

INVITED ESSAY

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Whose Death Is It Anyway? Perspectives on End-of-Life in Canada



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Maureen Taylor, BA, BHSc
Sunnybrook Health Sciences Centre, Toronto ON

Sandra Martin
Former Features Writer, *Globe and Mail*
Author, *Working the Deadbeat: 50 Lives that Changed Canada*,
and a forthcoming book on End-of-Life issues



ABSTRACT

People die every minute in Canada, but how they die has become increasingly contentious as the demand for physician-assisted death and euthanasia has become louder and more widespread. Several events have propelled the debate around choice in end-of-life care, including the posthumous release of a video in which infectious disease expert Dr. Donald Low expressed his frustrations over his inability to control the manner of his death, the passing of Bill 52 in Quebec and the Supreme Court's decision to hear the Carter case challenging the constitutionality of the law against assisted suicide. Baby boomers are demanding more autonomy and choice in dying. Is the medical profession listening?

ONE WEEK AFTER a CT scan revealed he had a midbrain tumour, Dr. Donald Low began talking with his wife, Maureen Taylor, about assisted dying. As an internist and microbiologist for almost 40 years, Low knew the tumour was virtually untreatable, and that the end would be messy. While he allowed his physicians to steer him towards a biopsy, a ventriculoperitoneal shunt, chemotherapy and radiation, he never let himself or his family be lulled into a sense of false hope. For seven months, Low and Taylor researched the means that would provide him with a peaceful death, in his own home, at the time of his choosing. But even with Low's connections in the international medical community, and despite his access to potent drugs, Low died the death he feared: paralyzed, unable to communicate with his family, sedated so that he could tolerate the intolerable.

Why make people suffer for no reason, when there's an alternative? asked Low in a video interview taped eight days before his death (Cancer View Canada 2013). A lot of clinicians have opposition to dying with dignity. I wish they could live in my body for 24 hours, and I think they would change that opinion.

While Low was dealing with his terminal brain cancer in the winter and spring of 2013, his Mount Sinai Hospital colleague, Dr. Larry Librach, was even closer to death. One of Canada's leading palliative care specialists, Librach died of pancreatic cancer in August, peacefully and at home, according to his family. Although he advocated for improved palliative care for all patients at the end of life, and would not have chosen an assisted death for himself, Librach believed that palliative care would not suffice for a minority of dying people.

Even before his own diagnosis, Librach was an expert witness at the British Columbia

Supreme Court in a legal challenge to the prohibition against medically assisted suicide. There were several plaintiffs, including Gloria Taylor, a B.C. woman suffering from amyotrophic lateral sclerosis (ALS). Librach later told CTV News (2013), "The best of palliative care will still not prevent people, like Gloria Taylor, from saying, that's great, but I still want control over the end of my life. And I don't see that there's any ethical or other reason why we shouldn't allow that when there are appropriate safeguards."

Urgency – Why Now?

As two high-profile physicians, Librach and Low spoke eloquently, in the last months and even days of their lives, about the pressing need to improve end-of-life care in Canada. Indeed, before he died, Librach co-authored a commentary published posthumously in the *Canadian Medical Association Journal*, arguing that doctors need to begin planning for the likelihood that physician-assisted death (PAD) will soon be legal in Canada (Downar et al. 2014). If the Supreme Court of Canada "strikes down the laws prohibiting physician-assisted death," the commentary suggested, "physicians may be left to operate in a legal vacuum (as they were when the provisions in the Criminal Code regarding abortion were struck down)." In other words, if doctors are content to let Parliament or the Courts make decisions on PAD, they may deny themselves a voice when it comes to articulating public policy and practice on one of the most pressing healthcare challenges of our time. That is the practical and ethical dilemma confronting doctors on the cusp of a demographic tsunami.

Aging Boomers: Dying Their Way

The baby boom demographic, which views choice and autonomy as a given in so many aspects of life, is beginning to demand choice in death. Surveys show a majority of

Canadians would prefer to die at home in the presence of loved ones (Lau and Menec 2007). If not at home, then they wish to die in a hospice where specially trained nurses and physicians provide symptom relief as their families gather at the bedside. Few would choose to spend their final days in a hospital ward or in an intensive care unit, and yet this is where almost 70% of Canadians die. Less than a third receive palliative or hospice services, with significant inter-provincial disparities (Canadian Hospice Palliative Care Association 2013).

