COMMENTARY

What They Want and What They Need: The End-of-Life Conflict

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When contemplating the state of ethical dialogue in our modern world, the philosopher Alasdair MacIntyre had this to say: "I can only answer the question, 'What am I to do?' If I can answer the prior question 'Of what story or stories do I find myself a part?'"[1] That is, our ethics must proceed from our understanding of ourselves, others, and the world. David Hume might scoff, but we do need an "is" to appreciate and grasp our "ought." This is just as true for medical ethics as it is for the rest of life. Questions about what we should do in medicine should draw us to deeper questions about identity and purpose.

In this issue, Ruskin et al present a tragic case of a man who spent his later years walking the line between life and a self-chosen death.[2] After enduring the chronic decline of Parkinson disease, he faced a final diagnosis of glioblastoma. The patient enrolled in hospice while considering how he might move elsewhere to avail himself of assisted suicide. Before he had a chance to do that, he was admitted to an inpatient hospice unit where he weakened further. In the throes of what may have been delirium or a last effort to enact his wish of a hastened death, he attempted suicide on the hospice unit. He survived only to die days later from the cancer.

The authors reflect on the complexities of this case, including the distress of a clinician who may want to satisfy a veteran's wish but cannot due to legal constraints, and the challenges of identifying pathologic suicidal ideation from an earnest and rational desire for a hastened death. How should they handle these conversations? They conclude by suggesting ways clinicians may assess and respond to requests for a hastened death, recognizing that assisted suicide remains illegal within the Veterans Health Administration (VHA).

Clinicians can return to the foundation of our profession to better consider these questions. The case report authors acknowledge this but avoid learning from what the conflict might teach us: "The inability to help veterans achieve their care preferences [to receive a hastened death] conflicts with the core mission of palliative care to reduce suffering and respect end-of-life wishes." Before feeling like they have failed the veteran, a clinician must ask if it is really within their scope of practice to end someone's life. While it is true that "the mission of VHA's [Palliative and Hospice Care] program is to honor veterans' preferences for care," this mission exists within a greater context of appreciating that not all preferences can or should be honored.[3] An obvious example is when a veteran requests an intervention that is not clinically indicated (eg, antibiotics for a viral infection). Clinicians are not bound to honor this preference; not because there is a law directing the clinicians' decision making (there is not) but because there is a standard of care that accounts for but can supersede the veteran's preference.

Is assisted suicide ever clinically indicated? While the answer shifts depending on the jurisdiction, the case report authors acknowledge why the preference for assisted suicide cannot be honored in a VHA facility: it is against the law.[4] However, as they explain, this is insufficient to assuage the moral distress that might arise for some clinicians who want to fulfill a veteran's request. They recommend several different strategies for clinicians to consider when receiving a request for assisted suicide. Distress in the form of cognitive dissonance may also arise from the tension that exists between stopping some forms of suicide while assisting in others.

While it is important to assess whether the request for a hastened death is driven by an untreated symptom or mental illness, this will only get a clinician so far when the request is made in earnest with no remediable drivers. While I cannot argue the point here,

I accept that there are forms of suicide which are rational. However, that alone is insufficient to justify the act or assist someone with it; we must assess the good that the rational choice seeks to realize.[5] If suicide can be rational, clinicians should ask whether it is within the goals of medicine to assist in suicide. The authors seem to take it for granted that the distressed clinician in the case hopes to hasten this veteran's death or at least refer him to someone who could. Perhaps his suicide attempt on the hospice unit was, in part, a consequence of being incapable of offering such assistance. These presuppositions should be considered explicitly to better align one's practice both with the mission of VHA and with the goals of medicine.

One way to do this is to consider whether we can cast assisted suicide as a medical therapy. Sulmasy proposes the provisional "canons of therapy" which might guide clinicians in assessing medical therapies.[6] This article distinguishes 3 types of clinically and ethically distinct practices. I have split his first canon (proportionality) into 2 for the sake of clarity.

Priority: Do the benefits outweigh the burdens of the intervention? The challenge of assessing priority when considering assisted suicide is that we cannot explain any benefits or burdens that might accrue after death; it is beyond our knowledge and informed consent is impossible. While there is always some uncertainty in discerning the benefits and burdens of an intervention, death presents an insurmountable procedural problem for informed consent to assisted suicide.

Fit: Are the means appropriate for the outcome of interest? The outcomes of interest when considering assisted suicide are many—they range from symptom relief or avoidance to reclaiming dignity. In the case described by Ruskin et al, the interdisciplinary team offered the veteran a number of interventions to assuage his symptoms. Dignity therapy may have been employed as a meaningful, useful way of bringing closure to a life.[7,8] Ultimately, however, some distress, particularly existential distress, may be intractable and clinicians must commit, as they did in this case, to doing what they can to remedy other symptoms and not abandon the veteran. Suicide is a tempting option because it may eliminate some of these concerns, but one must first grapple with the ethical question of whether suicide is ever an *appropriate* way to pursue any of these outcomes. Addressing that question is beyond the scope of this commentary, but both clinicians and patients should consider whether and why suicide should be considered appropriate and whether it is appropriate for the medical profession to assist with it.

Parsimony: Is this the least invasive, least burdensome intervention available? In US jurisdictions where it is legal, assisted suicide is considered an intervention of last resort. Assisted suicide seems to be neither invasive (it involves taking medications) nor burdensome: the medications usually work quickly and without adverse effects, although there are risks (eg, vomiting). Broadening our view beyond the individual reveals something different.

