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Abstract

Medical Assistance in Dying (MAiD) has been legal in Canada since 2016, and the implementation of MAiD for people who are incarcerated has raised ethical and procedural concerns. In this paper, we review the current Correctional Services Canada (CSC) guidelines on MAiD alongside a joint report by the Office of the Correctional Investigator (OCI) and the Canadian Human Rights Commission (CHRC) on aging and dying in prison. We echo concerns raised by the OCI and the CHRC about the limits of adequate end of life care (EOLC) currently provided to those in custody, and offer our analysis of the procedural guidelines for MAiD in prison, which we argue to be inadequate in support for patient-centered care and equality in access to health care.

Keywords: euthanasia, medical assistance in dying, prison, health care, end of life care

Since the 2016 legalization of medical assistance in dying (MAiD) in Canada, concern has been raised about the possibility of vulnerable people experiencing pressure to end their lives. Outside of a few studies (Shaw et al. 2019; Wright & Shaw, 2019) and a federally commissioned report on the possibility of MAiD for mature minors and for people with disabilities (Canadian Council of Academies, 2018), little MAiD research has been done that focuses on the expressed needs of marginalized and vulnerable people in Canada. People who are incarcerated in Canadian prisons experience unique challenges accessing MAiD, as well as other forms of end of life care (EOLC), and we are currently engaged in research with Correctional Services Canada (CSC) to explore these issues. In this paper, we explore procedural guidelines and reports that frame MAiD in Canadian correctional facilities, and offer our perspective on whether they adequately support the health care rights of people who are simultaneously incarcerated and actively dying.

Aging and End of Life Care in Prison

Across the globe, the number of people who are aging in prison and require quality EOLC has increased significantly, highlighting the reality that many people who are incarcerated will experience their last days in prison (Burles, Peternelj-Taylor & Holstlander, 2016; Stensland & Sanders, 2016; Wion & Loeb, 2016; Linder & Meyers, 2009;). In Canada, the number of individuals given life sentences per year has remained consistent for the past decade, yet the steady admission of such individuals creates a stacking effect as they age.

CSC is the institution responsible for facilities where individuals serve sentences of two years or greater (CCRA, 1992). Each year, 4% of individuals admitted to federal prisons are serving life sentences, yet they now make up 26.4% of the federal prison population, double the amount since 2000 (Office of the Correctional Investigator & Canadian Human Rights Commission, 2019). Incarcerated individuals over the age of 50 are disproportionately serving life

sentences in comparison to the rest of the prison population. Half (50.3%) of those aged 50 or over are serving an indeterminate sentence, including 4 in 10 women, and almost 6 in 10 Indigenous offenders (OCI & CHRC, 2019).

Incarcerated people's health status is "poor compared with the general Canadian population, as indicated by data on social determinants of health, mortality in custody, mental health, substance use, communicable disease, and sexual and reproductive health", and are typically diagnosed with chronic and terminal health care issues 10 years earlier than those who are not incarcerated (Kouyoumjian, Schuler, Matheson and Hwang, 2016, p. 215). The number of aging individuals in federal custody contributes to a growing proportion of people who require EOLC at an earlier age than people who are not imprisoned, and who need many of the same resources as those who are terminally ill outside of prison (Linder & Meyers, 2009; Sanders & Stensland, 2018).

Global human rights norms, as detailed by the World Health Organization (2007) and United Nations, should inform standards of health care in custody. One of these rights is that "decisions about a prisoner's health should be taken only on medical grounds by medically qualified people" (United Nations, 2005, p.6). Moreover, and of particular relevance to the question of access to EOLC in prison, "prisoners should enjoy the same standards of health care that are available in the community, and should have access to necessary health-care services free of charge without discrimination on the grounds of their legal status." (United Nations, 2015, p. 12).

MAiD in Canada

On June 17, 2016, Canadians received the right to have an assisted death if they are over 18 years old, are eligible for provincial or territorial health care coverage in their place of residence,

have the capacity to give free and willing consent, and are suffering from a "grievous and irremediable condition" (Department of Justice, 2016). At the time, the Government of Canada (2016) committed to further supporting the EOLC needs of Canadians through the establishment of a process for monitoring and reporting on MAiD to ensure that it is both adequately accessible and appropriately restricted.

