Title.

Palliative Care and Assisted Dying: Uneasy bedfellows.

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Text.

Wherever assisted dying becomes legal, the “Yes or No” debate must give way to a practical discussion about how assisted dying will be provided to eligible people. As part of that discussion, palliative care providers need to contemplate how this will affect their practice, as they care for patients who may be seeking an assisted death. They will also need to consider whether or how they will participate in the provision of assisted dying. Assisted dying refers to medications being prescribed to intentionally end the life of an eligible person who requests it. If a patient self-administers the medications this is sometimes known as assisted suicide, but if a practitioner administers the drugs, then it may be called euthanasia. Both acts are sometimes referred to as Medical Aid in Dying or Voluntary Aid in Dying.

Many of the founders of palliative care are outspoken opponents of assisted dying. The International Association of Hospice and Palliative Care and the European Association of Palliative Care are officially opposed to the legalization and practice of assisted dying, as are many national palliative care organizations. And yet, in jurisdictions where assisted dying is legal, some palliative care providers have come to accept and provide assisted dying and even take a leading role in developing policies around assisted.1,2 Some palliative care organizations from these jurisdictions have taken a neutral position on assisted dying (e.g. the American Association of Hospice and Palliative Medicine, the Canadian Hospice Palliative Care Association, and Palliative Care Australia). And although the IAHPC is officially opposed to the legalization of assisted dying, they recently surveyed their membership and found that 49% favoured legalising assisted dying compared to 45% who were opposed.3

People who oppose assisted dying as a matter of principle (either religious or secular) may never be reconciled to the practice of assisted dying. But in jurisdictions where assisted dying has become legal, many palliative care providers are comfortable discussing assisted dying, some refer patients to assisted dying services and even perform assisted dying procedures as part of their practice.1,2,4 There are lessons to be drawn from their experience.

*People cared for by palliative care providers will request assisted dying.*

Palliative care providers should expect to regularly receive requests for an assisted death, where this is legal. Despite concerns that assisted death would be driven by a lack of access to high-quality palliative care, most requests (75-90%) come from people who are being treated by palliative care providers or who are admitted to palliative care facilities.5 Requests are most common in populations known to receive the best palliative care, such as those with cancer, white ethnicity, higher education and income.5,6 In contrast, people with equally high palliative needs but little to no palliative care involvement, such as those with a non-cancer illness or from a racialized population, have a relatively low incidence of assisted dying. Notably, palliative care involvement often precedes assisted dying requests by months,7 meaning that the requests for assisted dying will frequently come in the context of a well-established therapeutic relationship.

A request for assisted dying should always prompt an exploration of unmet palliative needs, regardless of whether assisted dying is legal. Palliative interventions may alleviate the suffering that prompts a request for assisted dying, but we must accept the limitations of our treatments in this regard. The effect of palliative care involvement is greatest for physical symptoms, but most requests for assisted dying stem from psychological or existential distress, for which our effectiveness maybe modest at best.5 Palliative sedation, which is usually suggested for cases of refractory suffering, may also have a limited role in requests for assisted dying given the nature of the distress (often existential), the prognosis of the patient (often more than two weeks), and patient preference. The recent IAHPC survey found that only 39% of members agreed with the statement: “Physician-assisted suicide is not necessary, as there are alternative options such as palliative sedation and voluntary stopping of eating and drinking.” – a figure that was even lower than the number opposed to assisted death (45%).3

*Do patients want us to separate assisted dying from palliative care?*

There is a concern that palliative care is poorly understood and sometimes feared, and the availability of assisted dying alongside palliative care would exacerbate this misunderstanding and fear, leading to further barriers to the provision of palliative care. Palliative care providers are routinely asked to see patients who resist a palliative approach or comfort medications because they associate these with death. Although a palliative approach can be offered alongside life-prolonging treatments, many people (including some clinicians) see the two as antagonistic or sequential; palliative care should only be provided once curative options have been exhausted. Hence, the argument goes, to make palliative care more acceptable, we need to keep assisted dying illegal or at least hermetically separated from palliative care.

