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Caring to learn, learning to care: Inmate Hospice Volunteers and the Delivery of Prison End-of-Life Care

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Abstract

The increasing numbers of aging and chronically ill prisoners incarcerated in Western nations is well documented, as is the growing need for prison-based palliative and end-of-life care. Less often discussed is specifically how end-of-life care can and should be provided, by whom, and with what resources. One strategy incorporates prisoner volunteers into end-of-life services within a peer care program. This article reports on one such program based on focused ethnographic study including in-depth interviews with inmate hospice volunteers, nursing staff, and corrections officers working in the hospice program. We describe how inmate volunteers learn hospice care through formal education and training, supervised practice, guidance from more experienced inmates, and support from correctional staff. We discuss how emergent values of mentorship and stewardship are seen by volunteers and staff as integral to prison hospice sustainability and discuss implications of this volunteer-centric model for response-ability for the end-of-life care of prisoners.

Keywords

prison; hospice; palliative; end of life; volunteers

Introduction

Much of the literature on prison-based palliative and end-of-life care is devoted to highlighting its necessity based on a convergence of factors, including the rapid aging of the Western European and North American prison population and the high prevalence of serious and chronic illnesses, multiple comorbidities, and physical and mental disabilities among prisoners (Binswanger, Krueger & Steiner, 2009; Carson & Sabol, 2012; Chiu, 2010; Cloyes & Burns, 2015; Howse 2011; Maschi, Viola & Sun, 2012; Stone, Papadopoulos, & Kelly, 2012). These trends, coupled with decades of determinate sentencing practices, have resulted in the exponential growth of the number of prisoners who are likely to die of age-related and chronic illness while incarcerated (Aday & Kraybill, 2013; Human Rights Watch, 2012; Rikard & Rosenberg, 2007; Fletcher, Payne, Waterman & Turner, 2013). Arguing from an interconnected set of moral, ethical, and clinical premises, these reports establish that the

poor health and aging outcomes of incarcerated people creates an increased risk for dying while incarcerated, which itself is associated with a risk of undue physical and psychological suffering and a risk of receiving inadequate care—or no care at all—at the end-of-life (Aday & Krabill, 2013; Burles, Peternelj-Taylor & Holtslander, 2015; Maschi, Marmo & Han, 2014).

There are a smaller but growing number of studies focused on interventions to support access to palliative and end-of-life care in prison settings including those that a) identify needs and developing strategies to better equip correctional health care and custodial staff to provide end-of-life services in prison settings (Loeb, Penrod, Hollenbeak & Smith, 2011); b) identify salient outcomes related to the implementation of palliative or end-of-life services (Yampolskaya & Winston, 2003); c) disseminate key principles or elements essential to the development of successful and sustainable prison hospice programs based on expert and stakeholder consensus (National Prison Hospice Association, 1998; National Hospice and Palliative Care Organization, 2009); and d) case studies and reports that describe the policies and practices followed within prisons that have developed models for delivering palliative and end-of-life care within their institutions (Cloyes et al, 2015b; Tilman, 2000).

Implicit in all discussions of growing need and desired outcomes for prison-based palliative and end-of-life care are questions regarding how this care should be delivered, by whom, utilizing what resources. Correctional health systems in many regions across North America and Europe must grapple with ways to deliver services within the significant constraints of high security and custodial requirements. As we continue to delineate the scope of the problem and describe challenges to delivering prison-based palliative and end-of-life care, which individuals or groups should be directly responsible for the daily administration of palliative and end-of-life care in prisons, what skills they should possess, how they should be trained, and how quality of care should be determined are an interrelated set of questions yet to be fully explored.

A number of prisons in the U.S. have implemented inmate volunteer programs, based on peer- support models, to provide hospice and end-of-life care to fellow prisoners with life-limiting illness (Cloyes et al. 2014; Hoffman & Dickinson, 2011; Loeb, Hollenbeak, Penrod, Smith, Kitt-Lewis & Course, 2013; Wright & Bronstein, 2007; Yampolskaya & Winston, 2003). In these programs, which may be more or less formal in structure, inmates volunteer their time and services to provide end-of-life support and direct care for gravely ill inmates. As reported elsewhere (Cloyes et al. 2015a, Cloyes et al. 2015b), the participation of inmate volunteers may enable these prisons to provide more comprehensive and personalized end-of-life care than would be otherwise possible using available health care staff alone.