In a cultural sense, assisted suicide *is* invasive. It changes how clinicians and patients consider health and medical care. We no longer have the profession of medicine with another intervention in the toolbox; we have a totally different profession which now intends death instead of health for its patients. It changes medicine and society at large profoundly. This makes it culturally invasive.

Furthermore, although the veteran in the case recurrently grappled with the choice of suicide, most people do not. They live by default. Offering assisted suicide, even in broad, general terms, may still leave them *deciding* to live, but the offer has also taken from them the possibility of living *by default*. They must justify their choice if only to themselves, considering the reasons they continue to pursue life-prolonging treatment and incur financial, emotional, and physical costs for their family. This is a dangerous cultural burden ironically imposed by the offer of more choices.[9] Clinicians, by offering assisted suicide even if a patient declines it, also affirm the reasonableness of ending one's life given the circumstances. That affirmation may be burdensome (eg, "They see my life as not worth living") rather than validating.[10]

Restoration: Will this intervention help to restore the patient overall (even if not immediately)? It would seem restoration is impossible for someone who is dying. Dying is terrible and so one possibility would be to hasten the process with assisted suicide. If health is in view, though, clinicians could recognize that restoration is always possible as long as someone is alive.

For someone dying, restoration may look like symptom relief (restoring bodily distress) which in turn may restore one's capacity to sleep or to converse with loved ones. Assisted suicide does not fit in this paradigm. Is it intended to help patients sustain and restore their health, whatever amount they have (this is what the hospice and psychiatric services attempted to do in the case). Or is it intended to help patients pursue whatever goals seem good to the patient even those goals which conflict with health? Happily, most patients want their health sustained or restored so there is usually no conflict. As medical technology advances, though, conflicts arise: Should a clinician prescribe stimulants to enhance a healthy student's wakefulness during final exams? Should a clinician engineer embryos to provide parents with a particular kind of child? Should a clinician end a patient's life? Assisted suicide is obviously not aimed at restoration. It is a concession to the intractability of one's disease and disability and one's impending death. Without clarity and agreement on the goal of medicine, the default provision of care centers instead on satisfying patient preferences whatever they are.

Holism: Does the intervention prioritize the whole patient (vs prioritizing a part for the sake of the whole)? Clinicians offering assisted suicide suggest that providing a death on a patient's own terms restores autonomy and brings coherence to a life narrative that, at its end, is fraught with tragedy. This is what it looks like to honor "the whole patient." A clinician must scrutinize that judgment to determine whether the patient meets statutory criteria for assisted suicide. The impulse underlying the moral distress described by Ruskin et al and many other clinicians is that a patient's judgment, once determined to be sound, should trump a clinician's judgment about what is best for the patient's health and whether there are limits on what the clinician can do to satisfy a patient's preferences. Ironically, assisted suicide prioritizes a patient's judgment about how their life should end above other considerations, namely, that medicine has traditionally sought the patient's good by sustaining and restoring their health, not by intending and causing their death. Notably, there was no lack of holism in the care provided the veteran in the case both before and after his suicide attempt.

Discretion: What are the limits of the intervention itself? What is the scope of medicine in general? What is the limit of one's own individual knowledge and skill? Assisted suicide has a substantial limit: it does not offer relief from suffering because there will be no one left alive to experience relief. Assisted suicide cannot achieve *anything* for the patient because they are dead by the time they fully receive what has been given. This profound limit makes assisted suicide unlike anything else offered in medicine and should give clinicians pause before adopting it, prompting them to grapple with whether causing a patient's death is within the scope of medicine. If so, how did this come to be after thousands of years to the contrary across cultures and traditions, and what justifies this change? Finally, clinicians must contend with the limits of informed consent.

This brief reflection on how clinicians should consider medical therapies brings us back to MacIntyre's exhortation: We cannot decide what to do until we have discerned the story to which we belong. One way of telling the story of medicine is to tell it with the techniques front and center: we prescribe, we operate, we irradiate, make the numbers go in the right direction, cure infections, and shrink masses. We can also tell that story by rejoicing that technology is giving us increasing control over our bodies and we can put that power to whatever use we desire. Often that will align with health, but it may not and that is for many patients increasingly acceptable. There is another, better story to tell:

the profession of medicine exists to help people sustain and restore health, whatever bit of it they have and even as they lay dying. All those things just listed may help clinicians in that pursuit or they may not, given the specific context.

Ruskin et al tell a story of clinicians living in the tension of wanting to satisfy the desires their patients bring to them but must settle for the best that medicine can provide. Medical intervention as preference satisfaction is a story we have been living and practicing for 50 years since Beauchamp and Childress described the 4-principle framework for biomedical ethics: respect for autonomy, justice, nonmaleficence, beneficence.

Medicine-as-preference-satisfaction conflicts with the VHA mission to "honor America's veterans by providing exceptional health care that improves their health and well-being." VHA does not owe veterans whatever they request. VHA owes them exceptional health care. When a patient comes to a clinician, a clinician owes them a bounded set of things in service to their health. The dissonance a clinician might experience in trying to discern whether a patient's death can serve that patient's own health should signal a need to step back and reflect on how they understand the foundations of medical practice.

I do not disagree with the authors in their general approach to how clinicians might discuss this with patients who request a hastened death. I also seek to assuage symptoms, validate emotions, and remain steadfast through someone's dying. I also affirm my commitment as a physician to care for a person's health which, while someone is dying, usually entails managing symptoms. It never entails ending someone's life. The clinicians in the case did an excellent job caring for this veteran and could not have done better by helping him end his life.

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