Can medical assistance in dying harm rural and remote palliative care in Canada?

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> *From an autonomy and informed consent perspective, unless there is available, easily accessible, comprehensive, robust end-of-life care, palliative care, to offer the option of assisted death impedes the exercise of self-determination and autonomy because you haven't been given the option, and even if you have, it isn't available to you in a robust way that can be actualized.*
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Change has arrived in the Canadian health care system in the form of the Supreme Court of Canada's unanimous decision to amend section 241(b) of the Criminal Code. Before this decision, it was illegal for physicians to hasten a patient's death, known nationally as *medical assistance in dying* (MAID). The legal changes, however, made it a possibility for

> a competent adult person who (1) clearly consents to the termination of life and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition.[1]

During the court proceedings, it was suggested that MAID can be justified based on current palliative care practices, but is this truly the case?

> One of the main arguments for the proposition that physician-assisted death can be an ethical practice is that physician-assisted death is ethically indistinguishable from conventionally ethical end-of-life practices such as withholding or withdrawing treatment or administering palliative sedation.[2]

The Canadian palliative care community has thus far expressed concerns about MAID, with most physicians stating they would not participate in the practice.[3] The technical administration of MAID is unique in the traditional Canadian medical context, in that there is no existing specialist community to ensure appropriate training, standards of practice, competency, and expertise in troubleshooting (ie, the anticipation and management of adverse events). Physicians working in general practice rely heavily on guidelines and standards of care set out by subspecialty groups to manage various conditions. Canada's rural and remote GPs manage a remarkably wide scope of practice, competently managing patient populations from birth to death. When rural and remote GPs decide to extend their scopes of practice to manage complex subacute or chronically ill patients, or acquire any skill that allows patients to remain in the community, it is assumed there are high-quality resources available to inform practice.

We argue that MAID presents a unique set of challenges to rural and remote physicians, particularly those who endeavour to provide high-quality palliative services to patients suffering from terminal illness. As most medically assisted deaths traditionally occur in the community, there is no doubt that this intervention will be requested of Canada's rural and remote physicians. However, if these physicians are simultaneously committed to the provision of high-quality palliative care, should rural and remote GPs also be expected to provide MAID?

Universal palliative care?

Canadians strongly value universal health care, yet only 16% to 30% of Canadians have access to or receive palliative care.[4] Numerous factors have been identified as possible reasons for this disparity. With specialized health services typically operated out of geographically centralized locations, it should come as no surprise that our expansive geography itself has been identified as a substantial barrier to accessing care.[4] As well, individual provinces and territories are responsible for delivering health care, which can lead to inconsistencies.[5] For example, there are discrepancies in many areas of home-based palliative care, with some jurisdictions failing to provide access 24 hours a day, 7 days a week, to nursing or personal care.[6]

Some of the rationale for the legalization of MAID in Canada has relied on the absence of universal access to palliative services, implying that MAID is a stop-gap measure, an alternative, or a supplement to palliative care.

> Individuals may experience such suffering (physical or existential), unrelievable by palliative care, that it is in their best interests to assist them in hastened death. Physicians are required to respect patient

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autonomy, to act in their patients' best interests and not to abandon them.[2]

But is it premature to offer MAID to individuals who lack access to palliative care, which might alleviate their symptoms? There seems to be a considerable consensus opinion from proponents and opponents of MAID that patients should not be forced into one option merely in the absence of another. This sentiment is summarized well by the External Panel on Options for a Legislative Response to *Carter v Canada*: "Ultimately, Canadians should be able to make a truly informed choice between physician-assisted death, no medical intervention and excellent palliative care."[7]

