

FINAL REPORT

2nd Annual Medical Assistance in Dying Conference 2018



**Bureau du développement
professionnel continu**

**Office of Continuing
Professional Development**

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Executive Summary: LEARNINGS FROM THE 2018 MAID CONFERENCE

1. It took 10-15 years for legalized euthanasia to become completely integrated into Belgium's health-care systems. Belgium's experience may foreshadow the kinds of cultural shifts and trends in end-of-life care that Canada can expect in years to come.
2. Health Canada's upcoming federal reporting and monitoring system aligns with international best practices and will foster public trust. The take-home message following the consultations was to strike the right balance between minimizing reporting burden for practitioners and robust reporting for insight into how the law is being implemented.
3. From a medico-legal perspective, it is imperative that providers cultivate good, thorough documentation habits. This will become especially important once the "forgiving phase" of MAiD implementation ends and the agencies charged with reviewing MAiD switch from an education mode to one of enforcement.
4. Despite most families rating their experience with their loved one's MAiD provider as positive, many identified a lack of community support and follow-up care for grief as issues in a Bridge C-14 survey. The primary focus of Bridge C-14 is to bridge the gap between procedure and family experience. Contact info@bridgeC14.org for more information on how you can make links to community resources in your jurisdiction.
5. Regarding MAiD for minors, among the key professional and ethical considerations are the challenges around assessing capacity, the arbitrariness of the age of capacity, the fact that capacity is time- and task-specific, and the need for additional self-care for providers.
6. MAiD research in Canada is prospering and on the cusp of producing a national body of scholarship. Although at the time of the conference there were only two published Canadian studies so far, four were in press and more than 16 in progress.
7. As MAiD is maturing in Canada, it is getting more diverse in terms of practices and policies. However, common concerns across the provinces and territories include documentation issues, remuneration and billing, lack of intra-provincial consistency and standards, and increasing demand and capacity to provide.
8. For one family, humour, ritual and symbolism helped alleviate the burden of anticipating their loved one's death. A key insight from a daughter who lost her mother was that you are never ready to let go of someone that you love. Readiness should not in fact be an expectation at all, only acceptance.
9. During an organ and tissue donation process, time is of the essence to reduce the risk to organ quality following warm ischemia time. Donation agencies recommend that the "ask" of donation be decoupled from MAiD and made by donation experts

(who are trained in how to tactfully incorporate the donation conversation into MAiD).

10. The Ottawa Hospital's MAiD team is a large interdisciplinary group that has been able to thrive and grow thanks to a supportive leadership. Their model of collaboration provides a good example that other hospitals and academic centres may wish to emulate to professionalize and optimize their services around MAiD.
11. Despite a history of conflict, palliative care and MAiD share many principles and experiences, including suffering from misperceptions. In fact, there are many areas where the two disciplines could collaborate to great effect, including improving access to resourced palliative care, messaging and education for the public, and ensuring that every health-care provider learn how to respond to a MAiD request comfortably.
12. Dying with Dignity, although well-known for human rights advocacy, also works to provide personal support for people and help share their stories in the interests of public education and change. If providers are working in a facility that does not provide MAiD or actively resists it, Dying with Dignity can help mitigate this resistance.
13. Integrating social accountability concepts, such as an awareness of structural violence and how the health care system itself perpetuates inequity, can help providers make better assessments regarding a patient's social determinants of health. Providers can help empower vulnerable populations by helping them fight for options that would allow them access to MAiD and supporting them to reach capacity in the first place.
14. Barbiturates are the most common medication for oral MAiD worldwide. Canadian medications are mainly a mix of phenobarbital, chloral hydrate and morphine. Secobarbital, although not yet available in Canada for oral MAiD, is highly anticipated due to its predictable response and approximate 30-minute time to death. At the time of this writing, Canada has only provided 11 oral MAiD cases so far.
15. A pilot study on the impact of MAiD to providers suggests that the majority find it profoundly rewarding and positive; to some it is the best part of their practice. The biggest source of stress for providers was administrative and institutional obstacles. To mitigate burnout, organization, advocacy and continuing to show compassion are recommended.
16. The CAMAP listserv is a helpful resource for managing solutions to difficult cases. For example, cases focused on frailty, early dementia, and voluntary stopping and drinking are some examples of scenarios that have challenged providers and have been discussed on the CAMAP listserv.

Conference goals

By the end of the conference, CAMAP's goal was for participants to be able to

- Interpret the legislation governing MAiD
- Appreciate the current challenges in MAiD nationally
- Discuss future potential directions for MAiD in Canada

Special thanks to the CAMAP Planning Committee

- Dr. Stefanie Green
- Dr. Viren Naik
- Dr. Ellen Wiebe
- Dr. Konia Trouton
- Mr. Mike Kekewich
- Ms. Vanessa Chaput

Preconference session summary

Prior to the main conference, CAMAP hosted four pre-conference sessions at the University of Ottawa Skills and Simulation Centre on May 3, 2018. Pre-conference activities included sessions on MAiD research being done across the country, creation of care coordination for patients, an introduction to assessment and provision of MAiD, and a simulated "hands on" session that made use of the simulation facilities to enhance skills such as intravenous insertion. These sessions provided a unique opportunity for participants to gather in smaller groups, share knowledge, and build communities of practice. They were very well attended and received!



Assisted Dying in Belgium: Experience, Research and Lessons Learned

Speaker

Luc Deliens, Professor of Palliative Care Research, Ghent University and the Vrije Universiteit, Brussels, Belgium

BRIEF OVERVIEW

Prof. Deliens provided a global context to medically assisted death by describing the history and monitoring of euthanasia in Belgium, which was legalized 16 years ago. He presented similarities and differences between the Canadian and Belgium systems. He also shared data trends assembled from Belgium's death certificate surveys, which have occurred periodically since implementation. Prof. Deliens also described the impact that euthanasia has had on palliative care and how attitudes have changed over the years.

DETAILED OVERVIEW

Belgian and Canadian law: Three similarities

- Patient needs to be competent and conscious at the time of making a request
- Requests must be written, voluntary and well-considered
- Patient has a grievous and irremediable condition

Six differences

Belgian law of euthanasia	Canadian act for MAiD
Initiated by Belgian Parliament	Initiated by the Supreme Court of Canada
Only clinical doctors may be providers	Medical or nurse practitioners may be providers
Assisted suicide is not legal	Assisted suicide is legal (self-administration)
Patient may be a minor	Patient must be 18 years old or older
Patient does not have to be in an advanced stage	Patient must be in an advanced stage of irreversible decline and capability
Natural death does not have to be foreseeable	Natural death must be foreseeable
Allow one month between the request and the act	Need at least 10 days between the request and provision of MAiD
No witnesses required except the treating physician	Two independent witnesses required at time of written request

Why monitor?

Firstly, understanding the epidemiology is necessary to improve the service. Thanks to monitoring, we know that approximately two per cent of all Belgian deaths per year are now the result of euthanasia. We also know that the number of reported cases with psychiatric disorder or dementia diagnoses are increasing.

Secondly, monitoring helps a country to understand the clinical choices their doctors are making. Euthanasia is not the only choice in a treatment trajectory. Our monitoring has shown that, across all patient populations, the incidence of palliative sedation is decreasing as euthanasia is increasing.

Finally, monitoring is important for societal control of a last-resort medical practice. In Belgium, every case of euthanasia must be reported to the Federal Control and Evaluation Committee. Societal control also helps address many ethical concerns surrounding euthanasia, such as the potential for abuse or negative impacts on vulnerable populations.

The value of independent research

Independent research is so important in providing another source of information for societal control besides only the reported cases of euthanasia. For example, we collect data on ungranted requests for euthanasia and all the different end-of-life practices (nontreatment decisions, palliative sedation, intensified treatments, etc.). This provides a much broader context and fuller picture for the study and monitoring of end-of-life care in Belgium.

Death certificate surveys

One example of independent research is the death certificate surveys we run in Flanders, Belgium. We take a large-scale sample of death certificates (i.e. 6,200) and send out anonymous surveys to the attending physicians, asking them in-depth questions about what happened at the end of life of that patient. We sent out surveys in 1998, 2001, 2007 and 2013. Now we are preparing a new wave for 2019. In 2013, we had a 61% response rate.

Highlights from the survey results over the years

- One out of every two deaths are a medicalized death
- Continuous deep sedations have dropped, and euthanasia cases have increased
- The incidence of euthanasia was already at 1.1 per cent prior to the law (this analysis helped to convince parliament they needed to make a law on euthanasia)
- The number of ungranted requests has dropped whereas the number of granted requests has increased (among all patient categories)
- One out of every 10 cancer patients in Belgium are provided with euthanasia

Why is euthanasia increasing in Belgium?

- There's higher visibility because the topic is regularly covered in the media
- Patients are perceiving it as a good death compared to many natural deaths
- Society is increasingly valuing quality of life and patient autonomy
- We live in a much more secularized society than 50 years ago
- Physicians are more willing to grant euthanasia since the implementation of the law and the integration into health-care systems

Impact to palliative care in Belgium

Historically, palliative care and euthanasia have conflicted because euthanasia is incompatible with palliative care values not to hasten death. However, palliative care clinicians are increasingly confronted with euthanasia requests, especially in a country where euthanasia is legal.

Certain groups, such as the European Association for Palliative Care, still do not want to collaborate on euthanasia. However, elsewhere, attitudes are shifting. The Federation of

Palliative Care Flanders has vastly shifted its position over the years. They used to be against the legalization of euthanasia but are now willing to embed it into practice.

Regardless, palliative care is still thriving in Belgium and has become embedded in the health care system through laws of its own. From our research, we know that palliative care professionals play a key role in euthanasia processes in six out of ten deaths by euthanasia, sometimes even performing euthanasia themselves.

What can Canada learn from Belgium's experience?

- Monitoring of all end-of-life decisions, not just euthanasia, is essential for good societal control of a last-resort medical practice and for quality improvement
- The implementation of a euthanasia law had a considerable impact on the incidence of end-of-life decisions in general
- Since the law was implemented, the performance of euthanasia has increased substantially to four per cent of all deaths (from one percent).
- This is due to an increased number of patients requesting euthanasia, but also due to a higher granting rate by doctors
- Data show no evidence for slippery-slope or vulnerable-groups hypotheses
- Nor is there evidence for negative impacts on the development of palliative care; indeed, palliative care services were involved in the end-of-life care of 71 per cent of those who requested euthanasia.
- Although traditional groups (cancer patients, higher-educated patients) are most often granted euthanasia, the incidence of requests and granting rates are rising for all patient groups, regardless of education level or disease
- It took 10-15 years for euthanasia to become completely integrated into Belgium's health-care systems (hospitals, homecare, nursing homes)

COMMENTS, QUESTIONS AND ANSWERS

Can the one-month hold in Belgium ever be challenged? In theory it's not a problem, but if patients are advanced in their dementia and become incompetent, it becomes impossible to grant them a euthanasia request.

Is there any plan to separate out psychiatric versus neurodegenerative, Alzheimer's, dementia-type patients from one category? The reported cases have their own coding system and we cannot change that. We will instead focus our new wave survey on psychiatric illnesses and from other studies.

