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## Editor's Forum

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This issue of Health Ethics Today contains papers based on some of the presentations given at the 2016 Dossetor Centre Health Ethics Symposium on Medical Assistance in Dying (MAID). The symposium was attended by 130 attendees represented by physicians, nurses, academics, social workers, chaplains, clinical ethicists, administrators, researchers, consultants, students and other allied health professionals. This was the highest attendance at the Dossetor Centre's annual symposium. The symposium speakers were representative of a broad spectrum of opinion with respect to MAID from medicine, nursing, philosophy, clinical ethics, and law. The symposium was successful in presenting divergent views of MAID and generating lively discussion throughout the day. Attendee feedback was very positive generally rating the symposium high and requesting further opportunities for discussion of MAID.

It is clear that the legalization of MAID is only the first step in a complex process of including it as part of health care choices available in Canada. The symposium presentations dealt with theoretical and practical considerations concerning the legalization, integration, and eligibility of MAID in Canadian health care.

Anna Zadunayski presented a comprehensive review of the lengthy course of case law preceding the landmark *Carter* decision in 2015. The review gave insight into the task of taking on an issue of this magnitude and seeing it all the way through to the Supreme Court of Canada. As with the earlier Rodriguez case in 1993, there was no certainty of

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a Supreme Court outcome supporting *Carter*. The presentation gave a strong sense of the commitment of the people involved and the arduous nature of the process. This is an aspect of MAID that gets little attention and may act as reassurance that the *Carter* decision did not happen suddenly or that MAID did not simply appear as a novel addition to end-of-life care.

Daniel Garros presented a traditional medical philosophy of care rooted in the principle of nonmaleficence – primum non nocere. The rise of respect for individual autonomy in Western society has profound effects on this tradition as it relates to the "Doctor-Patient relationship". As it is no longer the doctor alone who decides what constitutes harm, various decision-making models have evolved based on the central role of the patient, in keeping with informed consent. Garros described his professional journey from medical student in a very traditional paternalistic system to becoming a consultant Paediatric Intensive Care doctor in a very modern shared decision-making environment. While he strongly supports the shared decision-making approach with respect to end-of-life care, MAID is one "step too far" that he cannot support as a physician. In this he is by no means alone.

Carla Ventura presented the challenges and alternatives involved with the availability of MAID for persons with mental illness. She emphasized the difficulty of establishing clarity around decisionmaking capacity in individuals with mental illness. But she argued that discussion about MAID and mental illness is too narrowly focused on this problem simply as a balancing act between respecting autonomy and ensuring competence. She described the need for a broader contextual understanding of suffering for those with mental illness, by considering their sense of systemic issues, i.e., hopelessness, social isolation, stigma, discrimination, and poverty. Ventura expressed concern that unless this broad context is considered when discussing MAID for this population within an ongoing therapeutic relationship, the criteria to satisfy MAID cannot be established. Ventura states that the need for major improvements in access to mental health services in Canada as well as educational initiatives to decrease stigma and discrimination is a pre-requisite to MAID for persons with mental illness.

Peter Brindley expressed concerns about the shift from physicians' acceptance that patients may refuse treatment recommendations towards a dynamic in which patients and family demand treatment against medical opinion and without evidence of efficacy. He is concerned that the language used in legalizing MAID is so non-clinical as to make eligibility judgments difficult for physicians who use clinical criteria. While the broadly accepted concept of a "standard of care" in health may be difficult to apply in end-of-life care, he asks if MAID is now part of this "standard of care".



Brindley worries that public attitudes will move over time towards demanding MAID over physician objections based on medical criteria, in a similar manner to how the demand for preemptive cardiopulmonary resuscitation occurs in cases where benefit cannot be demonstrated. He sees this as an example of professional codes of ethical practice being overcome by external social dictates. He suggests that one serious consequence of this trend would be a withdrawal by physicians from

patient based individualized discussions essential to safeguard appropriate utilization of MAID. While conscientious objection to MAID by physicians is ethically acceptable to Brindley, he is concerned that physicians' professional opinions of MAID in individual cases may eventually become irrelevant.

# "Protecting the Rule of Law and the Vulnerable": Examining the Canadian Legal Landscape Surrounding Assisted Dying

Anna Zadunayski, LLB, MSc

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For decades, access to medical assistance in dying in Canada has been the subject of significant ethical and legal debate. In 2011, the British Columbia Civil Liberties Association – a non-government organization funded by the British Columbia Law Foundation and public membership – combined with multiple stakeholders to initiate litigation that would ultimately be heard by the Supreme Court of Canada, creating a legal mechanism for access to assisted dying for some Canadians.

