

Is It Time to Get MAD?



COMMENTARY

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ABSTRACT

Like the rest of Canada, the vast majority of Quebecers do not have access to comprehensive, quality, palliative end-of-life care. Nevertheless, despite every substantive argument, compelling study, troubling precedent and cautionary tale regarding physician-hastened death, the Quebec Government has passed Bill 52 – a Bill legalizing euthanasia or what is euphemistically being called medical aid in dying (MAD). While the Bill purports to ensure that “everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering,” it states that organizational structures, institutions and palliative care hospices will carry out this mandate “within the limits of the human, material and financial resources at their disposal.” Perhaps, given the limitation of those resources, the only detail Bill 52 provides regarding how they will fulfill their mandate pertains to the administration and tracking of MAD. How will Quebecers feel when they realize that while their healthcare system can offer them euthanasia, it cannot assure them or their loved ones, access to healthcare professionals proficient in palliative care? All of which begs the question, is it really time to get MAD?

IT SEEMS THAT fear can dissolve pretty much anything that stands in its way. Connect that fear with the prospect of dying, and every substantive argument, compelling study, troubling precedent or cautionary tale regarding physician-hastened death simply melts away. How else can one explain that assisted suicide and euthanasia, the latter couched in less stark language – medical assistance in dying

(MAD) – are being touted, most recently in the province of Quebec, as death with dignity?

Fear is driven by expectation and often shaped by previous experience. When one considers that the vast majority of Canadians do not have access to comprehensive, quality palliative care, is it any wonder that people are so afraid? (The Honorable Sharon Carstairs 2000). Watching someone die a bad death

– where pain is not controlled, distress is ignored, patients and families feel abandoned and access to home-based services are inadequate – leaves an indelible mark: a memory that turns the promise of a peaceful exit from this life into a lie. For all too many Canadians, that is the lingering memory they carry of their loved one's death.

The chances of getting competent palliative care, designed to improve the quality of life of patients and families, are a crapshoot. If you are living in an urban setting, your odds are better than in rural and remote regions of the country. Even in major centres however, the quality of palliative care – even basic symptom management – often comes down to luck of the draw; the ward you happen to be admitted to or the expertise of those attending to your care. If you are First Nations, Métis or Inuit, the chances of receiving culturally sensitive palliative care are stacked against you. If you happen to be very young and dying, access to quality care and real choices that determine comfort and place of death are frequently lacking. There is in fact, no base minimum standard of care that every child and family can access; and many will have little choice but to die in tertiary care settings, simply because there are no community resources to support a home death. At the other end of the life cycle, things are not much better; particularly for the elderly living in long-term care facilities. These should not only be good places to live, but good places to die. As unfathomable as it seems, there are no national standards – regarding pain control, symptom alleviation, psychosocial care and spiritual guidance – dictating what palliative care these facilities, at a minimum, must provide. And so we roll the dice, hoping that things will work out for older Canadians in long-term care facilities, knowing – given the paucity of expertise and resources, and the frequent off-loading to the overtaxed acute care system – that this is more a plaintive wish than a solid plan.

Dying with Dignity

With such an abundance of suffering, is it any wonder that for some, the option of euthanasia and assisted suicide has such allure? That a lethal overdose or injection is euphemistically coined “death with dignity” is ironic, and surely an indictment of our healthcare system. Whether real or perceived, whether based on past experience or the absence of reassurances to the contrary, many people simply do not believe that they or their loved ones will get the care they need as they approach their final days; or fear that the sacrifice to their autonomy will be a fate worse than death.

Palliative care is not a perfect foil to suffering, anymore so than medicine is a perfect foil to death (Chochinov 2013). Leaving this life will always be tainted with sadness and grief; and while palliative care can address most physical suffering quite effectively, it cannot eliminate the reality that dying is physically, emotionally and spiritually challenging. It also cannot alter the fact that all humans are vulnerable, and that loss of ability, capacity or autonomy is not just possible, but inevitable. Self-sufficiency – particularly when we are very young, very old or seriously ill or injured – hangs precariously by a thread; and like life itself, can be gone in an instant.