If you could go back to when the legislation was made in Belgium, what would you change? I would change the review committee procedures and composition, and the form the doctor must use to report. Right now, there's no difference between Alzheimer's patients and mental illness patients, and that's unacceptable for researchers and clinicians.

Health Canada's Federal Reporting and Monitoring System

Speaker

Jacque Lemaire, Senior Policy Advisor, Health Canada

BRIEF OVERVIEW

Ms. Lemaire spoke about the context and consultations leading up to the new federal reporting regulations for MAiD that will come into force in the fall of 2018. She described the importance of these regulations and the benefits of monitoring, including how it will foster public trust. She summarized Health Canada's consultation process, what they heard and how they will respond. She also described how each province and territory has chosen to report to Health Canada, and the requirements for practitioners and pharmacists.

DEFINING TERMS

Both **monitoring** and **oversight** require information about individual MAiD cases, but they use that information to serve different purposes.

Monitoring: Monitoring refers to the collection, analysis and public dissemination of data to provide insight on the implementation of the criminal code exemptions that allow assisted dying in Canada. The federal government is responsible for a pan-Canadian monitoring regime.

Oversight: Oversight refers to the compliance and review of individual cases to determine whether the applicable laws have been adhered to, with a view to enforcement where there has been non-compliance. This is generally falling to the provincial and territorial jurisdictions.

DETAILED OVERVIEW

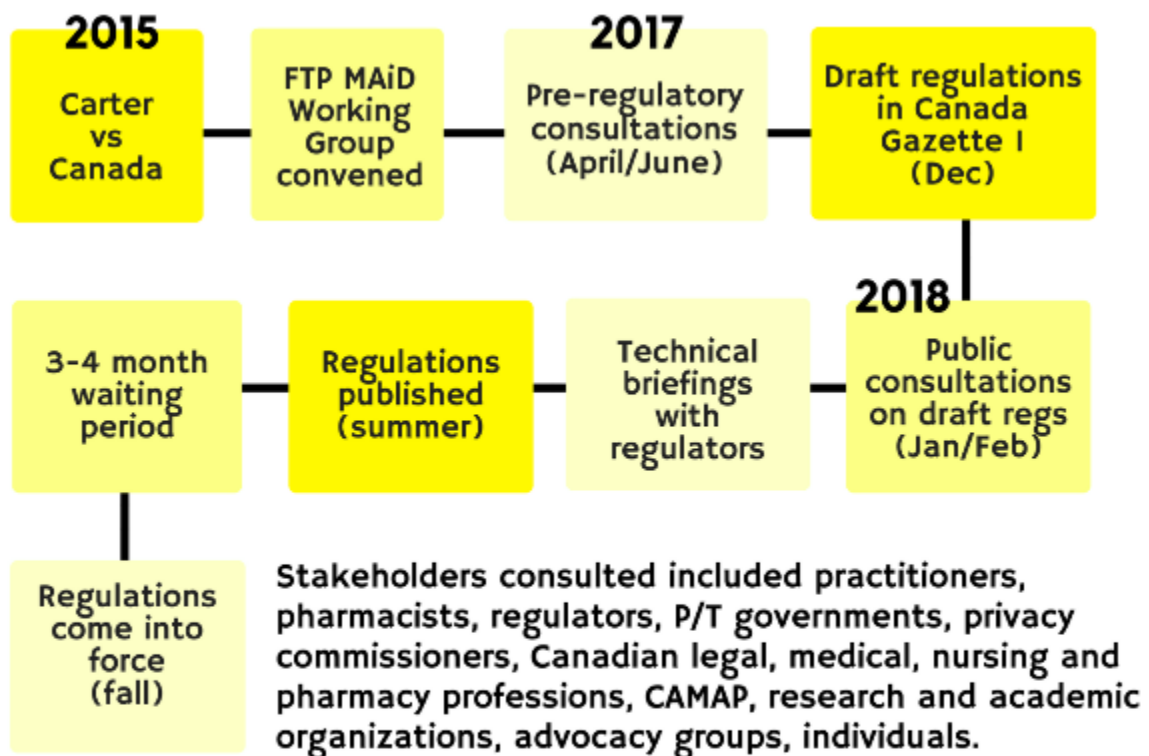
Why monitor?

- *The Act requires it:* The act that amended aspects of the criminal code to allow MAiD to take place for Canadians requires the federal Minister of Health to make regulations for the purposes of monitoring MAiD across Canada.
- *International precedence is making it best practice:* Monitoring is considered essential in virtually all permissive jurisdictions, including the Netherlands, Belgium and Oregon, among others.
- *It will foster public trust:* At the federal level, we are focusing on aggregate information to tell the story about what is happening in Canada. The public accountability and transparency associated with a federal monitoring regime will help us determine whether the legislation is fulfilling its policy objectives, inform further policy development and support independent research and analysis.

Context and considerations guiding the regulations

- The federal legislation - the most important element guiding the scope of the regulations. The Act requires us to collect information on all cases where MAiD has been requested, regardless of whether it was provided. This information yields important insight into the circumstances of those making the request, regardless of outcome. The Act also creates a *criminal offense* subject to providers who knowingly fail to comply with MAiD safeguards or provide MAiD-related reporting, including up to 18 months in jail.
- The *provider perspective* and the *constitutional division of responsibility* - a going concern from both providers and the provinces and territories (P/T) is the potential for duplication of reporting within existing P/T systems.
- *Privacy* - MAiD is a new, uniquely sensitive and complex public policy issue that spans several different disciplines: law, medicine and ethics. The importance of protecting the public's and an individual practitioner's privacy cannot be overstated.

Health Canada's consultations



TAKE HOME MESSAGE: Strike the proper balance between minimizing reporting burden for practitioners and robust reporting for insight into how the law is being implemented.

What we heard

What we'll do

Be mindful of the potential reporting burden on providers reporting similar information to multiple authorities. It should not be so burdensome as to affect the number of providers wanting to be involved and subsequently impact MAiD access to Canadians.

Limit the amount and complexity of information requested.

Respect privacy in practitioners and individual patients. The measures taken to protect personal information should meet or exceed the requirements of P/T privacy legislation.

Timelines for reporting should be extended and aligned to prevent confusion.

Provide more clarity on measures planned for compliance.

Practitioners need clear and timely information on what and how to report.

Provinces and territories may nominate a provincial or territorial designated recipient who would receive reporting information from practitioners and pharmacists and provide it to the federal government.

Where the P/T is designated recipient, it will work with P/Ts to integrate questions into already existing reporting systems.

We have limited the number of questions to those that would naturally occur between a practitioner and their patient. We are avoiding questions where information could be obtained through linkages with other databases.

All federal monitoring activities are subject to the provisions of the federal privacy act and we will be undertaking a privacy assessment.

We've lengthened the time period to 30 days (from 10) in cases where MAiD is provided by administering a substance and we've tried to align the reporting requirements as much as possible.

We will be developing guidance documents for practitioners and pharmacists to support their understanding of what their compliance and reporting obligations are. Where Health Canada is designated recipient, we will follow up with practitioners regarding incomplete reporting. Where province or territory is designated recipient, they will establish guidance documents and follow up.

We will not leave you to figure out the regulations on your own. We will develop guidance documents and help provinces, territories and organizations communicate the requirements and processes.

Who do I report to?

Jurisdictions where Health Canada is Designated Recipient

Jurisdictions where there is a Provincial or Territorial Designated Recipient

Manitoba, New Brunswick, Prince Edward Island, Nova Scotia, Yukon, Newfoundland and Labrador, Quebec*, Ontario (hybrid)

British Columbia (Ministry of Health)
Alberta (Ministry of Health)
Saskatchewan (Saskatchewan Health Authority)
Northwest Territories (Ministry of Health & Social Services)
Nunavut (Ministry of Health)
Ontario (Ontario Chief Coroner)

Health Canada is collaborating with Statistics Canada to develop a secure web portal for practitioners reporting directly to Health Canada.

* Quebec was subsequently moved after the MAiD 2018 conference to being a jurisdiction where Health Canada is the designated recipient

What do I report and when?

Practitioners

- A varying amount of information depending on whether MAiD was provided
- Patient, practitioner, type of request, eligibility, procedural requirements, administering substance, prescribing/providing substance, other details pertaining to reasons for withdrawal, referrals and date and cause of death.
- For patients deemed eligible for whom practitioners administer a substance, report outcome within 30 days of administration.
- For patients deemed eligible and who choose self-administration, wait 90 days before reporting, then report within a 30-day window after that. This is to increase the proportion of reports where the outcome is known.
- Please see Health Canada Slides 13-16 for more details

Pharmacists

- Within 30 days of dispensing a substance for providing MAiD
- Patient, pharmacist, prescriber, date and type of pharmacy
- Please see Health Canada Slide 17 for more details

COMMENTS, QUESTIONS AND ANSWERS

Is it true that if I don't give information on assessments of people for whom I have not provided MAiD that I will be liable for criminal prosecution?

You are required to report on receiving a written request for MAiD. In situations where MAiD is not provided, you are still obligated to report if the following situations occur within a 90-

day period after receiving a written request: you made a referral, you find the patient ineligible, you become aware they withdrew their request for MAiD, you become aware they died from a cause other than MAiD.

Regarding oral prescriptions and the 90-120 day waiting period, B.C. requires the prescriber to be with the patient at the time of consumption. How are other provinces not requiring this dealing with determining capability at time of death?

The number of self-administration cases in Canada is very small. Provinces and territories and their colleges are setting up their own policies with regards to the presence or non-presence of a clinician in the case of a self-administration.

To clarify, in the case of self-administration, MAiD provision occurs when the practitioner prescribes or provides the substance. Therefore, the individual would need to provide consent immediately prior to the act of the practitioner prescribing or providing a substance.

Medico-legal Landscape: Interpretation & Policy Perspectives (panel)

Speakers

- Prof. Jennifer Chandler, Full Professor, Faculty of Law, University of Ottawa
- Dr. Gus Grant, Registrar and CEO, College of Physicians and Surgeons of Nova Scotia
- Mr. Daniel Boivin, Partner, Gowling WGL, Ottawa
- Prof. Jocelyn Downie, University Research Professor, Faculties of Law and Medicine, Dalhousie University

BRIEF OVERVIEW

Mr. Boivin shared lessons learned from the legal community and the Canadian Medical Protective Association (CMPA), which has been advising providers about the risks of MAiD since 2009. Dr. Grant shared his concerns about the lack of national consistency across the regulatory colleges and the pros and cons of Nova Scotia's particular experience implementing MAiD. Through the lenses of various MAiD-related court cases, judicial challenges and parliamentary efforts, Prof. Jennifer Chandler and Prof. Jocelyn Downie shared how the law is evolving and will/may evolve in future.

DETAILED OVERVIEW

The legal perspective from Mr. Daniel Boivin

Eligibility is a medical decision

The determination of whether a patient meets the eligibility criteria (death as reasonably foreseeable) is a medical decision, not a legal one. Knowing what the standard of care is will be a key element of the defense in MAiD cases. Right now, there is insufficient data about standards of care and lawyers must rely on the legal definition a bit too much. As more experience is gained in the community, standards of care must be established. This will allow for the advancement of the law through academic literature, not in the criminal courts.

