

Palliative Care & the Injustice of Mass Incarceration: Critical Reflections on a Harm Reduction Response to End of Life Behind Bars

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Abstract

Due to the criminalization of marginalized people, many markers of social disadvantage are overrepresented among prisoners. With an aging population, end of life in prison thus becomes a social justice issue that nurses must contend with, by engaging with the dual suffering of dying and of incarceration. However, prison palliative care is constrained by the punitive mandate of the institution and has been critiqued for normalizing death behind bars and appealing to discourses of individual redemption. In this paper we argue that prison palliative care has much to learn from harm reduction. Critical reflections from harm reduction scholars and practitioners hold important insights for prison palliative care. Decoupled from its historical efforts to reshape the social terrain inhabited by people who use drugs, harm reduction can become institutionalized and depoliticized. Efforts to address the harms of substandard palliative care must therefore be interwoven with the necessarily political work of addressing the injustice of incarceration.

Keywords: palliative care, harm reduction, prisoner health, health equity, social justice

The philosophy and practice of palliative care is centred on accompanying patients and families through life-limiting illness, and death and bereavement. This approach is fundamentally rooted in dignity, compassion and a deep recognition of personhood. The values of palliative care and of nursing as a whole are closely connected, with nurses playing an important role in enacting a palliative approach to care across practice settings (Canadian

Nursing Association [CNA], Canadian Hospice Palliative Care Association [CHPCA] & Canadian Hospice Palliative Care Nurses Group [CHPCNG], 2015). Since death inevitably becomes a part of every life, access to palliative care for all is an essential dimension of health equity. The determinants that shape health and illness throughout the lifespan also shape the dying trajectory, such that marginalized people have specific palliative care needs (Reimer-

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Kirkham et al., 2016). A social justice approach to palliative care nursing is more than working towards nominal access for all members of society; it should empower nurses with the knowledge and the tools to provide whole person care that responds to each community's material and cultural needs. Within the emerging body of work on palliative care for prisoners specifically, additional scholarship is needed that explores the nursing role in this care and raises questions about the politics that underpin it.

Nurses work with people affected by incarceration in many settings: within prisons themselves, in specialist care settings where acutely ill prisoners may be transferred (e.g. intensive care units or emergency departments), or in almost any healthcare context where a nurse might encounter a prisoner's loved-one, a parolee or former prisoner. The notion that ill-treatment of prisoners is appropriate or deserved pervades society, from social stigma of prisoners, former prisoners and their loved ones, to 'tough on crime' sentencing policies, to mistreatment and deprivation of basic needs once in prison (Maeve & Vaughn, 2001). This ill-treatment extends to healthcare, with delayed diagnoses, withholding of treatment or analgesics, lack of accommodations such as wheelchairs or prosthetics, and substandard health care resources reported in the scholarly and lay literature (Lyckholm & Glancey, 2016). In these situations, nurses navigate a stark contradiction between nursing's mandate of care and the prison system's punitive mandate of confinement (Holmes & Jacob, 2012). Maeve and Vaughn (2001) use the term 'penal harm nursing' to describe the contradictory culture of nursing work that aligns with the punitive stance of the institution rather than the nursing value of caring. While the pressure to conform to this institutional culture is well documented (Maeve & Vaughn, 2001; Holmes & Jacob, 2012), even nurses who are able to maintain a stance of caring are constrained by the lack of resources that society accords to prison health care and the limitations placed on care provision by security measures. A recent example reported in the media underscores the degree to which basic health care is considered

secondary to security, if not altogether optional. Due to a shortage of nursing staff at the Surrey jail in British Columbia in 2018, prisoners went two days without receiving any of their medications (Mahichi, 2018).

Access to healthcare is but one of many losses experienced by those entering the prison system. In addition to the obvious loss of freedom, incarceration brings with it the loss of relationships with loved ones, of privacy, of autonomy over the most basic elements of daily life, and of the life one might have had in the outside community. Nurses working with dying prisoners are thus called to engage with the suffering of end of life and simultaneously with the harm associated with incarceration.

Bioethicist Ami Harbin (2015) offers a conceptualization of prison hospice work as a form of harm reduction, an area of practice rooted in social justice aspirations that is already bound up with nursing incarcerated people who live with HIV or hepatitis C. In this article we ask what questions about prison palliative care can be illuminated by the critical reflections already happening amongst practitioners of harm reduction, and by the lessons they have learned. After situating the emergence of prison palliative care politically and historically, we explore the insights a harm reduction lens might offer for a critical examination of nursing's stance in addressing the specific needs of those facing death and dying in prison.

