

Reflections from a provider of medical assistance in dying

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We all die. As family doctors, we care for patients as they die, sometimes peacefully and pain free, but often suffering from symptoms that are difficult to control. We have all seen “bad deaths,” with patients struggling and families in distress.

Palliative care can address many end-of-life symptoms, but it cannot manage all of them—for example, it cannot manage complete loss of mobility; shortness of breath even on rolling over in bed; the fear of sudden, rapid gastrointestinal bleeding from a terminal cancer; or the ongoing psychological stress of losing one's autonomy and dignity.

In June 2016, after many years of lobbying by patients and groups like Dying with Dignity, the newly elected Liberal government (with a family physician as health minister) moved quickly to legalize medical assistance in dying (MAID). This has profoundly altered the approach to death and dying in Canada.

My experience

My personal journey started before the legislation was introduced on learning the stories of people who had challenged the courts for permission to end their lives, hearing of those who had gone to Switzerland to access MAID, and talking to colleagues in Belgium, where it had been legal for many years. Although the idea of assisting death seemed to be contrary to my role as a physician, I had seen many of my own patients suffering when they died despite receiving dedicated palliative care; I felt this was cruel and unacceptable. Thus, I was interested in how other societies dealt with this issue. Some European countries seemed to have developed a humane and careful approach. A powerful moment for me was seeing a YouTube video of Dr Don Low,¹ who was a microbiologist at Mount Sinai Hospital in Toronto, Ont, during the SARS (severe acute respiratory syndrome) outbreak. In the video, he made a plea to the government to allow MAID, as he was dying of a brain stem cancer. He said, “I'm frustrated with not being able to have control of my own life; not being able to make the decision myself when enough is enough.”¹

At home, the Quebec analysis of MAID and subsequent legislation were well thought out and sensitive to patients' wishes and the concerns of conscientious objectors. Astonished at how quickly the federal legislation had passed, I saw an opportunity to become involved in a very personal way. I joined a committee to develop my

local hospital's policy for MAID and then decided to provide the care myself. For me, this was a natural evolution of my belief that patients have the right to choose how they might die, much as they choose treatments for their medical conditions. And if the situation ever arose I, too, wanted to have that choice.

I collaborated with another physician in my community, and we assessed our first case in December 2016. The patient was suffering from end-stage laryngeal cancer, unable to eat and afraid of bleeding or choking to death. He met all the eligibility criteria, so on a cold winter night in January we went to his home. He was there with his sister, his only family; a pastor; and a friend. We talked about his life and then he said he was ready. We injected the medications and he slipped peacefully away. It was a profoundly moving experience, one that has been repeated with each subsequent case. Sharing this care with another physician has provided mutual support in performing a medical intervention that runs counter to our normal practice. Since then, we have cared for additional patients and have developed more experience with the procedure.

Some thoughts

The most powerful factor in this care is the stories that patients tell us. They really solidify my conviction that this care is appropriate and compassionate. Each story is unique and often describes a long-standing struggle with a dreadful disease or the rapid progression of an aggressive condition. Several patients have had motor neuron diseases, such as amyotrophic lateral sclerosis, and faced an inevitable decline to helplessness, eventually succumbing to respiratory failure or other complications. Others have had end-stage cancer symptoms that were partially managed but faced, to them, an unbearable demise. Others were so debilitated that their quality of life was no longer meaningful—they were just waiting to die. In every case, when I hear the story, I understand the request for MAID and would likely choose it myself if I were in the same situation.

I have been struck by the determination and courage of those requesting MAID, right up to the moment of their death. These patients have made up their minds and faced their choices unwaveringly. Many describe the relief they feel knowing that they have control over the end of their lives and that they will not fear the unknown or a possible struggle when dying. Much of the anxiety of a terminal diagnosis has been relieved for them and their family members.

We have performed most of our medically assisted deaths at home where we believe it is most appropriate. We have found the cooperation with community nursing to be remarkably good. Palliative care nurses have been there to start intravenous drips and provide support to families; pharmacies have been responsive and helpful. The final process has been very smooth and peaceful, and is over in a few minutes. After all the buildup, it seems almost anticlimactic.

Families are extremely grateful for this care. They are relieved to see how peacefully their loved one dies and feel a sense of release from their own suffering as they witness that person's decline. Of course they are sad, and hugs go all around. But they tell us that their loved one died on his or her own terms and they view this outcome as positive. Follow-up telephone calls to families several days after each medically assisted death have all been very positive, with no regrets expressed by the family. My colleague and I have not second-guessed the care in our cases.

We have received a few referrals for MAID that we ultimately declined, as we believed that the cases did not meet the established criteria. The federal legislation on eligibility was deliberately conservative, and this is understandable while Canada gains experience with MAID. The criteria do require death to be "reasonably foreseeable,"² although no timeline is given; thus, we find it challenging to consider people with intolerable conditions that are not foreseeably fatal. There are also populations excluded from the current criteria: children, those with mental illness, and patients developing dementia who would like to "pre-qualify" for MAID when they are no longer living meaningfully. Addressing these situations is, apparently, on the agenda of a working group and I hope the criteria will be revised to be clearer and more inclusive.

Our involvement with patients and their families is short-term but involves a very profound experience. We quickly form relationships that continue with families after the death; we have received cards and had donations made as thanks for MAID care. We consider it to be an extension of palliative care. And personally, as a family physician, I have found providing MAID to be astonishingly rewarding, as it combines so many of the skills and art that make family medicine so fulfilling.

Almost universally, nurses are supportive of MAID, usually enthusiastically. In contrast, some physicians

have expressed reservations and even disapproval. Perhaps the nurses' hands-on perspective is more persuasive than the perspective of physicians, who spend less time with patients. At the same time, I suspect almost all family physicians have helped dying patients along the road to death with increasing doses of narcotics to relieve suffering. Is this really much different from providing a controlled death with less suffering, on the person's own terms?

Challenges

Naturally, there have been problems. Determining capacity is sometimes a challenge when a patient's level of consciousness fluctuates owing to his or her condition or medications. The paperwork is complex and requires careful documentation. The logistics of arranging nursing, medications, and schedules is very time-consuming. Travel to patients' homes adds more time to the process. In many provinces there is no specific fee schedule for this care and there are still many areas in Canada that do not have access. These issues need to be addressed.

Conclusion

Despite the problems, MAID has been an important step forward in end-of-life care for Canadians. I challenge physicians who have reservations about MAID to hear the stories of patients. I suspect most would choose MAID for themselves in the same circumstances.

We all die; in Canada we can now face death with a humane choice. 

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Competing interests

None declared

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