Issues fraught with legal risk

- What to do when self-administration fails – the range of views in the legal community is so wide as to be unhelpful, making this area a legal minefield for practitioners. The CMPA has encouraged CAMAP to push legislators and regulators to come up with guidelines and regulations to clarify this area.
- Where MAiD can be provided is becoming an issue - some patients are requesting MAiD in public places and parks, which raises a long list of ethical and legal issues.
- The “forgiving phase” of the implementation of MAiD is coming to an end – the agencies charged with reviewing MAiD are still in a mode of wanting to educate rather than prosecute, but this attitude will change soon, giving way to more enforcement.

- An extremely high-risk situation is when family members express disagreement with a patient's decision to proceed with MAiD. This creates an environment rife for post-MAiD legal difficulties.

Advice for providers

- Do cultivate good documentation habits. This is especially important whenever you're aware that family members are not in agreement as it provides the evidence base for a potential defence in court.
- Don't get complacent. As people are getting more comfortable, documentation is getting shorter and shorter. Having good documentation will become more important once the "forgiving phase" ends.
- Don't shorten the 10-day waiting period. We fully recognize that it's an irritant and may lead to unacceptable suffering, but it is still a legal requirement. Some reviewers believe this is an area where a lot of practitioners will get into trouble.

The regulator perspective from Dr. Gus Grant

Nova Scotia's pros

- When MAiD came into existence, there was a coalition of willing physicians and other practitioners who stepped forward and their charismatic leadership was influential
- Nova Scotia is a small province and the sense of community means that physicians there freely call the regulator to access advice
- Nova Scotia has enjoyed tremendous access to government and can easily get audiences with their minister or deputy minister
- Self-administration has not yet come on board

Nova Scotia's cons

- Stigma is strong and there's still a tremendous chill in small communities
- There tends to be conflict avoidance, which leads to workarounds that are not professionally or legally responsible behaviour
- Nova Scotia still hasn't come to terms with the conscientious objection of institutions

Advice for providers

- There really is no good reason to tolerate provincial, territorial or regional differences. Examine the relationship you have with your regulatory college and challenge yourself to be influential in advancing policies for national consistency.

The evolutionary perspective from Profs Jennifer Chandler and Jocelyn Downie

Justice Perell's decision in the A.B. versus Canada case created some clarity around the meaning of the phrase "reasonably foreseeable death." He noted that death did not have to be imminent and that it was not necessary to have a terminal condition, but there still exists a need for a more useful and operational definition for this clause.

Today, two cases – Lamb. v. Attorney General and Truchon and Gladu v. Canada and Quebec – are raising constitutional challenges to the eligibility exclusion criteria under the legislation. The following provisions in the Charter may form the bases for arguments during these cases and provide insight about potential ways the legislation could evolve:

- An exploration of Section 7, the provision of the Charter that guarantees the right to life, liberty or security of a person and stipulates those rights may not be deprived except in accordance with the principles of fundamental justice.
- An exploration of Section 15, the equality or non-discrimination provision of the charter. The legal perspective and challenge for MAiD is whether the law draws a distinction on a prohibited ground, such as disability, race, or gender, and whether this creates an unintended vulnerability paradox.

Conscientiously objecting providers and institutions

The courts are currently ruling on whether the duty to refer/transfer care violates the Charter. After a challenge to the College of Physicians and Surgeons of Ontario's MAiD policy, the court upheld the duty to refer. The essence of their ruling was the concept that the duty of effective referral is proportionate – the positive effects of the referral to the patient significantly outweigh the negative effects to the doctors.

In addition, Newfoundland and Labrador's Department of Health and Community Service has developed a policy saying that patients must still be able to request and receive MAiD at a faith-based facility if, in the view of the MAiD team, their transport will cause undue suffering. This is a promising development that could possibly challenge mission-assurance agreements that allow faith-based institutions to opt out of providing care that is inconsistent with their values.

What can we expect from Parliament?

A report on three groups previously deferred by the legislation is anticipated this fall: access by mature minors, access by an advanced request and the issue of people with solely psychiatric conditions who do not otherwise meet the eligibility criteria.

There are also several unanticipated and unintended issues that Parliament would do well to solve through amendments to the legislation:

- Remove the requirement of witnesses to "understand the nature of the request" for MAiD
- Remove the stipulation that patients must have "a grievous and irremediable medical condition" at the time of request to reduce undue suffering
- Introduce a definition of natural death that includes death brought about by voluntary stopping of eating and drinking (VSED)
- Adopt the Downie-Chandler Institute for Research on Public Policy report, which provides a set of interpretations to problematic clauses in the legislation

COMMENTS, QUESTIONS AND ANSWERS

I think that regarding capacity, the bar is different depending on the context. It's a duration. How do we respond to that?

This is a continuing difficulty across the medico-legal divide, because according to the law there is not a higher threshold, there is only one unitary threshold: "Do you appreciate the nature and consequences of the provision?"

We're highly inconsistent in our assessment of capacity because different disciplines look at patients through different lenses. I would hope that, as a profession, we get more disciplined and more consistent in how we assess capacity.

What happens when the first evaluator accepts but the second refuses, and the patient wants to continue? Do we start them over again?

The experience we've seen across the country is that the request does not start over because one of the two concludes that the patient does not meet the criteria.

Regarding the 10-day wait period, there's a tick box on both the provider and assessor forms, with the two qualifying things being imminent loss of competency or imminent loss of life because of the progressive nature of the disease. I would like to feel that two earnest medical opinions that state the same would be protected against any sort of negative proceedings against providers.

If the provider and the assessor agree that the limited circumstances where the 10-day period can be shortened, that's a pretty good defence. I can't see any likely prosecution if the two appropriately document and the reason for shorting is within the two circumstances that are listed in the legislation.



Bridge C-14: Supporting Patients and Families

Speaker

Ms. Jan Ditchfield, Executive Director of Bridge C-14

BRIEF OVERVIEW

Ms. Ditchfield spoke on behalf of families who are caregivers or walk the journey with loved ones requesting MAiD. Against the backdrop of her experience supporting her mother through MAiD, her plenary emphasized how different the family perspective is from that of MAiD patients and told the story of how lack of community support prompted her to found Bridge C-14. The primary focus of Bridge C-14 is to bridge the gap between procedure and family experience through compassion, respect, care and comfort.

DETAILED OVERVIEW

A pioneering family

Ms. Ditchfield's family was one of the first in the Champlain region to fight and advocate for her mother's right to community-based MAiD. Throughout the process, they tried to find others who had gone through the same process and who might be able to offer support and understanding. They just didn't seem to be there.

Enter Bridge C-14

After experiencing the lack of support first-hand, Ms. Ditchfield founded Bridge C-14 in November 2017. The not-for-profit organization provides compassionate support to families through all stages of the assisted death process. Its primary focus is to bridge the gap between procedure and family experience. Bridge C-14 is based on a peer model; families in the community tell them what's missing and the organization works to fill the gaps. Located in Ottawa, they are a national organization and are in the process of opening programs in British Columbia and Alberta.

Survey results

According to a Bridge C-14 survey, provider feedback from families is largely positive. All families rated their experience with their loved one's provider as "excellent" or "very good" and felt their loved one's needs were listened to. In addition, the majority felt that procedures were well explained, and questions were answered well.

However, gaps emerge in what families experience themselves during a MAiD process:

- Only 60 per cent of families feel prepared to witness the process
- Only 45 per cent of families have been offered follow-up care for grief afterwards
- Only 55 per cent of families feel able to speak openly about MAiD as the manner of death (there is still stigma attached to MAiD)

MAiD makes a unique emotional impact on families

Most lay people are not witnesses to medical procedures, let alone a MAiD procedure. They are not prepared for the emotional impact of seeing tools laid out or how quickly the process happens. Thirty minutes ago, they may have had a conversation with their loved one, only to see them slip away in a matter of minutes when it is impossible to go back.

The grief process with MAiD is unique and comes with a tremendous sense of responsibility for a loved one's death. Most communities have limited to non-existent resources for dealing with grief unless one is able to pay. This situation is creating a tiered grief system, which is incompatible with Bridge C-14's values that grief care should be universal and accessible free of charge for all families.

A community for MAiD families

It's very difficult for people to relate to MAiD-related grief unless they have gone through it themselves. Bridge C-14 bridges that gap by providing spaces and places for MAiD families to come together and reduce their feelings of stigma and isolation. Their programming includes a podcast, MAiD family meetups, MAiD Bereavement Group (in partnership with Dying with Dignity Canada and Ottawa Bereaved Families), an online peer support group and a MAiD community online forum.

Bring Bridge C-14 to your community

Contact info@bridgec14.org or visit www.bridgec14.org

MAiD for the Pediatric Population: Are we Ready?

Speakers

Dr. Christina Vadeboncoeur, Assistant Professor, Pediatrics, Department of Medicine, University of Ottawa

Mr. Mike Kekewich, Director, Clinical and Organizational Ethics, Regional Ethics and MAiD, The Ottawa Hospital

BRIEF OVERVIEW

Dr. Vadeboncoeur and Mr. Kekewich explored key considerations for when MAiD becomes available to the pediatric population. They provided an update on the expert panel convened by the federal government that is researching MAiD for minors. In addition, they shared national survey results about MAiD from the Canadian Pediatric Society. Lastly, they discussed ethical considerations and safeguards that should be in place prior to implementing MAiD for pediatric patients.

DETAILED OVERVIEW

Update on the Expert Panel on Medical Assistance in Dying

The Council of Canadian Academies panel is examining the available evidence on mature minors and how it could inform MAiD in pediatric populations. The panel is still collecting information but hopes to release a report by the end of 2018.

Canadian Pediatric Society survey results

Dr. Vadeboncoeur shared survey results released by the Canadian Pediatric Society in a 2014 position statement about mature minors and physician-assisted dying. The survey generated a 40 per cent response rate (1,050 pediatricians). Respondents reported exploratory discussions with 60 minor patients the previous year, and 17 requests for MAiD from minors.

A second survey to uncover attitudes was distributed to pediatricians and generated a 29 per cent response rate (574 pediatricians):

- 46 per cent of respondents were in favour of extending MAiD to mature minors experiencing progressive or terminal illness or intractable pain
- 29 per cent were in favour of extending it to children with an intolerable disability
- 8 per cent were in favour of extending it to children who's only identified illness was mental illness
- 39 per cent were not in favour of extending MAiD to minors under any circumstances
- Respondents identified the most important factors in extending MAiD to minors as an individual's capacity (55 per cent) and a minimum-stated age (22 per cent).

The challenges around assessing capacity

Ethically speaking, the conversations around mature minors versus children who do not/will never have decision-making capacity (also called not/never competent children) are very different:

- With respect to mature minors, the primary ethical motivation is respecting their autonomy and the protections/safeguards needed are like those for competent adults
- With respect to incompetent children, the ethical motivation is more beneficence and doing good for the children than autonomy, which these children do not have. That becomes a much more challenging assessment for providers.

