

Medical aid in dying: What matters most?

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With the passing of Bill C-14, Canadians who are mentally competent adults suffering from a grievous and irremediable medical condition may now seek medical aid in dying.¹ The policy has already resulted in ripples of controversy. For example, some large faith-based hospitals currently do not allow medical aid in dying on their premises,² and a Canadian Medical Association survey of Canadian physicians found that 61% would refuse to provide this service and 14% were not sure if they would.³ In a linked paper, Trachtenberg and Manns⁴ explore a provocative observation that medical aid in dying will curtail, for some, the end-of-life period that is associated with intensive and costly health care. They estimate the annual cost savings that might be associated with medical aid in dying in Canada to be between \$34.7 million and \$138.8 million. These potential cost savings, which are not trivial, should be considered in the context of the largely inadequate and haphazard delivery of palliative care across Canada.⁵ Despite some successful and exemplary palliative care programs, palliative care in Canada remains deficient; this is the reason that aggressive, institution-based and ultimately costly end-of-life care exists, and why such a large potential cost savings can be anticipated from medical aid in dying in Canada. Therefore, our response should be to transform end-of-life care.

Canada continues to offer a hospital-centric care system to those who are dying. A recent study comparing Canada with other developed countries found that 52.1% of Canadians with cancer die in hospital — the highest rate of the seven countries studied, and a far cry from the rates in the United States and the Netherlands (22.2% and 29.4%, respectively).⁶ As a result, the mean costs per decedent in the last 180 days of life were the highest in Canada, about double the cost in the Netherlands or England. My colleagues and I have shown that fewer than one in five Ontario residents will receive a physician home visit in their last year of life and, before death, only one in three home care recipients will receive an end-of-life designation that is associated with palliative care delivery.⁷ We have also shown that end-of-life costs are fairly stable in the last year of life until the last 120 days, at which point acute care costs (and not community care costs) rise steeply.⁸ This picture is concordant with the current shortfall of community supports in Canada for those who are dying, and it is why the federal government has promised \$3 billion in new Health Accord transfers for home and palliative care.⁹ This investment aims to enable frail and dying

KEY POINTS

- Canada continues to offer inadequate, costly and hospital-centric care to those who are dying, because a systematic and coordinated palliative approach to end-of-life care is lacking in many jurisdictions.
- Alleviation of suffering is the common ground that proponents and opponents of medical aid in dying can stand on.
- What matters most is increasing the reach of palliative care to prevent undue suffering and the excessive use of medical aid in dying.

patients to remain in the community — a prevalent and strong desire for most.

Trachtenberg and Manns⁴ explicitly state that they do not suggest that medical aid in dying be used to cut health care costs. The very notion of costing end-of-life care and estimating savings with medical aid in dying is a bitter ethical quandary for some. Yet in a system that has finite resources, such costing work can be helpful. We must recognize, however, that high end-of-life costs are often an unintended symptom of our failure to prevent undue suffering, the very thing that patients will seek to avoid by choosing medical aid in dying. Whether one supports medical aid in dying or not, it is clear that end-of-life care discussions need to shift toward how we can improve palliative care. New investments in care should aim to reduce the inadequate match of services to needs, reduce unnecessary emergency department visits and hospital admissions, and, ultimately, reduce suffering at the end of life.

We also need better surveillance data. Trachtenberg and Manns⁴ diligently examined many assumptions through sensitivity analyses, including what proportion of deaths will occur through medical aid in dying (1%–4%) and the length of life shortened (one week to one month). Their models, however, are based on best estimates because surveillance data are lacking. A coordinated and systematic national surveillance system is needed to enable ongoing evaluation and research to determine to what extent, to what level of appropriateness and to what consequence medical aid in dying is being delivered. Nevertheless, the variability in the estimates in the linked study speaks to uncertainty as to who will seek out medical aid in dying, and in what period before death. Policy-makers and physicians should focus on the opportu-

nity that this uncertainty affords. The difference between 1% and 4% of all deaths represents a grey zone of about 8000 Canadians annually who *may* choose to end their life. Whereas some patients who seek medical aid in dying are resolute in their choice, the choices of others may reflect the failure of our health care system to provide effective palliative care.

Patients may request medical aid in dying throughout different points of their dying journey — from shortly after they receive a shocking diagnosis of a terminal illness to when they are burdened with distressing symptoms close to death. Instead of simply referring to medical aid in dying services, we need to thoroughly explore the desires behind the request. The proper introduction of palliative care supports may alleviate the desire for medical aid in dying, not simply by relieving symptoms, but also by reducing the fear and uncertainty in the dying process, and the all-too-common fear of burdening family members with a dying process that is inadequately supported by health care services. Palliative care can address these concerns and help to make a good death part of a good life lived.

Alleviating suffering is the common ground that proponents and opponents of medical aid in dying can stand on. We should quickly move past counting dollars saved from medical aid in dying, and count instead the days of unbearable suffering that result from missed opportunities to provide palliative care. We should strive to save on suffering and to invest more in its reduction, which may in turn reduce requests for medical aid in dying. A continuing movement, pioneered by the World Health Organization, seeks to bring a public health approach to palliative care.¹⁰ This means introducing appropriate policies, education and surveillance to ensure the availability of care throughout all levels of society.

What matters most is that we address society's failure to provide adequate care for the dying.

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