregiving actions.

*Facilitating others in becoming good caregivers* entailed mentoring new inmate volunteers and workers. It was a role that a select few assumed, as noted in the following: "When new volunteers come in they almost always put them with me so that we can be supportive, comforting, and not cause discomfort [to our patients]…You must give them [patients] the utmost respect."

Finally, *protecting their charges* from predatory abuse was a responsibility of caregiving in prisons. One participant eloquently stated: "…one of the big games that people play is trying to take the [patients'] commissary away…you really have to be…on the lookout to protect those guys…"

**Transforming self through caring for others—"It's been a blessing for me to work and a privilege"—**Transforming self through caring for others was revealed when caregivers identified changes in perspectives that enabled them to connect with others, make contributions of value, and achieve success in attempts to change for the better. The opportunity to care for fellow inmates facilitated the following: *establishing bonds with other human beings; helping oneself through helping others; earning some measure of respect from staff*; and *finding something lost in themselves*. The following stories illustrate transformations experienced.

*Establishing bonds with other human beings* was an important factor in being a caregiver. For example, a participant, who committed a crime against an older person and felt that prior to prison he had no concern for his fellow man, had now developed compassion through caregiving for older, dying peers. "It's a blessing to make them happy…we are their families."

One inmate expressed a strong sense of *helping oneself through helping others*. "My experience caring for the chronically ill people has really opened my eyes more to continue to value life and continue to do good deeds for people. No matter what, you'll feel so much better about yourself." Another man linked his role with his road to recovery: "it [caregiving] helps me cope with reality without being on drugs or alcohol. We do this with a clear mind…"

*Earning some measure of respect from staff* within the institutional environment was appreciated and appeared to instill a sense of pride: "…Now they [staff] understand that we're people with a conscience. Some will ask us about our inmates we're caring for. Some will ask us how they are doing." Words of encouragement and appreciation from staff members also were viewed as being special, such as "…when the nurses say 'thank you'". Two participants shared accounts of corrections officers offering praise: "some of the hard guards are now saying, 'very good job.'"

Finally, accounts of *finding something lost in themselves* through the caregiving experience were frequently expressed: "the program really changed me from being a rough cat…I had

lost the caring aspect…and this program helped me to find it again…" Personal transformation was clearly articulated in the following, "it [inmate volunteer program] rebooted me and I'm hungry for it. I love it and I love the guys I care for. I found something that I thought I'd lost in myself. I'm not a throwaway object. I got something to contribute."

## Contextual features

Three levels of contextual features that impacted inmate caregiving were revealed: institutional level, peer (community) level; and personal (internal) level. Some contextual features held particular importance as facilitators of good caregiving, and were deemed critical to sustainable provision of high quality EOL care. Conversely, logistical issues, negative attitudes and non-supportive behaviors, as well as lack of adequate resources were reported to sometimes impede caregiving, thus serving as barriers to quality EOL care.

**Institutional-level features—"Staff really helps you provide a helping hand"—** An important institutional feature that positively impacted inmate caregiving was the selection of inmate caregivers who were equipped to deal with challenges such as dementia and criminal minds. Supportive actions by nursing staff and corrections officers also were viewed as important to providing quality EOL care. Emotional support from other staff also was noted: "the psychologist is on the block so I have full ability to talk to him…Sometimes they ask me if I need a break [from the program]." One caregiver summed it up best as, "if they [staff] didn't support you, you couldn't do it… the staff really helps you provide a helping hand."

Sustainable provision of EOL care by inmate peers was enhanced by the opportunity for a time of remembrance, as one inmate caregiver reported, "we were able to have a few laughs because that was the way [deceased inmate] was. Sharing those things about him with others was nice and it was a part of life also."

In contrast there were contextual features that got in the way of inmate caregiving, some exemplar quotes included: "it is a prison so issues of security may come into play"; "the staff doesn't have a lot of compassion for the dying"; "…the poor quality of cleaning material…people are developing scabies and other skin bumps and infections"; and lack of adequate training "…especially for the young porters." Lack of compassion was perceived by participants when they heard negative statements uttered by staff to their dying care recipients. For example, "one of the staff told a dying patient 'get ready to meet Satan' right before he died." Particular dismay was noted at how information traveled in prison:

> News of somebody dying doesn't spread formally through the institution; it goes by word of mouth…it may depend on who is working whether the inmate volunteers are notified about whether one of the people they've been caring for passed away.