Of the unresolved issues surrounding the Canadian implementation of MAID, those related to consent are certainly the most problematic. For a patient to consent to any procedure, 3 criteria must be met: the patient must have the capacity to make the decision (*capacity*); the patient must make the decision freely without coercion (*voluntariness*); and the physician must disclose to the patient a diagnosis or illness, a prognosis, the nature of the proposed treatment, the harms associated with refusing treatment, and, finally, what alternatives exist to the proposed treatment (*disclosure*). One might argue that for a physician to entertain the prospect of offering MAID to a patient, he or she must have an understanding of palliative practice to begin the conversation. If palliative practice is a legitimate alternative to MAID with respect to symptom management, it is then absolutely a requirement to address it in the process of disclosure for consent. If anything, the legal requirements of consent should be enough to compel the administrative health authorities rushing to implement MAID across Canada to pause and reprioritize palliative services and capacity building so that offering and choosing MAID are consistent with the well established ethical and legal backdrop that has served as the groundwork of the modern professional-patient relationship.

Unfortunately, there is a paucity of evidence regarding the effect of legalizing MAID in remote and rural areas. Although many questions remain unanswered, we hope to assist Canadian physicians by identifying a number of serious prima facie challenges that any physician should resolve before considering the facilitation of a request for MAID.

Rural physicians and access to palliative care

- If palliative medicine has the potential to alleviate the symptoms or suffering specific to individual terminal patients, should access to such services be a prerequisite condition to ensure a realistic choice for those patients and physicians considering MAID?
- Can a rural physician, in principle, advocate for and embrace a palliative care philosophy and simultaneously be a provider of MAID?

With proper training and support, any practitioner can deliver basic palliative care. Not every individual who is at the end of life will require the services of a dedicated palliative care physician. However, every patient would benefit from the philosophy, support, and ancillary services that are received through compassionate end-of-life care. Most individuals living in urban Canada have access to multidisciplinary clinics and dedicated home-care supports, which is not always the case for their rural counterparts. Many rural physicians go beyond the call of duty to provide care for their patients. If they had better resources, supports, or specific training to manage challenging end-of-life symptoms, including pain and suffering, would this curb the requests for MAID?

Palliative care physicians across the country have indicated a strong preference not to be involved in MAID. In fact, 75% of the 350 surveyed palliative care physicians in Canada indicated this stance on the recent Supreme Court decision.[3] Subsequently, key messages from the Canadian Society of Palliative Care Physicians were developed with the goal of reducing harm to segments of our population who might choose this intervention simply because they have no access to palliative care services.[8] If every individual had access to the same high-quality end-of-life care, would there be a need for MAID? Would some of the cases of suffering be alleviated with palliative care? Unfortunately, this is an unanswerable question at the moment. This question becomes more difficult to answer when we include patients who do not have a terminal illness, but rather just intolerable suffering. Medical assistance in dying poses a unique challenge to rural and remote physicians, even apart from the pressure to balance one's individual moral assessment of the practice against the expectations of the remarkably broad service provision that patients expect from their rural physicians. In a small community with few physicians, or even a single physician, regardless of the choice to participate or not, any choice might serve to isolate one portion of a patient population. It is difficult to anticipate how this might complicate the physician's practice. Further, are physicians able to exercise the option of refusing to participate if they have offered MAID once, regardless of the reason? This type of vulnerability has yet to be addressed in any legislation or policy, so it will be the responsibility and burden of rural and remote physicians to identify and mitigate such unique vulnerabilities.

Adverse events and intolerable suffering

- Will rural physicians have the resources to deal with foreseeable adverse events and outcomes in the process of providing MAID?

- Can the criteria outlined by the Supreme Court be readily applied to the clinical scenarios physicians will face to evaluate and determine the candidacy of MAID requesters? What will constitute "suffering that is intolerable"? Can anyone impose external views on the experiences of an individual and state what is intolerable or not?

Canada's vast geography could create unique challenges for dissemination of services that other jurisdictions have not had to contend with. Mobile clinics that provide assessments for MAID seem to be a solution in the Netherlands[9]; however, this approach is not likely to be a viable option here. Perhaps MAID assessments will be delivered through telehealth, which would solve the rural and remote issues that are inherent in a country such as ours. Telehealth services are already being used by Planned Parenthood in Iowa to deliver services for medical abortion.[10] If the decision is made to proceed, the question remains: Who will administer the life-ending medications in remote sites where a physician is not present or is unwilling to participate? While we only addressed physicians in this summary, it should also be noted that if this policy is enacted in rural and remote areas with limited physicians, allied health professionals might be required to provide support.