The Place of the Prison in Society

We want to begin by highlighting the place that prison as an institution occupies in the creation and maintenance of social injustice. The predominant Western view of interpersonal harm as 'crime' (that is, as an offence against the state rather than the person harmed, punishable by deprivation of freedom) is historically fairly new (Foucault, 1977). Yet today, crime—an illegal action that may or may not involve interpersonal harm—and imprisonment are regarded by most as natural and unchangeable phenomena, inextricably linked as cause and effect. Although

most people cannot imagine society without the penal institution, it is at the same time rendered invisible: those who have no direct connection to it are largely able to avoid seeing, knowing of, or thinking about prison. In the words of prison scholar Angela Davis, prison is “an abstract site into which undesirables are deposited, relieving us of the responsibility of thinking about the real issues afflicting those communities from which prisoners are drawn in such disproportionate numbers” (Davis, 2003, p. 16). It is against this broader understanding of incarceration as a political phenomenon that aging and dying in prison is best understood.

In Canada specifically, this history is closely linked with colonialism (Monchalin, 2016) and with slavery (Maynard, 2017), continuing into the present day as structural racism. Unlike some other industrialized countries, Canada’s overall incarceration rate has remained relatively stable during the neoliberal period (Boe, 2004; Public Safety Canada, 2018), yet inequity has increased sharply. The Black incarceration rate, for example, increased by 75% in the decade between 2002 and 2012 (Office of the Correctional Investigator [OCI], 2013). Indigenous people make up 28% of Canadian federal prisoners, but only 4.3% of the overall population (OCI, 2018). The over-representation of these groups in prison reflects both the historical legacy of the penal institution in establishing White supremacy and colonialism and its current function in maintaining these systems of domination.

More recently, within a neoliberal political and economic context, mass incarceration has increasingly replaced the welfare state apparatus as a way of managing poor and marginalized people (Wacquant, 2012). Under the guise of fiscal austerity, neoliberalism has increased health and social inequity both between countries and within Western states (Navarro, 2007). As social services are cut or marketized and responses to the erosion of resources are criminalized, marginalized people find themselves behind bars in greater numbers (Wacquant, 2012). It is no surprise then that

markers of social disadvantage such as racialization, poverty, mental health issues, and illiteracy are overrepresented among prisoners (Davis, 2003; Maeve & Vaughn, 2001).

Aging Prisoners & Palliative Care

Throughout recent decades, ‘tough on crime’ policies have led to longer sentences in Canada and other western industrialized countries. This, combined with the overall aging of the population, has resulted in a prison population ‘aging in place’. Moreover, many chronic and life-limiting diseases occur at higher incidences & younger ages within prisons than in the population as a whole including HIV, hepatitis C, kidney disease, diabetes, and heart disease (Linder & Meyers, 2007). Neither the physical infrastructure nor daily routines of prisons are adapted to the reality of older or chronically ill people (OCI, 2018). With increasing numbers of people facing end of life behind bars, prison palliative care has begun to emerge as an area of practice, research and policy development.

The large majority of prison palliative care programs, policy and research, are from the United States (Maschi, Marmo & Han, 2014; Wion & Loeb, 2016) reflecting that country’s leading role in the drive towards mass incarceration. A shift in criminal justice policy starting in the 1980s with the ‘war on drugs’ saw the US prison population rise from 300 000 to 2.3 million in less than 4 decades (Sentencing Project, 2017). While other industrialized countries such as Canada have not followed suit in terms of expanding their incarceration rates, the accompanying shift towards ‘tough on crime’ policies have been more universal. Such policies (longer sentences, the creation of new offences, stricter paroles) have led to an increased proportion of older prisoners and the growing magnitude of prison palliative care as a social, political, legal and economic issue (Maschi et al., 2014; Richter & Hostettler, 2017; Peacock, Turner & Varey, 2018). The yearly number of deaths attributable to illness or aging in Canadian federal prisons now far exceeds all other causes of death combined (OCI, 2018).

