



Editor's key points

► In Canada, it has now been more than 2 years since legislation was passed permitting medical assistance in dying (MAID). As MAID is a newer medical procedure, it is important that all aspects of its implementation in Canada be examined. This article describes the perspectives of 8 physicians who collectively represent the first cohort of MAID providers in British Columbia.

► These MAID providers experienced many challenges that complicated their ability to provide MAID: spending many hours traveling for assessments and care provision, navigating legal requirements, fulfilling the onerous paperwork requirements, and having to educate other health care providers. Trying to support patients who were in facilities where access to MAID was denied was described as one of the most frustrating challenges. Despite the many challenges, the physicians described providing MAID as rewarding.

► Peer support was essential for these physicians. During the first few months of MAID's legality, they turned to each other to discuss difficult cases and appropriate protocols, as well as for emotional support.

Providing medical assistance in dying

Practice perspectives

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Abstract

Objective To explore the experiences of the first cohort of physicians to offer medical assistance in dying (MAID) in British Columbia.

Design Qualitative study using semistructured, one-on-one interviews.

Setting British Columbia.

Participants Eight physicians who offered MAID in British Columbia in 2016.

Methods The physicians were interviewed by telephone or by e-mail between 4 and 6 months after MAID was made legal in Canada, with follow-up in January 2017. Interviews were audiorecorded, transcribed, and analyzed through qualitative thematic analysis.

Main findings Participants believed that MAID was rewarding and satisfying work. They explained that some of the structural and emotional challenges related to providing MAID included the following: the refusal of faith-based institutions to provide information about MAID to patients, as well as their refusal to allow assessments or deaths to occur on site; having to deny MAID to patients who did not qualify for it; disagreements with colleagues who did not support the provision of MAID; dealing with the grief of family and friends who were present at the death; and feeling like they were always on call. While a few participants thought that the legislative restrictions of Bill C-14 were appropriate in the beginning when MAID was first available in Canada, most would like to see changes to the legislation to make it more aligned with the intent of the Carter decision, including broadening the eligibility criteria to include mature minors and people with advanced psychiatric diagnoses, having the ability to honour advance directives, and removing the requirement of death being in the reasonably foreseeable future for patients with grievous and irremediable conditions.

Conclusion Physicians in this study explained that providing MAID is rewarding work; however, there are many challenges that complicate their ability to offer MAID to patients. The current MAID legislation in Canada should be updated to better serve the needs of patients.



Offrir l'aide médicale à mourir

Les défis à relever

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Résumé

Objectif Décrire l'expérience des 8 médecins qui ont été les premiers à fournir l'assistance à mourir (AMM) en Colombie-Britannique.

Type d'étude Une étude qualitative à l'aide d'entrevues individuelles semi-structurées.

Contexte La Colombie-Britannique.

Participants Huit médecins qui ont dispensé l'AMM en Colombie-Britannique en 2016.

Méthodes Les médecins ont été interviewés au téléphone ou par courrier électronique entre 4 et 6 mois après la légalisation de l'AMM au Canada, avec un suivi en janvier 2017. Les entrevues ont été enregistrées et transcrites pour ensuite faire l'objet d'une analyse thématique qualitative.

Principales observations Les participants estimaient qu'il était satisfaisant et gratifiant de fournir l'AMM. Ils mentionnaient avoir été confrontés aux défis d'ordre structurel et émotionnel suivants, en rapport avec le fait d'offrir l'AMM: le refus d'établissements confessionnels de fournir des renseignements aux patients sur l'AMM et de permettre qu'il y ait des évaluations de l'admissibilité ou des décès sur place; le fait de devoir refuser l'AMM aux patients qui ne s'étaient pas qualifiés; le fait de ne pas s'entendre avec les collègues qui n'approuvaient pas la fourniture de l'AMM; le fait d'être confrontés à la peine des amis et des membres de la famille qui étaient présents au moment du décès; et l'impression d'être constamment sur appel. Bien que quelques participants croyaient que les restrictions législatives du projet de loi C-14 étaient initialement appropriées lorsque l'AMM est devenue disponible au Canada, la plupart aimeraient qu'on apporte certains changements à cette loi pour qu'elle soit davantage conforme aux intentions de la décision Carter, par exemple un élargissement des critères d'admissibilité pour inclure des personnes mineures matures et celles qui souffrent d'une maladie psychiatrique avancée, le fait de pouvoir répondre à des directives préalables et la suppression du critère exigeant que la mort prévue survienne dans un délai raisonnablement court dans le cas de patients gravement et irrémédiablement malades.