In February 2020, after extensive consultation with the public and with various stakeholders, practitioners, and experts, the Minister of Justice and Attorney General of Canada introduced a bill that proposed additional changes to the *Criminal Code's* provisions on MAiD. After the prorogation of Parliament due to COVID-19, the proposed changes were reintroduced on October 5, 2020 as an important measure that would "reduce suffering, while also supporting individual autonomy and freedom of choice" by easing safeguards for persons whose death is reasonably foreseeable, strengthening safeguards for people whose death is not reasonably foreseeable, and allowing for people to waive the final consent requirement if they are at risk of losing capacity (Department of Justice, 2020, para. 8). The reintroduction of the proposed changes within two weeks of a new session of Parliament indicated the Government of Canada's commitment to addressing the changing needs of Canadians in relation to MAiD.

Correctional Services Canada's Guidelines on MAiD

In 2017, CSC released *Guideline 800-9: Medical Assistance in Dying* to provide operational direction for MAiD with federally incarcerated people. These guidelines outline the actors and steps involved in responding to requests for MAiD by individuals in custody, the assessment process, and the MAiD procedure. Upon receiving a request for MAiD, the Chief of Health Services, or an alternate institutional physician or nurse practitioner, has five days to meet with the patient (CSC, 2017). In this meeting, the health professional will determine the reasons the

patient is requesting MAiD and provide the patient with the CSC guidelines and a printout of MAiD eligibility criteria. At this time, the patient is referred to mental health, spiritual care or other related supports. The health professional then has up to seven days to arrange for the first MAiD eligibility assessment to take place. The patient must make a written request, if physically able, using the relevant provincial or territorial MAiD request form in the presence of independent witnesses (CSC, 2017).

After the meeting with the Chief of Health Services, the first eligibility assessment is performed by an internal institutional physician or nurse practitioner, or, if necessary, an external assessor. “If the inmate does not meet the eligibility criteria, the internal assessor will notify the inmate in person that they do not qualify for MAID and offer referral to support services” (CSC, 2017). If a patient’s request is supported by the first assessment, a referral is made for a second assessment by a physician external to CSC as soon as practicable. However, “if the result of the first assessment is that the inmate is determined not eligible for MAID, there will not be a referral for a second eligibility assessment” (CSC, 2017). The institution’s parole officer must support release to a community hospital for MAiD provision, in accordance with CSC’s pre-release decision-making directive.

The CSC guidelines on MAiD provision assume that a patient in custody who qualifies for MAiD must access a community health facility for the procedure, although they leave room for the possibility of a MAiD death occurring in custody in exceptional circumstances, at the request of the inmate. In this instance, the MAiD death must occur in a CSC treatment centre or regional hospital. Such exceptions must be approved by the Assistant Commissioner, Health Services, who is the highest executive overseeing health within CSC, and the procedure must include a health professional external to CSC.

An Access to Information and Privacy request revealed that as of August 2020, a total of 11 individuals in CSC custody had made requests for MAiD, of which three were granted. While details about the denied requests were withheld, the three MAiD provisions that were approved were said to have taken place at the preferred locations of the individual who sought MAiD (either in a prison hospital or in a community hospital). At the time of this writing, we have conducted interviews with MAiD assessors and providers of the three people who were incarcerated at the time of their MAiD request, and a qualitative publication on the perceptions and experiences of several incarcerated people in relation to end-of-life care is forthcoming.

Joint Report from the Office of the Correctional Investigator and the Human Rights Commission of Canada

The Office of the Correctional Investigator (OCI) and the Canadian Human Rights Commission (CHRC) have created an extensive and vital report on the state of aging and dying in prison (2019). The authors conducted investigative interviews with 250 individuals, including older (aged 50 years and over) incarcerated individuals, incarcerated peer caregivers, and corrections staff among others. The authors also claim to have reviewed and assessed relevant "CSC research, policy, services and interventions" (p. 9). However, noticeably absent from the policies reviewed are CSC's *Guidelines 800-9* on MAiD (2017). The context for the report is that "prisons were never intended to be nursing homes, hospices, or long-term care facilities. Yet increasingly in Canada, they are being required to fulfill those functions" (OCI & CHRC, p. 3). The report makes eight major findings, two of which pertain directly to dying in prison, namely that "prison is no place for a person who requires end of life care" and that federal corrections "lack adequate, compassionate and responsive release option" for older and dying individuals in custody (OCI & CHRC, p. 71-72).

