

Reply to Commentary on Our Paper “Palliative Care and Patient Autonomy.”

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We are thankful for the opportunity to reply to the thoughtful letter commenting on our manuscript, “Palliative care and patient autonomy.”

Based on the importance of patient autonomy, we attempt to adopt the perspective of the patient—not a philosophical perspective. Patients are the most directly affected by all medical decisions. All other stakeholders, including family, friends, loved ones, health care providers, and the society at large, are, in our view, secondary. To shed this in more direct light, consider the landmark case of Dax Cowart.¹ Dax was forced against his will to endure dunking in a Hubbard tank to clean his burns and protect him from infection. Dax described the experience as tantamount to being placed in boiling oil.² This was a gross violation of his autonomy and represented a misguided benevolence, despite the fact that his mother and the health care team wanted him to continue treatment.

The commentator claims that we ignore other important principles of bioethics and cites Beauchamp and Childress to support his claim. We made no direct appeal to Beauchamp and Childress. Even if we did, respecting autonomy would still have to be prioritized over the other principles of beneficence and nonmaleficence, which typically do not override respecting the autonomous wishes and preferences of competent patients. In addition, our emphasis on patient autonomy does not ignore the “holistic” aspect of palliative care because we advocate that more, not less information be provided to dying patients.

The commentator claims we state that patients in palliative are “Forced to endure symptoms, suffering and undesirable states of consciousness . . .” What is omitted is an important disclaimer. We state that patients “. . . *may be* forced to endure symptoms, suffering and undesirable states of consciousness” (emphasis added). This is certainly the case. Patients with terminal illnesses will experience a unique death just as expectant mothers will experience a unique birth. For those dying, the experience could be reflective of a good death, a horrific death, and every other possibility in between. Prohibiting terminal patients from hastening their deaths, then, exposes them to risks regarding their dying process they may want to avoid. Given the uncertain and precarious nature of dying, it is reasonable to take measures which would assure a dying patient’s

choice to avoid a difficult death. We fully understand that many patients would not elect to hasten their deaths. We are speaking for those patients who would.

The commentator also claims that the protocol involved in the Oregon Death with Dignity Act (DWDA) may lead to the forced endurance of unactable symptoms due to the required waiting period. This is incorrect. The case of Brittany Maynard that we cite is a clear counterexample. Not only did Brittany satisfy the protocol in the DWDA, she also did so after first having to establish residency in Oregon. Ultimately, the protocol did not prohibit her from having control over her dying process and escaping the fate she would have had to endure if it were not for Oregon’s legislation. The protocol in the DWDA does not present an undue burden on the terminally ill. We stand in support of such legislation, and we regret that physician-assisted suicide (PAS) is not available in other states and countries.

The author claims that our view would force us to accept voluntary euthanasia. This is not the case. Rational distinctions can be made between administering a poisonous agent to one’s self from having that agent administered to a patient. One reason is to help protect the practice from slippery slope concerns. The same reasoning is used in the current DWDA.

The author mistakenly claims that we advocate limiting patient information about successful palliative care. In a bullet point we state, “Keep in place all current guidelines concerning the mission of caring for dying patients through their illnesses and managing their symptoms.” We argue that *additional* information be presented to dying patients, not less information. Part of our argument is that dying patients are not provided options in an “open and honest” manner. In one of our case studies, a patient found out about voluntarily stopping of eating and drinking serendipitously. Why should it take a chance encounter for a dying patient to find out about a legal and reasonable option?

The commentator cites data from Belgium and the Netherlands indicating difficulties that have occurred with their practices. It is not clear that a slippery slope is occurring.^{3–5} Furthermore, there is evidence that Oregon’s PAS works in the vast overwhelming majority of cases.⁶



Our view on titration is mischaracterized. We do not claim it causes suffering or that it likely results in death. In our article, we argue that it may allow pain and suffering to continue beyond what is acceptable to dying patients.

The author compares the time period with the DWDA and in hospice claiming that although patients are typically only in hospice for a brief time, and so it is difficult to control pain, that is also true of those taking advantage of the DWDA due to its requirement of 2 oral requests. The DWDA is not an attempt to control pain, but to hasten death. Patients admitted into hospice are typically far closer to death than 6 months.⁷ The 6-month time frame makes reasonable the requirement of 2 oral requests and the approval of 2 physicians.

The author suggests we claim that a death due to natural causes is undignified and that a death brought on by rational suicide is somehow more dignified. We do not make this claim. To a large extent, dignity depends on an individual's point of view. For some, needing to be fed by another due to a condition of quadriplegia may be completely consistent with dignity. For another, this scenario could be unacceptable and undignified. We believe that with increased options, a patient is more likely to die in a way that the patient considers dignified.

Our position is centered on providing expanded options and respecting the autonomy of dying patients. Requests for hastening death made by dying patients should receive full support from palliative care experts.

Author Contributions

Both the authors contributed to all aspects of the manuscript.

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