Palliative care can address many of the things that drive a patient's wish to die. And palliative care that targets the preservation of dignity as its overarching goal and guiding principle includes optimal symptom management; accommodating informational, cultural and spiritual needs; paying exquisite attention to issues regarding personhood; a commitment to non-abandonment; and understanding the dynamics of ambivalence, meaning, purpose, continuity of self, role preservation, pride, acceptance and generativity. It includes attentiveness, and an ability to skillfully unravel, psychological and spiritual distress; and knowing how care tenor – a fundamental

stance towards patients imbued with respect and affirmation – can profoundly shape a dying person’s perspective, sense of self-worth, feelings of being a burden and even will to live (Chochinov 2002, 2006). In response to this dignity conserving approach to palliative care, even the former head of the Hemlock Society conceded, “if most individuals with a terminal illness were treated this way, the incentive to end their lives would be greatly reduced” (Girth 2002).

La Belle Province

This seems an appropriate time to trot out various studies on desire for death, will to live, euthanasia and assisted suicide, carefully delineating the associations between distress, despair, depression and ways in which proper care, or the paucity of such care, can influence requests for hastened death. However, in view of the recent passage of Bill 52 in Quebec, that rather feels like extolling the virtues of a padlock after the horse has exited the barn. In spite of every warning, every precaution and every study highlighting the dangers and pitfalls of doing so, on June 5th, 2014, the Quebec National Assembly passed what is being called *An Act Respecting End-of-Life Care* (Bill 52, 2014), with the Parti Quebecois member who spearheaded the bill, saying, “dying with dignity means dying with the least amount of suffering” (Retrieved June 23, 2014. <<http://www.cbc.ca/m/touch/canada/montreal/story/1.2665834>>).

Consider this: there are about 60,000 deaths each year in Quebec (Retrieved June 17, 2014. <<http://www.statcan.gc.ca/tables-tableaux/sum-som/l01/cst01/demo07a-eng.htm>>). If one extrapolates the Oregon Death with Dignity experience, which only allows assisted suicide and not euthanasia (Quill 2007), we would expect about one-tenth of 1% or 60 deaths as a result of MAD. If we apply the Dutch experience with euthanasia (van der Heide et al. 2007), which accounts

for about 2.8% of all deaths, we might anticipate about 1,700 Quebecers to die each year by way of MAD. Now consider that of the 60,000 annual deaths, about 10% will be sudden in ways that largely preclude a role for palliative care. If 70–85% of those remaining do not have access to comprehensive, quality palliative care (The Honorable Sharon Carstairs 2000), upwards of 46,000 Quebecers will die a worse death than necessary. That is a tsunami of suffering and a profound assault on human dignity.

What does Bill 52 propose to do about this? (Bill 52, 2014) The Act states its purpose is “to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy ... so that everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering” (p.6). Sadly, this wonderful statement, which would establish Quebec as a national leader in quality palliative care for all its citizens, turns out to be little more than sugar coating for its real agenda. Rather than delineating how it will tackle the overwhelming unmet needs of dying Quebecers, the Act includes the proviso that organizational structures, institutions and palliative care hospices will carry out their mandate “within the limits of the human, material and financial resources at their disposal” (p. 4). In other words, the government will not be making the necessary investment in caring for tens of thousands of underserved Quebecers who die each year. The words describing the mandate of a newly formed Commission on End-of-Life Care also ring hollow. While they are charged, “to examine any matter relating to end-of-life care” (p. 14), the only detailed description of duties pertain to “overseeing the application of the specific requirements relating to medical aid in dying” (p. 14).

Bill 52 includes another end-of-life option, which it refers to as *continuous*

palliative sedation. This is described as the relief of suffering by administering medications or substances intended to render a patient “unconscious without interruption until death ensues” (p. 3). Unfortunately, this is a misrepresentation of palliative sedation, which is a proportionate response that titrates sedation according to what the patient needs to achieve comfort. It can be reversed or adjusted, depending on the patient’s wishes and evolving clinical status. It is easy to see the strategic political rationale in conflating palliative sedation with euthanasia, in that it suggests that they are really no different; and if the former is acceptable, so too ought the latter be. The Act also implies that palliative sedation, like euthanasia, leads to the patient’s death. There is no evidence that palliative sedation hastens death (Maltoni 2012); quite the contrary, evidence suggests that people whose pain is well-controlled, and who elect to receive palliative care earlier on in their illness trajectory, actually seem to live longer (Temel et al. 2010).