Age of capacity is arbitrary

Although Quebec has a biological age for consent of treatment, both Dr. Vadeboncoeur and Mr. Kekewich thought it difficult to justify age restrictions given the different rates at which children mature. In addition, some developmental theories suggest the frontal cortex is not fully developed until at least age 25. An imposed biological age for consent for MAiD may be the basis on which it fails for minors given the challenges to our Charter so far.

Capacity is time- and task-specific

Another ethical consideration is the tendency of providers to assess their patients as either having capacity or not, as though it is a binary ability. In practice, it's much more of a grey area. Dr. Vadeboncoeur shared that in Manitoba — where physicians are required to consult a psychiatrist if decision-making capacity is in question — the view is that capacity is time- and task-specific. In the same patient, there may be capacity at one time but not at another. One cannot assess capacity separately from the task at hand.

What safeguards and protections are needed?

- *Include similar safeguards as for adult patients:* Although physicians and parents tend to be paternalistic toward minor patients, minors should still be involved in the decision-making as much as possible.
- *Involve parents when patient capacity is not clear:* Significant conversations need to happen around the role of parents as participants in decision-making.
- *Involve clinicians with advanced knowledge for a robust assessment:* Ensure clinicians providing the assessments of eligibility have specialized or advanced knowledge on the issues, and significant experience assessing competence.
- *Consider additional self-care for providers:* Providing MAiD to a minor would be a very emotional experience for providers, especially if they have a child the same age. What additional self-care would providers need to effectively maintain wellness?

COMMENTS, QUESTIONS AND ANSWERS

In Quebec the age of majority for MAiD is 18 years old, however, I anticipate one day there will be a legal challenge for a younger patient whose parents and providers agree. I don't think we are ready for MAiD for pediatric population yet. Given the complexity of the issues that we're discussing right now I don't think we are

ready either, but we need to prepare. I think there will be challenges made and we need to be ready for them.

Two cases have given me the impression that children tolerate suffering better than adults do. Given this resiliency and the fact that Belgium has gotten very few requests, do you think we need to spend a whole lot of time on it? In terms of numbers, I don't think there will be a lot of kids asking. Their connection to the world is too strong. However, I think we need to be prepared with a reasonable response that's better than "You have to wait until you're 18."

Will it be a distinct set of providers? I hope not completely. People don't magically become adults when they turn a certain age and they don't magically require different kinds of care. Families are no more or less involved just because they're a certain age.

Comment — I do research with families who have been through pediatric palliative care. These deaths are always tragic, but they're always meaningful for these families. There will be a case that pushes this forward legally if it's not happening from the panel. And I think it will make the cracks already there widen, and just make us do MAiD better for everyone.



— REFLECTIONS FROM A DELEGATE

Children are special from a cultural perspective. They've often never had autonomy. They've never lived independently from their parents. They are physically, socially, spiritually and emotionally enmeshed — appropriately so — to their care providers. And that attachment is one of the greatest predictors of the wellness and well-being longitudinally of children. In addition to figuring out the medical issues, we need to bring a cultural lens to how children need particular kinds of support to exercise and discern their own values and wishes, in conversation always with their family.

In anticipation of the grieving process, we need to figure out the kinds of supports that family members will need in anticipation of a child's death. This will require different kinds of resources and supports, different kinds of partnerships.

Our society is diverse and the role of children in families is culturally specific. How can we prepare for the fact that we will encounter some cultures where children are already given and perceived as being quite autonomous and self-directing? For example, in some Indigenous cultures, children are considered wise because they're closest to the ancestors. Having resources around cultural brokering or cultural translation will be essential with families who bring a very different lens to childhood rights, responsibilities and autonomy.

To conclude, children are a specific and unique population with layers of biological, social and cultural complexity. I think it goes far beyond autonomy and justice and issues of age discrimination.

Summary of MAiD Research in Canada

Speaker

Dr. Ellen Wiebe, Clinical Professor, Department of Family Practice, University of British Columbia, CAMAP board member and first provider to provide an assisted death to a Canadian outside Quebec

BRIEF OVERVIEW

Dr. Wiebe outlined the amazing breadth of MAiD-related research that's going on in Canada, from ethnographic studies to the oncologist perspective to why patients refuse the service. She outlined the research published in Canada so far (two publications), in press (four publications) and in progress (more than 16 publications). Conference delegates previewed the publications in progress during the pre-conference research forum. They can anticipate reading most of them in journals in the fall. "It was so much fun yesterday to hear all the research from across the country," she said.

DETAILED OVERVIEW

MAiD Research published as of today

At this point, Canada has two research publications so far:

- M Li et al.'s *Medical Assistance in Dying — Implementing a Hospital-Based Program in Canada*
- W.D. Robertson et al.'s *Case Review of Medicinally Assisted Deaths on Vancouver Island*

Health Canada has also published the *2nd Interim Report on Medical Assistance in Dying in Canada*, a valuable source of information for assessors and providers.

MAiD Research in press

- J Shaw et al.'s *Providing Medical Assistance in Dying: Practice Perspectives*
- S Holmes et al.'s *A Qualitative Study Exploring the Journey of Supporting a Loved One through a Medically Assisted Death in Canada*
- A Nun et al.'s *Experiences and perspectives of people who pursued Medical Assistance in Dying (MAiD) in Vancouver*
- ER Wiebe et al.'s *Reasons for Requesting Medical Assistance in Dying*

MAiD Research in Progress

This is by no means an exhaustive list of MAiD research in progress in Canada, but it gives an indication of breadth and depth of projects taking place:

- A Frolic et al.'s *MAiD to Last: Engaging Health Professionals, Leaders and Physicians to Shift Culture and Create Sustainable MAiD Programs*
- J Dunsford's *MAiD in Manitoba: Implementing an Assisted Dying Service*
- K Fletcher et al.'s *Social Work's Role in Medical Assistance in Dying: A Cross-Canada Analysis of Social Worker Experience*
- K Wiebe et al.'s *Dignity Therapy and MAiD: Early Experiences in Manitoba*
- A Farag et al.'s *Exploring Convergence and Divergence in the Practices of MAiD and Palliative Care*
- J Shaw et al.'s *Perceptions and Experiences of MAiD within Marginalized Populations*
- I Marcoux's *Factors Associated with Patient Requests to Hasten Death and with Related Medical Practices: Preliminary Results of a Pan-Canadian Study with Physicians*
- S Oczkowski et al.'s *Patient, Family and Provider Perceptions of the Quality of Care in Assisted Dying: An Exploratory Mixed Methods Study*
- L Thorpe et al.'s *Multivariate Survival Analysis of Patients Requesting MAiD in a University based MAiD Program*
- S Oczkowski et al.'s *Oncologists and Medical Assistance in Dying: Where do we Stand?*
- E Wiebe et al.'s *The Experiences of Volunteer Witnesses for Medical Assistance in Dying*
- M Kelly et al.'s *Experience of MAiD Care Coordinators*
- J Jokinen et al.'s *Patient and Doctor Experiences of MAiD Refusal*
- J Brown et al.'s *Completion of Medical Certificates of Death after an Assisted Death: An Environmental Scan of Practices*
- B Chauhan's *Legalizing Death: Lessons on How a Government Should Legislate and Operationalize Assisted Dying*
- E Wiebe et al.'s CAMAP survey data: Get the final results next year at the MAiD Research Forum in Vancouver, B.C.



Cross-country Checkup: Issues & Challenges (panel)

Speakers

- Dr. Claude Rivard, palliative care physician, Que.
- Dr. Kim Wiebe, internist and MAiD physician, Man.
- Dr. Konia Trouton, clinical professor, Department of Family Practice, University of British Columbia, B.C.
- Dr. Francois de Wet, family physician, chief of staff of rural medicine, Baie Verte, Nfld.
- Dr. Gerald Ashe, family physician, Brockville, Ont.

BRIEF OVERVIEW

Physicians from British Columbia, Manitoba, Newfoundland and Labrador, Ontario and Quebec each gave an overview of the implementation challenges they are facing while providing MAiD in their respective provinces. As MAiD is maturing in Canada, it is getting more diverse in terms of policies and practices. However, there are some common concerns across the provinces, including documentation issues, remuneration and billing, lack of intra-provincial consistency and standards, and increasing demand and capacity to provide.

DETAILED OVERVIEW

Populations and MAiD deaths at a glance

	British Columbia	Manitoba	Newfoundland & Labrador	Ontario	Quebec
Population (approx.)	4.8 million	1.3 million	500,000	14.3 million	8.4 million
# MAiD deaths (approx.)	867 as of March 2018	133 as of April 2018	22	1,352	1,269 as of Dec 2017

British Columbia

British Columbia has a population of approximately 4.8 million and has had 867 MAiD deaths since March of 2018. There are five health authorities, and each deal with MAiD differently. Uniquely, the province offers a consultative service called Rapid Access to Consultative Expertise (RACE) through a 1-800 number. Knowledgeable MAiD providers will return calls and give advice. MAiD is listed as cause of death on the death certificate.

Concerns

- Coordination: Some centers are busy, whereas rural areas still lack providers
- Reporting: Duplication between the health authority and the coroner
- Renumeration: Billing issues are starting to be addressed
- Ancillary care: Bereavement care is not integrated.

Manitoba

Manitoba has a population of 1.3 million and has had 133 MAiD deaths as of April 2018. A single multidisciplinary clinical team provides MAiD throughout the province and is fully funded by the government, including for travel. MAiD is not and has never been reportable to the coroner. The underlying condition is listed as cause of death on the death certificate.

Concerns

- Lack of consistency and mandated standards: Only physicians within the health authorities must use the MAiD team. Those in private practice can make and administer their own medication. No standards for prescription or provision have been mandated by the regulatory colleges.
- Increasing demand and capacity to provide: The central team model is doable because of Manitoba's small population but may not be sustainable.
- Lack of voice: The intimate relationship with the provincial government has made it hard to be vocal. There is concern that the interpretation and approach are becoming homogenous.

- Access: A single MAiD team has allowed the palliative care group to avoid determining how to deal with MAiD. Is this helping or hindering access?

Newfoundland and Labrador

Newfoundland and Labrador has a population of approximately 500,000 people and has had 22 MAiD deaths. Despite an aging population with lots of cancer, there has been low uptake of MAiD (34 assessments so far). This is likely due to a large religious population and low exposure in the media. The four regional health authorities each have their own team with contacts and coordinators. Uniquely, the province put together a MAiD “roadshow,” a one-day accredited course on MAiD for nurses and physicians across the province.

Concerns

- Renumeration: There are no fee codes.
- Reporting: There is no compulsory reporting/documentation in the province.
- Provincial policy: A provincial policy has wording that is problematic because it seems to restrict nurses from talking about MAiD to their patients.
- Faith-based facilities: There are issues when patients need to be moved.

Ontario

Ontario has a population of approximately 14.3 million and has had 1,269 MAiD deaths as of December 2017. Ontario is divided into 14 Local Health Integration Networks (LHINs), which all have different approaches to MAiD. Uniquely, five physicians are trying to establish a MAiD house in Toronto to accommodate patients who don’t want to die in their homes.

