End-of-life care

Between the idea
And the reality
Between the motion
And the act
Falls the Shadow
T.S. Eliot, "The Hollow Men"

Most people in Canada do not get to die as they would like to—at home, with loved ones and without suffering. Dr Ladouceur's editorial[1] is one example of the current quality of end-of-life care and of the confusion of the terms surrounding it—*euthanasia, physician-assisted death, physician-hastened death, palliative care,* and, in his article, *medical aid in dying*.

What morally differentiates these terms is the ethic of intention, of beneficence and self-determination. All terms relate to relief of suffering. Only palliative care provides a continuum of ongoing care managed by the patient, family members, and caregivers. Here is an excerpt from the World Health Organization definition of *palliative care*:

> Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.[2]

In the case example given in the editorial,[1] the patient died suffering and his family suffered, and the discussion of medical aid in dying is sadly ironic because the principal reason for requesting the means to one's own death is the fear of suffering.

Nonetheless, the term *medical aid in dying* is misleading: it is not aid in dying, but rather aid in suicide. Physicians do assist in the process of dying—it is called *relief of suffering*. That said, physicians relieve suffering in the process of saving lives as well. However, in the instance given, death was imminent. The patient's daughters wanted the suffering to end and to achieve this they were willing to accept the risk of death for the benefit of relief. Thus, they implied an informed consent along with the acceptance of the double effect of palliative sedation. This is morally acceptable albeit perhaps for some morally distressing. The family's focus was on the suffering, while the physician's focus was on the dying.

Suffering and dying need to be distinguished. When death is imminent and suffering apparent, this is not the time for moral confusion or stances on middle ground. Unconditional compassion for the patient and loved ones will provide creative solutions to achieve a peaceful and dignified death.

There is only one chance to get end-of-life care right. In Canada, most people die in hospital (more than 60%) and few receive palliative care services (less than 30%).[3,4] This is not how we wish to die. To that end, there are calls to action:

- The Canadian Society of Palliative Care Physicians issued recommendations in November 2016.[4]
- Bill C-277, a private member's bill to effect universal access to palliative care, was introduced in 2016.[5]
- Palliative care education is expanding. In particular, the College of Family Physicians of Canada now provides a Certificate of Added Competence in Palliative Care (430 practitioners across Canada in 2016[6]).
- Local initiatives have been implemented. The Neighborhood Network in Palliative Care in Kerala, India, has more than 60 units serving a population of more than 12 million, and is probably the largest community-owned palliative care network in the world.[7]

Dame Cicely Saunders, the physician pioneer for hospice care, best explains the philosophy for end-of-life care:

> A patient, wherever he may be, should expect the same analytical attention to terminal suffering as he received for the original diagnosis and treatment of his condition. The aim is no longer a cure, but the chance of living to his fullest potential in physical ease and activity with the assurance of personal relationships until he dies.[8]

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Competing interests
None declared

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Choice is led by values

It is disappointing to see *Canadian Family Physician* being used to perpetuate the myth that dying people request medical assistance in dying (MAID) because of inadequate palliative care.[1] This is simply false and misleading. People exercise their right to choose MAID in more than 90% of cases for existential reasons, not for inadequate pain and symptom management. Nor are the 2 options mutually exclusive.

Patients who choose MAID are commonly used to living autonomously according to their own values. These empowered people, when faced with suffering leading to death, choose to exercise control over this aspect of their lives, and in authoring the final chapter of their lives, choose the best death available to them according to their own values. Not what some religious group or palliative care "expert" opines.

They choose to make their own passing as peaceful as possible, and planned according to their values regarding where, when, and who is present.

Yes, they should be aware of and access any and all palliative care options, providing the best pain and symptom management they choose, and every effort should be made to find meaningfulness and closure in their time remaining. That is just proper palliative care—that goes without saying, but it has nothing to do with the reason for the recognition of MAID as a constitutional right by the Supreme Court and its presence as an option to Canadians.

The propaganda against MAID is rooted in falsehoods and religious dogma, none of which should be repeated in any Canadian medical journal in 2017.

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Competing interests
None declared

Reference
1. Collins A, Leier B. Can medical assistance in dying harm rural and remote palliative care in Canada? *Can Fam Physician* 2017;63:186-7, 189-90 (Eng), 195-8 (Fr).

Response

Through the Supreme Court decision, medical assistance in dying (MAID) has become a legal option allowing patients to choose the time and date of their death.[1] Palliative care should be provided to individuals at the end of life, regardless of their legal choice to expedite their death with the assistance of MAID.

Although health care in Canada is universal, there is a difference in resource allocation when it comes to equity versus equality. Palliative care consists of providing holistic care to the individual, treating him or her as a person rather than a medical diagnosis. This can provide comfort to the patient and family at the end of life. Rationales for completing MAID are as unique as the individuals requesting the service. Each case is unique. However, patients should still have access to palliative care—a limited resource without the same access across the country. If you cannot avail yourself of palliative care services at the end of life, what other options are available to you?

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Competing interests
None declared

Reference
1. Collins A, Leier B. Can medical assistance in dying harm rural and remote palliative care in Canada? *Can Fam Physician* 2017;63:186-7, 189-90 (Eng), 195-8 (Fr).

Family physicians' role in hidradenitis suppurativa management

I thank Dr Lee and colleagues for their very interesting review on hidradenitis suppurativa (HS) in the February 2017 issue of *Canadian Family Physician*.[1] It is hoped that family physicians will be more and more acquainted with HS, as I am convinced that the role of family physicians in HS management could be more substantial than it has been in the past.

There are at least 2 reasons for this. First of all, long delays in diagnosis are common, as HS is frequently misdiagnosed as a simple infection.[2] If left untreated, the disease causes substantial morbidity. In 40% to 70% of cases, family physicians are the first health care professionals consulted by patients suffering from HS. Even though patients suffering from HS have consultations with 1 or more dermatologists, family physicians are still the primary caregivers for 15% of patients after an HS diagnosis is received.[3] Therefore, family physicians might speed up a diagnosis and facilitate patients' access to HS-dedicated care if they acquire the skills to recognize and manage HS. Furthermore, HS is a systemic disease with a substantial comorbidity burden[4-7]: cardiometabolic comorbidities (obesity, dyslipidemia, hypertension, diabetes) are not rare, as they are possibly linked to HS through common genetic and