

A photograph of a person lying in a hospital bed, wearing a white hospital gown. Their eyes are closed, and their hands are being held by another person's hands. The scene is lit with a cool, blue light, creating a somber and intimate atmosphere. The focus is on the hands being held, with the person's face in the background slightly out of focus.

**IN AN ARTICLE PUBLISHED
FEBRUARY 20, 2019, *THE LANCET*
REPORTS THAT, IN 2017, MORE THAN
13,000 PATIENTS DIED THROUGH
EITHER LEGALIZED EUTHANASIA OR
ASSISTED SUICIDE IN COUNTRIES
WHERE THESE PRACTICES
ARE PERMITTED.¹**

MAID

MEDICAL ASSISTANCE IN DYING

Why counsellors need to think carefully about where they stand on the issues

BY CAROLYN CAMILLERI

When Margaret Easton addresses her Bill C-14: The Long History of Suicide, Euthanasia and Assisted Dying class at SFU, she starts by saying she supports Medical Assistance in Dying (MAID). She explains that she is grateful the Canadian government has made this available, in large part, because she has a better understanding today of how difficult some deaths can be, even with access to excellent medical treatment. But while Easton grew up following the stories of Sue Rodriguez and Robert Latimer and has always leaned towards supporting assisted dying, she has serious reservations about some issues.

“Your reservations are unlikely to be the same as mine,” Easton tells her class, “but you should know what yours are and why.”

The same message can and likely should be addressed to counsellors across the country. MAID has been legal in Canada since June 2016 and more Canadians are accessing MAID every year since the legislation passed. Nevertheless, controversy remains, and the issues can be challenging to talk about. As the number of Canadians using MAID continues to increase, mental health professionals will likely see more clients in their practices who are dealing with this issue for themselves or their family members and friends.

“It’s a very complex topic,” says Easton. “Counsellors need to know where they stand.”

FINDING OUT WHERE YOU STAND

Easton has helped to create an End of Life Studies program at Simon Fraser University and teaches several courses in the program. Margaret Isabel Hall, an associate professor in the Faculty of Law, Thompson Rivers University, also teaches in the program. Hall's course, Legal and Ethical Issues in End-of-Life Studies, will be offered for the second time in June of this year. Hall's research and legal work has taken her into the area of mental capacity and dementia and the legal and ethical issues at the end of life. The discourse around MAID was a natural expansion of her accumulated work.

"It's very complicated and I think people have an initial response — an emotional response — and they have to set it aside and then examine the whole thing very carefully," says Hall.

Hall explains that we need to understand that MAID legislation creates an exception to the criminal prohibition of MAID in the Criminal Code.

"The legislation says, these are the circumstances in which an exception

will be made," she says. "Unless a person's situation falls within that exception, they cannot access MAID. The sections of the Criminal Code that prohibit assisted suicide and provide that a person cannot consent to another person causing his or her death are still there. The legislation sets out the limited circumstances where they won't apply."

WHEN WE TALK ABOUT MAID, WE ARE NOT REALLY TALKING ABOUT WHETHER, AS INDIVIDUALS, WE HAVE A RIGHT TO DIE.

The questions we are struggling with now: does that exception go far enough? Is it too narrow? Should it be re-defined?

"The legislation did not create a right to MAID on demand," says Hall. "So the question of whether a person is eligible for MAID is a question about whether that person's circumstances

fall within the exception in which MAID is permitted."

Hall adds that it is also important to realize that when we talk about MAID, we are not really talking about whether, as individuals, we have a "right to die."

"The issue is, under what circumstances will society, through the law, approve of a physician — also a public actor — taking another person's life," says Hall. "Then, society will put in place the structures to enable that. So this is not a purely private question in the way that suicide is a purely private decision — society is involved. The rule that purposefully taking another's life is prohibited has long been part of our law and creating an exception to that is a significant social decision."

JUNE 2016 AND AFTER

MAID is often presented incorrectly as an issue of modern times.

"It goes all the way back to Plato and the Greek times — Greek playwrights wrote about assisted dying, and so it's not entirely new what we're facing today," says Easton. "We're still trying to cope with many of the same issues."