Finally and of little surprise, Bill 52 devotes most of its attention to MAD, i.e., euthanasia “the administration by a physician of medications or substances to an end-of-life patient, at the patient’s request, in order to relieve the patient’s suffering by hastening death” (p. 3). In this regard, there are several problematic issues. First and foremost, the Act casts physicians into the role of clerks, tasked with determining if patients meet various criteria, *without being under any obligation, or having the requisite expertise, to explore, understand or mitigate the underlying causes of distress*. And while the criteria for MAD are seemingly straight forward, they are worth examining carefully:

- *Be capable of giving consent to care*. This refers to the issue of competence; and if reduced to its most basic, means asking

the patient, “do you know this injection will result in your death?” and “do you know there are options other than MAD?” As a clerical task, this simple version of determining competence is pretty straightforward. On the other hand, only 6% of psychiatrists in Oregon felt confident in their ability to determine if a patient was competent to request suicide; and their own personal moral beliefs seemed to influence how they might evaluate such an individual (Ganzini et al. 1996). How Quebec physicians will determine competence and what level of complexity they will delve into, remain to be seen.

- *Be at the end of life*. It appears this has been kept purposefully vague, to provide Quebecers and physicians latitude in interpreting what this might mean. Does age itself qualify someone as being at the end of life? The Dutch are now considering making euthanasia available to anyone over the age of 70 who is tired of living (Pereira 2014). Quebecers may well discover that when autonomy is the driver, any destination may be deemed on course.
- *Suffering from a serious and incurable illness*. This criterion could cover a lot of ground, including various cancers, Alzheimer’s disease, Parkinsonism, Huntington’s, cystic fibrosis, polio, systemic lupus, osteoarthritis, rheumatoid arthritis, HIV/AIDS, amyotrophic lateral sclerosis, diabetes and schizophrenia, to name but a few. While these are serious and incurable, they have different trajectories of decline and variable implications for quality of life.
- *Be in an advanced state of irreversible decline in capacity, and experience constant and unbearable physical or psychological pain, which cannot be relieved in a manner the patient deems tolerable*. These are both highly subjective; while the Act might

anticipate someone in the final weeks or days of an end-stage illness, it leaves the door open to people with serious, protracted, non-curable conditions, who, on the basis of actual or anticipated suffering, believe they qualify for MAD.

- *Before administering MAD, the physician must make sure that the request is being made freely and without any external pressure.*

And yet, according to the Act, physicians are only able to speak with the patient's close relations if the patient grants permission to do so. If the Oregon experience has any bearing, about 10% of patients will refuse to have their family brought into the discussion; in another 6% of instances, the physician will not know if families are aware of the request (Ganzini et al. 2000). This is unconscionable; a physician who fails to speak with family members of someone who is suicidal because of patient objection is guilty of malpractice and negligence of duty. Why should the standards of care for patients requesting a physician to end their life be any less stringent?

- *Making sure that the request is an informed one, in particular by informing the patient of the prognosis of the illness and of other therapeutic possibilities and their consequences.* It is impossible to effectively describe someone's options without considerable expertise in palliative care and a deep understanding of the psychological underpinning of a wish to die. Take for instance the case of Helen, a woman in her mid-80s with metastatic breast cancer who died in Oregon as a result of a lethal overdose under the Death with Dignity Act (Hendin and Foley 2008). In a recording of her physician's consultation, which was released by the Compassion in Dying organization, she is told, "there is of course all sorts of hospice support that is available to you." One additional sentence is used

to offer chemotherapy "that may or may not have any effect," and another offering hormone therapy, to which she responds, "Yes, I didn't want to take that." The physician replies, "All right, OK, that's pretty much what you need to understand" (p. 1618). While she expressed concerns about being artificially fed – a concern that could easily have been eliminated by assuring her that no treatment would ever be given against her will – her concerns are ignored and an opportunity to assuage her fears, which are likely in part driving her wish to die, is tragically missed.

