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Assisted Dying: More Attention Should Be Paid to the Epistemic Asset of Personal Experience

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CONCLUSION

We have argued that in the case of disability, the liability side of the "paradox of experience" is overstated. First, the biases arising from a vested interest in the outcome of a debate are familiar ones. They require no special measures to mitigate, especially in the case of disability bioethics, where there is little danger that the first-person testimony of disabled people will receive excessive deference. Second, the problem of partial representation arises from a history of exclusion and is reinforced by the attitudes of non-disabled listeners. The primary responsibility for correcting it should rest with the bioethics community, not with those previously excluded.

We cannot have satisfactory debates on disability ethics without respectfully considering the personal experiences of disabled people. The "liabilities" associated with their personal experience not only *can* be mitigated but *must* be, to secure space for their neglected critical perspectives.

DISCLAIMER

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OPEN PEER COMMENTARIES

Assisted Dying: More Attention Should Be Paid to the Epistemic Asset of Personal Experience

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The target article (Nelson et al. 2023) offers a valuable contribution to the "paradox of experience," which was illustrated by using examples about access to unproven medical products and disability bioethics. As the authors noted, the paradox extends well beyond these particular issues, and appeals to experience are seen throughout bioethics. In this commentary, we will argue how the personal experience of patients serves as an epistemic asset and a liability in the debate around assisted dying. By weighing both

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elements of the paradox of experience in this issue, we believe that more attention should be paid to the epistemic asset of experience.

First, we analyze the global policy and data to illustrate the legislative demand for assisted dying.

Since the definitions of physician-assisted suicide and euthanasia vary between nations and are controversial (Emanuel et al. 2016), for simplicity's sake, we use the term "assisted dying" to encompass both "physician-assisted suicide" (a doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request) and "euthanasia" (a doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request) (Hendry et al. 2013). Since the 1980s, assisted suicide has been legally permitted in Switzerland, including for Swiss nonresidents. In 2002, the Netherlands and Belgium legalized both euthanasia and physician-assisted suicide. In 2009, Luxembourg followed. Euthanasia remains illegal in the U.S. However, since 1997, 10 U.S. states and the District of Columbia have legalized physician-assisted suicide. Colombia legalized euthanasia in 2015 and assisted suicide in 2022, and both types also became legal in Canada in 2016. Since 2019, similar laws have come into effect in several Australian states. In the past two years, Spain and New Zealand legalized euthanasia and assisted suicide legal; assisted suicide was also made legal in Austria (Dugdale, Lerner, and Callahan 2019; Emanuel et al. 2016; Sallnow et al. 2022; Statista 2022). In summary, around the world, there are still only a few countries that have legalized assisted dying, although their number has been growing recently. In contrast, helping someone to end their life by providing them with lethal medications is a criminal offense in the majority of countries, no matter whether the person is dying or requests death, or if the action is compassionate (Sallnow et al. 2022; Wang et al. 2022).

Approximately 100 million people (about 1.25% of the world's population) have access to some form of assisted dying legislation (Sallnow et al. 2022). People travel to other countries to receive assisted suicide because their national laws do not permit such a procedure, which has given rise to the phenomenon of "suicide tourism." According to the websites of six Swiss official right-to-die organizations, they assist in about 600 cases of suicide per year, of which "suicide tourists" account for 150–200 cases. A pilot study on assisted suicide showed that 611 suicide tourists from 31 countries around the world visited Switzerland for assisted suicide from 2008 to 2012. The majority of such tourists were from developed countries in Europe and North America, such as Germany, the UK, Italy, and the U.S., while very few came from Asia, Africa, and South America (Gauthier et al. 2015). As the whole process that begins with applying for assisted suicide lasts for months and the cost during the overall period is an enormous figure for these tourists, dying in a foreign country is not an accessible pathway for the majority of ordinary individuals. Indeed, in countries where assisted dying is illegal, the legalization of euthanasia and physician-assisted suicide is widely debated. There have been high levels of public support in some countries. For example, in recent cross-sectional studies, the majority of public participants in the UK (70%) and South Korea (76.4%) expressed positive attitudes toward the legalization of euthanasia and/or assisted suicide (Pentaris and Jacobs 2022; Yun et al. 2022).

Next, we analyze and weigh the two elements of the paradox of personal experience with respect to the issue of assisted dying, to illustrate that the epistemic asset of experience should play a more positive role.