Conclusion Les médecins qui participaient à cette étude ont dit que le fait de dispenser l'AMM était une tâche gratifiante; toutefois, ils ont dû faire face à plusieurs défis qui ont compliqué leur capacité d'offrir l'AMM aux patients. Une mise à jour de la loi canadienne sur l'AMM serait souhaitable afin de mieux répondre aux besoins des patients.

Points de repère du rédacteur

► Il y a maintenant plus de 2 ans que le Canada a adopté une loi qui permet d'offrir l'aide médicale à mourir (AMM). Comme il s'agit d'une nouvelle responsabilité médicale, il est important de s'interroger sur tous les aspects de son implantation au Canada. Cet article rapporte l'expérience d'une cohorte de 8 médecins qui ont été les premiers à dispenser l'AMM en Colombie-Britannique.

► Les médecins qui dispensaient l'AMM ont été confrontés à plusieurs situations qui rendaient leur travail difficile: passer des heures en déplacements pour des évaluations et pour fournir les soins, prendre connaissance des exigences légales, remplir toute la paperasse requise et former d'autres soignants. Ils mentionnaient qu'une des tâches les plus frustrantes était l'accompagnement de patients qui étaient dans des endroits où on n'acceptait pas de fournir l'AMM. Malgré toutes ces difficultés, les médecins ont dit qu'il était gratifiant de dispenser l'AMM.

► Ces médecins avaient besoin du soutien de leurs pairs. Durant le mois qui ont suivi la légalisation de l'AMM, ils se tournaient vers leurs collègues pour discuter des cas difficiles et des meilleurs protocoles à utiliser, mais aussi pour obtenir leur soutien sur le plan émotionnel.

On February 6, 2016, in the precedent-setting *Carter v Canada*,¹ the Supreme Court of Canada held that laws prohibiting medical assistance in dying (MAID) violated the right to liberty of the person, and that MAID ought to be legal in Canada.^{2,3} Between the Carter decision and the day that the new MAID legislation (Bill C-14) received royal assent on June 17, 2016, individual patients who wanted to receive MAID each required a court approval.⁴ The current MAID legislation in Canada allows competent adults (those aged 18 and older) who have a grievous and irremediable medical condition to make a voluntary request for assistance in dying. A grievous and irremediable medical condition is one where the person has a serious and incurable condition, the person is in an advanced state of irreversible decline in capability, the person's condition or decline causes intolerable physical or psychological suffering that cannot be acceptably relieved, and a natural death has become reasonably foreseeable.² Physicians and nurse practitioners can provide MAID, and allied health professionals, pharmacists, and patient-support persons are able to assist.

The first case of MAID in Canada outside of Quebec was a 66-year-old woman with amyotrophic lateral sclerosis from Calgary, Alta, who flew to Vancouver, British Columbia (BC), for her death on February 29, 2016.⁴ Partly owing to the media attention surrounding this first case, the 2 Vancouver physicians who were involved were joined by 6 other physicians in BC who were interested in providing aid in dying. This group of 8 formed a peer-support group and shared their knowledge, experience, and challenges as they started to provide assessments and assisted deaths for patients. They exchanged more than 1000 e-mail communications in this process, and held meetings in-person and over the telephone.