SUICIDE **vs** MAID

There is controversy in Canada about the use of the word "suicide" when talking about assisted dying. Suicide is defined as the act of taking one's own life voluntarily and intentionally. Medical Assistance in Dying, MAID, has been named that to separate it from suicide. Easton encourages people

to think deeply about why they believe MAID is or is not suicide. In some places in the world, the term physician-assisted suicide is still used and is less stigmatized than in Canada. "If you look at the suicide rates in Canada from 2008 to 2012, we've always averaged somewhere between 3,700 and 3,900

suicides," says Easton. "Until MAID was legalized, every one of those deaths was considered a tragedy, a preventable tragedy. As of June 2016, did they stop, or how many stopped, being preventable tragedies and what did they become?"

Hall and Easton both stress the importance of

understanding why we think the way we do about these issues — and not only for clients. "We will make better decisions for ourselves and family members and can participate more knowledgeably in the future as the government considers potential changes," says Easton.

MEDICAL ASSISTANCE IN DYING IS OFTEN PRESENTED INCORRECTLY AS AN ISSUE OF MODERN TIMES.



While suicide was decriminalized in Canada in 1972, MAID is the result of recent legislation. In June 2016, Bill C-14 passed federal legislation in response to the Supreme Court's 2015 decision in *Carter v. Canada*. The legislation includes stringent requirements around eligibility and competency. But almost immediately after the new legislation was proclaimed, it was challenged across Canada. It wasn't unexpected. When Bill C-14 was passed, the government of Canada, in response to a request from the Minister of Health, Minister of Justice, and Attorney General of Canada, asked the Council of Canadian Academies to prepare an evidence-based assessment of the state of knowledge on three current exclusions in the act: MAID for mature minors, advance requests for MAID, and MAID where a mental disorder is the sole underlying medical condition. The Council's reports were released in December 2018.²

Currently, depending on the province, a person must be 18 or 19 to be eligible for MAID. The mature minors investigation is looking at whether someone younger might have the mature capability to understand the consequences of their decision.

An advance request for MAID is when a person makes a decision about dying ahead of time — for example, when an illness reaches a certain stage.

"That's how some people want to use MAID, but currently, you can't do that," says Hall. "An underlying issue is that some people want to do this in anticipation of developing dementia at a later stage — and that's very complicated and something we need to have serious public discussion about."

For example, the person dying must be competent right to the very end. The legislation provides that a person must be capable of consenting to MAID at the point when the person receives it. A person with advanced dementia may not be capable of consenting to

MULTI-DISCIPLINARY PARTICIPATION

As noted in the recent reports from the Council of Canadian Academies, Belgium, a country that permits assisted dying for mental disorders, encourages the use of assessors with expertise in specific mental disorders and the use of multi-disciplinary teams — for example, the inclusion of social workers on assessment panels or teams.

CANADA'S AGING AND DYING POPULATION

BY 2026, THE NUMBER OF CANADIANS DYING EACH YEAR WILL INCREASE BY

40%

TO

330,000³



YET, CANADA RANKS ONLY

11th

IN THE 2015 QUALITY OF DEATH INDEX.⁴

MAID, meaning that person is not eligible to receive it.

Hall tells her students to remember that we don't know what our experience of illness or dementia will be until we have that experience, and our fear or dread may be very different from the experience itself.

"People change," says Hall. "Would we want our 25-year-old self to make decisions for our 50-year-old self? Our 80-year-old self? How do we feel about taking the life of a person with dementia who is not expressing any fear, distress, or physical suffering — who seems content — because of a directive from her previous self, when that previous self is so profoundly changed?"

When the person cannot tell us herself, directly, when her suffering has become intolerable and that "enough is enough" (in the words of one of the plaintiffs in *Carter*), how do we decide when that point has been reached?

"This is very different from the situation where the person can tell us herself, in real time, that she has now

decided enough is enough," says Hall. "We need real, public conversation about these questions."

MAID FOR MENTAL DISORDERS

Easton says expanding the criteria for MAID to include providing access to people where a mental disorder is the sole underlying medical condition presents many issues, and this is an area where Canada's mental health professionals will have much to contribute. Currently, many psychiatric and psychological associations have reservations about the use of MAID where a mental disorder is the sole underlying medical condition. These concerns include:

1) how to define irremediable in the

context of mental disorders;

2) worries that permitting MAID where a mental disorder is the sole underlying medical condition might alter mental health care in Canada;

3) identifying how to address the unique considerations of specific populations, such as Indigenous peoples, sociocultural and racialized groups, LGBTQ+ people and gender issues, seniors, Canadian Armed Forces Members and Veterans, and incarcerated people; and,

4) the impact of psychosocial issues such as grief, loneliness, stigma, shame, or lack of support for the patient or their caregivers (see The Council of Canadian Academies reports).