The authors express concern that the Parole Board rarely grants compassionate release, formally known as "medical parole" or "parole by exception", to those requiring EOLC in Canadian prisons(OCI & CHRC, 2019). The OCI and others have routinely documented this phenomenon (OCI & CHRC, 2019; Iftene, 2017). The report makes the noteworthy assertion that there is no public safety purpose to keeping people who are palliative in prison, and that there are hundreds of older individuals in custody who have passed their parole eligibility dates but have not been released (OCI & CHRC, 2019).

Although they note some individuals expressed a preference to die in prison amongst prison "family", the authors emphasize the frequency with which they heard the statement "I just don't want to die in jail" (OCI & CHRC, p. 55). They provide a wholesale rejection that MAiD or palliative care be offered in prison stating:

> CSC should not be in the business of providing palliative or end-of-life care, nor should it facilitate or enable medically assisted death to take place in federal correctional facilities. Coordinated and accelerated case management of seriously or terminally ill individuals is required between correctional and parole authorities. (p. 53).

This excerpt is the only explicit reference to MAiD in the document, though the authors do go on to argue that incarcerated individuals cannot truly consent or choose freely to die in custody due to the oppressive conditions of prison, which strip individuals of free choice in all manners of life and transform their internal psychology to be defined by institutionalization (OCI & CHRC, 2019).

> The fact that an inmate, for whatever reason, may not have a "community," or friends or family outside the prison context is not sufficient basis to conclude that the inmate wants or should be allowed to die in prison, either as a matter of "choice" (which it is not) or because there is no other more humane or dignified alternative available. (p. 55).

The OCI documented one MAiD death of a person in CSC custody in their 2017-2018 annual report. The individual had received a terminal diagnosis, applied for compassionate release, waited one year before that request was denied by the Parole Board, and then applied for MAiD

(OCI, 2018). The OCI recommends CSC only grant MAiD on a case-by-case basis, and better facilitate and expedite release upon terminal diagnosis. In the following annual report, the OCI argued that the provisions on compassionate release in the Corrections and Conditional Release Act (the act of government which governs CSC and all matters of parole) be reviewed "to ensure policy and procedure is consistent with the spirit and intent of Medical Assistance in Dying legislation." (OCI, 2019).

Discussion

We argue that under the current guidelines, patients who seek MAiD while they are incarcerated in Canada are denied patient-centred access to the procedure, and that this is unaddressed by their advocates. The CSC protocol contravenes central tenets of prison health rights, namely access to an equal standard of care for those inside prison as those outside prison and that only medically qualified people make medical decisions on the sole basis of health considerations. Instead of CSC ensuring those in its custody have equal access to care widely available in Canada, they have erected institutional barriers. None of the OCI's reports that comment on MAiD (OCI, 2018; OCI, 2019), nor the joint report (OCI & CHRC, 2019) discuss concerns about how to best assure equality of access to MAiD nor how CSC's Guidelines approach this objective.

As social workers and health care researchers, we advocate for patients to have the greatest self-determination, agency, and informed care available to them through the course of their medical care. Such patient-centred, or person-centred care, is increasingly important to other medical professionals as well. Patient-centered care has been defined as "care that is respectful of and responsive to individual patient preferences, needs, and values" and that ensures "that patient values guide all clinical decisions" (Committee on Quality of Health Care in America, & Institute

of Medicine, 2001, p. 6). In recognizing patients' and their families' values, priorities, and concerns, and supporting them in medical decision-making, it displaces physician-centered paternalism (Barry and Edgman-Levitan, 2012). Physicians involved in MAiD provision in Canada describe MAiD as fundamentally about delivering patient-centred care: respecting patients' choice and informing them about options to alleviate suffering as their death approaches (Buchman, 2019). We echo the call made by others that person-centred care be incorporated into all prison palliative care (Hudson & Wright, 2019).