Palliative Care Overview

The emphasis on patient-centred care has revolutionized medicine today, but our health-care system is still more comfortable over-treating patients in hospital at the end of their lives than in withdrawing treatment or intervening to end suffering. Largely that's because universal medicare was legislated in 1966 as a hospital-based and physician-delivered pay-for-service model. That system worked when most hospitalizations were for acute episodic conditions; the earliest boomers were in their 20s and life expectancy was 75. As the baby boom matures, the average age is soaring – 15.3 per cent of Canadians were over 65 in 2010 – and so is life expectancy. It reached 83 for women in 2011 and is projected to hit 87 in 2030.

Many of those people are living with complex and chronic illnesses, a phenomenon that has created service gaps in our healthcare model. Largely because homecare was not part of the original medicare equation, it remains a healthcare orphan, consisting of a series of underfunded and patchwork operations that are not portable from one province to another. Consequently, many families turn to hospital emergency rooms rather than primary care providers when a patient is in a perceived crisis. More than 40% of cancer patients visit

an emergency room in the last two weeks of their lives, an often futile and inappropriate use of these services (Picard 2014). If these patients and their doctors had honest discussions about their prognosis, if they had access to free and powerful palliative drugs at home, if their families could count on home nursing and personal support, surely emergency room visits and hospitalizations would plummet.

Not every person has the resources and support to be able to die at home, and for them, hospice facilities provide a warm and compassionate place. Usually these facilities require that patients have a prognosis of less than three months, but in reality, most don't need that long. The average stay is less than three weeks. The economic advantages of hospice and home palliative care over hospital care are stark: less than \$500 per day for the former versus \$1,000–\$3,000 per day for the latter (Parikh et al. 2013). That the majority of hospices rely on charitable donations to operate in the absence of more support from governments is astounding. And the waiting lists for beds in hospices means many patients never get there – the local hospital is their last and least appealing resort.

Palliative Care – The Patient's Perspective

Several studies show that providing advanced cancer patients with palliative care improves the quality of their end-of-life experience and in fact, extends their lives. Good palliative care offers patients relief from many of the symptoms that cause them suffering and focuses on their emotional and psychological health. If the symptom is pain, this could mean strong opioid medications or even targeted radiation therapy. If the symptom is anxiety or insomnia, benzodiazepines or hypnotic agents can be used. Patients with severe shortness of breath often get relief from opioids along with oxygen. All of these

medications can be administered in hospice and at home. When a patient's illness is very advanced, some palliative specialists will offer continuous palliative sedation with intravenous midazolam and other drugs, which effectively puts the patient into a coma until death occurs naturally. Under palliative sedation, the patient presumably feels no hunger or thirst, pain or anxiety. This also means the patient can no longer move from the bed; requires toileting and frequent position changes to prevent bed sores; and, most important, can no longer speak to or hear their family and friends.

I'm not afraid of dying. I could make that decision tomorrow, said Low in his interview. I just don't want to see a long protracted process where I'm unable to carry out my normal bodily functions and talk with my family and ... enjoy the last few days of my life.

The time from initiation of continuous palliative sedation varies depending on the function of the heart, lungs, kidneys and other systems. Being otherwise fit and healthy before his diagnosis, Low died six days after sedation was initiated. He received excellent palliative care in his own home, but it was certainly not the death he would have chosen.

Assisted Dying

While there will always be patients and their families who want to prolong life for religious, cultural or psychological reasons, polls show a solid two-thirds of Canadians consistently say they'd like to have the option of a PAD at the end of life (Enviroics 2013). Language is important when discussing issues around hastening death, and those who advocate for this option avoid using the loaded word "suicide" for people who get medical aid to help them die.

There are almost two decades of experience with euthanasia and assisted dying in other jurisdictions: the Netherlands, Belgium and Luxembourg allow both assisted suicide and euthanasia under prescribed circumstances for adults of sound mind who are terminally ill or suffering from an incurable condition causing intractable physical or psychological suffering. The Netherlands and Belgium have amended their legislation to make euthanasia and PAD available to terminally ill children (12 and older in the Netherlands and of any age in Belgium). Switzerland allows non-residents to have PAD at a private clinic called Dignitas, but doesn't sanction euthanasia. Other European countries including France and Great Britain are discussing policy options, as are Australia (where PAD was briefly legal in the Northern Territory) and New Zealand.

In 1994, Oregon became the first jurisdiction in North America to pass a Dying With Dignity Act (DWDA), allowing PAD (but not euthanasia) under strict conditions for terminally ill adults of sound mind. Washington State and Vermont have adopted variations of the Oregon protocol, and courts in two other states, Montana and New Mexico, have established legal defences for doctors who have helped terminally ill patients to die.