Additional contextual features that reportedly served as barriers to quality EOL care included insufficient or a lack of the following: debriefing meetings, opportunities to memorialize the deceased, grief counseling, and continuing education for the inmate caregivers; as well as preparation of security staff for dealing with inmates suffering from dementia. Also, the limited ability to provide a comforting environment was noted in the following: "Guys who are going downhill don't want to go to the medical observation room…Since it's so dark and dreary all that some people do is roll over into the fetal position." A final barrier noted was the locations of most of the state's SCIs in remote, rural settings.

**Peer (community) level features—"we as right-thinking convicts don't judge people…"—**Many participants touted the importance of support by fellow inmate

caregivers, “I have a few close associates that I can talk to. We have a bond between us, me and the other volunteers and workers.” Another participant echoed this sentiment: “these two [fellow inmate volunteers] are like my counselors.” Peer support prompted some inmates to learn more about caring for the dying—this was accomplished through comparing notes with their peer volunteers and workers. Role expectations amongst the inmate caregivers promoted quality care, as noted in the following expectation that inmates had of one another: “informal reports between the volunteers really help with continuity of care…” The provision of bias-free care regardless of the patient’s race, religion, or criminal history was highly valued and viewed as being critically important, “we as right-thinking convicts don’t judge people or we wouldn’t be sitting here in browns [brown jumpsuits] all together today. I don’t judge.”

Some inmates who were not caregivers were reported to sometimes negatively impact caregiving. One participant summed it up best as, “many of the inmates are very ignorant and say bad things in front of people who are dying.” Finally, the characteristics of one dying inmate were viewed as a barrier: “he was just miserable and ugly and his death was probably a good thing because his life wasn’t good.”

**Personal (internal) features—“…we keep our noses clean because we love this program…”—**The importance of personal (internal) support was noted by one man who shared, “I pray a lot”, while another dealt with death “…by going to the gym.” Another positive personal contextual feature was maintaining good conduct in order to continue as caregivers. One man succinctly said, “[you] think about the patient before you let yourself get in trouble” and another shared “…you might get kicked out for a year if you got infractions so we keep our noses clean because we love this program and want to stay involved…” The only potentially negative personal level contextual feature shared was one inmate’s reference to self in the following statement, “…the only thing that would get in the way of me helping someone else is me.”

## Discussion

As prisoners serve in the important role of caregiver, it is critical to recognize that positive and negative contextual features occurring at the institutional, peer, and personal levels hold potential for influencing inmates as they contemplate *getting involved* in providing care for their peers, forge onward in *living the role* of caregiver, and make strides toward *transforming self through caring for others.* For example, supportive contextual features may serve to facilitate prisoners in initially *getting involved,* later *living the role,* and finally *transforming self through caring for others.* Conversely, institutional, inmate peer, or personal features may serve as barriers to such achievements. At the same time, staff observing inmates *living the role* of caregiver and recognizing positive changes occurring in prisoners involved in caring for peers has the potential to inspire staff to work on changing the institutional environment in ways that would improve end-of-life care. Staff supportive perspectives could lead to such things as improved treatment of chronically ill and dying inmates by institutional staff, increased positive statements to inmate caregivers that serve as positive feedback to reinforce the perceived value of their continued contributions in caring for dying peers, and ultimately an environment that supports continuous improvement of end-of-life care.

A recent report from Human Rights Watch (2012) pointed out the importance of treating older offenders with respect for their humanity, which is congruent with the goals of nursing care. The inmate caregivers simultaneously provided companionship and protection to their peers who were approaching EOL, congruent with a national survey of prison hospices (Hoffman & Dickinson, 2011).

Through assisting peers who are approaching end of life, some inmate caregivers believed they had found their own humanity and valued the opportunity to expiate for past offenses. Such opportunities are not often afforded in the prison setting (Feron et al., 2008; Streeter, 2011) and have been referred to as psychological rehabilitation (Yampolskaya & Winston, 2003). Caregiving opportunities can contribute to good behavior in inmate caregivers, as can their desire to remain in their caregiver role. Bonds were reportedly established with their dying charges. Earning some measure of respect within the harsh environment of prison was valued and a noteworthy gain as well. Benefits realized by the inmate caregivers were congruent with the findings from Wright and Bronstein's (2007b) study of hospice coordinators and with an anecdotal report from the Guiding Responsive Action in Corrections EOL demonstration project (Ratcliff & Craig, 2004).

