

Time to move beyond the debate on assisted suicide

By Tarun Ghose

The long smouldering debate on physician-assisted suicide (PAS) flared up early this summer when on June 5 the Quebec National Assembly passed Bill 52, An Act respecting end-of-life care. The legislation gives patients in some situations the possibility of requesting medical aid in dying, widely considered a euphemism for euthanasia. Its passage followed province-wide public hearings on a 2012 bipartisan Quebec committee report recommending doctors be allowed to provide life-ending medications at the express request of terminally ill patients, or patients suffering from intractable physical or emotional pain with no hope of relief.

Polls show substantial if not majority support for right-to-die legislation, in Quebec as well as the rest of the country. But what is the position of other principal actors who have a responsibility or practical interest in the outcome of laws like Bill 52? Are we prepared for a looming Supreme Court decision that could knock down existing legal prohibitions on assisted suicide? And how is this debate distracting from the fundamental absence of adequate end-of-life care in Canada? The stakes are too high to let events overcome us without being prepared.

Laws and legal challenges

On October 4, 2013, at the annual conference of federal, provincial and territorial health ministers, Health Minister Rona Ambrose commented, "We do not support assisted suicide—that is our government's clear position." Parliament has debated the issue several times and voted down a pro-PAS bill in 2010. The Senate also failed to develop a consensus on PAS and euthanasia. And after the passage of the Quebec law this summer, Justice Minister Peter MacKay said it is "not our intention to reopen the debate."

A month before the October 2013 ministerial, a majority of representatives to the annual Canadian Medical Association (CMA) conference defeated a motion urging all levels of government to conduct public consultations on

whether PAS could be accepted as a justifiable end-of-life-care procedure. With this defeat, CMA is left with its 2007 policy that discourages doctors from participating in PAS or euthanasia, emphasizing that it is up to society at large to change the laws with respect to assisted suicide. In Quebec, despite popular support, hundreds of physicians have signed a declaration against Bill 52.

In Canada, suicide is not a crime but PAS is. Section 241 of the Criminal Code states: "Everyone who (a) counsels a person to commit suicide, or (b) aids or abets a person to commit suicide, whether suicide ensues or not, is guilty of an indictable offence and is liable to imprisonment for a term not exceeding fourteen years." The courts have intervened in PAS in three important cases. The first, *Carter v. Canada*, or the "Death with Dignity" case, which comes before the Supreme Court of Canada again this month, is by far the most important.

In January 2010, Lee Carter and her husband, both residents of British Columbia, accompanied Lee's 89-year-old mother, Kathleen Carter, to Switzerland where she planned on ending her life with physician assistance. The elder Carter was suffering from incurable progressive narrowing of her spinal canal that caused severe pain and paralysis.

In April 2011, the Carters joined the B.C. Civil Liberties Association (BCCLA) in challenging Canada's *de jure* ban on PAS. The lawsuit claimed the Criminal Code offence against assisted suicide was unconstitutional because it denies individuals the right to make choices that are fundamental to their physical, emotional and psychological dignity while also restricting the freedom of physicians to deliver end-of-life care to incurably ill patients. In June 2011, the plaintiffs were joined in their case by B.C. resident Gloria Taylor, 63, who was suffering from ALS, a fatal degenerative disease of the central nervous system

with no effective treatment. ALS was in the news often this summer as people all over the world took part in an "ice bucket challenge" to raise money for the disease.

In an unprecedented decision in June 2012, the B.C. Supreme Court ruled that the right to die with dignity is protected by the Charter of Rights and Freedoms. The Court gave Parliament a year to draft new legislation on PAS and granted Taylor a constitutional exemption to seek

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PAS. (She died of her ALS in October before that could happen.) The federal government appealed the decision on the grounds that the existing law is necessary for the protection of vulnerable people. In October 2013, the B.C. Court of Appeal upheld, by a 2-1 decision, Canada's ban on PAS. The BCCLA appealed to the Supreme Court of Canada, which agreed to hear the case beginning this month.

In *Rodriguez v. British Columbia* (1993), the Supreme Court of Canada heard another challenge to Section 241(b) from 42-year-old B.C. resident Sue Rodriguez, who was diagnosed with ALS in 1992. By 1993 it was clear Rodriguez would not live longer than another year. She embarked on a spirited legal and multi-media campaign to strike down the criminal code provisions on assisted suicide, which she insisted violated Sections 7 (on the right to life, liberty and security), 12 (on protection against cruelty and unusual punishment) and 15(1) (on equality) of the Charter of Rights and Freedoms. The Supreme Court, in a 5-4 decision, turned down her challenge. In 1994, Rodriguez took her own life with the assistance of an anonymous physician.

The final case is that of Hassan Rasouli, a 61-year-old retired engineer on life support at Toronto's Sunnybrook Hospital since 2010 after surgery for the removal of his benign brain tumour went wrong, causing bacterial meningitis. When intensive care unit physicians gave Rasouli little chance of a

meaningful recovery, his attending physicians, doctors Brian Cuthbertson and Gordon Rubenfeld, proposed to unilaterally withdraw his life support, claiming that discontinuing care did not constitute "treatment" as defined by Ontario's law, and therefore the withdrawal of life-sustaining measures required neither the consent of the patient (or surrogate decision-maker) nor the permission of the Ontario Consent and Capacity Board.