In Oregon, patients who receive prescriptions for lethal medications must be terminally ill adults with a prognosis of less than six months to live, verified by two physicians. The patient must make the request twice, at least 15 days apart. If either physician is concerned about an underlying psychiatric issue, the patient must be assessed by a qualified psychiatrist. Patients get mandatory counselling on other end-of-life options, including palliative care, and they may withdraw the request at any time. No physician or pharmacist is compelled to write or fill the prescription,

but must refer the patient to other providers if they decline. No one can assist patients in taking the medication, which imposes an anxiety-inducing time constraint. If patients wait too long, they may be unable to consume the lethal potion on their own; if they plan their deaths when they are still physically capable, they may die sooner than they wish and before it is medically necessary.

Barbiturates such as secobarbital and pentobarbital are the most commonly prescribed drugs for assisted dying. According to reports over the past decade from Oregon, time of death after ingestion is usually a matter of minutes, though there have been case reports of up to four days.

The Slippery Slope

Those who oppose PAD often argue it will make disabled, elderly, poor and demented patients vulnerable to bureaucratic death squads or soft-headed healthcare workers who take it upon themselves to determine who should die and who should live. Expanding PAD and euthanasia to terminally ill children and the chronically depressed, as well as sensational examples (including a young man who requested euthanasia after a botched sex change operation and middle-aged deaf twins who feared incipient blindness would mean they could no longer communicate with each other or live independently) are cited as evidence of the slippery slope (Hamilton 2013).

We feel these rare examples disregard the clear evidence in medical literature that the slippery slope has not been realized. Studies in Oregon and the Netherlands show that legalizing assisted dying has improved palliative care options for all citizens (Rietjens et al. 2009; Steck et al. 2013). Those who pursue assisted dying are more likely to be white and of higher socioeconomic status, which should allay fears that the poor and disadvantaged will be steered towards this decision (Sandeen 2013).

For more than 14 years, both legislators and the public in Oregon have reported high levels of satisfaction with the DWDA (80% in 2012) (Oregon Public Health 2013). In 2012, Oregon doctors wrote 122 prescriptions for lethal medications, and there were 71 deaths attributed to the DWDA program. This corresponds to 21.9 DWDA deaths per 10,000 total deaths (Okie 2005). The vast majority are cancer patients, and the most cited reason for seeking assisted dying is fear of loss of autonomy and loss of dignity. Fear of pain remains a distant third reason, which reflects improvements in palliative control of pain. The number of requests for lethal medications has increased only slightly over the years, and the state has never expanded its inclusion criteria. Although the number of physicians who write prescriptions for lethal medications under the law has increased incrementally each year in Oregon, it appears the program works even with only a handful of physician participants. In 2013, 62 physicians wrote 122 prescriptions (range: 1–10 prescriptions per physician) (Okie 2005). Many patients' families report their loved ones feel less anxiety and more contentedness just having access to the medication, but die peacefully without needing to use it (Okie 2005).

The Legal Landscape in Canada

PAD has made headlines in Canada for more than two decades, and stirred private murmurings around dinner tables ever since Sue Rodriguez, a B.C. woman suffering from ALS, unsuccessfully petitioned the Supreme Court of Canada for help in dying in 1993. "If I cannot give consent to my own death, whose body is this? Who owns my life?" Rodriguez asked rhetorically in an impassioned video plea for an end to the prohibition in the Criminal Code against assisting a suicide – a crime that carries a maximum penalty of 14 years in prison. The following year Rodriguez died with the help of an any-

mous doctor. Her friend, former MP Svend Robinson, was at her side. Twenty years later he remains strongly committed to legalizing PAD. “You either have to have a death set in the shadows,” he said of the current situation in Canada, “or, if you can afford it, you go to Zurich” (Martin 2013).

A legal challenge is again before the highest court in the land. When Gloria Taylor became part of the Carter et al. lawsuit, filed in April 2011 in the British Columbia Supreme Court, the plaintiffs argued that the Criminal Code prohibition against assisting a suicide was unconstitutional. Madam Justice Lynn Smith agreed with them. That decision was successfully appealed by the federal government in October 2013, but the matter is still not settled. The Supreme Court, which narrowly ruled against Rodriguez in 1993, will revisit assisted dying in October 2014 when it hears the B.C. case on appeal. If the Court decides that the Charter of Rights and Freedoms guarantees a dying person’s right to have help ending his or her life, as seems likely, Parliament will have to drop or redraft Section 241 of the Criminal Code, a move that the current government has steadfastly resisted.

Robinson contends that ordinary people are ahead of the politicians on PAD. “People believe profoundly and strongly and overwhelmingly in what Sue was fighting for 20 years ago,” he said. “If anything, that is even stronger today” (Martin 2013).