The federal government published an interpretation of the law to help clinicians understand the restrictions.⁵ In addition to complying with the federal law in the Criminal Code, clinicians must also follow the standards and guidelines of their licensing bodies and the provincial group of the regulatory authority to which they belong (eg, Royal College of Physicians and Surgeons of Canada, the Canadian Nurses Association, or the Canadian Pharmacists Association). These are similar but not the same across the country. The participants in this study complied with the College of Physicians and Surgeons of British Columbia guidelines, which included the submission of all documentation to the coroner's office.⁶

There are a few reports about experiences with euthanasia requests from the Netherlands that suggest that such requests can be stressful for primary care physicians.^{7,8} It is important to research all aspects of MAID implementation in Canada to ensure the development of best practices and the use of appropriate inclusion criteria and safety guards. This article describes the perspectives and experiences of 8 physicians who collectively represent the first cohort of providers to offer MAID in BC.

— Methods —

This research project used semistructured interviews to explore the experiences of a cohort of physicians who were among the first to provide MAID in Canada. When little is known about a subject, exploratory descriptive qualitative research is used to begin to understand characteristics of phenomena, upon which additional research and theorizing can be built.⁹ Semistructured interviews with small sample sizes are especially suitable for this type of research because they allow researchers to extend the conversation beyond standard questions and to follow research participants' leads into new areas of conversation.¹⁰

Eight physicians were interviewed by telephone or by e-mail between 4 and 6 months after MAID was made legal in Canada, and the opportunity for the physicians to provide further information was offered in January 2017. The interviews were conducted by 2 medical resident investigators (S.H. and A.N.). One of the authors (E.W.) was also an interviewee, serving as a form of member checking. Interviews were audiorecorded and transcribed by a research assistant (M.K.). Identifying features were removed and the investigators (J.S., A.J., S.H., and A.N.) analyzed the interviews using thematic qualitative analysis. Identified themes were compiled and evaluated in the context of what was already known about the provision of MAID in jurisdictions where it is legal (eg, Oregon, the Netherlands, Belgium). Investigators had discussions through e-mail communications, teleconferences, and in-person meetings, and consensus was reached on the main themes. This research project was approved by the University of British Columbia Behavioural Research Ethics Board.

— Findings —

Of the 8 physicians who were interviewed, 3 were from greater Vancouver, 3 were from Victoria, and 2 worked in a small community on Vancouver Island. Seven were family doctors and 1 was a general internist. Their ages ranged from 37 to 64 years. There were 2 men and 6 women; 6 worked full-time and 2 worked part-time. Collectively, by the end of December 2016, the 8 physicians in this study had assessed 332 people who were seeking MAID and had completed 135 assisted deaths. Assessments and deaths took place in hospitals, homes, hospices, clinical offices, and outdoors. Most of the patients who received MAID were not patients who were previously known to the providing physicians. However, in one case in which it was the participant's own patient who had received MAID, the participant explained that "in many ways they are less stressful, because I know the patient and family better than my referral patients."

Most of the participants were supportive of MAID before it was legalized, a few had not thought about

it much before the media attention around MAID, and 1 participant was opposed to MAID before its legalization. The following is a description of a conversation a participant had had with a colleague before the legalization of MAID: “[When] we knew that this was coming about, we looked at each other and we said, ‘Well, where are the providers? Perhaps we better become them.’” The participant who had made the transition from opposing to supporting MAID simply stated that once it became legal, “patient choice and rights trump my personal feelings.”

All 8 participants described the steep learning curve that they experienced once they decided that they were interested in offering MAID. There were few regulations and no protocols that were immediately in place after MAID was legalized, and the physicians took it upon themselves to become educated in standards of best practice from international jurisdictions where MAID was already implemented. Two physicians traveled to the Netherlands in January 2016 to learn from colleagues there, and 5 attended an international euthanasia conference in the Netherlands in May 2016. As described by one of the participants:

The most useful thing we did was go to the Netherlands and speak to providers there. We spent some time there and we read everything we could and we talked to providers in Oregon and Washington and just were sort of like sponges and soaked up any information we could get from anyone who was providing medical assistance in death, up to date.

Throughout the process, the participating physicians turned to each other to share knowledge and to provide mutual support while developing protocols. Many are currently involved in teaching other health care providers about MAID both locally and nationally.