Rasouli's wife, herself a doctor, obtained a court injunction to stop physicians from unplugging Rasouli's life support on the grounds that "He understands everything," and that her husband was getting better, as noted in the hospital's records. Subsequently, two lower Ontario courts ruled that under the province's Health Care Consent Act (HCCA), Rasouli's doctors did need his wife's consent to withdraw life support or, failing that, permission from the OCCB. The doctors appealed to the Supreme Court of Canada but were unsuccessful. Supreme Court Chief Justice Beverley McLachlin wrote: "While the end-of-life context poses difficult ethical dilemmas for physicians, this does not alter the conclusion that withdrawal of life support constitutes treatment requiring consent under the HCCA." The court's ruling applies only in Ontario.

The PAS debate

Like Canada's courts, the country is also sharply divided over the issue of life-ending practices, with passion, intense emotion and intransigence (and a wisp of self-righteousness and crusading zeal for a 'just cause') on all sides. The debate has been clouded by the use of a wide array of terms, some of which are interchangeable while others differ in meaning and connotation. For any useful debate, we need to clearly define these terms and assess their current legal status.

Physician-, doctor- or medically-assisted (or aided) suicide (or death or dying) are all synonymous terms referring to the practice in which qualified physicians provide, upon request from fully competent terminally ill patients, a life-ending dose of medications. PAS is legal in Belgium, Luxembourg, the Netherlands, Switzerland and four U.S. states (Oregon, Washington, Vermont and Montana). Switzerland is the only country that allows foreigners to seek PAS inside the country, giving rise to the term 'suicide tourism.'

Dying (or death) with dignity are emotionally charged code words that try to dignify and promote assisted suicide. Lee Carter, Gloria Taylor, Dr. Donald Low and others have cited loss of dignity as a justification for PAS. This perception might be based on the loss of autonomy and resulting absolute dependency on others that people with chronic illnesses feel. However, it is important to realize that natural death is a universal biological event. Whether it is dignified or not is subjective. Dignity, or its lack thereof, lies in the eyes of the beholder.

Assisted suicide is a general term in which a suicide is committed by someone with assistance from one or more persons. Assistance in the commission of suicide by unauthorized persons is a criminal act. *Euthanasia*, meaning good death in Greek, is a deliberate act of killing, or deliberately permitting the relatively painless death of,

incurably sick or injured individuals, usually for reasons of mercy, hence the term 'mercy killing.' A basic difference between the two is that in assisted suicide the actor (i.e. the person whose action directly causes death) must also be the patient whereas in euthanasia the actor is someone else.

Euthanasia can be voluntary (conducted with the informed consent of the patient), non-voluntary (when it is not possible to get the patient's consent, for example when the patient is an infant), or involuntary (against the patient's will). Non-voluntary euthanasia is illegal in most countries and involuntary euthanasia is regarded as murder in all countries. However, the Belgian government recently

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legalized euthanasia for terminally ill children of all ages. The Belgian law goes well beyond the 2002 Dutch legislation setting 12 as the age at which children can legally decide to end their lives.

Euthanasia can also be passive or active. Passive euthanasia entails the withholding of treatment (e.g. the administration of antibiotics), nutrients or fluids necessary for the continuance of life. Withholding or withdrawing life-sustaining treatments with a patient's consent, or the consent of family members, is a fairly common practice in North America but the practice needs re-examining. Active euthanasia entails the deliberate administration of lethal substances or forces, such as pulling off life support plugs, with the intention to stop life. In end-of-life care it is a common practice to administer pain control medications in high doses that relieve insufferable pain but can also hasten death. This practice has been regarded as legal in several court decisions.

The pros and cons

The argument for assisted suicide is based on several things, including: the incurability of the disease; the assumption that painless death might be a better option than the continuation of life with pain and suffering; the patient's right to choose their own fate, and; the increasing evidence that assisted death has been mostly unproblematic in those jurisdictions that allow some form of PAS.

The most-used argument against assisted suicide is the 'slippery slope' scenario in which the legalization or decriminalization of assisted suicide creates a spiral of unintended and unacceptable consequences, including the involuntary euthanasia of disabled persons. Famously, in 1993, a Saskatchewan farmer, Robert Latimer, could no longer tolerate the suffering of his 13-year-old daughter, Tracy, from severe cerebral palsy. He took matters into his own hands and put an end to his daughter's life using carbon monoxide from the exhaust of his truck. Latimer was eventually convicted of second-degree murder, which was upheld by the Supreme Court of Canada. The recent inclusion of children as subjects of PAS in the Netherlands and Belgium might also be examples of a slippery slope.

The anti-PAS group also questions the validity of the consent-to-die statements obtained from terminally ill patients. In a recent survey of 988 such patients in the U.S., only 10.6% seriously considered euthanasia, or PAS, even though 60.2% of the same group supported the practice hypothetically.