Concerns

- Divergent policies among the LHINs: For example, only three LHINs will allow nurse practitioners to assess and provide. Eight will allow only assessments. Three will allow neither.
- Accessibility of information: The 1-800 number is very hard for prospective MAiD patients to find on the Ministry of Health’s website.
- Coordination: People have been reluctant to put their name on the MAiD coordinator’s list. Although more than 300 physicians have provided in Ontario, fewer than 100 are on the list. It’s a problem to get people to sign up.
- Renumeration: The current billing guide needs to be updated.

Quebec

Quebec has a population of approximately 8.4 million and has had 1,269 MAiD deaths as of December 2017. Quebec started providing MAiD six months earlier than the rest of Canada due to provincial legislation. Quebec is divided into 35 *Centres intégrés de santé et de services sociaux* (CISSS) and each CISSS is responsible for health care given on its territory, including MAiD. In Quebec, only physicians can provide MAiD. There is no self-administered protocol. The underlying condition is listed as cause of death on the death certificate.

Concerns:

- Access: Only 64 per cent of patients requesting MAiD have access to it.
- *Commission des soins de fin de vie*: Reviewing 43 per cent of all MAiD cases is considered harassment by providers.
- Reporting: The forms to be completed are more adapted to the needs of lawyers than those of clinicians
- Increasing demand and capacity to provide

COMMENTS, QUESTIONS AND ANSWERS

I get a lot of calls from patients asking if their insurance will be okay. With MAiD on the death certificate in B.C., how does that work?

(Composite answer from multiple delegates) We've had no issues with death certificates affecting life insurance in B.C. Our understanding is that life insurance policies in Canada reflect that MAiD is not suicide. (Except for potentially one, an outlier that considers MAiD a suicide and will not honour the policy.) Ontario passed legislation to ensure MAiD would not be treated as suicide from an insurance perspective.

Comment - I'm from Saskatoon the coroner is our oversight. They felt they must legally say "suicide" as the mechanism of death and this has led to some unpleasant conversations with patients. It was the single biggest concern of families and patients that suicide is not on that death certificate.

Comment - I do want to speak more generally for the chief coroners and medical examiners across Canada. These discussions about death certificates and cause of death are ongoing in our national group, and things are evolving.



MAiD Through the Lens of Those we Serve

Speaker

Ms. Gillian Szollos, Health Policy, Promotion and Education Consultant; daughter of MAiD patient Rosemary (Rossy) Lewis

BRIEF OVERVIEW

Ms. Szollos told the story of her mother's MAiD death on November 7, 2017. Having suffered for years from the after-effects of transitional cell carcinoma, her mother, Rosemary Lewis, expressed interest in MAiD as soon as the legislation passed. Ms. Szollos took the audience through her family's MAiD journey: watching her mother's intolerable suffering from the worst case of restless legs syndrome her doctors had ever seen; their worry and collective relief when she passed her two assessments; and the humour, ritual and symbolism that they relied on to alleviate the burden of anticipating their mother's assisted death.

DETAILED OVERVIEW

Rosemary (Rossy) Lewis, 1933-2017

Rosemary Lewis was born in Burma and raised India. She was a prolific writer and loved poetry, giving each of her children and grandchildren sonnets at all their major life events. Ms. Szollos was very close to her mother and lived next door with her family. "It was a rich and fulfilling extended family dynamic, rare in today's society," said Ms. Szollos.

In June 2013, Mrs. Lewis was diagnosed with transitional cell carcinoma in her left kidney. Although she had it promptly removed, the remaining kidney was poorly functional at best, and the family knew the timer had been set. Mrs. Lewis also suffered from restless leg syndrome and would beat her legs with a little wooden club at night to ease the symptoms. Increasing doses of narcotics provided less and less relief, and she spoke often of death.

Finding comfort in humour, ritual and symbolism

After Mrs. Lewis passed her two assessments, the family knew that her wish for an assisted death would come true. Ms. Szollos found humour, ritual and symbolism very important during this time. The family began to find ways to unite themselves around their mother's choice. They made new memories with her, times of laughter and celebration before her death that also served as tools to help their collective grieving. They referred to the date of her assisted death as Transformation Tuesday. They had their hands hennaed and wore red thread bracelets, which have symbolic meaning in nearly every faith.

"In my mind, the red thread connected us all and would serve as a visual reminder of our mother for the year it usually takes for it to fall off. And I liked the fact that it was individual, that it would take a different length of time for each of us, just as our own grieving is very individual," said Ms. Szollos.

Death is a natural part of life

The experience preparing for her mother's assisted death made Ms. Szollos realize how much death is a natural part of one's life cycle and not a failure of the medical system. "It can be wonderful when rescued from the hospital, bright lights, machines and strangers, and returned to the bosom of the family at home, supported by the community," she said.

"One of the hardest things about this route is that when are letting go of someone you love, you are never ready. Readiness should not in fact be an expectation at all, only acceptance. And we had accepted. We had accepted she was ready, time stopped marching, and the end had arrived," said Ms. Szollos.

Mrs. Lewis died in her daughter's arms with her family by her side. "My uncles had jokingly said that I would be reverse birthing her that day, and quite frankly, that's exactly what it felt as if I was doing," said Ms. Szollos, who has worked as a doula.

Everyone deserves a death well-lived

Ms. Szollos talked about how grateful she was for all the systems that made it possible to take time from work to care for her parents in their last weeks and months, to the MAiD program, which made this release a possibility for her mother, to Dr. Naik and her palliative nurse for making the process on the day painless and without stress, to her caregivers for their caregiving, and for everyone in the audience for supporting this humane approach to end-of-life, because everyone deserves a death well-lived.



Organ and Tissue Donation for MAiD

Speaker

Dr. Andrew Healey, Chief Medical Officer – Donation, Trillium Gift of Life Network

BRIEF OVERVIEW

Dr. Healey spoke to assessors and providers about what an organ/tissue donation procedure would look for a MAiD patient. He spoke mostly from the perspective of the government of Ontario's Trillium Gift of Life Network (TGLN). The opportunity to donate organs and tissues is offered to every medically eligible Ontarian as part of high-quality end-of-life care.

DETAILED OVERVIEW

Is your patient eligible for donating?

TGLN is a not-for-profit agency that aims to save and enhance lives through the gift of organ and tissue donation and transplantation in Ontario. Ontario legislation requires that organizations to notify TGLN of imminent deaths, including MAiD deaths. However, patients must meet certain medical eligibility criteria. These include being free from malignancy, receiving therapy intravenously, being in a hospital with an operating room and having their death confirmed using cardio-respiratory criteria. Patients with malignancy, although excluded from organ donation, can still be potential cornea donors and tissue donors. There is some debate about whether ALS or ALS-like illnesses are transmissible.

Timing is so important during the donation process

- A patient must complete their decision to seek MAiD prior to the conversation about donation. It is also vital that the "ask" of donation be decoupled from MAiD, and that a TGLN donation expert ask instead of a MAiD provider. Ideally, there is sufficient time to

incorporate donation into a patient's planned end-of-life care (allowing time for suitability workups, which usually involve an X-ray and lots of bloodwork).

- Determining an accurate time of death is also crucial when an organ donation is planned. Even 30 minutes can be warm ischemia time for organs and reduce their quality. In fact, donation after a circulatory death (after life support is withdrawn) is better for organ quality because warm ischemia will be short. Patients who receive these transplants do very well. The challenge is placing an arterial line. Although it allows the organs to be of highest quality, patients know that it can hurt.
- After five minutes of confirmed death, the body is taken to the operating room and the organs are recovered quickly. Most families are very supportive once they understand in advance that this decision is important to the patient and that it has been planned.

How to tactfully incorporate the donation conversation into MAiD

Discussion of donation is an expert conversation. Approaching patients about this topic can be challenging and their first response is usually enduring (they cannot change their mind without also having to admit they were wrong and we shouldn't expect them to do so). As such, it is important that the idea of donation be offered in a practiced way by experts.

In Ontario, if you have a MAiD patient who you believe would meet the eligibility criteria and be a potential donor, there is a 1-800 number to reach TGLN's provincial resource center. It can provide you with tactful language for broaching the topic and providing an introduction without directly making an ask. For example, "Because you are having an anticipated death, we want to make sure you have an opportunity to consider organ or tissue donation, and I'd like you to speak to an expert in that field."

By the numbers

Between July 1, 2016 to April 25, 2018, TGLN has facilitated nine organ donations in the province and 70 tissue donors, saving 30 lives in through the process.

COMMENTS, QUESTIONS AND ANSWERS

What's my duty to the patient to inform them that I'm going to extend beyond what they would logically see as their circle of care in a way that is respectful but also allows for the first conversation to be with TGLN? You have a duty to report patients who are going to experience an anticipated death. Although the legislation specifically applies to facilities and not to individual providers, I would still encourage you to make that notification. The TGLN Act covers the extension of the circle of care to TGLN to share personal health information.

I'm a MAiD provider we provide MAiD in our small town's hospital where I have admitting privileges. However, organ donation requires going to a bigger center where I don't have admitting privileges. What do I do? If your hospital has an operating room, we can send the retrieval team and the experts there to do the procedure. We can go anywhere there is an OR.

MAiD: A Team Approach (panel)

Speakers

- Ms. Vanessa Chaput, MAiD Coordinator, The Ottawa Hospital
- Mrs. Lauren Clark, Social Worker, The Ottawa Hospital
- Mrs. Kelly Jarvis, Critical Care and MAiD Registered Nurse, The Ottawa Hospital
- Dr. Alan Karovitch, Head/Chair, Division of General Internal Medicine, Department of Medicine, University of Ottawa

BRIEF OVERVIEW

A panel consisting of a MAiD coordinator, a nurse, a social worker and a medical physician — members of The Ottawa Hospital (TOH) MAiD team since its inception in 2016 — shared their interdisciplinary approach to MAiD and explained the roles of the different professionals on their team. Thanks to a supportive leadership, their team is fully resourced and has been able to thrive and grow. Today, they support approximately 15 cases at any given time. Panel members encouraged many solo providers in the audience to share their challenges and experiences.

DETAILED OVERVIEW

TOH MAiD by the numbers

An interdisciplinary team

- 11 social workers
- 18 nurses
- 18 medical physician assessors, nine of which are also providers
- 1 MAiD coordinator
- 1 pharmacy

Caseload

- 15 MAiD cases on the go at any given time
- Approx. 40% home procedures/60% inpatient and outpatient procedures

Medical physician team make-up

- General internists
- ICU doctors
- Psychiatrists
- Palliative care physicians
- Anaesthetists

A supportive environment

Group huddles before and after a procedure, social events and whole group meetings are just some of the ways The Ottawa Hospital MAiD team supports each other. As the logistics

get harder, whether around organ donation, Health Canada reporting requirements or challenges determining eligibility, they are grateful for the opportunity to solve problems together.