EXPERIENCE AS AN ASSET

We agree with Nelson et al. (2023) that patients are often in the unique position of being an epistemic authority and that it is difficult for the inexperienced to garner others' experience through observation or testimony alone.

Many studies on assisted dying have revealed that suffering is understood within the subjective dimension, namely only by those who actually suffer from the disease and are aware that death is an imminent event. It contains the following four main areas: physical, psychological, social, and existential or spiritual suffering. Pain, fatigue, decline, loss of self, negative feelings, fear of future suffering, loss of autonomy, dependency, being worn out, feeling of being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness, and being tired of life were constituent elements of unbearable suffering (Dees et al. 2010, 2011; Hendry et al. 2013; Sperling 2022). A pilot study conducted in Canada suggests that terminally ill patients generally agree that individuals with life-limiting illnesses should be able to access assisted dying (Hizo-Abes, Siegel, and Schreier 2018).

Indeed, some of the most convincing arguments in favor of assisted dying come from patients' experiences that have influenced policy settings (Dugdale, Lerner, and Callahan 2019). For example, the case of Brittany Maynard. In early 2014, Maynard was diagnosed with an astrocytoma. To stop the tumor from growing, she had a craniotomy and a partial temporal lobectomy. However, in April 2014, not only did her tumor relapse, but it also became more aggressive. Doctors told her that she had only six months to live. To avoid weeks or even months of suffering in hospice care, Maynard believed that death with dignity would be the best option for her and her family. She moved from her home state of California to Oregon so she could have access to its Death With Dignity Act. She said, "Having this choice at the end of my life has become incredibly important. It has given me a sense of peace during a tumultuous time that otherwise would be dominated by fear, uncertainty, and pain" (Maynard 2014). On November 1, 2014, she died peacefully at the age of 29. By sharing her personal story, Maynard propelled the "Death With Dignity" movement forward. Her well-publicized death influenced California to legalize aid for dying in 2015 (Dugdale, Lerner, and Callahan 2019).

EXPERIENCE AS A LIABILITY

It is undeniable that the patients' experience has the potential to generate conflicts of interest and unrepresentative perspectives (Nelson et al. 2023) in the debate about assisted dying.

These conflicts of interest, however, are not financial or material (Nelson et al. 2023), but simply related to dying with dignity. Studies have indicated that pain is not the key motivation for the requests for euthanasia and physician-assisted suicide. Loss of dignity is mentioned as a reason for euthanasia for 52 and 61% of the cases in Belgium and the Netherlands, respectively (Emanuel et al. 2016). Many terminally ill patients are unable to take care of themselves and have to rely on other people or medical devices. They are forced to spend the rest of their lives in bed facing humiliating conditions, such as constant pain, changed appearance, incontinence, and feeling of being a burden. Euthanasia and physician-assisted suicide are viewed by them as a tool to guard their sense of dignity and regain their right to autonomy. We believe that the vested interest in dignity in death is not sufficient to prevent euthanasia and physician-assisted suicide legislation.

The problem of partial representation may lead to concerns about whether the legalization of assisted dying could be abused. First, compared with other groups, people with financial pressure and those belonging to vulnerable groups (such as people with inadequate healthcare insurance, people with disabilities, vulnerable women) may have limited options for life-sustaining treatment. For instance, a UK study showed that people suffering from terminal illnesses felt that the burdensome cost of care contributed to their motivation for considering assisted dying (Hendry et al. 2013). Second, psychological distress, including depression and hopelessness, are significantly associated with patients' suicidal thoughts and their interest in hastened death (Emanuel 2005). A Dutch study revealed that the risk of requesting euthanasia among patients with depressed mood was about four times higher than in those without depressive symptoms (Emanuel et al. 2016). Although the risk of partial representation may arise in these situations, we believe that a comprehensive and compassionate evaluation, including psychiatric evaluation, can help reduce the probability of partial representation and promote ethical decision-making.

We agree with the authors that acknowledging the paradox of experience may help inform best practices for bioethics in policy settings (Nelson et al. 2023). As assisted dying is being discussed in many nations and legalization appears likely to spread, we believe that based on taking countermeasures against the liability of personal experience, bioethicists and policymakers should pay more attention to the epistemic asset of personal experience.

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