As with most aspects of medicine, complications can arise that must be anticipated and there should be a plan in place to deal with these issues. Will the physician have to be present at the bedside while the patient ingests the medication? Research has demonstrated various problems that can occur, including vomiting, failing to die as soon as expected, or awaking from a coma after ingesting these medications.[11] This can necessitate the delivery of a lethal injection, yet physicians do not receive education about administering these injections. The inherent difficulty in establishing a unique service such as MAID is attempting to balance the virtue of continuity of care (and the potentially damaging effect of having one's own trusted physician offering MAID) against the benefits of expertise acquired by specialized dedicated teams who gain experience and competence, particularly in managing adverse events and complications. The recent legalization will broaden the scope of knowledge that GPs require, and could create deficiencies in other areas of training.

How will objective criteria be developed to identify those patients who will qualify for MAID? Terminology such as *intolerable suffering* has enormous subjectivity. Conditions deemed intolerable to one person might not be viewed as intolerable to another. Further consideration should be given to the suffering that can be experienced by those administering MAID, as dealing with the tangled emotions and psychological toll of ending a patient's life can have a substantial effect on the emotional state of the physician.[12] Questions have also been raised about conscientious objectors in the battle between patient rights and physician autonomy.[13]

Effect on rural physicians

- Do rural physicians have a special obligation to provide MAID for the benefit of a rural population (ie, the desire to die at home)?
- Are rural physicians susceptible to an "only game in town" problem? If a physician is providing medical service alone or in a small group, providing MAID might have a negative effect on the practice as a whole. Is this anticipated effect of MAID on a professional practice enough to refuse to offer the service?

If services are not provided in a rural area, will patients be required to travel? Access to abortion services has been limited in some regions

of Canada. A tracking study based on a Canadian abortion clinic found that 73.5% of patients spent more than 60 minutes traveling to the clinic.[14] Patients who are dying are often physically weak and might find travel too onerous at the end of life. There might also be an emotional or financial toll as they leave their supportive home environment. In January 2016, Abortion Access Now PEI announced it would be taking the province to court to ensure it will provide full and unrestricted access to publicly funded abortion services on Prince Edward Island.[15] Questions remain as to whether institutions such as Catholic hospitals will be forced to carry out MAID once it has been implemented on a national level.

Specific consideration must be given to practitioners in rural and remote areas. If you are the sole practitioner in a rural or remote area, will you be able to opt out of participating? What will be the referral process if you choose not to participate? Very few have self-identified as willing to offer the service; thus, it is uncertain to whom you would refer patients requesting MAID.

In Oregon, 62 physicians wrote the 122 prescriptions provided to patients requesting a hastened death in 2013.[16] It is unclear if these prescribers were clustered in an urban centre. A stand-alone clinic has been offered as an option in urban sites for MAID; however, this would be difficult to implement in all rural areas. Rural and remote areas are often underserviced and physician recruitment is challenging. This new legislation might have an effect on recruitment of future medical practitioners to rural Canada. There might also be personal and professional implications if you live in a rural area and decide to provide assisted suicide or voluntary euthanasia.

Final thoughts

Canada has added its name to the list of jurisdictions that have legalized physician-assisted death, which includes Switzerland, Belgium, the Netherlands, Luxembourg, and Columbia, as well as Oregon, Washington, Vermont, and New Mexico in the United States.[17] Medical assistance in dying has been provided to various degrees in each location.

A study completed in Switzerland indicated that divorced women who lived alone and did not have children or religious affiliations tended to use physician-assisted death more than their counterparts did.[18] We should be cautious about the vulnerable populations of our society that might request MAID disproportionately. The full effect of MAID on our society remains to be felt, but we must ensure that individuals who are geographically isolated or who reside in inner-city environments will not view MAID as their only source of respite from end-stage disease.