Furthermore, half the patients changed their minds after a few months. The mental state of patients at the time of consent must be taken into account before all life-ending procedures. Terminally ill patients might be depressed, for example, or may opt for PAS because of a real or perceived pressure from tired caregivers, or from a feeling of guilt.

There are other considerations outside the issue of consent. In spite of all the advances in medical science, it is extremely difficult to correctly forecast the outcome of a patient's illness. Both diagnosis and prognosis can change. Patients allegedly in irreversible coma have occasionally regained consciousness. Recently developed functional brain imaging technology reveals that many patients diagnosed as brain-dead might fully or partially retain their brain function. Thus a proportion of previously diagnosed brain-dead people might have been wrongly considered for PAS or withdrawal of life support. These limitations must be taken into account by lawmakers, doctors and patients considering the irreversible decision.

Arbiters of life and death

Doctors should not assume the responsibility to make life-or-death decisions concerning their patients, for several reasons.

First, patients implicitly trust their doctors' intentions and their ability to heal. This trust is likely to erode when patients learn that their doctors are empowered to kill. Second, and related to the first caution, doctors must take the Hippocratic oath, "Do no harm." Physician assisted suicide, or withdrawal of life support, are not acts of healing but harmful to patients. In the Rasouli decision, Chief Justice McLachlin touched on this, stating, "In forestalling death, life support arguably falls within 'therapeutic' and 'preventative' purposes."

Third, natural justice demands that a person or persons associated with terminating life should not be part of the decision. This is consistent with another aspect of the Supreme Court ruling in the Rasouli case, that decisions over disputed end-of-life cases should be resolved by an independent body, as well as the recommendation of the CMA in 2007 that such decisions should be

the prerogative of the society at large. Fourth, most medical school curricula do not teach any structured course on the technical, legal and ethical aspects of PAS or euthanasia.

A fifth concern is that doctors represent a cross section of society. Most are hard working, honest individuals. But as you would expect among any other group, there might also be a small minority with problems such as addiction, psychological instability and criminality, as illustrated by Dr. Jack Kevorkian, the so-called Doctor of Death, and Dr. Harold Shipman, the most prolific serial murderer who preyed upon the elderly, mostly women, for financial gain. A sixth, more common consideration is that doctors are often under pressure to vacate hospital beds because of scarce resources. Most doctors would surely resist pressure to use PAS or euthanasia to free up beds but some might not be so strong.

Finally, distancing the medical profession from any form of killing could be a powerful bulwark against forced participation of doctors in state-sponsored torture, mutilation and murder, as happened in Europe during and after the Second World War and, prior to that, within the eugenics movement in Canada.

When considering who should be involved in decisions related to PAS, we must also take into account ongoing advances in pain control. Some of these techniques have made it possible to alleviate pain and suffering to the extent that PAS on those grounds no longer makes sense. A recent study in the U.S. shows that patients receiving hospice care suffer less pain, are more relaxed and live a few weeks longer than those receiving terminal care outside hospices. This is not surprising since pain and suffering in terminally ill patients are associated with, and aggravated by, anxiety, fear of the unknown, and the fear of being left alone when confronting death.

A week before his death of brain cancer, Dr. Low, the microbiologist who played an important role in controlling Toronto's 2003 SARS (Severe Acute Respiratory Syndrome) epidemic, made an impassioned appeal on video to allow assisted suicide in Canada. What was bothering Dr. Low most was the

question: "what the end is going to look like?" He was afraid of losing his sight and of not being able to use the washroom without assistance, in other words his autonomy. Dr. Low needed assurance and emotional support that hospice care is designed to provide.

Where do we go from here?

After hearing the appeal in *Carter v. Canada*, if the Supreme Court makes PAS available in Canada, adequate safeguards must be in place to protect the vulnerable and those who do not wish to die. Moreover, PAS must not be allowed to compete for funding with terminal and hospice care, or be regarded as a cheap alternative to palliative care.*

It appears the heat of the PAS debate has distracted us from the real problems of death and dying in our progressively aging society. There is a very real lack in Canada of adequate facilities for both terminal and hospice care. Of the approximately 260,000 Canadians who die every year, the vast majority die of old age or age-related ailments. Palliative care is available to only 30% of those who need it. The rest have nowhere else to go, and the majority end their life blocking urgently needed acute-care beds and missing the high-quality care available in a hospice set up. Unfortunately, in 2007, the Harper government disbanded the secretariat on palliative and end-of-life care, and stopped work on developing a national strategy.

Canadians, especially senior citizens, should join and lead the effort to ensure that those in need have access to high quality end-of-life care. We need more hospice care, delivered either at home or within an institution, more palliative care facilities, more support for caregivers, and more research to improve the quality of care in all these areas.

* *Palliative care* is for the palliation of the distressing symptoms of a serious illness, or to alleviate the symptoms of aggressive curative treatment. *Hospice care* is an end-of-life care after curative treatment stops.

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