It is important to underscore the grassroots, peer-initiated beginnings of the prison palliative care movement. In the US, the AIDS crisis of the 1980s and 1990s led to prisoners self-organizing to provide both peer education (Gilbert & Berger, 2017) and end of life care (Maull, 2005; Radcliffe & Craig, 2004) in the face of institutional inaction. In 1991, the American National Prison Hospice Association was founded, and by 2009 there were 75 prison hospice programs operating in 40 states (Hoffman & Dickinson, 2011). The same year, the U.S. National Hospice and Palliative Care Organization (2009) published *Quality Guidelines for Hospice and Palliative Care in Corrections Settings*, reflecting an uptake of the initial prisoner-initiated programs. Yet given the punitive stance of the prison system, these guidelines represent a significant discursive shift, making them difficult to implement in practice. Lest the numbers imply that high quality palliative care is widely available to U.S. prisoners, it should also be noted that this care is fraught with shortcomings: unavailability of opioids and other essential medications, lack of basic equipment & resources, delayed or withheld care, and care relationships constrained by security measures, to name but a few (Linder & Meyers, 2009; Loeb, Penrod, Hollenbeak & Smith, 2011; Lyckholm & Glancey, 2016). In some cases, prison hospice programs consist solely of a death vigil by fellow prisoners so that no one dies alone (Loeb et al., 2011). Although the international literature is scant, several themes appear to hold true: conflict between custody & care felt by healthcare staff; fellow prisoners providing much of the hands-on care through formally recognized programs or otherwise; security measures overshadowing and restricting care relationships; lack of resources; and apathy from the general public and prison/staff (Maschi et al, 2014; Turner & Peacock, 2017; Chassagne, Godard, Cretin, Pazart & Aubry, 2017). Palliative care is often difficult to enact even outside the prison context due to the dominance of curative medicine, the inability to accept the dying process, and the assumption that palliative care is equated with the end of life. In this regard prisoners are doubly

disadvantaged, having to endure the injustices of prison including its effects on health and healthcare access, in addition to the more universal barriers to palliative care.

Canadian Context

In Canada's federal prison system, which holds all prisoners serving sentences of two years or more, aging persons constitute over a quarter of the prisoner population and acute and chronic health problems now exceed all other causes of death combined (OCI, 2018). Correctional Service Canada (CSC) does have written palliative care guidelines, which state that CSC endorses the principles and standards of the Canadian Hospice Palliative Care Association (CSC, 2009, p. 2). Yet in outlining how these standards are to be implemented, the term 'whenever possible' appears frequently; for example when discussing family involvement, or patient involvement in decision-making. This recurring caveat points to the reality that custody and security, rather than palliative care philosophy, are the institutional priority. Moreover, no scholarly research has been published that specifically addresses dying or palliative care among Canadian prisoners, either at the federal or provincial level, making it difficult to know how these guidelines are actually implemented in practice. Further, CSC itself, rather than Health Canada or the provincial and territorial health ministries, provides health care in Canada's federal prisons. Flagel and Bouchard (2013) have questioned whether organizing healthcare in this way interferes with prison healthcare staff's autonomy of practice, and their exposure to the values and practice standards of the wider health care system.

A recent joint report by the Office of the Correctional Investigator and the Canadian Human Rights Commission (CHRC) found that older prisoners have a high burden of chronic health issues and that CSC lacks a comprehensive strategy for responding to the needs of the aging population, thereby falling short of meeting their health care needs in several areas including palliative care (OCI & CHRC, 2019). Legal

scholar Adeline Iftene (2017) identifies older prisoners as a vulnerable group, particularly noting issues with the management of chronic pain, and recommends reforms to CSC's healthcare policies to make them age-sensitive. One noteworthy example from Iftene's (2017) research: in order to obtain their medications on a daily basis, prisoners must wait in line at the prison infirmary; that is, they cannot collect multiple doses to store in their cell, or have it brought to them by staff, nor can they send someone to collect their medication on their behalf. Institutional rules prevent nurses from circulating freely and accessing their patients as they would in most settings, and prisoners are forbidden from possessing any item that could be deemed dangerous, including medication. Thus, anyone whose health condition prevents them from standing in line, for up to an hour, in some cases outdoors in all weather, simply does not have access to their prescribed medication.

In addition to responding to physical health needs, palliative care by definition ought to also attend to the emotional, psychological and spiritual needs of those facing death, and their loved-ones (World Health Organization [WHO], n.d.). Further, given the severe overrepresentation of racialized and Indigenous peoples in prison, 'whole person' care must also be culturally competent. All of these therapeutic aspirations, however, are severely constrained by the custodial relationship between prisoners and staff, and by the very nature of the institution (Chassagne et al., 2017; Maeve & Vaughn, 2001; Holmes & Jacob, 2012).