# The Carter Criteria and Subsequent Developments

In Carter v. Canada (Attorney General), 2015 SCC 5 ("Carter 2015") the Supreme Court of Canada unanimously decided that Criminal Code provisions prohibiting assisted dying violated an individual's s. 7 Charter right to life, liberty and security of the person, in a manner that did not accord with the principles of fundamental justice<sup>1</sup>. In balancing competing values of great importance – the autonomy and dignity of a competent adult seeking death as a response to a grievous and irremediable medical condition on the one hand, and the sanctity of life and the need to protect the vulnerable on the other – the Supreme Court established a legal test for individuals seeking an assisted death (the Carter criteria):

A) Whether the applicant is a competent adult; B) Whether the applicant clearly consents to an assisted death;

- C) Whether the applicant suffers from a grievous and irremediable medical condition;
- D) Whether the condition causes the applicant enduring, intolerable suffering; and
- E) Whether the applicant's suffering cannot be alleviated by any treatment acceptable to him or her

In January 2016, the Supreme Court of Canada granted a personal constitutional exemption for competent adults who (1) clearly consented to the termination of life, and (2) had a grievous and irremediable medical condition causing enduring, intolerable suffering to the individual in the circumstances of the condition, and that could not be alleviated by treatment acceptable to the individual ("Carter 2016"). Individuals wishing to avail themselves of the exemption could apply to the superior court of their jurisdiction for relief, namely, judicial authorization for an assisted death. Such applications had a defined scope and were intended to operate for a limited duration, until Canadian legislation was in place. On application, the question for the courts was whether the applicant qualified for the exemption granted by the Supreme Court. If the Carter 2015 criteria were satisfied, an applicant could obtain court authorization to proceed with an assisted death, and health professionals (including pharmacists) involved were exempt from prohibitory Criminal Code provisions.

<sup>1</sup> Canadian Charter of Rights and Freedoms, Part I of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11.

### Assisted Dying Applications in the Superior Courts

Following the Carter ruling and constitutional exemption by the Supreme Court, numerous assisted dying applications were brought forward by individuals in many Canadian jurisdictions. Such applications were typically initiated by way of an Originating Application with notice to the Attorneys General for the provinces and Canada, and many applications involved restricted court access and identification bans to protect the parties (patients and professionals alike). In at least one case, an applicant did not seek to prevent his own name from becoming public because he believed very strongly in the availability of assisted death for any person considering the option important to their personal dignity and integrity. While the applicant was prepared to accept some loss of privacy in order to support others choosing to follow the path of assisted death, he did seek to protect the identity of his family members and physicians out of concern for their personal and professional welfare<sup>2</sup>. Privacy, dignity and autonomy were important interests in such cases as applicants sought court authorization for the most personal of decisions, "... concerning a subject of the highest order, that of life and death itself."3

In all cases, the motions judge was to consider the personal circumstances of the applicant within the context of the *Carter* framework. The courts were not called upon to conduct a full blown inquiry as to whether an applicant had established an individual case for a personal constitutional exemption, rather, the role of the motions judge was to determine whether the applicant met the *Carter 2015* criteria; an individual and fact specific inquiry within the larger legal and constitutional context. The focus of the judicial authorization process was on the individual applicant, the circumstances of his or her particular medical condition, and the actual record before the Court.

#### HS (Re), 2016 ABQB 121

One of the first post-Carter assisted dying applications was brought forward in Alberta, wherein the applicant met the Carter criteria and qualified for a personal constitutional exemption allowing an assisted death.4 In that case, the motions judge did not "see any need to unfairly prolong the suffering of those who meet the clear criteria ... set out in Carter 2015". It was clear that the applicant was such a person. While counsel for the applicant suggested that the resulting Order need only declare that the applicant qualified for an assisted death, in the Court's view, a greater role and responsibility was intended when judicial authorization was established "as the safeguard to protect the rule of law and the vulnerable".5 Charting a novel course and considering cross-jurisdictional questions (the applicant was resident in Alberta but wished to die in British Columbia), the Court granted the application, expanding the Order to provide express protection for the physicians and pharmacists who would be involved,<sup>6</sup> and establishing an important, persuasive authority for future cases.



HS (Re), 2016 ABQB 121.

<sup>2</sup> Tuckwell (Re), 2016 ABQB 302 at paras 10-14.

<sup>3</sup> Ibid, per Greckol, J. at para 16.

<sup>5</sup> Ibid, per Martin, J. at para 120.

Ibid, at para 126.

#### Bill C-14

In June 2016, weeks after the deadline imposed by the Supreme Court, Canada's newly-elected federal government enacted Bill C-14, an Act to amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying), in response to Carter and the judicial authorization process of obtaining an assisted death. Whereas Carter 2015 established that with judicial authorization, assisted dying could be available to clearly consenting, competent adults with "grievous and irremediable" medical conditions causing enduring and intolerable suffering, Bill C-14 is more restrictive, limiting medical assistance in dying only to those whose illness is terminal and who are near death. While some have argued that Canada's legislative response was rushed or pushed through despite the informed positions of stakeholders, others have argued that the legislation is confusing, and overly restrictive7. Sources of confusion have included defining a "grievous and irremediable" medical condition and predicting a "reasonably foreseeable death" in a "period of time that is not too remote" - terms which have no clinical or legal definition. Under the new legislation, some individuals may not qualify for an assisted death, as their condition may not be advanced enough. In other cases, the request for assistance in dying may be brought forward too close to death, wherein the "period of reflection" criteria mandated by the legislation cannot be met. Nevertheless, assisted dying is now a legislated, accessible option for some individuals in Canada who meet the specific legal criteria.