We present a case study report as one example of a long-running formal peer-care model: the Louisiana State Penitentiary (LSP) Prison Hospice Program at Angola. This report, based on field study of this exemplar case, describes the formal and informal structures and processes by which inmates learn to provide end-of-life peer-care, including volunteer education and development, formal mentoring structures, and informal, ongoing peer support provided by experienced volunteers. The volunteer program, and its peer-centric structure, is noted by both inmates and staff as foundational to the daily function and sustainability of their prison

hospice program. We conclude with a discussion of implications of this model for the essential question of who cares for prisoners and end-of-life, and why.

Methods

All research activities were undertaken with the full approval of the University of Utah Institutional Review Board for the Protection of Human Subjects. This multi-method study employed a focused ethnographic approach and included chart review (Cloyes et al. 2015b) and fieldwork including formal and informal interviews and observations conducted during multiple multi-day site visits to LSP and the Robert E. Barrow Jr. Treatment Center, the medical unit where the prison hospice program is housed, from August 2011 through May 2013.

We describe LSP and the prison hospice program in greater detail in previous publications (Cloyes et al. 2015a, Cloyes et al. 2015b; Cloyes et al. 2014.) Briefly, LSP is the largest maximum security prison in the U.S. and incarcerates more than 5000 men, an estimated 85% of whom are serving lengthy or life sentences without parole and will not leave prison. In 1998 LSP opened its prison hospice, among the first in the U.S., and it has been in continuous operation since. LSP prison census and hospice records data show that from the official opening of the hospice program to September 2014, 227 patients had been admitted to the prison hospice unit. The input and participation of prison inmates was included in the program design from early stages of development (Tilman, 2000).

Data Collection

Observational and interview data were gathered during multiple on-site visits to the treatment unit housing the prison hospice program. Field observations included interactions among patients, inmate volunteers, hospice and medical staff, correctional officers and administrators working within the LSP prison hospice program. In-depth interviews were conducted with 43 participants including five correctional officers (COs), 14 medical and hospice staff, and 24 inmate hospice volunteers. Interviews ranged from 30 to 75 minutes, and some participants were interviewed more than once. Informal conversations with additional LSP prison hospice volunteers and staff also supported assessment and relation of emergent interpretations in context.

Data Analysis

Interviews were audio recorded, transcribed, and imported into NVivo 10 for coding, which proceeded inductively and iteratively. Members of the research team read transcripts multiple times, developing a list of codes concerning various aspects of volunteer development including volunteer training, education, mentorship, program structures and policies. Through a series of team meetings, these initial codes were compared, discussed, refined into hierarchical categories and a codebook defining each code was constructed. Each interview was coded line-by-line by two team members, and variations were discussed and resolved. Coded data were then aggregated, compared, and the coding process was reiterated with these more focused content categories. Throughout, refinement of the coding scheme and analysis and our interpretations were informed by team debriefings.

Findings: Learning to Care

This section summarizes training and education elements described by participants as essential to sustaining their volunteer program in terms of three central categories: developing knowledge through formal training and experience, formal and informal mentorship structures, and interactions with medical and correctional staff. Throughout, quotes from participants illustrate their perspectives on these elements and support key points.

Formal Training and Education

Prospective volunteers undergo extensive formal training that includes basic clinical competencies, didactic education related to pathophysiology, the dying process and hospice philosophy, shadowing experienced volunteers during a period of supervised hands-on training, and ongoing in-services and development.

The hospice volunteer training manual—During the 1990s, hospice experts from the community began working with LSP staff and inmates to develop a prison hospice program, with the support of LSP administration and the Louisiana-Mississippi Hospice and Palliative Care Organization (LMHPCO). These processes of program development have been described in previous publications (Evans, Herzog & Tillman, 2002; Tillman, 2000); they included identification of key volunteer training and education needs that were consistent with hospice philosophy while being responsive to the constraints of the correctional setting and the unique role of inmate volunteers in providing direct patient care. The original prison hospice coordinator, LSP nursing staff, and community experts collaborated to develop the LSP Hospice Volunteer Training Manual, a 200 page curriculum that provides the backbone of inmate volunteer training.