Themes

The interviews with the participating physicians revealed the following common themes.

Providing MAID is rewarding work. There was a strong consensus among participants that providing MAID was rewarding work. Each of the participants spoke about how meaningful the practice of MAID was to them and to their patients. As one participant stated:

I think when you see the patients that we see, it's very clear that you're doing an incredible service. And that's wonderful. There isn't a single moment when I see these patients that I don't think, “Oh my God, I'm so happy to be here to help you.” So that's tremendously reinforcing ... I'm very proud to be doing it, and as I say, it's incredible work, really, for the patient.

To be able to fulfil someone's dying wish—to be able to offer someone a comfortable death that would end the intense suffering—was described as both an honour and a responsibility. One participant explained that “being able to give someone this gift, people are incredibly thankful—the families, the patients—it's a bit overwhelming.”

Another participant stated the following: “[The] work is so wonderful ... to offer something that these patients really, really want and deserve and have the right to. And they are so grateful. Oh, my heavens, they're so grateful.”

While each of the deaths was different, the gratitude that was offered by patients and support persons to the attending physician were similar.

Many considerable challenges complicated the ability to provide MAID. There were many important structural and emotional challenges that complicated and delayed the ability to offer MAID. While each physician anticipated that some of the challenges would be mediated as MAID became a more normal part of Canadian health care, often considerable efforts were required to ensure that patients received the care that they needed. The dedication of these physicians to work through structural and emotional challenges to offer MAID reflected their belief that offering it was an important service.

Structural challenges: Four of the 8 participants talked about problems they encountered with faith-based institutions refusing to provide information to patients and not allowing assessments on site, as well as other facilities refusing to allow MAID on the premises. When discussing how this affected patients beyond the facility itself, a participant explained the following: “Our hospital is Catholic and does not allow MAID. This policy has a knock-on effect in the community by limiting the number of nurses willing to attend a person's home to site an IV [intravenous] cannula.”

When facilities refused to allow MAID to occur on the premises, patients still accessed it, but they often had to be transported to another facility. When describing what it was like to move patients in order to offer MAID, one participant explained how complicated the process was:

She was completely ambulatory, into the hospital for a short stay admission for 4 hours to do MAID, but the short stay admission probably took me 16 hours to arrange because then I had to do in-services with the staff, where it's going to occur, talk to the director of admissions, try and arrange a bed, verify the bed, confirm the bed, and then deal with pharmacy and how we were going to [do] this because [she was] not a patient in the system, because she's an outpatient.

Other considerable challenges included privileges not being honoured, having to spend many hours traveling for assessments and care provision, navigating legal requirements, having a lack of protocols, fulfilling the

onerous paperwork requirements, and having to educate other health care providers along the way. As being part of the first cohort of MAID providers, participants said the following:

Once it became legal, it was a matter of winding it all up to start. The challenges were putting in the time and the effort to get it going. I spent 2.5 hours, at least, with the pharmacist the first time he was going to drop medications with me. We devised the protocol ... I used a form that nobody else had ever used because they had just been developed the week before

[While supporting the logistical arrangements of patients] can be overwhelming, [the] actual patient involvement is fantastic. That's really rewarding and that keeps me going. It's the bureaucratic stuff that takes the stuffing out of you.

Emotional challenges: The most difficult and most common emotional challenge was having to deny MAID to people who desperately wanted it but did not qualify under the current legislation. Having to turn people away when they would have qualified for MAID under the Carter decision but did not under Bill C-14 was especially distressing. For example, a patient who suffers from a serious and irreversible condition such as dementia would have qualified under the Carter decision, but no longer qualifies under the more restrictive current legislation because the patient's natural death is not in the "reasonably foreseeable" future. Having to deny MAID to such patients was described as distressing because while the suffering of the patient was likely to increase, they would not be eligible for MAID until their condition progressed to such a state that death was reasonably foreseeable; and by the time the prognosis of a patient with dementia reaches that point, he or she is likely unable to give consent, thus rendering the patient's eligibility for MAID null. A participant described such patients as "people who are suffering but are excluded by the law." Another participant explained the following:

Saying no to patients does not ever get easier It still feels like the worst part of this work because those patients have come seeking help and as a physician I very much want to help them. But I am clear when I cannot and will always work within the [current] law.