7 British Columbia Civil Liberties Association on-line article, 26 July 2016, *Lamb v. Canada*: The Death with Dignity Case Continues. https://bccla.org/our-work/blog/lamb/

### Current Realities and Remaining Questions

While the recent Canadian legislation regarding assisted dying creates a new legal option for some individuals, numerous questions remain. In many cases, death can be difficult to predict, and the "reasonably foreseeable" criterion embedded in the legislation means that some individuals seeking assistance in dying could be turned away. Some physicians will struggle with the time limitations tied to the law; the current legislation creating a "grey zone" that may be interpreted differently by professionals. Other professionals still may conscientiously object to participate in or even discuss the option of an assisted death. As such, some Canadians may continue to be compelled to seek assistance elsewhere, or take matters into their own hands – a reality that the Supreme Court was looking to prevent in Carter. Although the judicial authorization process established by Carter prior to legislation was a potentially cumbersome and expensive step for individuals seeking assistance in dying, it provided a measure of clarity and security for all involved. It remains to be seen whether new legal cases will result in legislative reform<sup>8</sup>.

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Carter v. Canada (Attorney General), 2015 SCC 5, [2015] 3 SCR 331, at para 127 (hereinafter Carter 2015).

Carter v. Canada (Attorney General), 2016 SCC 4 (hereinafter Carter 2016).

Criminal Code RSC 1985 c C-46, ss. 14 and 241(b), wherein it remains a crime to assist a person in ending his or her own life.

<sup>8</sup> Ibid.

## MAID is legal in Canada: ... I was not trained to do this!

Daniel Garros, MD

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With the introduction of Medical Assistance in Dying (MAID) in Canada in 2016, many aspects of end of life care are being challenged, and a new chapter in our Canadian practice as health care professionals (HCP) has begun.

As a pediatric intensive care (PICU) physician, I have removed life sustaining treatment (LST) in infants, children and teenagers under my care many times. I have participated in many sad face to face meetings with families where the outcome was a decision accepting that the disease had overpowered the child, and the only course was to "let go" by providing no resuscitation and/or removing LST.

What differentiates MAID from withholding or withdrawing LST is **intention** and **proportionality**. Forgoing or withdrawing LST is a well-accepted clinical practice in cases where death is not preventable and it may also occur with regard to serious morbidity that is unacceptable to the patient. However, there is a different "feel" to the practice of actively killing the patient, so called euthanasia. Death is the primary intention of the actions in MAID. A few times over the years, some families have asked me: "doctor, could you please speed things up, we can't see our son like this anymore"! My ICU team's answer has been:

(...) No, we can't... but we will make sure your son dies under the best care we can provide, with comfort, warmth, no pain and distress, with you holding or staying beside him. We will remove the tubes, wires, etc. not needed anymore and allow him to die peacefully in his own time (Garros, Rosychuk & Cox, 2003).

The traditional ethical justification of this approach is characterized by the statement of Dr. E. Pellegrino, "In letting the patient die, the illness is the cause of death" (Gillett & Chamberlain, 2013).

When forgoing LST, the principle of proportionality is established by the condition of the patient, the urgent need to relieve suffering, and the consent of the caregiver. It can be said that death under such circumstances, with the help of palliative sedation is "foreseen" but not "intended" and the sedation itself is not causing the death of the patient. The removal of mechanical ventilation and supporting medicines is performed because they no longer serve their original purpose, which was the cure (Sulmasy & Pellegrino, 1999).



With the legalization of MAID in Canada in 2016, I will offer some personal insights why I am not prepared to include it in my own clinical practice, even if I was a HCP looking after adults.

## What is the motivation behind requests for MAID?

Somewhat surprisingly, pain is not the most reported primary motivation for requesting MAID. A large portion of patients receiving MAID in Oregon and Washington reported being enrolled in hospice or palliative care (PC), as did patients in Belgium (Emanuel, Onwuteaka-Philipsen, Urwin & Cohen, 2016). In the Netherlands, when patients requested MAID, 49% characterized part of their suffering as loneliness, 53.7% who got approval were 80 years old or older. The same is true in Belgium, where women over the age of 80 living in nursing homes and less educated are the largest group. The majority are enrolled in PC. In one analysis of several European and US studies, pain or physical suffering are not the main reasons to request MAID, but rather being a burden, dependence on others, loss of autonomy, loss of control of bodily functions, loss of dignity, loss of meaning for their lives, being tired of life, unable to pursue pleasurable activities, etc., have been quoted in various degrees (Bascom & Tolle, 2002).



One concern expressed is the potential influence of financial savings to the health system if MAID becomes more common. Could the motivation for the Canadian government be "financial gain"? Depending on how many people choose MAID, somewhere between \$34.7-million to \$138.8-million per year could be saved by the health care system. The authors of a recent study in the Canadian Medical Association Journal came to this conclusion by analyzing factors including how long patients might otherwise live, what disease they have and, crucially, what percentage of deaths every year are medically assisted (Trachtenberg & Manns, 2017).

# Any ethical principles guiding such decisions?

"I am the master of my destiny!" Patients have the right to choose their destiny, their fate, their mode of death. Traditionally in medicine, autonomy has been used as the right to refuse treatment and not the right to request or demand treatment. Associated with autonomy is the process of informed consent, which presupposes 1) free will without coercion; 2) competence/intact mental capacity; 3) being fully informed of all the ramifications and consequences of the decision; 4) being capable of understanding the information and its consequences. Henceforth, for patients who meet such requirements, the Supreme Court's commitment to autonomy "yields a prima facie right to choose the time and conditions of one's death, and consequently to request aid in dying from medical professionals" (Landrya, Foremana & Kekewichba, 2015).