Outcomes of caring for dying peers in this study were parallel to some highlighted in the Gold Coat dementia caregiving program (Belluck, 2012). Examples include reports by inmate caregivers of being "moved by the work", and reflections such as, "I'm a person who was broken", and "I was a predator…now, I'm a protector". The perceived need by inmate caregivers to assume a protector role for their charges in this study indicates that correctional nurses should be alert for predatory behaviors against aging and dying inmates as described by Kerbs and Jolley (2007).

In prison settings with inmate caregivers, the reported unmet needs for debriefings, grief counseling, and opportunities to memorialize the deceased revealed care issues that need to be addressed (Tillman, 2000). This study also highlights inmates' belief that adequate training and continuing education, both for inmate caregivers and corrections officers are important. Wright and Bronstein (2007b) emphasized the importance of training for security staff so that inmate caregivers may provide care in a manner which promotes dignity and hope, while allowing corrections officers to maintain security and control. Human Rights Watch (2012) points out the need to train officers about changing physical and medical conditions and appropriate means of communication—suggestions that were raised by inmate caregivers in the current study.

Finally, in contrast to the Yampolskaya and Winston (2003) study in which 70% of prisons included inmate caregivers on their interdisciplinary hospice teams, our study indicated that no interdisciplinary teams were yet in place. However, all four SCIs were in the process of developing a multidisciplinary team in response to a unit in our recently developed *Toolkit for Enhancing End-of-Life Care* from our broader parent study. As of mid-2012, none of the four SCIs were yet planning to include inmate caregivers in team meetings.

## Limitations

Research conducted in restricted settings is constrained by a number of factors that must be strategically addressed in order to enhance the credibility or truth value of the findings. For example, in this study, researchers were prohibited from using electronic recording devices with the inmate participants. This restriction poses a potential threat to the integrity of data which was carefully addressed in the protocol for data collection. First, the data collectors were experienced researchers in corrections settings. Hand-written field notes and techniques for recording key segments of the interviews were refined in earlier work by the researchers. Second, the use of two researchers during initial data collection sessions was strategic. This approach promoted accuracy of data collection as two sets of field notes could be triangulated to provide a rich, detailed account of the interviews and establish consistency in approach prior to conducting interviews individually. Finally, the researchers dictated complete field notes (integrating the hand-written notes into a fuller, more detailed account) immediately following their exit from the restricted area in order to minimize recall

bias. These procedures minimized threats to the validity of the data and are standard approaches to research in restrictive environments.

Member-checking (i.e., a process of sharing insights and the interpretation of the data with the original participants) was also constrained in this restrictive setting. In order to mitigate this threat to the credibility of findings, as noted earlier, two consistent principal investigators conducted the interviews. Emergent insights were verified serially during the process of data collection, as the researchers explored these areas with subsequent participants in a form of verification. In addition, the use of a team approach to analysis ensured that the findings were grounded in the data as each interpretation was carefully substantiated by data in field notes.

Transferability of the findings generated by this study is best judged by the goodness of fit with context. Since men constitute the vast majority (nearly 95%) of inmates in the state where the research was conducted, the initial focus of this work was on men's prisons exclusively. While the contextual similarities of men's and women's prisons are strong, there may be differences in prevalent value systems in women's prisons that make these findings less relevant to inmate caregivers in women's prisons. Further research in women's prisons is recommended to discern variations in values and beliefs held by female inmate caregivers.

This study provides a descriptive account of the care and compassion provided by inmates attending to dying peers by examining the values, beliefs, and perceptions of EOL care expressed by prison inmates caring for peers in advanced stages of chronic illness and approaching end of life. In future studies, an expanded investigation of the influence of demographic variables, such as length of incarceration, time left on sentence, and prior work history could provide a clearer picture of the men who elect to participate as caregivers for their chronically ill and dying peers in prison. Since training programs are not standardized, an investigation of the effect of varied training curricula and formats is recommended. Finally, further research on the organizational and economic impact of peer-caregiver programs is warranted.

