

Physician-assisted suicide is not a failure of palliative care

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want to die.”

That was how I received my first request for assisted suicide. Jean was a single, 50-year-old woman with advanced cancer. She had just been told that she could not receive any more chemotherapy, and a palliative treatment plan was recommended. “I watched my mother dying and I don’t want to go through that. Sitting in a wheelchair is death to me,” she asserted. I was in the sixth month of my palliative medicine fellowship. I took a detailed history and tried to assure my patient that although physician-assisted suicide (PAS) was not an option, we—the palliative care team—would take good care of her. I asked for an urgent psychiatry consultation. Despite all our efforts, after 2 months she was still insistent about her request to die and she became more distressed as she became more dependent. The care team started to discuss whether we should offer Jean continuous palliative sedation. However, she died in comfort, sooner than we expected.

This was a challenging case for me. I hear Jean’s words every time I am involved in a discussion about the request to hasten death (RHD) or the request for PAS. I also recall the referring team’s frustration about our “failure” in palliative care to change Jean’s views about suicide. This expectation that the palliative care team should change the patient’s views also surfaced in the divisive debate about legalizing PAS in Canada. Sadly, this debate was often derailed by attempts to exaggerate or undermine the importance of palliative care. Opponents to the legalization of PAS suggested that “proper” palliative care makes PAS unnecessary. Proponents argued that palliative care fails to fully address the needs of all terminally ill patients and proposed adding PAS as an option in palliative care. I argue that palliative care is not an “antidote” for PAS and, equally true, that failure of palliative care is not driving PAS and euthanasia requests.

Before I further explain my argument, I have to declare my personal bias. I do not support the legalization of PAS because my religious beliefs do not support any form of death assistance. I do not intend to delve into this debate. I argue that palliative care has a principal role in relieving the suffering of all terminally ill patients and that there is no causal relationship

between palliative care and requests for PAS. In other words, sustained requests for PAS from terminally ill patients are unrelated to the quality of palliative care.¹ Requests to hasten death are complex personal wishes that generally reflect patients’ values and perceptions of what makes a good life and a good death, and they do not represent a failure of palliative care.¹⁻⁴

Requests to hasten death are unrelated to pain

Requests to hasten death are rare and challenging. Traditionally, the public pictures patients who express the desire for PAS as being in agonizing pain. As palliative care provides effective pain and symptom management, most terminally ill patients who wish for assistance with dying are not driven by intractable pain.^{1,3-5} Data from the Washington and Oregon death and dignity programs—programs that provide terminally ill patients with PAS options—showed that most patients who opted for PAS chose it because of concerns about the fear of loss of autonomy (90%), loss of dignity (70%), and dependence (52%).⁶ Pain was highlighted as the reason for seeking PAS in only 22% of cases. Further, data for euthanasia patients from the Netherlands showed that pain was the reason for euthanasia for only 36% of patients.⁷ However, Raus and colleagues suggest that because respondents can choose multiple reasons for requesting PAS, these data indicate that the number of patients who chose euthanasia only because of pain might be lower.⁸ Further, in the Netherlands, despite the availability of euthanasia and PAS options, most terminally ill patients with intolerable physical symptoms, such as pain, choose continuous palliative sedation for symptom management.⁷ In addition, other studies have made similar observations about the relationship between pain and RHD.⁵

Good palliative care does not prevent RHDs

Further, if we propose that the failure of palliative care is a cause of RHDs, then we assume that good palliative care prevents RHDs. However, the existing reality does not support this suggestion. In their report “The Quality of Death,”⁹ *The Economist* ranks the quality of existing palliative care programs globally. Countries with better-ranked palliative care systems (such as Belgium) have more PAS cases compared with Canada, for example, which only recently legalized PAS.⁹

If pain and physical suffering are not motivating RHDs, then what is the cause? A systematic review by Monforte-Royo et al² concludes that RHD is a complex

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and multifactorial phenomenon. It involves a mix of different concepts including fear of suffering and dying, response to total suffering (physical, psychological, and spiritual), the need for an exit plan, and the loss of meaningful life.² Research shows that RHD is not always a sustained desire for death, and such requests can be viewed as a “cry for help”^{2,10} or as reflecting a fear of being stuck in pain or becoming dependent. These patients want an exit plan in case one is needed. In fact, in the Washington and Oregon death and dignity programs, 40% of the patients who received prescriptions for lethal medications did not use them.⁶ The palliative care team aims to address these fears.

Values influence choice

Despite extensive provision and use of multidisciplinary palliative care, there are patients—such as Jean—who have firm wishes about controlling their lives and deaths. These are rational, capable patients who are not depressed and who want to die early based on their personal values and views of suffering and life. These wishes are not driven by a failure of palliative care but by a desire to live “on their own terms.” In the review by Monforte-Royo et al, all RHDs were driven by patients’ desire to control their lives.² This desire for control and self-determination is a dominant value in Western medical ethics and Canadian law.


Obviously patients have different values: some prefer to focus on quality of life; others prefer to prolong their lives even when health care providers believe that the quality of life is poor. For example, one of my patients, Sara, had amyotrophic lateral sclerosis. She was completely dependent and required a ventilator for breathing and a feeding tube for nutrition. She could not eat, drink, or speak properly. She communicated by blinking. My first reaction was that Sara had a miserable life. Yet as I was discussing her goals of care, she expressed that she felt strongly that her quality of life was good and she wanted to live her life to the last minute. Despite pain and compromised function, Sara’s religious values gave her the strength to continue with her life. As I was discussing my recommendations with the referring team, I heard the same frustration about the role of the palliative care team and Sara’s wish to continue with life support. For both Jean and Sara, their choices were based on their values and beliefs. Many factors contributed to Jean’s request, but the desire for control and autonomy was central. By comparison, Sara had different religious and personal values that shaped her desire for aggressive care. As medical practitioners we should acknowledge that patients’ values—whether personal, religious, or cultural—influence all end-of-life decisions.

Effect on PAS debate

In the discussion above I argued that sustained RHDs are unrelated to the quality of palliative care. I now would like to add a further comment about the effect of the PAS

debate on palliative care. Although some experts argue that the PAS debate improved public understanding of death and dying, I argue that debating palliative care in the context of PAS reinforced the idea that palliative care is only limited to the time around death. Despite the proven benefits of early palliative care,¹¹ many patients and health practitioners resist early referral because they think that palliative care is limited to when patients are close to death. Many terminally ill patients are denied timely referral because “it is too early,” as patients are not yet dying. This debate about PAS reinforced this wrong message and might have hindered early palliative care delivery.

Conclusion

Clearly, the divide about the legalization of PAS in Canada stems from conflict between our values and principles. Palliative care maintains good life for seriously ill patients for as long as possible. Palliative care should not shoulder the burden of the disagreement, as it distorts the image of palliative care. Assigning unrealistic expectations and goals to palliative care teams—such as changing patients’ values—will set palliative care up for failure, and undermining palliative care will affect all vulnerable, seriously ill patients.⁹ Palliative care is distinct from PAS and should not be part of the debate. 

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Competing interests

None declared

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