## What about my autonomy as a HCP?

As the principle of respect for patient autonomy is MAID's pillar, it follows that the HCP's autonomy in deciding to refuse to participate in MAID should be equally respected.

The obvious option for a HCP is not to take part in and apply a well-recognized principle called "conscientious objection", i.e., the refusal to participate in actions that are contrary to one's own deeply held values or beliefs (Landrya, Foremana, &

Kekewichba, 2015). The Canadian Medical Association (CMA) position is clear:

(...) conscientious objection aims to ensure two equally legitimate considerations: (1) protection of physicians' freedom of conscience (or moral integrity) in a way that respects differences of conscience and (2) effective patient access to a legally permissible medical service. Hence, the patient who requests it cannot be abandoned, which is also not ethically and morally acceptable (fulfill the duty of non-abandonment).

# The case for refusing to refer a patient as part of the conscientious objection

Some people feel that the argument about HCP's rights to refuse to refer is weaker than the previous consideration of refusal to participate in MAID because of the diminished proximity or degree of involvement to the proposed act, and to the patientphysician relationship. How can we address this tension between HCP conscientious objection and non-abandonment of the patient? I see it primarily as an administration issue, and should be dealt with as such. In Quebec, the legislation allows for such HCP objection, stating the executive director of the institution (where the patient who requests MAID is) must take the necessary steps to find, as soon as possible, another physician willing to deal with the request (Bill 52, 2014). Others have suggested that, to avoid this problem, society needs to make the ability to provide MAID widely publicized so patients can look for it and find it easily, with the help of their families or close support systems, without the HCP referring it directly (Canadian Medical Association, 2015). The College of Physicians in each jurisdiction needs to take on the responsibility to make the public aware of available HCPs willing to participate in MAID.

Further, institutions should promote open moral dialogue, advance measures to minimize moral distress, and generally foster a culture that respects diverse values in the health care system, as stated by The American Thoracic Society on its official policy

statement on conscientious objection (an Official American Thoracic Society Policy Statement, 2015).



#### Should one human kill another?

The debate over MAID reflects a new understanding about morality. Thomas Aquinas, in the 12th century, stated that "taking innocent life is immoral at all times" (Gaylin, Kass, Pellegrino & Siegler, 1988). The old, classical belief is that human life is inherently valuable and should not be purposefully ended; right and wrong are defined according to what humans ideally should be (telos). Modern society's new morality asserts that autonomy is more important than the inherent worth of life; right and wrong are defined according to what humans want (Laio & Chan, 2016).

Indeed there is evidence that it is inherently difficult for humans to kill each other. Even the professionals, our soldiers, need massive techniques of desensitization to be able to live with the consequences of killing during war. Brig. Gen. S. L. A. Marshall first observed this during his work as an official "U.S. Army historian" in the Pacific and European theaters of operations in World War II. Based on his post-combat interviews, Marshall concluded in his book Men Against Fire (1946, 1978) that only 15 to 20 % of the individual riflemen in World War II fired their own weapons at an exposed enemy soldier. Crew-served weapons, such as machine guns, almost always were fired. And action would increase greatly if a nearby leader demanded that the soldier fire. But when left by themselves the great majority of individual combatants appeared to have been unable or unwilling to kill. The application and perfection of basic conditioning techniques increased the rate of firing to approximately 55% in the Korean War and around 95% in Vietnam. Every warrior society has a "purification ritual" to help the warrior to deal with his "blood quilt" and to reassure him/her that what he/she did in combat was good. Virtual Reality (VR) applied proactively to soldiers before they enter combat can effectively make them immune to combat stress and has the added benefit to reduce the incidence of post traumatic stress disorder. It prevents what is called "freezing on the line of fire" (Grossman, 2000).

Do I need desensitizing to start my MAID practice? Or should we use people that are trained to kill, experts, to perform MAID (POLYGON, 2014)?

A famous executioner, who had worked in federal penitentiaries in US, has given interviews about his experience killing inmates. He stated:

If I had a choice, I would choose death by electrocution. That's more like cutting your lights off and on. (...) But with chemicals, it takes a while because you're dealing with three separate chemicals. You are on the other end with a needle in your hand. You can see the reaction of the body. You can see it going down the clear tube. So you can actually see the chemical going down the line and into the arm and see the effects of it. You are more attached to it. I know because I have done it. Death by electrocution in some ways seems more humane (The Guardian, 2017).

Dr. Jay Chapman, the Oklahoma coroner who essentially created the modern lethal injection protocol, observed in the New York Times in 2007:

It never occurred to me when we set this up that we'd have complete idiots administering the drugs.

This observation was made when one execution was botched and a prisoner started to gasp and wither after he was being declared unconscious and called out "oh, man"! The intravenous line had blown and the drugs stopped flowing. The prisoner actually died of a heart attack later in the execution chamber (Eckholm, 2014).

