

What drives requests for MAiD?

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Medical assistance in dying (MAiD) is now legal in many jurisdictions with strong public support, as well as some strong opposition, mostly on moral grounds. As more jurisdictions consider legalizing MAiD, policy-makers ask important questions about what drives people to request MAiD; whether better access to timely, high-quality palliative care would prevent MAiD requests; and whether people experiencing structural vulnerability would be induced to request MAiD because of poverty, neglect or an inability to access supportive services, including palliative care. We discuss these questions using available evidence from jurisdictions in which MAiD has been legal for some time.

In all jurisdictions in which MAiD is currently permitted, the requestor must have an incurable illness and either intolerable suffering (e.g., Belgium, Netherlands, Canada), a short prognosis (e.g., the United States) or both (e.g., Australia, New Zealand). Despite differences in eligibility criteria, the populations receiving MAiD in different jurisdictions appear to be very similar. Most recipients (> 70%–80%) have a terminal illness such as cancer or amyotrophic lateral sclerosis (ALS), while most of the remainder have end-stage organ failure or multimorbid frailty.^{1,2} Most MAiD recipients are deemed to be close to the end of their natural life, even where a short prognosis is not an eligibility criterion.^{1,3} A large proportion of MAiD recipients (75%–90%) are followed by palliative care services, often for many months, before receiving MAiD.^{2,4–6} Across jurisdictions, recipients of MAiD are, on average, wealthier, better educated and less likely to be residing in institutions than people who die without receiving MAiD.^{2,5,7} Although not everyone who requests MAiD is a wealthy, educated, well-supported person with cancer who has been receiving high-quality palliative care, the evidence shows that, at a population level, socioeconomic deprivation and service gaps appear, statistically, to be protective against MAiD.

Many have suggested that MAiD requests may be driven by poor quality and timing of palliative care. No objective measure of palliative care quality or accepted ideal timing for palliative care involvement exists. However, early palliative care is known to improve symptom scores and quality of life, compared with usual care,⁸ and MAiD recipients are far more likely to receive palliative care than the average decedent. Could earlier or better palliative care have relieved the suffering that prompts MAiD requests? This is unlikely for 3 reasons.

Key points

- Despite fears that availability of medical assistance in dying (MAiD) for people with terminal illness would lead to requests for MAiD driven by socioeconomic deprivation or poor service availability (e.g., palliative care), available evidence consistently indicates that MAiD is most commonly received by people of high socioeconomic status and lower support needs, and those with high involvement of palliative care.
- Increasing the availability of palliative and psychotherapeutic interventions should be a priority, but is unlikely to affect the incidence of MAiD because most MAiD recipients already have access to these interventions, and they have only modest effectiveness for the type of suffering that drives MAiD requests.
- Whether the aim is to reduce the use of MAiD or to reduce suffering among those who are dying, more effective and scalable interventions are needed to manage distress among those nearing the end of life, as well as a better understanding of the complex factors that drive patient choices at the end of life.

First, differential provision of palliative care exists between cancer and non-cancer illnesses, even when those illnesses cause similar impairment in symptoms and quality of life.⁹ In Ontario, compared with people with organ failure, people with cancer are twice as likely to receive palliative care (88% v. 44%), they are 4 times as likely to receive palliative care at home (68% v. 17%)¹⁰ and they receive palliative care much earlier (median 3 mo v. 3 wk before death).¹⁰ In other words, even without standard measures of quality, access or timing of palliative care, people with cancer receive better palliative care, on average, than those without cancer. If poor access to, quality of or timing of palliative care were responsible for MAiD to any degree, a higher incidence of MAiD would then logically be expected among people with non-cancer illness than those with cancer, yet published data show the opposite.

Second, the effectiveness of palliative care is known to be limited. Palliative care consultation can substantially improve symptoms and quality of life among people with serious and advanced illness compared with usual care, yet meta-analyses indicate that the average effect of specialist palliative care consultation, while significant, is small for both symptoms

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(standardized mean difference [SMD] 0.14–0.23) and quality of life (SMD 0.12–0.33), and no effect is seen for improving mood symptoms (SMD 0.09–0.11).⁸ Studies of patients enrolled in world-leading palliative care programs show that, despite receiving the best palliative care available, at least half of patients may still experience moderate or severe physical or psychological suffering in the final days of life.¹¹ Palliative interventions can reduce suffering, but symptoms and quality of life may not be improved sufficiently to deter some people from requesting MAiD.

