

## **There is a fundamental ethical difference between “allowing to die” and “killing”.**

There is no question that Americans fear suffering at the end of life. And they have good reason to. The advanced technology of our modern health care system enables us to keep people alive, often without getting them better. In our intensive care units, patients can be kept on ventilators and dialysis machines almost indefinitely, without the hope of ever getting them well enough to leave the facility.

Arguments commonly presented in favor of Physician - Aid in Dying (PAD) are relief from suffering and respect of one's autonomy to determine their own fate. These are good and noble goals, ones which palliative care seeks to address every single day. So while I agree with these goals, I disagree that the solution to achieving them lies in the form of killing our patients.

Brittany Maynard's husband offered Brittany's uncontrolled pain in the ICU as one of his reasons for being in favor of PAD. This is not at all surprising. We, the health care system collectively, have not done an adequate job in managing pain especially in the environment of opiate misuse, abuse and diversion. For example, opiates may be limited by insurance companies to 60 hydrocodone tablets a month. While this may be appropriate for someone with chronic back pain, this is not appropriate for patients with rapidly advancing cancers whose pain levels change daily. These patients may sit at home in agony waiting days for prior authorizations to get approved or end up in hospitals where keeping people alive takes precedence over keeping people comfortable. This is unfortunate because trained experts are able to adequately control most pain once comfort becomes the goal and the entire care team is educated and committed.

Sometimes, pain can remain unrelieved despite high doses of opiates and other interventional procedures. In these rare cases, we have the procedure of palliative sedation available to us. This is where, at the patient or their surrogate's request, we intentionally decrease their level of awareness so they do not continue in unrelenting misery. This is usually done with the means of a continuous infusion of a medication such as a benzodiazepine or barbiturate while continuing other medications for symptom management. The goal of this procedure is to relieve suffering as the patient is dying and not to intentionally hasten death. While some would argue this is equivalent to PAD or even euthanasia, I would unequivocally deny this.

Many argue that we already do PAD in the form of disconnecting ventilators, stopping hemodialysis or discontinuing artificially provided hydration or nutrition. However, there is a fundamental difference between:

- a) “Allowing to die” - stopping an intrusive intervention that is not meeting a patient's goal and is simply preventing them from dying

b) "Killing" - actually writing a prescription for the explicit goal of making them dead.

I believe intention matters and means matter and there is a fundamental ethical difference between "allowing to die" and "killing."

One of the supreme tenets in medicine is the Hippocratic oath of "do no harm." I would define harm as both doing too much aggressive care when patients are dying as well as giving them a lethal prescription to cause their death. I fear that assisting in suicide carries the danger of compromising the patient-physician relationship and the trust necessary to sustain it. It also undermines the integrity of the profession and diverts attention from the real issues in the care of the dying.

Another failure in our health care system is in medical education. If you go to any medical school in the country, including our own, you will find that hundred percent of medical students are required to rotate through OB-GYN when only about ten to fifteen percent of medical students actually go into this field. But how many students or residents are required to take a palliative medicine rotation in this country? Zero percent - it's simply not a requirement.

Now consider how many students will eventually care for seriously ill patients needing symptom management, goals of care discussions, and attention to social, emotional and spiritual distress (they will, unless they go into pathology or radiology). Because medical education does not prioritize training students how to relieve the suffering of our patients whether or not they can be cured, our patients and families continue to suffer.

I believe that what's at the center of this debate revolves around meaning. If you look at the Oregon data, loss of autonomy, rather than fear of pain, is the number one reason patients choose PAD. Although I believe in giving patients as much control as possible, autonomy is really based in a negative right. That is, if you are a patient with decision - making capacity, you are allowed to refuse anything and everything even if that may save your life. In the same way, autonomy is not a positive right - you cannot demand things that are inappropriate.

Americans believe they can eliminate death and often request inappropriate or ineffective treatments. Just as this is not the answer to dealing with death, neither is the demand for death to come at the time and place of our choosing. While patients should be allowed to refuse things, I don't believe there is an underlying right to demand PAD and the Supreme Court has upheld this. I would also disagree that having control is the ultimate achievement of being human. Viktor Frankl, psychiatrist and holocaust survivor said, "Life is never made unbearable by circumstances, but only by lack of meaning and purpose." He went on to say that, "Those who have a why to live, can bear with almost any how."

The Oregon data also shows us that the majority of those who chose PAD were white - 95% and almost 2/3 had at least some college education. In effect, we have essentially created another "right" for our more socioeconomically well - off patients who are choice - enabled

while leaving those who are disadvantaged in our society with an option that they are not interested in and that does not meet their needs. This should give us pause when we reflect on health care disparities in this country.

The biggest irony of all in this debate is that we have now created, by legislation, this new “right” to PAD. But Americans still don’t have a right to health care. The United States is the only developed country that allows its citizens to go bankrupt over health care costs. Families are left with the overwhelming burden to care for their loved ones and one of the greatest fears Americans have is going to a nursing home. Without good family support, this is often inevitable for a large majority of us. Another irony of our health care system is that almost every American is within 5-10 minutes of having a hospital on wheels show up with lights and sirens to their doorstep to provide things such as defibrillator paddles, intubation, and epinephrine. But if I want to provide a bath and a warm, nutritious meal to my frail elderly patient at home, it’s almost impossible or takes considerable effort.

It saddens me to think of the enormous time, emotional energy and monetary resources that have gone into promoting the End of Life Option Act. We likely could have provided palliative care to thousands of Californians who need it with those funds. When we resort to PAD, we are relying on a technological and medical answer to an existential problem. Just as this does not work to fend off death, it is not the solution to make death come at our choosing. John Donne, the 17<sup>th</sup> century metaphysical poet wrote, “Any man’s death diminishes me, because I am involved in mankind.” Both society at large and medicine in particular have a duty to safeguard the value of human life. This duty applies especially to the most vulnerable members of our society – the sick, elderly, the poor, the disabled, ethnic minorities and other vulnerable persons.



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