Other emotional challenges included disagreements with colleagues who did not support the provision of MAID, dealing with the grief of family and friends who were present at the time of death, and feeling like they were on call all the time. To work through these challenges, peer support was identified as essential. As the first cohort of physicians providing MAID in BC, and with few guidelines from the College during the first few

months of its legality, they turned to each other to discuss difficult cases, to think about appropriate protocols, and for emotional support. While one participant did feel strongly about practising MAID alone so as to keep the experience "less medical" for the patients and their support persons, they all relied on their ability to have open conversations about the process with each other, based on the fundamental value that "none of us are going to put ourselves in a position where we're doing something that we don't think is right."

The current MAID legislation in Canada should be updated. While a few of the study participants thought that the legislative restrictions of Bill C-14 were appropriate for when MAID was first available in Canada, most would like to see changes to the legislation to make it more aligned with the intent of the Carter decision. In particular, they believe the eligibility criteria should be broadened to include mature minors and people with advanced psychiatric diagnoses, and they should have the ability to honour advance directives. Furthermore, participants thought that the qualifying requirement of death being likely in the reasonably foreseeable future should be removed for patients with grievous and irremediable conditions. Because *reasonably foreseeable* was not defined in the initial legislation, it had been up to individual physicians, often with legal advice, to determine what they defined as reasonably foreseeable. Since this study was conducted, Justice Paul Perell clarified in the 2017 court case *A.B. v Canada* that in formulating an opinion about whether a patient's death is reasonably foreseeable, "the physician need not opine about the specific length of time that the person requesting [MAID] has remaining in his or her lifetime."¹¹ This has expanded how physicians and nurse practitioners can apply the concept of reasonably foreseeable in practice.

— Discussion —

In this study, all 8 physicians found providing MAID to be very rewarding, despite the logistical challenges. We anticipate that many of the challenges mentioned above will be mitigated as Canadian physicians and the public have more exposure to and experience with MAID. Over the course of the study, developments were made as health authorities and individual institutions created and posted protocols, hired new staff to facilitate access to MAID, and offered training sessions across Canada. The physicians in this study described some of the stress that they experienced due to the extra hours that they worked during the early stages of the implementation of MAID, as they and their patients tried to navigate various legal and medical systems.


Globally, there are social taboos related to assisted death.¹² We expect that as MAID becomes more socially acceptable and more readily available, both the number

of physicians who are willing to offer MAID and the number of patients who request it will increase. In places like the Netherlands and Belgium, where MAID has been legal for years, assisted deaths account for 4% to 5% of all deaths.^{13,14} In Canada, this would translate to roughly 12 000 MAID deaths per year. This means that the need for providers will continue to increase, and that training about both the referral process and the actual provision of MAID will also need to increase.

Limitations

This study was limited to inquiring into the experiences of 8 physicians from BC who were early adopters of MAID and the findings are not generalizable to the experiences of other physicians. However, as a new medical procedure for which guidelines are still being developed, we believe that it is imperative that research about all aspects of MAID be conducted and shared.

Conclusion

The most consistent theme throughout this research was that providing MAID was incredibly satisfying and rewarding work. The biggest emotional challenge that participants identified in relation to providing MAID was having to deny care to a patient who did not qualify, especially if the patient would have qualified under the Carter decision, but no longer did under the current Bill C-14 legislation. Logistical challenges included having to travel to see patients who were bedridden, onerous documentation requirements, a lack of administrative support for arranging the actual MAID process, and privileges being denied by care facilities. Trying to support patients who were in facilities where access to MAID was denied, especially when they were in faith-based facilities, was described as one of the most common and most frustrating challenges. In order to overcome barriers and to prevent feelings of isolation, logistical and emotional peer support from other providers was identified as very important. 

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Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

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