The material of the Volunteer Training Manual is delivered through a series of training courses over a series of sessions lasting 40 hours over two weeks. Core principles and concepts of hospice care are discussed in general, and in terms of how these principles can be adapted within the prison setting. Specific sections focus on an introduction to hospice and concepts of death and dying, interpersonal communication, the bereavement process, the psychological and spiritual dynamics of dying, communication with the dying, symptom management of disease and conditions, care and comfort measures, and legal choices in living and dying.

Clinical competency training—In addition to this curriculum, which volunteers refer to as “paper work” or “book work,” new volunteers also receive hands-on clinical training. They begin by practicing with each other, under the direction and guidance of a hospice program RN and more experienced volunteers, then progress to supervised care of hospice patients as they gain clinical skills. Hands-on training focuses on practicing basic nurse aide skills including infection control, hand washing, clean technique, avoidance of cross-contamination, proper body mechanics, safe patient transfers, use of adaptive equipment, assisting with patient hygiene and ADLs, prevention of skin breakdown, and maintaining the bedside environment.

Throughout, assessment of the physical and emotional state of their hospice patients is emphasized by nursing staff and more experienced volunteers, who caution newer ones to proceed slowly and gently, attend to patient cues regarding pain and self-sufficiency, and keep the disease process of each patient in mind as they assess patient needs and provide supportive care.

Practical Experience at the Bedside

Outside of the formal curriculum and more structured training, many opportunities for ongoing learning present themselves as volunteers engage in the daily activities of patient care at the bedside. A number of volunteers expressed the high value they placed on hands-on experience compared with “book learning” and structured clinical training, especially when it came to intimate patient contact and end-of-life care. One volunteer reported that the act of caring for a patient is a surprising experience, even with training, because books and practicing with each other cannot fully prepare volunteers for the realities of patient care and their own reactions: “When you have to change a man’s diapers and it goes against everything that you ever really stood for, what you realize is it’s this whole different side of you that says this is the humane thing to do, this is the right thing to do... It was real humbling.”

Other examples include the multiple interactions that volunteers have with medical and nursing staff during the provision of patient care. For example, one volunteer described being instructed by a doctor on how to provide wound care for a patient with an advanced pressure ulcer, something that was not covered in formal training sessions but which the volunteer learned at the bedside then passed on to other volunteers.

Sitting vigil—The process of vigil is a highly significant event for volunteers and a paradigmatic example of the role of practical “bedside” experience in learning how to provide end-of-life care. Sitting vigil with dying patients—which is the special purview of volunteers—is a central feature of the LSP prison hospice program. When a patient is thought to be nearing the final 72 hours of life, a 24 hour vigil is initiated during which volunteers take turns, in four -hour shifts, remaining at the patient’s bedside constantly until the patient dies. During vigil the volunteers, most of whom have worked with the same patient since their hospice admission and have come to establish a relationship, use their knowledge of the individual patient and his preferences to inform interactions with the patient and any attendant family members during vigil. Ways of being present with and providing comfort for dying hospice patients have included speaking to them, telling stories, singing, reading letters from family and spiritual texts, reassurance of being present, massage, hand-holding and maintaining patient comfort by administering comfort measures and communicating issues like pain and agitation to nursing staff.

Sitting vigil presents a significant occasion—seen by volunteers and staff as encompassing two rites of passage in learning to become a volunteer—during which new volunteers test their understanding of, and comfort with, the hospice process. The first rite of passage occurs when volunteers witness the death of their first hospice patient, always with a more experienced volunteer. At this time, these mentors often take the opportunity of reviewing

end-of-life care principles with newer volunteers. This is also often the first time new volunteers are involved in after care, including care of the body after death and preparation for transfer to the morgue. One experienced volunteer said he helps prepare new volunteers for sitting vigil by emphasizing the focus on the patient: “I say [to the new volunteer] ‘The more you work with a patient, the more you get attached to them. But it’s good; it’s good in a way because he [the patient] knew one thing. He knew he was loved, he was cared for, he was treated right... That’s something you want to show your patient when you’re with them, that... I’m here for you.’”