A Critical Nursing Perspective

Since nurses provide the bulk of direct patient care, in prison and elsewhere, the issue of comprehensive palliative care for prisoners is eminently relevant to a social justice nursing perspective. Nurses have a responsibility to provide and to advocate for palliative care across practice settings (CNA, CHPCA & CHPCNG, 2015). Thus nurses' advocacy for health equity ought to include working towards access to high quality comprehensive palliative care for

marginalized communities (Reimer-Kirkham et al., 2016), no matter where this care is taking place.

Grounded in principles of dignity, autonomy, and compassion, a foundational message of the palliative care movement is that "you matter because you are you, and you matter until the last moment of your life" (Saunders, 2006, p. 273). This message is eminently applicable to the struggle for social justice: if each person truly matters then all people deserve dignity, equity, and justice. And yet, despite its challenge to the hegemony of curative biomedicine, palliative care has in other important ways remained immersed in the dominant assumptions of the healthcare sphere. Shaped and constrained by the larger discursive and material terrain within and beyond healthcare, mainstream palliative care scholarship and practice is limited in universally applying that foundational message. In recent years, critical scholars have intervened from within broader palliative care discourses, pointing out that end of life care services are not on the whole accessible to marginalized people, nor do they correspond to their material or cultural needs (Reimer-Kirkham et al, 2016; Lolich & Lynch, 2017). Moreover, in the context of neoliberal austerity, the notion of choice that is so central to palliative care (e.g. in advance care planning, or with regard to place of death) is commodified and rendered unattainable to those who lack the consumer power to enact it (Borgstrom & Walter, 2015). A critical palliative care discourse is emerging, where, to borrow Reimer-Kirkham and colleagues' (2016) expression, "death is a social justice issue" (p. 293).

Such equitable palliative care clearly includes prisoners, who lack all semblance of choice in healthcare (and otherwise) and also disproportionately represent the communities with the least access to the determinants of health. Yet a concept analysis of a good death in correctional settings questions whether such a thing is even achievable (Burles, Peternelj-Taylor & Holtslander, 2015), given the tensions and contradictions described herein. What, then, is

the social justice nursing stance in the face of this political phenomenon? What would a critical response to this situation look like?

Problematizing Prison Palliative Care

While prisoners clearly need access to palliative care, scholars have critiqued prison hospice programs for normalizing end of life behind bars, instrumentalizing the unpaid labour of peer volunteers, and appealing to discourses of individual redemption (Chavez, 2016). Focus on the *how* of prison palliative care by scholars and policy makers has forestalled people asking *why* so many people, particularly those already marginalized in other ways, are facing end of life in prison (Hudson & Wright, 2019). Moreover, popular and academic representations of both patients and caregivers finding peace and forgiveness through palliative care reinforces the notion that prisoners bear individual responsibility for their circumstances (Harbin 2015; Chavez, 2016). The Foucauldian concept of governmentality is useful in understanding these representations. Governmentality holds that people's conduct can be shaped through three forms of power: sovereign (direct force or coercion), disciplinary (punishment or reward), and pastoral (obtaining compliance through the establishment of care, framed as a concern for the recipient's wellbeing) (Holmes, 2002). Within a carceral setting, the more visible use of repression and disciplinary power are complemented by a more subtle pastoral power, that is, through interventions that mold the prisoner into a better (rehabilitated or corrected) person. Pastoral power in particular is enacted by nurses within prisons (Holmes, 2002). Specifically within an end of life context, nursing and other healthcare roles are invested with pastoral power, allowing them to establish a relationship of trust with the patient to achieve (among other things) forgiveness or redemption. Rather than recognizing the forces that criminalize social disadvantage, prisoners are constructed as inherently criminal (i.e. bad) people finding redemption through either receiving or providing palliative care – gesturing towards its 'correctional' potential (see for example Wright

& Bronstein, 2007). By accepting the inevitability of large numbers of people aging and dying behind bars and incorporating hospice programs into the overall functioning of the prison system, in-prison palliative care can serve to uphold the inequity of mass incarceration.