Are we trained and do we know all the drugs and best approach to induce death, safely and humanely? The CMA now teaches how to perform MAID as a 2 day in person course as Continuing Professional Development, or as an online module.





#### How about our Oath?

According to a recent Canadian and US survey, 11% of Medical Schools are actually utilizing the original Hippocratic Oath; the modern version, adapted by Dr. Lasagna, is used by 33.3% of schools and 15.6% utilize the Oath of Geneva. Basically, Dr. Lasagna's oath states that:

(...) most especially must I tread with care in matters of life and death. If it is given to me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play God. (...) (Crawshaw, Foster, Iles-Shih, & Stull, 2016).

It is becoming more and more apparent that we can change and adapt our oath according to the circumstances, so much so that at Harvard Medical School, each class of students now writes its own oaths (STAT, 2016).

Does taking an oath influence our practice anyway? In a study of medical students, 97% of respondents had taken an oath during medical school. Only 26%

indicated that the oath influenced their practice a lot; another 37% responded somewhat (Antiel, Curlin, Hook, & Tilburt, 2011).

# And if we all embark on this, what are the consequences?

It has been said that physicians participating in killing patients runs counter to the goals of medicine and its eudemonic origins that focus on flourishing and wellbeing. Hence, physicians participating in killing patients can undermine the trust that grounds the therapeutic relationship.

Another important factor is the possible consequences on PC. There are enough barriers to good PC already; the association with MAID will unfortunately reinforce misconceptions. What we don't want is for families to hesitate or refuse proper palliation because of these misconceptions. The fact that doctors will be participating in MAID may make already difficult conversations more problematic.

Suffering has a new meaning! Is suicide or euthanasia going to become somehow normalized in our society as a reasonable response to suffering? Would medicine's involvement somehow provide further legitimacy for that perception? Will we become oversensitized to what constitutes a life-not-worth-living? Judging by the testimonies of people who have chosen the MAID path, one can start to see this trend

(The Globe and Mail, 2017). If the medical profession accepts MAID, it will be declaring decisively that "physicians" are mere providers of services, to be guided only by the desires of the individual patient, the will of the state or other third parties, and what the law allows (Yang, & Curlin, 2016).

The idea of medicine as a profession, which embodies a shared commitment to care for persons who are sick and debilitated so as to restore their health, will quickly fade into memory. Those made vulnerable by sickness and debility, to whom physicians owe their solidarity as physicians, will have much less reason to entrust themselves to physicians' care.

This issue touches medicine at its very moral center; if this moral center collapses, if physicians become killers or are even merely licensed to kill, the profession – and therewith, each physician – will never again be worthy of trust and respect as healer and comforter and protector of life in all its frailty. For if medicine's power over life may be used equally to heal or to kill, the doctor is no more a moral professional but rather a morally neutered technician (Gaylin, Kass, Pellegrino, & Siegler, 1988).

#### Am I alone on this?

The American Medical Association code of ethics on its 5th chapter, #5.6 states that:

When a terminally ill patient experiences severe pain or other distressing clinical symptoms that do not respond to aggressive, symptom-specific palliation it can be appropriate to offer sedation to unconsciousness as an intervention of last resort.

(...) Sedation to unconsciousness must never be used to intentionally cause a patient's death.

#### On #5.7, it states:

(...) however, permitting physicians to engage in assisted suicide would ultimately cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks.

In the UK, the British Medical Association on its last updated code (30/June/2016),

(...) opposes all forms of assisted dying; supports the current legal framework, which allows compassionate and ethical care for the dying and; supports the establishment of a comprehensive, high quality PC service available to all, to enable patients to die with dignity and (...) insists that if euthanasia were legalized there should be a clear demarcation between those doctors who would be involved in it and those who would not.

#### Furthermore, they stated that

(...) Only a minority of people want to end their lives. The rules for the majority should not be changed to accommodate a small group.

I think, at least for now, I am in good company! Further, some of my colleagues are asking to have their names removed from the list of HCPs who perform MAID in Canada, according to a recent news report (The National Post, 2017).



## Are we doing things backwards?

In Canada, only 30% of adults in need have access to PC. For children, PC services is currently only providing

care to fewer than 19% of those who die of nonsudden causes (Widger, Davies, Rapoport, et al., 2016).

We have a duty to invest much more in good PC, before MAID is widely used and becomes accepted by many as the best option to end of life care. In the Netherlands, pediatric PC guidelines were only published by the Dutch Pediatric Association in 2013; interestingly, between 1997 and 2005, 15-20 cases of neonatal euthanasia were happening per year (Verhagen, 2014).

#### Conclusion

It is clear that our current practice of compassionately withdrawing or withholding LST in specific clinical situations has become a standard approach to end of life care, one that is accepted within our values as physicians, and one for which I was trained. Fortunately, very few patients actually request MAID, but the numbers are growing while PC investments and availability are not.

Medical societies still affirm that MAID is not part of the "Medical Ethos", so conscientious objection should be validated. Institutions need to adapt and respect such choice.

Finally, "...we must say to the broader community that if it insists on tolerating or legalizing active euthanasia, it will have to find non physicians to do its killing" (Gaylin, Kass, Pellegrino, & Siegler, 1988). In Canada, some physicians and other HCPs are willing to take part in MAID. Although I truly respect their views and their willingness to do so, for the reasons I have demonstrated above I am not willing to partake in it.