Going solo with support—A second rite of passage occurs when new volunteers go “solo”, sitting vigil with dying patients independently. No volunteer is asked to do this until he expresses readiness to the hospice coordinator and his peer mentors. One volunteer recounted the moment he felt prepared to take the lead and provide after care for a patient that had just died: “[The patient] passed and they [COs] were waiting for the most seasoned guys to come. Security asked me, ‘Do we need to call someone?’ I’m kind of like ‘You can if you choose to, but I feel like I’m ready to do this’ having experienced this with the first one, my patient.”

Caring for a hospice patient during vigil may also be the first time newer volunteers have interacted with family members of hospice patients. While many volunteers report drawing on their hospice training and network of mentors to navigate these interactions, which are made even more complex by institutional rules governing inmate-visitor contact, they also describe how each volunteer must develop his own way of interacting with families while maintaining professional boundaries.

Formal and Informal Peer Mentorship

Peer mentorship plays a large role in the education and development of inmate hospice volunteers. Those men who were among the first cohort of inmate volunteers at the inception of the LSP hospice program have been participating for over 15 years; they attest to caring for dozens of patients during this time and attending as many deaths. This is one aspect that distinguishes these inmate volunteers from their community-based counterparts: Because of their hybrid role and unique situation, they are likely among the most experienced—and directly involved—hospice volunteers.

The LSP prison hospice volunteer program embraces this experience by building mentorship into its structure through a formal mentorship model where new trainees are paired with more experienced volunteers by the RN hospice coordinator. In consultation with other hospice IDT members, and particularly the social worker, the hospice coordinator pairs mentors and mentees based on knowledge of each person’s history, level of experience, social connections, and perceived fit between the needs of each volunteer and strengths of the mentor. New volunteers “shadow” mentors as they transition into hands-on hospice patient care on the unit, taking on more independent responsibility as they build skills and confidence. Eventually mentees take on direct patient care themselves as they are matched with and assigned their own patients, often with the input of their mentor.

Volunteer participants described how mentorship was a deeply ingrained and positive aspect of prison culture among “real men” who want to care for others and elevate themselves, their prison family and the community.

This strong value of mentorship is present in the relationships among inmate volunteers, and it supports the informal mentoring that continues long after newer volunteers begin taking their own patients independently. Many volunteers, at all levels of experience, described how this helped mitigate the stress of providing end-of-life care and tempered their initial anxieties about encountering new situations and doing something that could cause patients pain or risk their safety. Knowledge that more experienced volunteers always “had their back” and were available to debrief and help process emotional responses was considered invaluable. Volunteers noted that they feel comfortable seeking guidance from more experienced mentors. As one volunteer explained, “When they tell us things we listen at them. They don’t ever try to guide us in the wrong direction.”

In addition to support from mentors, inmate volunteers know they can confide in their peers because they share a common goal: caring for the patient. This enables them to work effectively as a team, as one volunteer explained, “We’ll even juggle between us, ‘Okay, well [the patient] wants to be with you, he opens up to you more. So you do this and I’ll do this.’ So we always compromise and make adjustments as needed, where needed, for the best interests of the patients.”

Mentors themselves report that they continue learning through the process of teaching others, gaining new insights into improving patient care in this way. Their teaching role also helps them identify areas of knowledge deficit or need, and several described approaching the hospice coordinator, social worker and other staff requesting additional information in these areas. This has become a feedback loop that connects mentorship back into organized education and training efforts, demonstrating how informal processes have grown to influence more formal structured elements of the program.