Many have argued that the only just course of action is to release dying prisoners to receive palliative care in the community, a measure known as compassionate release (Mitchell & Williams, 2017; Linder & Meyers, 2009). However, there are also barriers to this approach: slow, limited or lacking legal mechanisms; lack of political will and public support; lack of (accessible) community beds; and sometimes an absence of community connections outside prison (Linder & Meyers, 2009; Peacock, et al., 2018). Though some see these barriers as a rationale to focus instead on in-prison palliative care provision, the aspect of suffering that stems directly from the fact of dying in prison cannot be overstated (Aday, 2005-2006). In that regard, compassionate release is in itself a form of palliative care.

Beyond compassionate release, which is restricted to people with a documentable limited prognosis, broader policy or legislative changes should allow for the release of older or chronically ill prisoners. Interestingly, the Office of the Correctional Investigator and the Canadian Human Rights Commission call for this approach in their recent joint report (OCI & CHRC, 2019).

End of Life in Prison as Harm

Davis (2012) characterizes incarceration as *civil death*, in that it removes those in prison from their communities and from participation in broader society. She writes from an American perspective, where many jurisdictions curtail basic forms of civic participation such as voting, in some cases for former as well as current prisoners. In Canada too, a criminal record restricts many forms of social participation, limiting employment options, travel and adoption, but more importantly the simple loss of relationships, and of time in the community deprives current and former prisoners

of full participation in society. Davis (2012) underscores that civil death is therefore often permanent even for those eventually released from prison. Combined with the conditions of imprisonment itself, this removal from social life sends a profound and ongoing message that prisoners' lives are insignificant, less than fully human. This dehumanization causes suffering for all those whose lives are touched by imprisonment (both those incarcerated and their loved-ones). For older prisoners and for those serving long sentences, even in the absence of illness, the prospect of end of life in prison thus entails the dual suffering of incarceration and of dying and grieving, intersecting to produce a kind of existential distress unique to death behind bars (Aday, 2005-2006).

It is here that the conceptualization of harm reduction becomes a useful tool for examining prisoner end of life. Harbin (2015) brings Davis' (2012) notion of civil death into dialogue with Judith Butler's (2004) concept of *grievable lives*, to frame prison hospice programs as a form of harm reduction. Butler underscores the relational aspect of death and grief, writing that: "loss and vulnerability seem to follow from our being socially constituted bodies, attached to others, at risk of losing those attachments" (Butler, 2004, p. 20). Through civil death with its thorough-going message of insignificance, the prison system casts prisoners' lives as not being grievable. Ultimately, that is the harm – the suffering – with which nursing is called to engage, if we are to respond to the call to bring to bear a palliative approach to care within prison.

While recognizing the ways in which prison palliative care upholds both the logic and the structures of the carceral system, Harbin (2015) articulates the importance of prison hospice peer caregiving programs in addressing this harm. It re-inscribes significance onto the lives of not only those dying, but of the peer caregivers, most of whom live with the knowledge that they too will likely face death behind bars, and by extension to the community of prisoners as a whole. This observation about prison hospice programs can be extended to other instances of prison palliative

care, from care provided informally by other prisoners in the absence of hospice programs, to health professional-delivered palliative care, or release into the community at end of life.

Harm Reduction Philosophy: from Substance Use to Prison Palliative Care

Usually associated with a particular set of health care approaches to criminalized substance use, harm reduction is well suited to, and well known in, prison health. According to the CNA (2017), harm reduction's underlying philosophy is based on dignity, compassion, acceptance and empowerment; it seeks to reduce risks and harms and works to complement other strategies such as prevention and abstinence-oriented treatment in the context of drug use. There have been calls to integrate this work with actions that address the social circumstances causing harm in the lives of people who use drugs and more broadly in the communities where (criminalized) drug use is most prevalent, such as lack of housing, employment, educational opportunities and other determinants of health (Pauly, 2008; Souleymanov & Allman, 2016). While the term harm reduction is often understood to denote this area of practice rather than the underlying philosophy, the fundamental principles of harm reduction bear a remarkable similarity to those of palliative care: dignity and compassion are also cornerstones of its philosophy, aimed at relieving the whole person suffering and improving the quality of life of people living with life-limiting illnesses and their families (WHO, n.d.). In both areas of practice, empowerment serves as a way of restoring dignity through asserting (self)worth. Broadly speaking, the notion of reducing harms parallels palliation, in the strict sense of symptom control as well as in the larger conceptual stance of palliative care with its orientation towards comfort and quality of life rather than prolonging life or curing disease at all costs. In palliative care, there has been a movement towards implementing a palliative approach throughout the course of illness rather than only at end of life, integrated with curative treatment (see for example CNA, CHPCA & CHPCNG, 2015), much like harm reduction is integrated with