The hastening of a patient's death is a provocative topic, and many questions remain about the delivery of MAID to rural and remote areas. Access to palliative care, implications for both patients and health care workers, and the effect it might have on the rural health care environment must all be taken into consideration. The best patient care should be provided, while ensuring health care professionals are supported. The real effect of MAID on rural and remote physicians and the more than 9 million patients who reside in these areas is uncertain. We are adamant, however, that MAID must not come at the expense of high-quality, accessible palliative care.

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Competing interests
None declared

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References

1. *Carter v. Canada (Attorney General)*. 2015. 5 S.C.C.
2. *Carter v. Canada (Attorney General)*. 2012. B.C.S.C. 886 (CanLII).
3. Eggertson L. Most palliative care physicians want no role in assisted death. *CMAJ* 2015;187(6):E177. Epub 2015 Feb 23.
4. Canadian Hospice Palliative Care Association. *Policy brief on hospice palliative care. Quality end-of-life care? It depends on where you live … and where you die.* Ottawa, ON: Canadian Hospice Palliative Care Association; 2010.
5. Carstairs S. *Raising the bar: a roadmap for the future of palliative care in Canada*. Ottawa, ON: Senate of Canada; 2010.
6. Collier R. Access to palliative care varies widely across Canada. *CMAJ* 2011;183(2):E87-8. Epub 2011 Jan 10.
7. External Panel on Options for a Legislative Response to *Carter v. Canada*. *Consultations on physician-assisted dying. Summary of results and key findings. Final report.* Ottawa, ON: Department of Justice, Government of Canada; 2015.
8. Canadian Society of Palliative Care Physicians. *Submission to external panel on options for a legislative response to* Carter v. Canada. Surrey, BC: Canadian Society of Palliative Care Physicians; 2015. Available from: **www.cspcp.ca/wp-content/uploads/2014/10/CSPCP-Federal-Panel-Submission-Oct-22-2015-FINAL.pdf**. Accessed 2017 Jan 25.
9. Snijdewind MC, Willems DL, Deliens L, Onwuteaka-Philipsen BD, Chambaere K. A study of the first year of the end-of-life clinic for physician-assisted dying in the Netherlands. *JAMA Intern Med* 2015;175(10):1633-40.
10. Grossman D, Grindlay K, Buchacker T, Lane K, Blanchard K. Effectiveness and acceptability of medical abortion provided through telemedicine. *Obstet Gynecol* 2011;118(2 Pt 1):296-303.
11. Groenewoud JH, van der Heide A, Onwuteaka-Philipsen BD, Willems DL, van der Maas PJ, van der Wal G. Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands. *N Engl J Med* 2000;342(8):551-6.
12. Stevens KR Jr. Emotional and psychological effect of physician-assisted suicide and euthanasia on participating physicians. *Issues Law Med* 2006;21(3):187-200.
13. Nelson B. In right-to-die debate, a new focus on practicality. *Cancer Cytopathol* 2015;123(7):385-6.
14. Sethna C, Doull M. Far from home? A pilot study tracking women's journeys to a Canadian abortion clinic. *J Obstet Gynaecol Can* 2007;29(8):640-7.
15. Abortion Access Now PEI [press release]. *Abortion Access Now PEI files a notice of application in the Supreme Court of Prince Edward Island against the government of PEI.* Charlottetown, PE: Abortion Rights Network; 2015. Available from: **www.abortionrightspei.com/content/page/front_news/article/43**. Accessed 2017 Jan 25.
16. Oregon Public Health Division. *Oregon's Death with Dignity Act—2013.* Portland, OR: Oregon Health Authority; 2013. Available from: **https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf**. Accessed 2017 Jan 25.
17. Dyer O, White C, García Rada A. Assisted dying: law and practices around the world. *BMJ* 2015;351:h4481.
18. Steck N, Junker C, Maessen M, Reisch T, Zwahlen M, Egger M, et al. Suicide assisted by right-to-die association: a population based cohort study. *Int J Epidemiol* 2014;43(2):614-22. Epub 2014 Feb 18.