One noteworthy area in which peer mentorship appears to be especially effective is in helping inmate volunteers deal with the grief, bereavement and burn-out that accompanies close involvement in end-of-life care for familiar patients over extended periods of time (Supiano, Cloyes and Berry, 2014). Despite the availability of grief counseling offered by the hospice social worker, every volunteer interviewed stated that they preferred to discuss their experiences with their mentors and fellow volunteers. Most acknowledged that processing the emotional impact of multiple losses was particularly challenging because of the prison culture, and so a volunteer who has had similar experiences is better positioned to counsel another volunteer. As one volunteer stated, “If I’m going through something that I need to talk, I can go to one of my hospice volunteers and we can sit down or walk the yards and talk about it. They don’t give me the wrong advice.” For their part, mentors reinforce the message that they are available for support: “We let them know you’re going to see this, if it happens come talk to us and we’ll sit down and talk. If you want to deal with it by yourself that’s your personal issue, you can do that. That’s the main thing, we let them know we’re there for them.”

Interactions with Medical and Corrections Staff

Correctional staff and health providers play a critical role in supporting inmate volunteers to become skilled and knowledgeable, and in facilitating the delivery of end-of-life care in this challenging environment. In the LSP prison hospice program a number of nurses, including the LSP hospice coordinator, the Director of Nursing, the RN who teaches clinical skills to the new volunteers and community-based hospice nurses who visit LSP to provide support and education, played pivotal roles in facilitating volunteer development.

In addition to this more formal involvement, nurses and nursing aides cited a number of practical ways that they supported inmate volunteers of all experience levels. Nurses reported that it was important to be responsive to and available for inmate volunteer questions and to give them clinically accurate responses, engaging with inmate volunteers as learners invested in improving their ability to provide the best patient care possible.

Nursing staff and volunteers described many instances where volunteers seek more detailed information from nurses about patient care; the nurses welcome and encourage patient care questions, just as they encourage less experienced volunteers to seek input from those with more experience. One nurse noted that health care staff should “[b]e a resource to them. When they ask questions, answer the questions; give them the best answer that you can; and do the research that you need to do in order to give them that. They’re going to suck [the information] up like a sponge. And then they’ll be able to use it in the future. They want this to work.”

Both nurses and volunteers described how this level of interaction ultimately “pays it forward” in time saved and better patient care, especially when nurses must rely on inmate volunteers because they are “the eyes and ears” at the bedside when nurses are attending to many other responsibilities. Following this, the nursing staff highlighted the importance of listening to volunteers as they share their insights about patient histories, preferences, and psychosocial concerns. One nurse reported, “They get a very, very close relationship or rapport with the [patients]... That’s why we really respect whenever they say something’s wrong with one of the patients, they see those declining health issues.” A different nurse noted that “sometimes they’ll even tell us things like he’s depressed, and they know the reason why.”

LSP nurses also stressed the importance of interacting with volunteers in a professional manner, maintaining appropriate boundaries while also recognizing the value of volunteers as the front-line members of the hospice care team. Several nurses described using their own teaching skills to support volunteers in taking on patient care responsibilities commensurate with their skill and experience level, such as monitoring and reporting change in patient status, symptoms such as pain level and medication response or side effects.

Informal conversations and formal interviews with corrections officers indicated that inmate volunteers are regarded as an important source of knowledge and insight for screening applicants seeking to become hospice volunteers. There is a formal multi-stage process by which inmates apply to be considered for hospice volunteer training, which includes interviews and vetting by COs, hospice staff and current volunteers. COs and nurses

described a preliminary “behind the scenes” process whereby seasoned volunteers recruit inmates who they see as having potential and discourage others they feel do not understand the hospice mission, are seeking secondary gains, or are otherwise “risky” to the volunteer program. The opinions of current inmate hospice volunteers are respected due to recognition of their investment in the volunteer program, ensuring that only those applicants who will uphold the mission and values of the program will become volunteers.

Discussion: Caring to Learn

Becoming an LSP inmate hospice volunteer is a well-developed process of recruitment, training, mentoring, accountability and stewardship that has evolved throughout years of implementation. The combination of formal and informal training, education, mentorship, and volunteer-staff interactions described here have evolved over time, through experience and adjustment on the part of inmate volunteers, medical staff, corrections officers and administrators responding to emergent program needs and the challenges of providing end-of-life care in a high security environment. Some elements, such as the formal hospice training manual that adapts conventional hospice volunteer education to the unique needs of a prison setting where inmate volunteers perform a more hybrid role of volunteer/nurse aide, have been part of their prison hospice model from the beginning. Others, such as the informal network of mentorship among inmate volunteers emerged as both volunteers and staff gained experience, but have nonetheless come to be seen as key structural elements in how the program continues to function.