## Implications

As the largest group of health care professionals in the prison setting, nurses are well positioned to advocate for improved care measures. By guiding the development of inmate caregiver services and support, ensuring that adequate materials for caregiving are available (e.g., cleaning materials, pillows and blankets), and calling for closer alliances between interdisciplinary colleagues (Perry, Bennet, & Lapworth, 2010) "…a socially responsive system of supports" (Maschi et al., 2012, p. 7) can be established that addresses many of the institutional level contextual barriers to caregiving for inmates at end of life. These services will likely be perceived by inmate caregivers as reflecting care and compassion. Measures to improve care at EOL for prisoners such as those outlined in the *Quality Guidelines for Hospice and Palliative Care in Correctional Settings* (National Hospice and Palliative Care Organization, 2009) can also help nurses who are obligated to base care on their professional code of ethics (American Nurses Association, 2001) to bridge any unconscious bias and view these patients as being as worthy of their care and consideration as any other patient (Hayes, 2006). Inmate caregivers in this study emphasized the importance of not judging patients and of "bias free care."

Hayes and Jones (2007) pose the important question, "does the nurse emerge as that person who can purposefully and intentionally create a new environment of care within prison that promotes health and fosters personal change and transformation beyond the prison walls?" (p. 66). We believe the answer is a resounding "yes." However, factors that may serve as

barriers to or support for nurses assuming a leadership role in new models of care, are not clearly understood and may vary from setting to setting. Achieving a new environment of care that promotes effective use of inmate volunteers or workers can be accomplished through the following: providing initial and ongoing inmate training sessions; holding debriefing meetings; including inmate caregivers in some team meetings or some portion of team meetings; and acknowledging the need for inmate caregivers to grieve deaths and remember those whom they cared for. Together, such actions could go a long way toward breaking the vicious cycle of mistrust between inmates and prison health care professionals (Feron et al., 2008), and contribute to what Wright and Bronstein (2007a) have described as *decent prisons*. If inmates witness "humanity and caring within the prison context, they likely will perceive the system as working for them" (Loeb & Steffensmeier, 2011, p. 194). Nurses in correctional health settings are in the pivotal position to change the face of dying in prison—the time is now!

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**Table 1**

Discussion Guide for Inmate Workers/Volunteers Who Care for their Fellow Inmates

| | |
|---|---|
| **1** | Could you tell me a bit about your role in caring for your fellow inmates, what you do here at SCI _____? |
| **2** | Is this a volunteer or a paid position? |
| **3** | Can you tell me about a time [a specific story] when you were involved in providing care for a dying inmate (Note: need not be at the moment they died)?<br><br>If they have never provided care for a fellow inmate who was nearing their end of life, inquire if they have ever witnessed a fellow inmate dying and if they could describe that experience (including the care received)?<br><br>[Note: here we are seeking experiences they have had (could be in their role as a volunteer/worker or personal experience with an inmate friend who was dying).] |
| **4** | Did you consider their death to be a good death? (if so, how so, if not why not?) |
| **5** | How did that experience affect you personally? |
| **6** | What kinds of things support you in providing good care to your fellow inmates with serious health conditions or those who are dying here at SCI _____? |
| **7** | What kinds of things get in the way of good end-of-life care here at SCI _____ [here we are looking for barriers]? |
| **8** | What are some things you think that you do really well in regard to end-of-life care here at SCI _____? [better than most] |
| **9** | Can you tell me about some area(s) in regard to end-of-life care here are SCI _____ where there is room for improvement? |
| **10** | Before we close is there anything else about end-of-life care here at SCI _____ that you would like to share? |

**Table 2**

Care Provided by Inmate Peers

- Assisting with bathing, shaving, applying deodorant, and filing nails
- Assisting with changing adult diapers and linens
- Cleaning up blood and body fluids, as well as general cleaning of cells
- Assisting with meals
- Programming radio or TV
- Transporting/escorting
- Filling out commissary requests, transporting purchases, putting them away, and protecting belongings
- Protecting from predatory abuse
- Listening to their peers (patients) and acting as intermediaries with officers and nursing/medical staff
- Talking with, spending time, and being willing to do good
- Preparing for family visits
- Protecting privacy and confidentiality
- Reporting changes to nursing/medical staff
- Reading and writing letters
- Praying with dying inmate and holding their hand
- Keeping dying inmate comfortable at the end and sitting vigil
- Providing post-mortem care