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# Mental Health Professionals, Medical Assistance in Dying and Mental Illness: challenges and possible alternatives

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In February 2015, the decision of the Supreme Court of Canada regarding the case Carter vs. Canada (Attorney General, 2015) declared the criminal prohibition against physician-assisted death unconstitutional. This landmark case motivated a broad national discussion about physician-assisted death, its meanings and possible slippery slope effects. As a result of this process, Parliament voted to pass Bill C-14 on June 17th, 2016: an Act to amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying). The term "Medical Assistance in Dying" was chosen instead of Physician-Assisted Death, as the service can be legally provided by physicians and nurse practitioners (in provinces where this is allowed). It allows both voluntary euthanasia and assisted suicide (See Bill C-14).

Medical Assistance in Dying (MAID) is legal in Canada, the Netherlands, Belgium, Luxembourg, Switzerland, and in the US states of Vermont, Oregon, Washington, Montana and California (Duffy, 2015; Marcoux et al., 2015). However, there is substantial variability regarding procedural requirements within these legislations and practices differ considerably in European countries, Canada and the US. Notably, among the variations is the explicitly expanded access for persons with mental illnesses by the Netherlands and Belgium (Ganzini, 2016).

Although previous recommendations (Parliament of Canada, House of Commons, 2016) regarding non-terminal suffering (such as that due to mental illness) included it as eligible for MAID in Canada, this did not appear in the legislation. Requests for MAID of

patients suffering from mental illness are embedded with controversy due to ethical and clinical difficulties. In Health Ethics Today, Volume 24(1), Gill and Byrne (2016) discuss physician assisted suicide in psychiatric patients, emphasizing that as medicine moves away from paternalism, "arguments made to enact legislation for patients suffering from incurable somatic illnesses can be applied to the psychiatric population with incurable mental illness as well" (p.7). They argue that not to do so would dis-empower persons with mental illness. Our article revisits this issue and is aimed at highlighting challenges and possible alternatives involving MAID for persons with mental illness.

There are some guidelines on MAID published by professional psychiatric associations recommending psychiatrists be particularly careful regarding actions that can lead to the death of those who cannot protect themselves because of their disability (Duffy, 2015). Thus, jurisdictions which legalized MAID have specific legislation for cases involving mental illness. Among the safeguards established, regulations generally recommend the person's assessment by a psychiatrist or mental health care professional (Duffy, 2015). The presence of a mental illness by itself does not mean a person is unable to express consent or dissent to treatment (Frati et al., 2014) but it is a clinical challenge to find a balance between safeguarding the patient's right to refuse treatment and protecting their best interests when their capacity to make those decisions are compromised (Leeman, 1999).

Western legislation follows the assumption that persons with capacity are able to determine their own concept of dignity, including their wish to end treatment or to ask for MAID (Laundry et al., 2015). In psychiatry, however, there is a long-standing tradition that considers a choice of death over life predominantly an expression of mental illness, and which may represent lack of insight and incompetence to make decisions (Leeman, 1999). Psychiatric labelling can be a real possibility that can have important moral consequences in terms of the individual's autonomy and thus persons suffering from mental illness may be vulnerable to having their rights paternalistically

violated. Of course the suffering from the mental illness can be as great (or greater) than that of somatic illness. What is unbearable can be, however, more from the absence of hope, social and financial support, meaningful work, and rewarding relationships rather than from mental illness. Stigma and discrimination associated with mental illness is said by persons living with it to result in greater suffering than the illness itself, affecting every aspect of their lives from housing, work, and education to relationships and self-image (Mental Health Commission of Canada, 2012). In addition, literature on this theme shows a concern that the legalization of MAID in a context of social and economic inequalities may result in patients choosing MAID because they cannot afford a better health care (Barutta & Vollmann, 2015) or because they feel they are a burden to others.



Despite the important arguments for excluding patients with mental illnesses from eligibility for MAID, there are arguments emphasizing that in specific conditions suicide can be rational, including in cases where the person suffers from a mental illness (Hewitt, 2013; Cholbi, 2012). The paramount difficulty is to understand the extent to which the person's judgment is impaired by mental illness. In this context, mental health professionals assume a fundamental role in the review of requests for MAID (Frati, 2014). Imperative as well, is the use of a systematic approach to determine capacity in such assessments (Weinberger et al., 2014), as evaluation based only on assessing the patient's abstract understanding of clinical facts is not enough (Leeman, 1999). In their article, Gill and Byrne (2016) acknowledge that a formal capacity assessment needs to be performed and note that this is a "routine practice for psychiatrists" (p.8). Psychiatrists, however, find

competence assessments very challenging, despite the fact they are called upon to do them regularly (Peruzzi et al., 1996).

Mental health professionals must be able to assess patients' concrete appreciation of their own clinical situation (Leeman, 1999). It is crucial to understand and explore patients' vulnerabilities in order to address them with appropriate methods and personnel. This assessment must result in a shared decision (Berghmans et al., 2013) within a therapeutic relationship. However, an investigation of 66 Dutch psychiatric euthanasia and assisted suicide cases from 2011 to 2014 indicated that 27% had not previously met the physician who assisted in their deaths (Kim et al., 2016).