- *Verify the persistence of suffering and that the wish to obtain MAD remains unchanged, by talking to the patient at reasonably spaced intervals given progress of the patient's condition.* Without some specificity regarding time interval, this will be interpreted according to the whim of those involved, i.e., several hours, several days, several weeks, depending on the circumstances and, likely, the degree of hopelessness shared by the patient and the physician.
- *Obtain the opinion of a second physician.* The difficulty is that people will seek out the opinions of physicians who support MAD. This is in fact happening in other jurisdictions, such as Oregon, where, according to the former executive director of Compassion in Dying, "if I get rebuffed by one doctor, I can go to another" (Hendin and Foley 2008: 1617). As in Oregon, Bill 52 contains no provisions on how differences of opinions between physicians will be reconciled. In essence, if two doctors agree to sign off on the request – with no requirement that either one be the primary care physician who knows the patient well – the request will proceed. It is also worth speculating which physicians are most likely to agree to provide MAD. Prior studies have shown

an association between concerns regarding analgesic toxicity, diminished empathy, less knowledge of symptom management and least experience looking after dying patients, and those most likely to support legalization of assisted suicide, with those most experienced being oppositely inclined (Bachman et al. 1996; Cohen et al. 1994; Portenoy et al. 1997).

The Act indicates that the end-of-life services provided in “every institution” attending to dying patients must “be made known to the personnel of the institution ... and to end-of-life patients and their close relations” (Bill 52, 2014: 5). In other words, there appears to be an obligation to tell patients and families about end-of-life care options, including MAD. This is highly problematic, and ignores how the obligation to introduce MAD may undermine trust, provoke fear and heighten vulnerability. Previous studies have shown that patients who are depressed are more likely to find discussions that include explicit mention of euthanasia or physician-assisted suicide as increasing trust in their physician, whereas patients with pain believe such discussions would not increase trust (Emanuel et al. 1996). Terminally ill patients who felt appreciated were also less likely to consider euthanasia or assisted suicide (Emanuel et al. 2000).

A Way Forward

All parties engaged in this conversation agree that the needs of dying patients and their families are important and, currently, woefully underserved. The following recommendations are offered as a way forward, recognizing the needs of dying patients and families, and the autonomy aspirations of those supporting MAD:

1. Quebecers hold their government accountable to deliver on its promise, as stated in Bill 52 “to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy ... so that everyone may have access, throughout the continuum of care, to quality care that is appropriate to their needs, including prevention and relief of suffering” (Bill 52, 2014: 6). This would see Quebec emerge as a national leader in caring for the needs of its dying citizens and their families.
2. Quebec set up its Commission on End-of-Life Care, with its mandate to “examine all matters related to end-of-life care” (Bill 52, 2014: 14). The first task of this commission should be to work with the Quebec Government, to secure the resources necessary to address the comprehensive palliative care needs of all Quebecers. This commission might also establish a provincial ombudsman, thus determining where resources and expertise are lacking, how community investment in home palliative care should be directed, how choice regarding place of death can be accommodated and what educational initiatives are required to develop capacity among healthcare professionals, thereby holding individual practitioners, institutions and the health-care system itself accountable to a higher standard of palliative end-of-life care.
3. The Commission on End-of-Life Care established a Patients’ Bill of Rights, underscoring end-of-life choices that Quebecers are entitled to, including (1) access to comprehensive, palliative end-of-life care; (2) the right to refuse any treatment they deem unacceptable or unwanted; and (3) the right to have any treatment they no longer wish discontinued.
4. Given the Act has distorted the meaning of palliative sedation, or what it has called *continuous palliative sedation*, the Commission on End-of-Life Care

introduced new language into the lexicon of end-of-life choices, i.e., *Proportionate Palliative Sedation* (Quill et al. 2009). This option will enable patients within the final weeks of life, whose suffering cannot otherwise be managed, to receive whatever degree of sedation they required to make themselves comfortable; this can always be adjusted – either more or less sedation – and reevaluated, based on the patient’s comfort and evolving clinical status.

5. The Commission on End-of-Life Care, in conjunction with provincial palliative care experts/organizations, bolstered efforts to increase the uptake of advanced care planning, end-of-life conversations (Chochinov 2014), advanced directives and the naming of healthcare proxies.

The Canadian Medical Association and the Parliament of Canada (Motion 456) have recently called for a national strategy on palliative end-of-life care. In following the previous recommendations, Quebec could chart an inspiring course, leading the way for the rest of the country. Should these efforts fail to deliver on their promise to provide quality palliative care for dying Canadians and their families, surely that is when all of us need to get mad.

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