While that appears to be true in most parts of the country, Quebec is at the forefront of change, as it was with abortion. In June 2013, the Quebec National Assembly tabled Bill 52, the most far-reaching end-of-life legislation in North America thus far. Taking a jurisdictional end run around the federal government, Quebec argued that end of life (combining PAD and euthanasia) falls under the provision of healthcare, a provincial

responsibility, and has nothing to do with the Criminal Code, a federal responsibility. The Bill, which was the product of years of study and consultation on end-of-life issues, died on the order paper this spring when Parti Quebecois Premier Pauline Marois called a provincial election. Even though her party was defeated, the new Liberal government of Phillippe Couillard plans to reintroduce the Bill, which had all party support in the last session of the Assembly.

Quebec remains the only province that has conducted extensive public consultations on end-of-life care. As far back as 2009, the National Assembly created a bi-partisan Select Committee to study PAD. The Committee interviewed experts, circulated a public questionnaire, conducted public hearings in eight cities and tabled a 175 page “Dying with Dignity” report in March 2012 with two dozen recommendations for drafting a comprehensive law. With the report in hand, the Quebec Ministry of Justice struck a panel, headed by lawyer Jean-Pierre Ménard (accent), to examine the legal issues raised by the Select Committee’s recommendations, including the jurisdictional issue of circumventing the (federal) Criminal Code by treating medical help in dying under provincially regulated healthcare. The Ménard Report supported the Select Committee’s recommendations, which included the right of ordinary people to make decisions about the timing and manner of their deaths, improvements to palliative care and the provision of assisted suicide and euthanasia (under strict conditions) in end of life care – all of which became the basis for Bill 52.

If Quebec’s newly elected Liberal government reintroduces and passes Bill 52, the federal government has already signalled its intention to challenge it. “The laws that prohibit euthanasia and assisted suicide exist to protect all Canadians, including those who

are potentially the most vulnerable, such as people who are sick or elderly, and people with disabilities,” said Justice Minister Rob Nicholson after the Bill was introduced in the National Assembly in 2013.

But at least one member of the Harper government has had the courage to publicly disagree with his colleagues in parliament. Indeed, the life and political career of Manitoba MP Steven Fletcher is an encouraging example of the shifting signs of progress. In late March, he introduced two private members’ bills. Bill C-581 called for amendments to the Criminal Code to allow PAD (which he defines as both assisted suicide and euthanasia), and Bill C-582 sets out criteria for establishing a Canadian Commission on PAD. The Commission would collect information, produce an annual report, commission research and make recommendations to the Attorney General. Fletcher, a quadriplegic, who survived a devastating collision with a bull moose on a remote highway in northern Manitoba, contends that life should always be the first choice, but for some it will not be the only choice. Both decisions should be respected in his view. His PAD Bill, which faces huge odds, establishes strict conditions under which adult Canadians of sound mind, who are suffering physically or psychologically from an illness, disease or disability that cannot be alleviated by any acceptable treatment, may apply for PAD.

Conclusion – How Do We Move Forward?

While the public, some lawyers and even some politicians, especially in Quebec, are actively involved in the conversation about dying, what are oncologists, primary care and palliative care physicians and other allied health workers – the professionals who are most acutely involved with end-of-life care – doing to mobilize public and private conversations with their patients about PAD and

euthanasia?

Surprisingly little. And as Canadians look to health professionals for leadership on health issues, this must change. There are some positive signals. The Royal Society of Canada convened an expert panel on end-of-life decision-making and released its recommendations in November 2011, calling for the legalization of “some form of assisted suicide and voluntary euthanasia.” It also suggested that if the federal government refuses to amend the Criminal Code, provinces and territories, under whose jurisdiction the administration of justice falls, should refuse to lay charges in cases of assisted suicide and euthanasia. That’s another attempt to take an end run against federal intransigence on PAD, but it could encourage amateurs and non-medical personnel to intercede in end-of-life care – without facing legal or criminal consequences.