At a prison-focused satellite meeting of scholars and community stakeholders that took place after the 2nd International Conference on End-of-Life Law, Ethics, Policy, and Practice (September 2017), participants determined that while the implementation of MAiD for those in Canadian prisons is fraught with ethical dilemmas, in order to align with federal policy stakeholders needed to determine how – not whether – MAiD ought to be offered to federally imprisoned individuals. Attendees, who shared the goal of better supporting incarcerated individuals at the end of life, asked "What obligations does the new MAiD legislation place on Correctional Services Canada and how can these be fulfilled, with particular attention to potential barriers?"

In order to facilitate equitable access to health care services for people who are incarcerated in Canada, quality EOLC – which includes MAiD - must be available. CSC's Guidelines on MAiD present several points where patients may not receive comparable quality of care to patients requesting MAiD in the general Canadian public. We believe the steps prior to a patient filing an official MAiD request form, which are unique to CSC's policy, may cause bureaucratic delay and, ultimately, aggravate a patient's suffering. The initial meeting with the Chief of Health Services, may functionally serve as a third assessment, while current MAiD legislation only requires two. Further, we imagine such patients may perceive a significantly larger power imbalance between

themselves and the Chief of Health Services, than they may already perceive with other health care staff.

We are also concerned that in the event of an approval for MAiD, the last bureaucratic steps contravene the United Nations (2005) recommendation that medical decisions made about prisoners ought to only be made by medical health care professionals. Specifically, the requirement that a person's request for in-community MAiD provision is ultimately granted by a parole officer, and that a person's request for in-prison MAiD provision must be approved by the highest ranking health executive in CSC, who may have no actual contact with the person who is incarcerated.

The guideline does not provide information on possible recourse for a patient should there be a finding of ineligibility by an assessor, and expressly prevents a patient from seeking a further opinion if either of the two assessors finds them ineligible. In contrast, Canadian residents outside the prison system have the option of seeking another assessment should their health care provider decline eligibility, and some Canadian jurisdictions require a health care provider who refuses to assess based on conscientious objection to refer the patient to someone who is willing to do an assessment (Ontario, 2018).

In addition to better facilitating access to MAiD assessments in prison, we offer that truly compassionate person-centered care would allow for a person who is incarcerated and dying to be able to choose either: a transfer to a community facility, or the ability to remain in a CSC health care facility that is equipped to support EOLC if they desire to do so. MAiD advocates argue that one of the most common and significant institutional barriers to accessing the procedure among the general Canadian public is the practice of forced transfers. A forced transfer is "when a health care facility requires a person who requests assisted dying to go off-site to receive – or even be assessed for – (MAID)", often adding to patients' physical and emotional distress (Dying With

Dignity Canada, n.d.). We cannot imagine a practicable or ethical policy surrounding EOLC that denies autonomy to a patient that is otherwise mentally fit and capable of consent due to their legal status in the prison system.

For those desiring release from custody as they near death, we agree with the OCI and the CHRC that release must be expedited. That requests for release in advance of death are routinely denied is an egregious affront to the virtue of "death with dignity". In addition, rather than in contrast, we also believe that consideration must be given to the desires of people who want MAiD to occur within the correctional health care treatment centre with which they are familiar. While CSC states that EOLC and MAiD should happen off-site whenever possible, we wonder about people for whom being able to stay in a prison facility with which they are familiar may circumstantially be considered as an act of compassionate care. If a person desires to be surrounded by recognizable faces at time of death, or if they would rather not go through the humiliation and physical pain of a shackled forced transfer, truly person-centered care would focus on the dying wishes of that person.

Conclusion

We suggest that both CSC's and the OCI/CHRC's firm position on forced transfers for EOLC and MAiD do not align with the principles of person-centered care. The wishes of any person – including persons who are incarcerated – regarding the location of their death must serve as the primary factor for location selection. We fully support expedited releases for people who are incarcerated while actively dying, and empathize with the interviewees of the OCI/CHRC report who view death in prison as extremely undesirable. We are also troubled that the report's authors completely reject MAiD as a valid EOLC option for incarcerated individuals. Ultimately, we argue that further EOLC and MAiD research with people who are incarcerated and with their

healthcare providers is necessary. Sound policies and guidelines require both generalizable principles and attention to nuance. Especially when it comes to impending death, understanding and uplifting an individual's dying wishes is paramount.

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