The Unique Position of Inmate Volunteers

The inmate hospice volunteer role represents a unique hybrid between the roles of hospice volunteers, nurse assistants and family caregivers found outside the prison in community-based hospice programs. In community hospice programs, volunteers play a vital but circumscribed role focused primarily on providing companionship to patients and respite to family caregivers (Berry & Planalp, 2009, Claxton-Oldfield, Gibbon, & Schmidt-Chamberlain, 2011). In the prison peer-care volunteer model described here, in contrast, volunteers provide the majority of hospice patient care and psychosocial support on a one-to-one basis, including symptom assessment and non-pharmacological management, assistance with activities of daily living such as bathing, toileting, assistance with eating or feeding, skin care, and mobility, companionship, and spiritual support if this is what the patient requests. Inmate volunteers are not compensated and their hospice work is in addition to other assigned work and responsibilities. Their participation cannot be considered in any classificatory or administrative decisions made about them by corrections administration or parole boards.

More than simply receiving clinical training and hospice education, the process of becoming a volunteer not only builds the skills of inmate volunteers but creates a shared culture and specific outcomes that support the long-term sustainability of this prison hospice program, including teamwork, stewardship, and outreach beyond the hospice program. It involves a cycle of constant/ongoing development as inmate volunteers transition from learners to teachers and mentors who value continuing education and development in order to provide

better care for their patients. Volunteers described how an ongoing willingness to learn from their patients and each other was essential to being a “good” volunteer. For example, one volunteer explained: “Never go into a situation with a closed mind, always be open minded and be willing to listen, look, listen, learn, pay attention because sometimes no matter how much you read, you’ll never be ready for some of the things that you’ve experienced until you’ve actually experienced it.”

For the more experienced volunteers, the process of becoming a volunteer eventually progressed into the ongoing process of becoming the best volunteer they could possibly be. Learning was seen as continuous and ongoing, as “book learning” translated into experience, then into teaching and mentorship as volunteers taught others, participated in a conferences (Cloyes et al, 2014), mentored new volunteers, recruited potential volunteers, and acted as stewards of the volunteer program. This ethic of continuous learning is valued; good volunteers continue to educate themselves and each other as they gain more experience.

Many new volunteers described entering the program with a level of uncertainty about their capacity for direct care and end-of-life work, but working in a supportive environment of mutual trust helped to foster confidence in their ability to care for hospice patients. The work of becoming a volunteer involves learning to trust; being able to trust not only others, but also trusting oneself and being trustworthy. This sense of trust is foundational to the teamwork and sense of stewardship described by inmates and staff, and to how they represent the hospice program to inmates outside the unit.

Volunteers become invested in and take ownership of the program, and feel that it is entrusted to them. “We’re the first line of defense to make sure that this program continues because without us there would be no hospice... We make the program. And since we make it, let’s protect what we have.” Staff frequently echoed that sentiment in interviews, noting that it is essentially the volunteers’ program. As one nurse explained, “The guys that are in [the program] want it to continue to work, they don’t want those guys that are halfway into it. Because it’s going to put a blemish on the program that could potentially shut it down. Then they have nothing.”

Volunteers also actively work to promote a positive image of the hospice program both within and outside prison, seeing themselves as ambassadors of hospice. Many volunteers take it upon themselves to educate others—including prisoners in general population, their own family members on the outside, and families visiting patients—about the mission and values of hospice in general, and about the goals of the LSP hospice program, attempting to counter predominant narratives about hospice and prison culture in general. A volunteer explained, “A lot of family, they really don’t understand, and all they know is what they hear about prison, whether it comes from people in society that watch TV or wherever...Most of them come in with a misconception of hospice...And what we have to do, we have to change their way of thinking.” Additionally, many volunteers described being approached by inmates outside of hospice seeking assistance and knowledge about providing care and support for friends.