prevention and treatment. Similar to the calls for a broader definition of the problems to be addressed by harm reduction, critical palliative care scholars have pointed out that a good death for marginalized people encompasses addressing the structural inequities that shape their circumstances throughout the life course prior to, as well as during, end of life (Reimer-Kirkham et al., 2016; Lolich & Lynch, 2017). Given these parallels, as well as the overlap between the harm reduction and prison health contexts, we now turn to an examination of some of the critical reflections of harm reduction scholars and practitioners for insights that might inform a social justice orientation to prison palliative care.

Pastoral Power & the Imperative of Health: the Pitfalls of a Lens of Redemption

Not unlike prison palliative care, harm reduction began as a grassroots oppositional (and in the case of harm reduction, often illegal), user initiated/led movement (Souleymanov & Allman, 2016; Smith 2012; Kerr et al., 2006). In this sense, both movements were expressions of communities deemed expendable, self-organizing to reclaim both their dignity and their right to survival. However, operating on a sociopolitical landscape where people who used drugs were, and continue to be, marginalized, stigmatized and criminalized, a discursive shift occurred in the construction of illicit drug use with the advent of HIV as a public health concern. The harm that was already affecting people who used drugs, including those in prison, became a threat to non-drug users now placed at risk by the proliferation of HIV. It is noteworthy that the broader policy uptake of harm reduction in Canada and other Western countries coincided with a perception of threat to a broader non-stigmatized public, belying the notion that it is based on societal concern for the wellbeing of stigmatized and criminalized drug users themselves (Souleymanov & Allman, 2016). While this uptake has led to broader access to harm reduction interventions (such as needle exchange programs and safe consumption sites) it has been at the cost of their depoliticization and institutionalization (Smith, 2012). No longer in

the hands of drug users themselves (with some exceptions), harm reduction takes on the qualities of a public health strategy. Pereira and Scott (2017) refer to the work of Foucault to point out that harm reduction is a technique of self-governance where people who use drugs are called upon to self-monitor, and produce themselves as responsible (i.e. non-harming) subjects within an imperative-of-health framework. Deborah Lupton's (1995) concept of the imperative of health — the assumption that all people want and strive for an externally defined state of health above all other goals — permeates many if not most theoretical models underpinning public health (O'Byrne, 2012). That is, individuals receiving the public health intervention are assumed to want the intervention (irrespective of their other needs or priorities), and to be responsible for achieving health, for their own well-being and for that of society. Health professionals, including nurses, take on a monitoring role in this regime of governmentality (Souleymanov & Allman, 2016), that is both disciplinary and pastoral (Holmes, 2002). We raise these critiques not to diminish the very concrete positive impact of harm reduction interventions and their greater availability, but rather to point out the pitfalls of institutionalizing a self-organized movement of marginalized people in the context of their ongoing stigmatization. To the extent that harm reduction functions within a broader public health regime in a neoliberal society where people who use drugs occupy a marginal social position, it may work to maintain and perpetuate their marginalization. Within the context of their stigmatization, the relevant harm is understood as that ostensibly caused *by* the marginalized group, rather than *to* them, towards the wider (non-stigmatized) population. This moral disposition places an additional burden of responsibility on people who use drugs to alleviate this perceived harm towards society, as a way of redeeming or redressing their stigmatized status.

The individual-redemption view of prisoners 'finding peace' at end of life and/or prison hospice volunteers being 'changed by the work' risks serving a similar function, and in so doing

upholding the notion of prisoners as inherently criminal, rather than criminalized, and in need of ‘correction.’ This concern is a significant one, since, as Harbin (2015) points out, palliative care resists a central function of the institution. Though it is not clear from the prison palliative care literature whether institutional recognition has reduced the overall responsiveness of prison hospice programs, once the prison takes ownership of a palliative care program, it does so from within its overall mandate of custody, necessarily affecting the ethical underpinnings of whole person palliative care. Of course, it is very difficult to do anything within a total institution without official knowledge and approval: broadly available prison palliative care is likely unachievable without some form of institutionalization. Be that as it may, informal caregiving relationships between prisoners persist, as do palliative care efforts originating outside the prison. For example, in Canada public health nurses visit some provincial prisons, while in the U.K. in-reach by external hospice organizations is the main model of prison palliative care provision (Peacock, et al., 2018).

