

Deliberately Dying Is an Appropriate Example to Challenge Current Definitions of the Concept of Occupation

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We wish to begin by recognizing the importance and necessity of having people with experience of disability at the forefront of this sensible reflection, as well as those among them who are part of critical disability studies. Thus, we would like to thank the commentators for contributing to this dialogue about the question we have raised: What if deliberately dying is an occupation? We agree that it is essential to avoid fueling eugenic ideologies and perpetuating ableist notions (i.e., that the world would be better off without disabled people and that living with disability is worse than death). That said, we are concerned that the commentators have not accurately presented the ideas we conveyed in our column, given that we highlighted the necessity for occupational therapists and their professional organizations to advocate against such notions.

The commentators accuse us of omitting bioethics insights. Although we acknowledge as a caveat in our article, “We did not consider whether deliberately dying is moral, legal, or ethical but instead whether it could be considered an occupation” (Guay et al., 2022, p. 6), this does not mean that we did not discuss the ethical implications of considering deliberately dying as an occupation. In fact, ethical considerations are one of

the six main areas of reflection we indicate that occupational therapists might consider as they deliberate on their role in this area. We ask questions such as “What are the potential abuses of deliberately dying?” and “What potential ethical conflicts could arise with such new practices?”

Similarly, the claim that we have ignored the voices of people with disability is also inaccurate. It is precisely their stories, such as those of Sue Rodriguez, Ginette Leblanc, Donald Low, Nicole Gladu, and Jean Truchon, to list only a few, that have in part inspired our work. Honoring the legitimate concerns of many disability rights activists in this area in Canada, we indicate that with the possibility of considering deliberate death an occupation:

There is also the potential for coercion. Without being provided with alternatives, some people may believe their lives are unalterably poor. For example, people may choose to deliberately die if they do not have adequate community supports (e.g., home care) or palliative care services. To that extent, it is critical that deliberately dying as a potential and final occupation does not become a means for policymakers or managers to reduce workloads or health care costs. There is a potential danger of abusing vulnerable people, such as those living with disabilities or

those who have reached old age. Occupational therapists and their professional organizations may need to advocate in this situation. (Guay et al., 2022, p. 5)


In this regard we are very sympathetic to concerns that the construct could be invoked to promote nonvoluntary euthanasia, but we are emphatic that this position is untenable. That said, to treat people with disabilities equitably requires us to offer them the same permitted occupational choices as to everyone, including freely and capably planning, organizing, and precipitating their own death if this is their genuine wish.

We would like to point out that the commentators are taking out of context our remarks about the necessity of subsequent work to focus on deliberately dying in relationship to others rather than the self, in making the point that deliberately dying should not be studied from only Western perspectives. We did not choose to describe occupation as connected to community obligations; instead, we are suggesting to occupational scientists and occupational therapists, including those working in palliative care, that occupations are “necessary or meaningful activities (performed singularly or repeatedly, alone or with others) that allow people to fulfill social roles, meet self-identified needs, pursue

interests, engage in rituals, or find purpose, such as deliberately dying” (Guay et al., 2022, p. 5).

We acknowledge that insights from critical disability studies theories have application to occupational therapy’s past and present (Desormeaux-Moreau et al., 2022) and would shed a broader light on deliberately dying as an occupation. However, it is disconcerting to position the academic and professional conversations as something in opposition to “the voice of the disabled,” as the commentators are suggesting. Even if paternalism is an issue, such dichotomization ignores the existence of people with disabilities who are occupational therapists or academics (including some of the authors) and seems to undermine the potential for collaborative efforts to address occupational injustices.

We believe that deliberately dying is an excellent example of what may be an uncomfortable conversation for some but one that is important to have in challenging preconceived notions in occupational therapy and occupational science. Making a topic taboo does

not help people who are grappling with these concerns. We are grateful to the editors of this journal for providing a forum to us as well as to our commentators to keep the dialogue open to reflect on how deliberately ending one’s own life fits with the current definitions of the concept of occupation, stemming from our column and information gathered elsewhere. 

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