The problem with this argument is that it conflates different concepts and fears. People with serious illness pursue curative treatments because they want to live or perhaps, they fear acknowledging they are dying. But polls routinely show that very few people are opposed to the existence of palliative care or the availability of assisted dying. When they believe that a cure is possible, they don’t want to die; they may reject palliative care because they fear acknowledging their mortality or *unintentionally* shortening their lives. But most still want assisted dying as an option for themselves at some point in the future and may have no opposition to the existence of assisted dying as an option for others.

At the same time, we must acknowledge that efforts to separate palliative care and assisted dying may backfire. A substantial proportion of people who consider or request assisted dying will ultimately not proceed with it. They derive comfort merely from the knowledge that the option is available to them, and they continue to benefit from the involvement of palliative care. But if they are forced to choose between palliative care and assisted dying, either due to policy or to overt opposition from their palliative care provider, we should not assume that they will choose palliative care. The separation of the two creates another potential barrier to accessing palliative care for people that would embrace it. It also creates discomfort for a patient and family who might perceive that their palliative care provider is not sympathetic to their values.8 And if we truly believe that some requests for assisted dying could be averted by high-quality palliative care, then it is hard to understand why we would want high-quality palliative care kept at a distance.

*Impact upon health care providers*

Ultimately, patient choice is only one side of the coin. Health care providers in countries where assisted dying is legal need to decide how far along a patient journey towards an assisted death they are comfortable travelling. There is a continuum of involvement: some may have none, others will discuss end of life options including assisted dying, others may perform eligibility assessments, while others will prescribe or administer medications for an assisted death. In Canada, approximately 20% of assisted deaths are performed by palliative care providers.7 In Belgium, palliative care providers perform 40% of assisted deaths and are eligibility assessors in nearly 60% of cases.1

Palliative care providers have reported a range of responses to the legalization of assisted dying. Some report a need for better education, and challenges with communication and symptom control in patients who want to prioritise decisional capacity.9 Others describe a transition over time, with increasing involvement driven by a desire to accompany patients to the end of their journey. Some palliative care institutional policies restricting or excluding assisted dying have relaxed over time, driven in part by distress and advocacy from healthcare providers and family members within the institutions themselves.10

Involvement in assisted dying can take an emotional toll on health care workers. The impact might be greater for providers with an established therapeutic relationship than for an external provider. While providers often describe feeling satisfaction from respecting patient wishes, some also describe emotional labour and the need to restrict the number of cases they perform to allow for recovery. Ultimately each clinician will need to decide for themselves their level of involvement.

Conclusion and Thoughts for the Future.

Palliative care practitioners working in jurisdictions that are considering legislation, can learn from the experience of jurisdictions where assisted dying is legal when deciding what role, they will play in policy development and provision of assisted dying. Regardless of our personal views on assisted dying, most requests for assisted dying will come from patients being treated by palliative care providers. We need to be prepared to respond in a way that ensures respect for patient values; encourages open and honest communication about treatment options and likely outcomes; and provides the highest quality of care throughout the course of illness. Depending on the volume of requests, and the experience and attitudes of team members, palliative care teams may choose to manage requests internally,4 or to involve an external dedicated team.

There are still some knowledge gaps around the practice of assisted dying, but the focus of academic palliative care providers should be on how to improve the quality of care delivered whether or not a person has requested assisted death. And it is important to acknowledge the limitations of palliative interventions regardless of the moral status of assisted dying, because we should not view assisted dying in general as a failure of palliative care, nor should we imagine that the purpose of palliative care is to dissuade people from seeking an assisted death. No field of medicine can fix every problem it encounters; if anything, this should be further motivation to identify new, effective and scalable interventions for the kinds of distress people experience as they approach the end of life.

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