***Nurse as Expert versus Nurse as Ally:
(Re)politicizing the Harm Reduction
Philosophy***

Although many health care workers (nurses and others) understand the social forces constraining the lives of people who use drugs, frontline harm reduction as usually practiced does not necessarily address larger social harms such as criminalization, poverty, underhousing or stigma, focusing instead on the more proximal harms such as overdose and HIV (Pauly, 2008). Historically, drug user self-organizing has taken on a much broader, more social and structural view of harm, as illustrated by the work of the Vancouver Area Network of Drug Users (VANDU) which has included, for example housing advocacy, street protests, and hospital accompaniment as well as strictly defined harm reduction work (Kerr et al., 2006). Decoupled from these efforts to reshape the social terrain inhabited by people who use drugs, harm reduction becomes subsumed by the healthcare

system with nurses and other professionals positioned as clinical experts and drug users as unknowledgeable clients (Smith, 2012). This runs counter to a central principle of harm reduction work, namely *nothing about us without us*, which casts health professionals as allies rather than service providers, with people who use drugs in a decision-making and leadership role (Canadian HIV/AIDS Legal Network, 2005). Harm reduction nurses are not unaware of this dynamic and its constraints on their work. For example, the Harm Reduction Nurses Association (HRNA) points out in its position statement on safer injection that since nurses are not legally permitted to assist with injection within supervised injection sites, peer-led assisted injection initiatives are better positioned to reduce the significant harm faced by people who are unable to inject their drugs independently. They point to the work of VANDU in developing exactly such a program (HRNA, 2018). At best, officially sanctioned harm reduction programs operate in concert with grassroots efforts by drug-using communities themselves who may have more latitude to work outside the system. Again, this approach may not translate seamlessly into the highly regulated environment of the prison, but the principle of allyship and the importance of thinking strategically about potential limitations on the nursing role remain.

Harm reduction is at its most powerful when it is visible and political, at once a form of protest and of direct action to improve the lives people who use drugs (Smith, 2012). The repoliticization of harm reduction presents a potential way forward, one that may be already happening in the new wave of grassroots, deinstitutionalized harm reduction work taking place, as noted most recently in Canada with the creation of pop-up safe injection sites in response to the current overdose crisis. Like the opioid crisis, the current state of end of life in prison is a palliative care crisis, insofar as deaths in custody are not on the whole attended to by the healthcare system or by society at large (Wright, 2016). In these types of spaces, the nurse is an ally rather than service provider – even when providing a service –

bringing in resources and protection rather than taking over spaces of self-organizing. Grounded in this ally-relationship, nurses can then amplify the calls for change from those directly affected, acting as advocates in public policy forums, as well as through research and education.

Closing Remarks

Harbin (2015) argues for a shift from a palliative ethics to a palliative politics both within and outside of prison to attend “to ways that health care and other systems might better relieve suffering at the level of oppression, marginalization, and civil death” (p. 168). A nursing voice has much to contribute to these discussions. *A nothing about us without us* approach does not preclude nurses taking a stance in the absence of a large and visible movement of prisoners for palliative care. Based on the nature of the carceral institution, prisoner self-organizing for dignity at end of life may not become as visible as drug user-communities’ historical and current movements. We can listen deeply to prisoners and their families wherever we encounter them and foster self-organization efforts wherever we see glimpses of their beginnings.

The main lesson that prison palliative care can draw from a harm reduction approach is that effective work to address the concrete proximal harms – i.e. the substandard palliative care, and the dehumanizing impact of imprisonment – through providing and advocating for in-prison palliative care is inextricably linked with addressing the broader social harms of prison. Since these harms are not restricted to end of life, compassionate release is but one tool for undoing them. Broader strategies for reversing the trend of mass incarceration – known as decarceration – go hand-in-hand with palliative care in providing dignity and compassion to those facing end of life in prison. By learning from the successes and pitfalls of harm reduction work, palliative care nurses, and nursing organizations more generally, can position themselves to respond to the full range of suffering associated with end of life in prison. By understanding the work of prison

palliative care as political, and continuing to do so even if and when access is nominally improved, we can resist the normalization of end of life behind bars, and more broadly the normalization of imprisonment as a response to the issues afflicting marginalized communities (Davis, 2003).

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