Pre- and post-huddles

On the day of the procedure, the pre-huddle is an important moment for group support. It is especially valuable for the nurses, who have not met the patient or their family, and who need to validate what they have read in the other team members' notes. Once the procedure is finished, when the family is given time, the post-huddle occurs. The MAiD team then reconvenes to decompress, support each other and discuss things that went well or things they could improve.

Professional roles

Medical physicians

Dr. Karovitch described the MAiD team at a glance. He mentioned how grateful he was to the TOH pharmacy for completing most of the paperwork and making drug acquisition very seamless. He also credited the MAiD coordinator for always finding the right second assessor, depending on the patient's situation. For example, if the prognosis is unclear, the next assessor will be a general internist. If IV access is a worry, they are an anaesthetist. If there are mental health issues, they are a psychiatrist.

Thanks to the flexibility of the system, the team is not only able to use each other's expertise, but also call in professionals who are not part of the regular MAiD team. For example, when two recent patients had difficulty communicating due to stroke and cerebellar ataxia, the MAiD coordinator called in speech-language pathologists. Without their expertise, the medical physician may not have been able to conclude that these patients were in fact both competent and clearly eligible for MAiD, which they both received.

Nurses

Mrs. Jarvis talked about her experience as a MAiD Registered Nurse (RN) with TOH MAiD program. Nursing is component of the inpatient/outpatient process and care is provided by two registered nurses per procedure. The nurses do not get the privilege of meeting the patient or their families. As such, they depend heavily on the social worker's and assessor's notes to get to know the patient, their family dynamics, and their prognosis and diagnosis.

The nurses are responsible for stocking and bringing the MAiD cart, which is funded and supplied through the intensive care unit (ICU). It contains IVs, flushes, tubing, linens, a shroud and a death package with many forms. During the procedure, they provide backup, sometimes even putting in the IV. They document important details, such as time the medication was given, what was given, doses, time of death, who was in the room, etc.

After the procedure, the nurses contact Trillium Gift of Life Network and prepare the body. They wrap the body and wait for the porters to take it to the morgue. Lastly, they return and stock the MAiD cart so it's ready for the next procedure.

Social workers

Mrs. Clark spoke about her experiences during assessments and procedures, and her advocacy for social workers to be included on the TOH MAiD team. The social workers support patients, their families and hospital colleagues before, during and after the procedure. They identify and address psychosocial needs and wishes, deal with any problems and share coping strategies. They take on tasks that might otherwise fall to the family or other team members, such as identifying items that bring personal meaning, pleasure or peace on the day of the procedure and helping to set up the room.

The social workers identify the patient's support system and provide the family with immediate support after the procedure, which frees up the rest of the MAiD team for administrative tasks. Thanks to social workers, there is reassurance that someone is checking in with the family and making links to community resources, such as Bridge C-14.

COMMENTS, QUESTIONS AND ANSWERS

Where do you do it in the hospital: in the patient's room or in a special room?

If they're admitted to hospital, we make sure they get a private room and do it in their room. For outpatients, it tends to be on Saturday. We have an outpatient area specifically designed for this: quiet, private, peaceful and quite nice.

What's your advice for getting hospital management and the medical committee on board?

We are lucky that we had a supportive leadership team from the beginning. One of our success factors was that leadership didn't just try to direct from above, leadership members got in with the team and have been part of it the whole time. Even from nursing, there was support at the management level.

I'd like to invite further conversation about the sacred dimension and how do we find each families' journey - how can we give more breathing room for that?

Spirituality is a very important component and has become a part of the conversation that the social workers have with patients at The Ottawa Hospital.

Comment – A lesson learned for us was that when your intensivists come in to declare death, they should be cognizant of what the MAiD provider and team put in to the relationship with that family, and not take over. Please remember to try to keep the spirit of MAiD intact, and not let the intensivists or the organ donation team take over.

Palliative Care and MAiD: Finding Common Ground

Speakers

Dr. Stefanie Green, co-founder and current president of CAMAP; clinical faculty member at the University of Victoria and the University of British Columbia

Dr. David Henderson, palliative care physician and Assistant Professor in the Faculty of Family Medicine at Dalhousie University

BRIEF OVERVIEW

“You must be as much fun at parties as I am.” – Dr. Henderson, palliative care physician, to Dr. Green, MAiD provider

DETAILED OVERVIEW

Shared principles – we are not so different

Dr. Green outlined many things that palliative care and MAiD physicians have in common:

- They both serve patients who are at the end of life,
- They both serve patients who are at the centre of their care,
- They both believe that all patients and clinicians deserve respect, and
- They both strive to provide excellence in care, which includes following the law and respecting provincial/local facility guidelines.

The MAiD community’s wish list

Speaking from the MAiD perspective but with great reverence for the work of palliative care physicians, Dr. Green compiled a wish-list for the MAiD community:

- No stigmatization by the public, our colleagues or our families
- That patients have access to all options of care
- That palliative care colleagues be able to explain MAiD well to those who enquire
- That anybody who wishes to be involved in MAiD be welcomed
- Ongoing and clear communication between teams

A heart-warming story about teamwork

Dr. Green told a story about one of her patients to illustrate how a constructive relationship between MAiD and palliative care teams could work. A physician colleague in palliative care once referred a patient who was asking for information about MAiD to her. What this patient really wanted was to die at home naturally with his wife by his side, but he asked Dr. Green to stay in touch once a month. The patient’s wish came true in the end: he received a natural death at home with support from palliative care and support from MAiD, with both teams talking together throughout the months leading up to his death.

A personal reflection about how MAiD has helped palliative care

Dr. Henderson reflected on the history of palliative care in Canada and how no one was willing to take end-of-life issues seriously until MAiD discussions came along. He credited MAiD for giving the push that was needed for politicians and health-care leaders to consider end-of-life as an important phase in life, to enquire more and finally listen. "We had been trying to talk to them for a long time already," said Dr. Henderson.

Palliative care's long journey towards trust

Dr. Henderson offered a theory rooted in history as to why tension sometimes exists between palliative care and MAiD communities. As palliative care has been slowly and gradually integrating within health-care systems, it has suffered from misperceptions. Unfortunately, many patients and physicians still believe that palliative care medications and treatments shorten life when in fact they simply manage pain. "That's one of the reasons why some palliative care physicians are hesitant to provide MAiD; it would potentially undermine 40-odd years of effort reassuring people that we're not going to hasten their death," said Dr. Henderson.

Palliative care survey results

The Canadian Society of Palliative Care Physicians conducted a survey in October 2017 about MAiD. The response rate was 54 per cent (213 responses).

- 22 per cent conduct MAiD assessments
- Eight per cent provide MAiD procedures
- 40 per cent believe MAiD has neither improved nor worsened palliative care access or delivery in their area; 35 per cent cited negative impacts; 17 per cent cited positive impacts
- 60 per cent expressed a desire to develop public statements around what palliative care is, what the access is like for Canadians, respect and protection for conscientious objectors, respect for the diversity of opinions (including those who choose to be involved in MAiD)

Messages that need to be said (and heard)

Dr. Green recommended that conference attendees make local conversations happen (because this is how you start change). She shared some messaging and encouraged both communities develop a common language for describing what each care team does:

- We value and support what the palliative care community does
- We support any initiative that would improve access to good palliative care
- We understand the historical need for the palliative care community to justify their existence to other disciplines, because we feel that too
- We endorse a good knowledge of palliative care principles and practices among MAiD assessors and providers
- We do not encourage anyone to stop taking analgesia to maintain capacity
- We recognize that a stated desire to hasten death could mean several things (including simply the invitation to have a conversation)

Potential areas for collaborative work

- Improving access to resourced palliative care (some programs have waitlists)
- Messaging and education for the public (to combat stigma and change the culture that dying is something to be feared and avoided)
- Rally around the common goal of supporting patients/families to minimize suffering
- Every health-care provider learns how to respond to a MAiD request comfortably

Dr. Henderson also introduced the idea that palliative care and MAiD consultants be credentialed and certified. This would ensure quality of service, lend credibility to the profession and help foster relationships between local palliative care and MAiD teams.

COMMENTS, QUESTIONS AND ANSWERS

The World Health Organization stated that palliative care will neither delay nor hasten death. Can we not in Canada just accept that? And accept that in some cases, it's acceptable to hasten death?

In 2018, the answer is probably no, only because relationships still need to be built, skilled providers need to be ensured on both sides, good work must be done, mutual respect must be given time to grow. However, over time, perhaps 10 years from now, I think this conversation will happen again. If we push it now too hard and too fast, I think that will just put more wedges in.

I think that they're not necessarily mutually exclusive, even though, in certain organizations, if you choose to proceed with MAiD you're booted off the palliative care service.

I agree. It doesn't matter if you agree or disagree with a person's decision. There's no reason why you can't still be there for them. Patients shouldn't be discharged from a palliative care service. We should continue to provide the same support. For example, we see patients all the time taking their 12th round of chemotherapy, but we don't walk away from them. This should be no different.

Comment – I'm a MAiD provider but I've also done euthanasia for 15 years because I'm a veterinarian. My humble suggestion to CAMAP is that you speak to veterinarians. I must make very emotionally charged decisions about magnificent creatures who cannot return to the wild. I take that emotional baggage home and do not have a team. There are differences, but there also are huge similarities. For example, we're euthanizing beloved family members, too. And we routinely and seamlessly talk to our patients' owners about palliative care and MAiD in the same breath. I think that we will eventually get there as human providers, but right now we're in a very early and steep part of the learning curve.



Dying with Dignity: Advocating for Patients

Speakers

Ms. Shanaaz Gokool, CEO, Dying with Dignity Canada

Prof. Daphne Gilbert, Associate Professor, Faculty of Law, University of Ottawa

BRIEF OVERVIEW

Ms. Gokool and Prof. Gilbert explained the role Dying with Dignity (DWD) plays in the advocacy for MAiD patients. Prof. Gilbert spoke about DWD's human rights work to intervene in court cases deliberating forced transfers out of conscientiously objecting institutions. Ms. Gokool shared a different side of DWD – its work to provide personal support for people and share their stories. She spoke about her own experiences helping famous MAiD patients, including AB, Mr. Barry Hyman, and Shirley and George Brickenden.

DETAILED OVERVIEW

Institutional objections

Institutional refusal has led to several forced transfers of patients to hospitals where MAiD can happen. Dying with Dignity (DWD) intervened in one recent case to support a provincial regulatory college position that an effective referral is one way to reconcile patient and practitioner rights. The college's argument was that physicians are gatekeepers to services. Equity must be proactively encouraged and supported by the profession.

Do institutions have Charter rights?

The Charter of Rights and Freedoms says that "everyone" has the right to freedom of religion and conscience, but does "everyone" include institutions? Currently there is no resolution for institutional refusals, however, there are two ways that could happen:

- The government could act and pass legislation. However, the political will to speak out against Catholic institutions around MAiD has not yet been forthcoming.
- The courts could resolve the issue. Although progress here is underway, there is still one problem: the court process needs litigants and the plaintiff would have to be the patient who was forced to transfer out or their family.