Therefore, recognition of a mental illness and understanding its impact on medical decisionmaking can prevent inappropriate, indifferent, or premature decisions (Leeman, 1999). Recognizing the importance of considering and discussing the patient's perspectives is key to respecting their dignity and rights. It is fundamental to assure that the rights of persons with mental illness are being fully respected, but this discussion goes beyond only affirming their rights. We must recognize that the suffering experienced by psychiatric patients who lack autonomy can be as difficult as the distress patients with other somatic illnesses undergo when asking for MAID (Varelius, 2016). Their competent decisions to live or to die in a context traditionally characterized by stigma, discrimination, poor living conditions, and lack of access to mental health services involve more than issues of autonomy and decisionmaking capacity. Assessment for MAID requires meaningful understanding of the person's story and predicament and of the causes underlying their suffering. Within the therapeutic relationship, mental health professionals have privileged knowledge and opportunities to relieve suffering (Maher, 2016) and to deal with these dilemmas.

If access to MAID is to be expanded to persons whose suffering is situated in their mental illness, Canadian society has much to do in the way of improving access to mental health services and to necessary social and economic support, as well as in diminishing the stigma and discrimination associated with this form of illness. A broad application of the principle of beneficence must be as active as the focus on respect for autonomy, where assistance in dying for persons with mental illness is concerned.

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# "Conscientious Objection" and Medical Assistance in Dying (MAID): what does it mean?

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(...) Answers only raise new questions. We are as confused as ever, but on a higher level. (A favorite quote of former Canadian Prime Minister, Lester Pearson)

### Background

"Conscientious objection" typically means: "to refuse to participate based on strongly held ethical beliefs". It originated with the refusal to fight in wars, and because of pacifist beliefs. Like other military allusions ("life in the trenches", etc.) it has been co-opted into wider societal use. Specifically, it is now being applied to euthanasia in Canada, which in turn is now known as Medical Assistance in Dying (MAID). Because many of the medical practitioners and hospitals that object do so because of their opposition to "killing", the analogy is not wholly unreasonable. What is less clear is how this construct will ultimately affect patients, practitioners, administrators and politicians.

Many patients will posit that medical "conscientious objection" is simply inappropriate: end of discussion. This is typically based upon a growing sense that the

physician- and by proxy the hospital, the nurse, pharmacist or allied healthcare worker- has a duty to carry out the patient's wishes. In short- and regardless of whether we are discussing euthanasia at one extreme or cardiopulmonary resuscitation (CPR) at the other- there is a growing sense that if the patient wants it done then the healthcare team has to make it happen. It is worth emphasizing that the letter of



Canadian Medical law is currently less strident: patients have a right to refuse a medical intervention; they do not (yet) have the right to demand.

It is appropriate that Canadian MAID legislation, and Provincial College regulations provide some form of "opt out". However, opting out cannot mean abandoning the patient. It also cannot become an easy excuse to avoid any medical interventions that are complex or time-consuming. Currently, the only proviso is for the patient who requests MAID to be provided with an "effective referral". Unfortunately, this "effective referral" is imprecisely defined, and, ironically, may be left to a physician who opposes the idea. Moreover, much of the MAID language is legal (i.e., "medical conditions that are grievous and irremediable...") rather than clinical (i.e., "with the following medical conditions; provide the following referral..."). It was one thing for the Supreme Court to give bill C-14 Royal Assent; it was quite another to expect health regions to iron out the wrinkles within an arbitrary one-year deadline.

# Objection: not always inappropriate; not always surprising

The idea that practitioners and hospitals can recuse themselves reflects Canada's history of independent practitioners and autonomous institutions. For example, surgeons have routinely refused to offer operations such as transplantation, craniotomy, or laparotomy. Provocatively, the rationale need not be that the practitioner is inadequately skilled, or morally conflicted, but rather that they deem it not to be in an individual patient's "best interest". If the surgeon refuses based upon "medical judgment", they are rarely forced to refer the matter forward. However there are limits, and medico-legal precedents for restricting "conscientious objection" do exist. For example, quidelines rein in Canadian physicians who refuse to prescribe birth control pills or countenance abortion.

"Conscientious objection" is associated with "moral distress". However, "moral distress" is another term plagued by lack of a precise, common, or quantifiable definition. Much like conscientious objection moral

distress suggests psychological discomfort from doing what one believes to be morally wrong. However, it may also reflect a sense that Canadian doctors no longer feel that they are adequately supported, whether by legal statutes, societal deference or common sense. As stated, MAID reflects an age where patient-autonomy increasingly supersedes medical judgment. Accordingly, "refusal to engage" may be the "safest" response from practitioners who feel that they are otherwise forced to follow external dictates before internal moral codes. When medical regulatory bodies and society ignore practitioners there is a cost. For example, doctors and nurses may become increasingly burnt-out and disengaged, and at a time when we need the very opposite.

Regardless of whether we are discussing resuscitation or palliation, practitioners need to be listened to when we feel that we are hurting more than helping. There is already an expectation that CPR be performed on everyone without explicit contrary documentation. In other words, physician judgment is becoming largely irrelevant, and patients and families are not expected to offer any reasoned justification. As such, CPR "conscientious objection" may seem preferable too. This is especially true if CPR feels akin to "patientassault". This is also true because our very own Medical Colleges (and the courts) are increasingly deciding against physicians. Accordingly, we should accept that societal and license governing attitudes towards those who object to MAID might well harden over time.