In summary, the volunteers, nurses and COs we interacted with throughout our field study emphasized how the inmate hospice volunteer role has transformed over the years from a necessary element in being able to sustain the delivery of end-of-life care within their setting into a source of personal and collective identity with specific personal, social and community meaning for inmates, correctional health nurses and security officers who work in and around the prison hospice program (Cloyes et al. 2015a).

Who Cares? The Question of Response-ability

As noted earlier the growing need to provide incarcerated people with adequate palliative and end-of-life care services raises serious questions about who should be responsible for providing this care, who is best positioned and equipped to do so, and where the necessary resources should come from. On one level this can be read as a question of attribution of state or institutional responsibility. On another more literal and pragmatic level, it becomes a question of who is best positioned to deliver this care, and how. Within some prison systems this may seem a foregone conclusion: Prison palliative and end-of-life care will be delivered by whomever among correctional health care staff is available to do so, in addition to attending to the other health care needs of prisoners with whose care they are charged. Other systems, as evidenced by examples such as the one examined here, have exercised more flexibility in thinking beyond immediately available economic and health care resources toward designing programs and models that integrate and deploy institutional resources in new ways, creating new roles and norms in the process.

Yet while these peer-care programs receive public attention for their compelling rehabilitative and redemptive potential, they are not uncontroversial (Craig & Ratcliff, 2002). Correctional administrators express concern regarding interactions among inmates that transgress institutional codes such as those that prohibit close personal contact between inmates; correctional officers charged with maintaining safety cite the potential for victimization inherent in placing vulnerable and sick inmates in the care and control; correctional nursing staff may be concerned about a “de-skilling” of nursing care and the attraction of replacing paid staff with cheaper—even unpaid—labor.

Certainly the use of peer-care volunteer programs to meet these needs also raises questions as to whether this use of human capital is feasible or ethical. The inmate volunteers, correctional health staff and corrections officers responsible for daily operation of the LSP Prison Hospice Program overwhelmingly endorse that it is both. As reported elsewhere (Cloyes et al. 2015a), staff participants told us that the utilization of inmate volunteers within the peer-care model has allowed this program to provide more comprehensive end-of-life care than is possible using available health care staff alone. In an earlier phase of the study reported here (Cloyes et al. 2015b) we reviewed the medical charts of all inmates admitted to the LSP prison hospice and found that prison hospice patients had lower end-of-life symptom prevalence and severity when compared with community-based samples. We hypothesize that this might be due in part to inmate volunteers providing constant personalized and focused care for their patients during the dying process. Moreover, inmates who have the opportunity to participate as volunteers describe undergoing a process of transformation in the course of providing end-of-life peer-care that they experience as

building personal strength and community empowerment (Cloyes et al. 2014; Loeb et al., 2013).

Our findings and the accounts of the LSP prison hospice volunteers and correctional staff should be located within a larger political, economic and cultural context. We are mindful of the historical context in which the LSP Prison Hospice operates, as are the participants we interviewed: the violent past of the institution itself, the plantation grounds and economy of slavery on which it stands, and the fact that three quarters of its prisoners are Black. We are also mindful that the current climate in the U.S. is one in which neither lawmakers nor the general public often favor allocating more resources to providing care for prisoners, even at end-of-life. Those living and working in corrections who acknowledge the burgeoning need for sustainable end-of-life care—from prison inmates to top administrators—are also aware of the fact that they may be need to, in the words of several LSP officials, health staff and inmates, “provide for their own” (Cloyes et al. 2015a; Evans, Herzog & Tillman, 2002).

Conclusion

While acknowledging the tension produced by a complicated custody-care dynamic, this report shifts focus from more global arguments about the need for prison palliative and end-of-life care to one specific example of how it can be done. The program presented here integrates peer-care delivered by inmate volunteers as an intentional structure within a model of prison hospice that—while formal—nonetheless allows room for evolution and a growing sense of ownership for those who are perhaps among the most response-able to provide meaningful care in this context. Future work should aim to advance empirically-supported knowledge of best practice, including who is best positioned to provide needed services, how to develop capacity and resources to equip prison hospice caregivers with needed skills, the sustainability of such resources, and specific outcomes at patient, community, and cultural levels.

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