In addition, the criteria of what defines a mental disorder continues to change and access to treatment options remains uneven. For example, with each edition of the DSM and ICD, mental disorders are added and deleted. As Easton points out, when she was in her 20s at SFU, homosexuality was listed in the DSM as a mental disorder but was deleted in 1973, while the fifth edition of the DSM includes disorders unknown at that time, such as Gender Dysphoria, Internet Gaming Disorder, and Social Communication Disorder.

Moreover, you have to consider what might be listed in a DSM-6 or ICD-11, and particularly, what might influence those changes.



THE DEATH DEBATE

The Death Debate is a video released in February 2016 that tracks the story behind Supreme Court *Carter v. Canada*. www.youtube.com/watch?v=-Vot5bkR_VQ

AN ECONOMIC PERSPECTIVE

A recent study, “Cost analysis of medical assistance in dying in Canada,” reported in the *CMA Journal*, suggested that medical assistance in dying could reduce annual health care spending across Canada by between \$34.7 million and \$138.8 million, exceeding the \$1.5–\$14.8 million in direct costs associated with its implementation.⁵ While the authors were adamant that health care savings should not be the deciding factor, it may become an issue. Cost of care is also a critically important issue in health care spending for mental disorders. Oftentimes, the barriers to service and treatment for mental disorders are economic. “It is very difficult for counsellors to resolve mental health issues in the four or five appointments that are covered by most extended medical plans,” says Easton. “This unfortunately creates inequality in access to good quality psychological care.”

And finally, with MAID law in Canada defining intolerable suffering in subjective terms, and Section 15 of the Charter of Rights and Freedoms stating that “every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age, or *mental or physical disability*,” it will be extremely difficult to avoid and/or adequately address charges of discrimination about which disorders will be allowed access to MAID.

UNFORTUNATELY, THERE SEEMS TO BE A MOVE TOWARDS SHIFTING THE CURRENT CONVERSATION ABOUT “GOOD” DEATHS TO “SUCCESSFUL” DEATHS, WHICH MAY RESULT IN PEOPLE FEELING THEY COULD FAIL AT BOTH AGING AND DYING.

SUCCESS AS IT RELATES TO DYING

As of 2016, for the first time in history, the population in Canada over age 65 is greater than the population under 50. At the same time, new standards are being set for both aging and dying — successfully.

“I’m doing my PhD thesis on successful aging and successful dying, and I have issues with both of those terms, because the vast majority of us cannot meet the criteria out there now for successful aging,” says Easton.

Unfortunately, there also seems to be a move towards shifting the current conversation about “good” deaths to “successful” deaths, which may result in people feeling they could fail at both aging and dying. Easton sees a growing inclination towards seeing MAID as successful dying, rather than simply as one of the ways we have of ensuring people have access to a good death. It is a development she worries raises serious ethical issues that need careful and thoughtful consideration.

Keep in mind, the idea of death on our own terms with dignity and

autonomy at the end of a long life is not new. In ancient Greece, people would go before city councils to present their case as someone old and finished with life and to ask for a portion of hemlock. Perhaps our approach to MAID is similar and certainly bears close review and consideration.

REFERENCES

- 1 Borasio, G.D., Jox, R.J., Gamondo, C. (February 20, 2019). Regulation of assisted suicide limits the number of assisted deaths. *The Lancet*, online. DOI: [https://doi.org/10.1016/S0140-6736\(18\)32554-6](https://doi.org/10.1016/S0140-6736(18)32554-6)
- 2 The Council of Canadian Academies State of Knowledge Reports, issued in December 2018, can be accessed at <https://scienceadvice.ca/reports/medical-assistance-in-dying/>
- 3 Blueprint for Action 2010 to 2020. (2010, January). Quality End-of-Life Care Coalition of Canada. Retrieved from http://www.qelccc.ca/media/3743/blueprint_for_action_2010_to_2020_april_2010.pdf
- 4 The 2015 Quality of Death Index. (2015) *The Economist Intelligence Unit*. Retrieved from <https://eiperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>
- 5 Trachtenberg, Aaron J. and Manns, Braden (2017, January 23). Cost Analysis of medical assistance in dying in Canada, *CMA Journal*, 189(3). Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5250515/>