Comparing and contrasting MAID and CPR offers further insights into medical decision-making and moral objection. For example, if a practitioner's major focus is to do everything to preserve life then they should presumably object to MAID but promote universal CPR. If the major concern is quality-of-life over quantity-of-life then they should support MAID but not default CPR. If they are uneasy about active euthanasia but comfortable with natural death then presumably they would object to both MAID and also to widespread CPR. Regardless, the biggest danger is that meaningful self-reflection is not supported professionally, almost never occurs, or is clouded by

denial or discomfort or fear. If so then "objection" is not a moral stance but just a convenient excuse. Perhaps the best test of whether objection is appropriate is whether these decisions are individualized, include safeguards, and maintain patient-focus. In other words, we need a mechanism to ensure that objection is principled and not merely expedient.

The likelihood of objection also reflects how practitioners and institutions regard the current performance of Canadian Palliative Care (PC). Palliative Care can increase both the length and the quality of terminal life. In contrast, CPR may lengthen life but risks worsening quality of life; whereas MAID will shorten life but should improve its quality. Accordingly, regardless of what one thinks about MAID or CPR, we should all be objecting to the lack of focus, funding and resources for PC. "Conscientious objection" to MAID is more understandable if it is motivated by worries that it will weaken existing PC Services. Provocatively, however, much of the motivation for MAID originated with a sense that PC was underperforming. Physicians have long been criticized for under-resuscitation. Medical Assistance in Dying is, to some degree, the result of objection to under-palliation.

Despite estimates that 8-out-of-10 Canadians currently support euthanasia, enthusiasm may wane when the public discovers that MAID mandates lengthy screens, after which a majority of applicants are turned down. In other words, more members of the public may ultimately "conscientiously object" to MAID. Euthanasia also requires that the public overcome the cognitive dissonance of seeing trusted professionals and institutions offering curative therapy alongside lethal palliation. Opposition may also increase when patients, families and surrogates face the choice between local familiarity (i.e., remaining in their home town even though MAID is not offered) versus sacrificing those social support in return for greater medical intervention. Canada's 1984 Health Act "guarantees" not just public

administration but also comprehensiveness, accessibility, portability, and universality. Medical Assistance in Dying will challenge whether these tenets apply not just across the country, but also from birth to death.



Other healthcare professions may also "conscientiously object". For example, what if a hospital physician agrees to MAID but the bedside nurse or the pharmacist does not? Is the doctor the team leader, or just primum inter pares (firstamongst-equals)? Other questions include what to do when a healthcare worker agrees but is restricted by his or her hospital privileging? What if healthcare workers are willing but are restricted by technical skill set (inability to manage infusion pumps; inadequate knowledge of analgesics/anesthestics). What if they are willing but inadequately skilled in communication or in dealing with terminal patients? In short, MAID is forcing a lot of "inconvenient" questions, but has not yet provided definitive answers.

### Finding a better way forward

Without clear definitions "conscientious objection" can be a simulacrum: it can mean what you want it to mean. Worst of all, it becomes an excuse for those that wish to avoid patients who are time-consuming, emotionally-draining, or legally-perilous. If it is too easy for busy practitioners and over-subscribed hospitals to opt out then we should not be surprised

that they do. Moreover, while MAID has captured a lot of attention, it may distract from providing end-of-life care for greater numbers of dying patients who would prefer *less* rather than *more* medical intervention. Canada already has one of the highest rates of institutionalized and technology dependant death. In terms of end-of-life care, we should be looking for all opportunities to engage, not to disentangle.

During the World Wars, conscientious objectors were not merely excused to do as they pleased. Instead, they were expected to find ways to benefit the wider war effort. If we borrow the term then we should more fully apply the analogy. We should expect more from medical "conscientious objectors" then to simply "push" the problem away. In these cases our professional obligation should not to just to shrug and accede, but rather to redouble efforts. This includes referral but can also mean more discussion, better symptom control, fuller explanations, and closer follow-up. It is one thing to voice your opposition, it is quite another to remove yourself entirely.

In Greek mythology, Pandora (the earth's first woman) was given a box (strictly speaking a jar) in which were contained all the evils of the world. She opened it and all the evils of the world flew out. This left her with only "hope". Accordingly, the phrase "to open Pandora's box" means to perform an action that may seem small or innocent, but has far-reaching consequences. Even proponents of euthanasia should not be surprised if MAID poses more tricky questions than it provides definitive answers. It is not enough to "hope" that we get MAID right: it requires a lengthy commitment, clearer guidelines and franker debate. Practitioners should push for "conscientious engagement".

Postscript: The above manuscript is based upon a more comprehensive and fully referenced publication by Brindley, P. G., & Kerrie, J.P. (2016). Conscientious Objection and Medical Assistance in Dying (MAID) in Canada: Difficult Questions - Insufficient Answers. Canadian Journal of General Internal Medicine, 11(4), 7-10. We thank the editors and would steer interested readers to this journal.

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