Third, the type of suffering that prompts most MAiD requests is not well addressed by current palliative care services. People generally request MAiD because of a loss of autonomy or dignity, or an inability to engage in activities that they used to find enjoyable, rather than pain or physical symptoms.^{1–3} This type of suffering, sometimes called existential distress, is common; as many as 38% of people report existential distress as they approach death.¹² Existential distress is also difficult to treat; a meta-analysis of psychotherapeutic interventions intended to reduce existential distress found that none of the primary outcomes were improved by the interventions, and while some of the secondary outcomes showed moderate improvements, none of these improvements were still evident at short-term follow-up (3 mo).¹³ Limited evidence is available on how new, scalable therapies such as psychedelics, repetitive transcranial magnetic stimulation¹⁴ and other interventions may affect existential distress or the desire for MAiD among patients with terminal illnesses.

To be clear, the evidence does not show that psychotherapy and early palliative care are ineffective. Even a small improvement can be very meaningful when amplified over a large population, which justifies ongoing efforts to make such interventions available to all; however, their modest effects, coupled with an already high degree of palliative care involvement among those who receive MAiD, do not support a hope that more widespread use of current interventions could substantially reduce desire for MAiD among people with life-limiting illness. Developing effective and scalable interventions should be a priority, regardless of whether MAiD is legal.

Another question to be addressed is whether MAiD requests could be the result of inadequate supportive resources for people with disabilities. Socioeconomic deprivation is known to be a strong driver of mortality and chronic illness worldwide, and people with disabilities often struggle to obtain the supports they need even in high-income countries. Although MAiD reporting from most jurisdictions does not include data on disabilities or support services, Canada's federal reports suggest that fewer than 2% of MAiD recipients lack access to needed disability supports in the opinion of the MAiD provider,⁶ which is difficult to either confirm or refute, since no objective measure of access to services exists. However, similar to the provision of palliative care, important differences exist in the supportive needs and the resources available to different population groups as they near the end of life. On average, people with non-cancer illnesses or frailty conditions require assistance with at least 1 activity of daily living for more than a year before death, while people with cancer only become dependent in the final 5 months of life and their support needs are lower than those of

people with non-cancer illnesses until the final month of life.¹⁵ In other words, people with non-cancer illnesses and frailty are far more likely to need (and thus, potentially not receive) supportive services than people with cancer.

At the same time, supportive resources are more plentiful among populations in which MAiD is more common. Publicly funded supportive services are generally focused on people with cancer; in Ontario, for example, people with lung cancer are more likely to receive both supportive services (odds ratio [OR] 5.1) and home visits (OR 2.4) from a palliative care physician than people with chronic obstructive lung disease.¹⁶ Furthermore, people with socioeconomic privilege are better able to self-advocate for publicly funded resources or afford private services, and are also more likely to receive MAiD.^{2,5,7}

In other words, social distress may contribute directly to the suffering that drives a MAiD request, yet, if unmet supportive needs were driving requests for MAiD to any substantial degree, the incidence of MAiD would be higher in populations with greater supportive needs or lower socioeconomic status. Once again, the opposite is true.

So, what is driving MAiD requests? Observational data are more helpful for disproving incorrect theories than for proving correct ones, but the strong associations between MAiD and specific illnesses (e.g., cancer and ALS), high socioeconomic status, and palliative care provision may suggest a causal link. For example, people with cancer and those with ALS share a similar trajectory of illness; compared with people with organ failure or frailty, they have a higher level of function overall, but a more rapid decline near the end of life. This suggests that the pace, rather than the degree, of deterioration in function may be important to those requesting MAiD and that people with higher expectations for function and quality of life may experience greater distress when these deteriorate. People who are followed by palliative care may be more keen to prioritize quality over quantity of life if they have refractory suffering. Palliative care itself may also lead people to request MAiD, by fostering acceptance of a terminal diagnosis and creating space for a discussion of treatment options. This could explain why roughly 20% of MAiD procedures in Canada take place in a palliative care facility.⁶

The morality of MAiD will continue to be debated. However, whether the aim is to reduce the use of MAiD or to reduce suffering among those who are dying, understanding the complex factors that drive patient choices at the end of life is important.

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Competing interests: James Downar has received honoraria from Joule for developing educational material related to provision of medical assistance in dying (MAiD), and is a former advisor to Dying with Dignity Canada, an advocacy group. Susan MacDonald reports royalties from Oxford for *Palliative Medicine: A Case-Based Manual*, and is president of and board member with the Newfoundland Labrador Medical Association. Sandy Buchman is a palliative care physician, a cofounder of Neshama Hospice in Toronto, a MAiD assessor and provider, a member of the Canadian Association of MAiD Assessors and Providers, and a cofounder and advisor to MAiDHouse, a not-for-profit organization aimed at providing a home-like setting for eligible patients to receive MAiD. He reports honoraria from the University of Toronto, ALS Society of Canada, Maggid Institute of Hebrew University and World Hospice Association and was the past president of the Canadian Medical Association. No other competing interests were declared.

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