The challenge for Dying with Dignity

DWD faces the challenge of trying to be very supportive of people's rights and entitlement to MAiD, while at the same time not being perceived as scavenging around for potential litigants to bring forth a case. It's very difficult and unfortunate that this must happen on the coattails of somebody who is dying or a very bereaved and vulnerable family.

Although there is often a tension between law and medicine, MAiD is an area where there is a common deep engagement and where medicine and law can have the best possible partnership. Prof. Gilbert urged the audience to think about MAiD as a political issue, not just a medical or legal one. Many of the gaps and problems will be addressed by political advocacy as issues, such as forced transfers, are moved forward.

The case of AB

AB suffered from severe osteoarthritis and was a plaintiff in a landmark Ontario MAiD case in 2017. Although AB eventually won her case, her original provider had reservations about providing and changed her mind, worried that AB's case would be appealed. Ms. Gokool helped AB find another provider and pledged to help share her story so other patients and their families would benefit from her ordeal. AB's case didn't solve the problem of a "reasonably foreseeable" death, but for many people, her case is the difference between being eligible and not being eligible.

The case of Mr. Barry Hyman

Mr. Barry Hyman was a patient in a Vancouver Jewish retirement home that refused to allow MAiD on its premises. His case gave DWD the opportunity to work with MAiD provider Dr. Ellen Wiebe and Lola Doyle (Mr. Hyman's daughter) to tell his story and raise awareness about the issue of forced transfers for MAiD. A day after his story came out in *The Globe and Mail*, DWD Canada and CAMAP issued a joint statement, the first public statement in Canada referencing and using the term "forced transfers for medical assistance in dying."

Shirley and George Brickenden

Shirley and George Brickenden, both World War II veterans suffering from underlying conditions causing them much pain, met Ms. Gokool two years ago. She supported their request to stop their suffering and pain, and access MAiD together. Their story came out after they died. They told their story because they wanted to inspire others and provide hope and comfort. They wanted their story to provide an entry point for others into discussions that are often so uncomfortable. They have inspired the kind of conversations we all need to be having and thinking about.

Why do these stories matter?

Ms. Gokool said that at some point, they may become future evidence in court. Eventually, issues are going to be punted back to the legislators, who will have to legislate with fairness and compassion. No one single group, organization or area of expertise owns this issue. As it should for all human rights issues, it is owned by the public. Change is going to come from them. Ms. Gokool truly believes in the power of storytelling and that eventually the personal story will win the day for all of us.

COMMENTS, QUESTIONS AND ANSWERS

Comment - Forced transfers also have a significant impact and ripple effect on providers. They must let go of a therapeutic relationship with a patient they've been following for weeks or months. And the patient then must try to rebuild a therapeutic relationship with someone else at a most tender and vulnerable moment.

Is DWD working to engage with faith-based facilities or local providers at a smaller relationship-building level? I think it's a conversation about resistance and will require more than legislation.

We only have eight staff, so it's hard for us to engage one-on-one in small communities nationally. However, we do have many volunteers. We would urge people in the room to come and talk to us if you are working in a facility that doesn't allow MAiD. You have rights, too, in those facilities, and we can help.



Providing MAiD to Vulnerable, Indigenous, Homeless and Frail Elderly populations (panel)

Speakers

Dr. Jeff Blackmer, Vice President, Medical Professionalism, Canadian Medical Association

Prof. Jocelyn Downie, University Research Professor, Faculties of Law and Medicine, Dalhousie University

Dr. Christine Gibson, Family Physician and Social Innovation Specialist

BRIEF OVERVIEW

Panelists provided a definition of vulnerability and a brief history of the kinds of vulnerability discussions in Canada leading up to Bill C-14. They introduced the concept of structural violence, how the health care system itself can perpetuate inequity, and how important it is to integrate social accountability concepts into MAiD assessments. They also described ways providers can help empower vulnerable populations and shift the lens from vulnerability to ability.

DETAILED OVERVIEW

What is vulnerability?

Dr. Blackmer defined vulnerability as a susceptibility or weakness, often associated with a situation, such as illness, poverty or illiteracy. In medicine, a vulnerable patient is one who is unable to protect themselves from significant harm or exploitation.

The history of vulnerability leading up to the legislation

Dr. Blackmer gave a brief history of the kinds of vulnerability discussions in the Canadian Medical Association (CMA), community and courts leading up to the final federal legislation.

In 2014, the Canadian Medical Association consulted with the Canadian public and with physicians about end-of-life issues, including assisted dying and vulnerability, during a series of cross-country roadshows. The public expressed a wish for strict protocols and safeguards to protect vulnerable individuals and populations if Canadian law was to allow assisted dying.

The CMA later produced a document called *Principles-based Recommendations for a Canadian Approach to Assisted Dying* following consultations with its members. Consent and capacity were two foundational principles relating to vulnerability. So was the concept of voluntariness, which means among other things that attending physicians must be satisfied that a patient's decision to undergo assisted dying has been made freely without coercion.

In 2016, the Vulnerable Persons Standard was developed by a group of ethicists, medical professionals, lawyers and advocates. The Standard was a response to the Supreme Court of Canada's Carter Decision and an aide for the Government of Canada to develop Canada's first medical-assistance in dying law, Bill C-14. Although not formally endorsed by the CMA, the Standard was an important document at the time because it proposed principles around vulnerability and different perspectives on possible solutions.

The courts essentially found vulnerability to be part of everyday medical care. Although they agreed on a need for process and a carefully designed and monitored set of safeguards, they found the regime need not be substantially different from the other types of medical decisions that health-care professionals are already making.

Although there are some differences, additions and deletions, Bill C-14 does essentially reflect much of the profession's voice. Many of the concepts that the CMA originally recommended were ultimately reflected in the final legislation, including consent, capacity, waiting periods, and different assessments by different providers.

Integrating social accountability concepts into MAiD assessments

Dr. Gibson introduced the idea that the health-care system itself is trauma-inducing, and to some patient groups more than others. She proposed a theory that we are all vulnerable once we enter the health-care system as a patient on an illness journey.

She introduced the concept of **structural violence**, which is suffering induced by historical and economical forces that constrain a person's ability to rise above their situation. To

understand suffering, one must embed an individual's biography in the larger matrix of culture, history and political climate.

The health-care system is particularly trauma-inducing for patients who lack resources, social connections and resilience, often because of adverse childhood experiences. For providers helping patients navigate an end-of-life decision, it's important to consider the social determinants of health in that person's life history and acknowledge what that their journey looked like along the way.

How the health care system itself perpetuates inequity

It is well-known that the social determinants of health – living and working conditions, level of education, access to food, housing, etc. – confer a risk of disease. And while it's important for physicians to think about those root causes, it's also important to acknowledge that the health-care system itself can perpetuate inequity, especially on certain populations.

For example, Indigenous Peoples and new immigrants have dramatically fewer cancer screenings than the rest of the population. This may be due to cultural beliefs, but there are also systemic barriers. Many homeless people do not even know that assisted dying exists as an option. Logistically, how do you perform MAiD for somebody who's homeless? What does that look like and how do we advocate for these people?

Dr. Gibson challenged the audience to integrate these concepts into their thinking. "I want you to think about what structural violence and systemic discrimination does in the context of medical assistance in dying. How might each stage of this process be affected?" she said.

Shift the lens from vulnerability to ability

Dr. Gibson shared a story about a patient who has been homeless on and off for years. Following a request for MAiD, he asked her to help fill out a bank form so that he could donate his RSP money to buy a property and create transitional housing for people who are part of the safe needle exchange program. "How can we shift the lens from vulnerability to ability, as my patient has done?" she said.

Reframing the conversation around vulnerability

Usually people talk about vulnerable populations being over-included in MAiD, however, Prof. Downie expressed a concern about how, in the name of protectionism, the health care system has excluded vulnerable people from MAiD.

To show how we can flip the vulnerability conversation, Prof. Downie included many inspirational quotes by Canadian women senators, including Senators Lillian Dyck, Francis Lancin, Chantal Petitclerc and Mobina Jaffer. All these senators have advocated for various groups frequently described as vulnerable, including Indigenous youth and disabled people.

Shifting the gaze to expand the conversation

Prof. Downie recommended expanding the conversation to include not just the traditional foci for vulnerability discussions (concerns about coercion and voluntariness), but also alternative foci. These include relational autonomy, the fact that a vulnerable person's

wishes are less likely to be followed, their lack of resources and advocates to gain access to MAiD, and their lack of trust in health care providers.

MAiD is an issue of privilege in Canada

When you are fighting for clean drinking water, you are not finding time to write a report or submission to a parliamentary committee. We must be respectful of that and attentive to the threats to access experienced by vulnerable people, such as not having a doctor. In addition, we must consider the threats to their capacity, including gendered assumptions and the paternalism towards the disabled and Indigenous Peoples. Shifting this view moves us to a new underlying philosophy – one of empowerment instead of determinism.

Ways providers can help to empower vulnerable populations

- Help patients fight for options that would allow them to have access to MAiD
- Consider what supports you can put in place to help a patient reach capacity
- Be open to requests for a second opinion (and the fact that there may be bias in your own assessments)
- Advocate about the duty to refer and the duty to transfer care – recognize the harm to vulnerable populations that comes with the assertion of freedom of religion
- Fight for self-referral pathways and access to oral MAiD
- Figure out different ways to consult on MAiD for Indigenous communities, who want to have the conversation in a different way

The bottom line: It's not autonomy versus protection of the vulnerable; it's advancing the interests of the vulnerable by respecting and promoting their autonomy.

COMMENTS, QUESTIONS AND ANSWERS

I have a First Nations patient who meets all the criteria for MAiD, but much of their suffering is due to a life lived in poverty. If I could change their social determinants of health, their situation might improve. How do I tackle this?

Composite answer - Trying to get their basic needs met is a good place to start and our first duty of care. As soon as a patient tells me their suffering is enough, whether I like it, that is their situation and that is their context. Let's let it motivate us to try to change the system whilst responding to their suffering.

I wanted to bring access to MAiD to individuals in a community who wanted it, but the community and the government were quite against it. What can I do?

Composite answer - Trying to get their basic needs met is a good place to start and our first. Often people who are at most risk of not having equal access are held back by structural barriers, such as religious-affiliated organizations running homeless shelters. It's up to us to fix the system. Prove there's a need, prove there's an interest. If you dig a little deeper, you'll find that you are probably not the only one who feels this way, and there's a fair bit of power in that.

Clinical Practice Guidelines: Oral and IV Protocols

Speakers

Dr. Christopher Harty, PGY1 resident in anesthesiology, University of Ottawa

Dr. Viren Naik, Professor of Anesthesiology and Medical Director (MAiD Program), University of Ottawa; Director of Assessment, Royal College of Physicians and Surgeons of Canada

Dr. Konia Trouton, Clinical Professor, Department of Family Practice, University of British Columbia (cross appointed to UVIC).

BRIEF OVERVIEW

Dr. Harty, Dr. Naik and Dr. Trouton reviewed the menu of medications available for oral MAiD, the Canadian and worldwide experiences so far and the CAMAP recommendations for an oral MAiD procedure. Secobarbital, although not yet available in Canada for oral MAiD, is highly anticipated due to its predictable response and approximate 30-minute time to death.