Last year a Canadian Medical Association (CMA) survey found that 26% of doctors in this country are already prepared to help patients die, should the laws change to allow them to do so. While that result dismayed Don Low during his illness (he would have liked broader support), many in the assisted dying movement saw it as encouraging. As the experience in Oregon shows, only a fraction of doctors are required to implement a safe and successful assisted dying program, and the counselling of patients who want to choose the time of their own death should be the purview of physicians trained and knowledgeable in end-of-life issues. We don’t need dermatologists and plastic surgeons writing prescriptions for barbiturates. We do need provincial and national medical organizations to show leadership and a willingness to hear the views of Canadians who want this option. Nevertheless, a motion at the annual meeting of the CMA in August 2013 calling for national public consultation “to regard medical aid in dying as appropriate care” was

defeated. To its credit, the CMA has recently held four town-hall meetings in four regions of the country to discuss end-of-life healthcare, including palliative care, euthanasia and PAD. As well, Doctors of B.C. (formerly the B.C. Medical Association) issued a policy paper in March advocating that primary healthcare professionals should discuss end-of-life goals with patients on an ongoing basis and encourage them to complete advance care directives in consultation with their families. The report also suggests that a copy of advanced care plans, which should be updated as changes in life goals and medical conditions warrant, should be filed with other medical records so that everybody (and that includes family as well as medical personnel) involved in a patient's care knows his or her wishes.

We agree that physicians must be consulted on any proposed legislation that sanctions PAD and euthanasia and their concerns must be addressed. But there is no time for foot-dragging. The Supreme Court will hear this issue in the fall and many experts expect it to overturn the present law, as it did with abortion back in 1988, creating the legal vacuum and the uneven access issues that exist to this day.

Canadians should raise these end-of-life issues with their political candidates in the next federal and provincial elections. We must hear them articulate how they would vote on any new legislation around improved access to palliative care and the option of medically assisted dying. We must not let politicians hide behind a 20-year-old Supreme Court Case ruling, as the Harper government has done, or avoid a public stand, as Liberal leader Justin Trudeau did when his party voted to adopt a pro-assisted dying policy last winter.

We also look forward to a policy shift among medical organizations that supports patient autonomy and choice at the end of life. We call on individual physicians and politicians to educate themselves on the wealth of literature on the experience with

PAD in other countries and to advocate for the optimization of palliative care for all Canadians, and the option of a self-determined, peaceful, assisted death for the exceptional cases such as Gloria Taylor and Donald Low.

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DEFINITIONS

Advanced Care Directive

People who anticipate a situation in which they may not be able to make healthcare decisions for themselves, can complete an advanced care directive setting out their end of life wishes. This may include a Do Not Resuscitate Order. The directive usually includes two parts: a living will stating the patient's wishes and a separate document naming a power of attorney for health charged with making medical decisions on the patient's behalf. A copy of the directive, which can be modified as a person's life goals change, is often filed with the patient's primary health care physician.

Palliative Care

The word palliative comes from *palliare* in Latin, meaning to cloak or shield. It refers to a patient-centred multi-disciplinary approach to healthcare that focuses on relieving physical and psychological suffering rather than aggressively treating the causes of a chronic or terminal disease. Unlike hospice care, which primarily occurs at end of life, palliative care is appropriate for all patients, no matter the nature or stage of their disease.

Hospice

Hospice comes from *hospes* in Latin, a term referring to both guests and hosts. Hospices, as places to house and care for the dying, date back to the Crusades. They flourished in the Middle Ages, but began to decline with the dispersal of religious orders during the Reformation. The modern hospice movement, is either a designated place (especially as pioneered by Dame Cecily Saunders in England in the 1960s) including a special ward in a hospital, or a service, delivered to terminally ill patients in their homes. In either case, healthcare professionals,

including palliative care doctors and nurses, social workers and volunteers care for the physical, emotional and psychological needs of the dying and their families.

Continuous Palliative Sedation

Doctors can try to alleviate pain, agitation or restlessness in patients who are very close to death by giving them a continuous infusion of a sedative such as midazolam, either intravenously or subcutaneously. The patient may be awakened from time to time to assess whether symptoms are being controlled. The goal is to control symptoms even if the process may shorten life, especially for patients for whom nutrition and hydration have been withdrawn.

Physician Assisted Death

There are two major forms. indirect and direct. In indirect PAD, an eligible patient requests a prescription for lethal drugs from a physician and then ingests it according to prescribed conditions. In direct PAD (euthanasia) a doctor administers a lethal injection to a qualifying patient. Both forms of PAD are regulated under legally sanctioned circumstances. The criteria for eligibility and the extent of PAD vary from one jurisdiction to another. For example: Oregon only allows indirect PAD for terminally ill patients who are of sound mind and legal age; Switzerland allows indirect PAD for foreigners; Quebec will offer indirect and direct PAD, to patients of full age and sound mind who are at the end of life and suffering from an "incurable serious illness" or "constant and unbearable physical or psychological pain." The Netherlands and Belgium primarily offer direct PAD and extend it beyond terminally ill adults and people suffering from intractable or psychological suffering to include terminally ill children under specific circumstances.