DETAILED OVERVIEW

Medication review

- *Barbiturates* are the most common medication for oral MAiD worldwide. They trigger a predictable response and there is a low likelihood of tolerance since most people do not regularly take them. These medications include secobarbital, pentobarbital and phenobarbital.
- *Opioids* are not ideal because they cause nausea, vomiting and regurgitation. In addition, people are often tolerant to these medications.
- *Benzodiazepines* are not useful for routine MAiD because there are no predictable respiratory depression or cardiac depression effects.
- *Chloral hydrate* has been used in MAiD but is burning and irritating to the oral mucosa, which doesn't align with the ideals of patient comfort at the end of life.
- *DDMP and DDMP2* are mixtures recently developed in the United States in response to the expense and availability issues of seco- and pentobarbitals. Although cost-effective, the time to death is considered too long (more than the two hours).

Canada's experience so far

- Bill C-14 permits self-administration; presently oral MAiD is allowed in all provinces except Quebec
- Canada has only provided 11 oral MAiD cases at the time of this writing (eight of those have been in British Columbia)
- The medications are mainly a mix of phenobarbital, chloral hydrate and morphine
- The time to death has varied from 45-90 minutes
- In many cases, an IV intervention was required
- The three cases outside of B.C. were all complicated with protracted times to death

Oral MAiD worldwide

- In the Netherlands, patients are allowed IV and oral administration. Typically, IV is the most common. The oral medication is secobarbital, 15 grams. Belgium and Luxembourg have very similar practices.
- In the United States, the DDMP2 medication regime is becoming quite common. A patient must self-administer and cannot be helped, which is very different from the Canadian model.
- In Switzerland, assisted dying organizations are common and access is gained through them.

CAMAP's recommendations for oral MAiD

1. Fasting is recommended six hours prior since absorption is most efficient on an empty stomach
2. An antiemetic pretreatment is recommended to maximize delivery to the GI tract. (Metoclopramide, 20 mg, and either ondansetron, 8-24 mg, or dexamethasone, 8 mg, orally one hour prior to the coma inducing medication)
3. The recommended coma-inducing medication is secobarbital (15 mg) by mouth
4. The alternate recommended coma-inducing medication (if secobarbital is not available) is DDMP2, professionally compounded just prior to ingestion
5. The presence of a clinician is recommended for all oral MAiD provisions. This will ensure the patient is still able to take oral medication at the time of provision. It will also respect the chain of custody for medications and interventions should there be prolonged coma or no death.

The presentation team's supplementary recommendations for success

- Obtain specific dual consent for both oral medication AND IV supplementation if necessary (get this in writing, even if it's not explicit in your province).
- Encourage patients to swallow medication within four minutes, while seated
- Review with the family the plan for the timing of IV supplementation
- Reduce the bitter taste of the medications with HurriCaine dental spray, cherry flavoured benzocaine spray or cocktails.

COMMENTS, QUESTIONS AND ANSWERS

If a person does self-administer and their death does not take place, what would happen if they were converted to palliative sedation?

Since the desired outcome is death, the MAiD provider should carry on and complete the process. This is why we strongly recommend getting that dual consent up front.

There are some devices that allow a person to self-administer something intravenously. Is that feasible in Canada?

Yes, theoretically that's feasible. In Europe, they're using something called the elastomeric pump. However, with any device there is the potential of failure, so this is not an option we'd recommend leading with.

Comment – I had a positive experience with an oral case, where a wife and son were grieving openly. Because it took 83 minutes, they were able to complete a grieving process during the time the patient was dying. By the end, they were in a whole new place and it had allowed them time. IV is great because it's quick and controlled, but it's only 10 minutes and that can be shocking. There is a flipside to this and I'm looking forward to secobarbital being 30 minutes.

Self Care/Burnout Study Results

Speaker

Dr. Margaret McKee, Professor, School of Social Work,
Lakehead University (in collaboration with Dr. Megan Sellick)

BRIEF OVERVIEW

Dr. McKee presented research from a pilot study co-conducted with her colleague, Dr. Megan Sellick, on the impact of MAiD to providers. She shared quotes and trends following interviews with 21 providers and described strategies to mitigate burnout. Their research suggests that providing MAiD is profoundly positive and rewarding for every provider they interviewed. The biggest source of stress was administrative and institutional obstacles to providing. To mitigate burnout, Dr. McKee recommended several strategies, such as staying organized, advocating as one voice and continuing to show care and compassion.



DETAILED OVERVIEW

Pilot study population

Dr. McKee and Dr. Sellick interviewed 21 physician providers of MAiD who responded to their call via the CAMAP listserv: 14 women and seven men from all over Canada. Half practiced in urban centres, half in urban and rural or rural only. A quarter identified as palliative care specialists, another quarter identified as other specialists of the Royal College of Physicians and Surgeons of Canada, and the remaining half identified as family physicians. The goal of the study was to learn the emotional and psychological impacts of providing MAiD on Canadian MAiD providers and how the learnings could inform strategies to mitigate burnout.

Recurring themes and trends

Although their findings were very rich, Dr. McKee and Dr. Sellick simplified significant and recurring themes for their presentation:

- All providers found the experience of providing MAiD as profoundly positive and rewarding (see quotes below)
- All providers said that what moved them most was the gratitude in the room, gratitude that gave them a sense that this provision was a profound gift to the patient.
- Many providers said this has been the most rewarding work in their career to date, and they plan to continue providing until the end of their career.

Quotes from providers

“It’s beautiful to know that we could do something that made such a difference. I had one patient say to me, “you know this is going to sound weird, but thank you for saving my life.”

“To be able to do that for another person, it’s a gift, it’s just very, very special and I really feel that I am very lucky to be able to do that.”

“You go home, you see your loved ones as if for the first time and you appreciate every single moment you have for the rest of that day.”

Sources of stress

The number one source of stress cited by providers was not the provisions themselves, but administrative and institutional obstacles to providing MAiD, especially when they resulted in delays that put the patient at risk of no longer being eligible. For example, difficulty finding second assessors and backup providers, institutional blocks like a long-term care home not having a policy in place or colleagues dragging their heels. Other sources included having to say no to a patient, a lack of proper fee schedules, and geographic isolation and emotional isolation following backlash from colleagues and from church communities.

The perfect storm is created when you have an idealistic and highly committed group of people plus high rewards for the work and huge administrative headaches. That is the perfect set up for burnout, because providers will keep going despite the obstacles, past the point where it will hurt them.

Strategies to mitigate burnout

- Do something that brings comfort and peace: taking time to develop a relationship with the patient; seeking consultation or family support; private rituals, such as writing in a journal or walking the dog; movement or emotional expression through art, music or literature.
- Organize, speak as one voice and advocate for administrative and institutional changes that will make your work sustainable – make burnout a collective, political issue
- Don’t let anyone tell you to stop caring. Caring confers a protective benefit. It is what sustains you and is a remedy to the stresses of providing MAiD.

COMMENTS, QUESTIONS AND ANSWERS

Comment – We may feel that the rural or isolated practitioner is more at risk than the one in a wonderful team. It really doesn’t matter because it’s the emotional discord that you take home with you.

Difficult Cases and Scenarios

Speaker

Dr. Jonathan Reggler, family physician, MAiD Provider and Board Member, CAMAP and Dying with Dignity Canada

BRIEF OVERVIEW

Dr. Reggler developed and presented four difficult cases and scenarios, each a chimera of his own experiences as a MAiD provider and discussions that have occurred on the CAMAP listserv. After a brief introduction to each case, audience members were invited to interpret the eligibility criteria and share their decisions. The cases focused on frailty, early dementia, fixed delusions and lymphoma, and voluntary stopping of eating and drinking (VSED). (Please see Dr. Reggler's PowerPoint presentation for full details.)

DETAILED OVERVIEW

The key enablers to MAiD

Dr. Reggler summarized the two key criteria for allowing a medically assisted death: you've got to be capable and you've got to have a grievous and irremediable condition. A grievous and irremediable condition has four dimensions, all of which have caused confusion to providers and assessors on the CAMAP listserv:

- incurability,
- an advanced state of irreversible decline and capability,
- enduring physical or psychological suffering that is intolerable, and
- a death that is reasonably foreseeable.

Case 1: Frailty

Dr. Reggler's first case investigated the various manifestations of frailty through a fictional 90-year-old male patient with severe osteoarthritis. Would you be surprised if this man died in six months? Points raised by the audience included the following:

- It's the whole person not the illness that has to be in an advanced state of irreversible decline.
- The Canadian life tables from Statistics Canada are a good resource when estimating a reasonably foreseeable natural death in elderly patients.
- The fact that the patient declined many options, including a pain clinic, made one delegate question whether he fully understood the options and alternatives available to him, and raised the question whether he was making an informed decision.

Case 2: Early dementia

The second case described a 50-year-old man diagnosed with Alzheimer's Disease. The main issue in this case was can one have MAiD when the loss of capacity is imminent due to dementia? Points raised by the audience included the following:

- Early-onset dementia usually progresses much faster than late-onset
- Continuous monitoring of dementia patients who still have capacity is advisable
- Bringing up MAiD right after a patient receives a dementia diagnosis may be premature (they are understandably devastated and need time to come to terms)
- It's unfortunate no advance care planning exists with respect to MAiD with dementia
- One delegate is routinely asking patients 75-years-old and older whether they want to include MAiD as part of end-of-life discussions. So far, 87 per cent have said yes.

Case 3: Fixed delusions and lymphoma

A 75-year-old man, a widower, has fixed delusions that are causing him severe suffering. He has also been diagnosed with a high-risk follicular lymphoma but is refusing treatment. He wants MAiD and has capacity. His children are supportive, however, his brother, a Catholic priest, is not. Is he eligible for MAiD and does it matter what he wants it for? Points raised by the audience included the following:

- In this case, a very thorough before and after comparison would help to document the potentially advanced state of decline due to fixed delusions
- It *doesn't matter* what he wants it for: You can request MAiD due to psychological suffering and if that's what caused his changed state, it would be reasonable.
- It *does matter* what he wants it for: His fixed delusions are untreatable, but his lymphoma is treatable. Would treating the lymphoma reduce his mental suffering?
- In choosing not to treat the lymphoma, does he maybe lack capacity?

Case 4: Voluntary stopping of eating and drinking (VSED)

A 45-year-old woman has advanced multiple sclerosis and is chair-bound and bed-bound. She wants MAiD, but her assessors agree that she does not have a reasonably foreseeable death (although she is eligible in every other criteria). After seeking advice from family and friends, she decides to VSED, requests MAiD again 10 days later, and receives it. A family member blames the provider for putting her up to VSED. Points raised by the audience included the following:

- One audience member said they would walk away from this case unless they had solid backing from their malpractice association.
- Another said that the standard for counselling for suicide is very high in the criminal code and involves active encouragement and proactive steps; speaking in general about how a person could die does not approach the level of counselling for suicide.
- If her MS was secondary-progressive by the time she was bed-bound, her life-expectancy would not be long — perhaps she would have met the criteria for a reasonably foreseeable death.