Freedom to Decide: The Role of Autonomy in Medical Ethics

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"It is our choices that show who we truly are far more than our abilities." –J.K. Rowling

So ingrained has the notion of self-determination become in our society that it has seeped into a realm that for centuries was dominated by those we once considered god-like in their expertise. Where at one time physicians made all medical decisions on behalf of their patients, patients can now decide for themselves whether or not to accept a physician's recommended intervention. In fact, this transition of power to the patient is evident in the passage of the 1991 Patient Self-Determination Act, which requires that "hospitals, nursing homes, and other health-care facilities…provide patients with written information about relevant state laws and the rights of citizens under those laws to refuse or discontinue treatment," and in the host of cases that have been disputed over issues of consent.[1] Put simply, patients now have the right and responsibility of managing their own health. This newfound autonomy has given rise to efforts to control even the ways in which we die. With advances in medical technology, it is now possible to evade death for longer periods of time, and more and more human beings are choosing to prolong the inevitable. At the same time, this emphasis on free choice has left those who are unable to choose stuck in the dominion of neither the living nor dead.

The art pieces that I chose to examine through the lens of autonomy and medical ethics included a painting by Childe Hassam, "At Dusk (Boston Common at Twilight)" and an untitled photograph showing a nicely-dressed couple standing on a sidewalk, selected by Peter J. Cohen as a part of an assortment of unfinished works. The painting of Boston Common drew me in because of the stark divide between the greenery of the Common on the right hand side and the rising buildings lining the block on the left-hand side. The painting depicts a then modern mid-19th century Boston Common, which at the time of the painting's conception had already been transformed from a cattle grazing field into a park of elm trees and promenades.[2] At that time, the scene would have been seen as distinctly modern due to the distinguished building facades at the side of the park and the bustling street full of horse-drawn carriages and an orange trolley. Several figures, including one well-dressed woman and her children feeding the birds in the foreground, can be seen in the painting. The scene is not only one of tranquility, but also of prosperity. There is a certain ease with which the mother and her children, with their little fur muffs and fur capes, regard the birds. The city lights shine bright in anticipation of the coming gloom. To me, the traffic on the left side of the painting is representative of how humanity is constantly running against the course of nature. The streak of progressivity captured in this painting is the same element reflected within our current society, which largely encourages the expansion into greater and greater unexplored biological territories.

What was once impossible is now a reality; human beings can now linger among us even when they are beyond the capacities of breathing and normal braining functioning. The rise of machinery, such as the ventilator, spawns questions of what it means to really be dead and what qualifies us as living. We can now distinguish between several categories of dead, such as "total brain dead" in which there is no electrical activity in any part of the brain, or "traditionally dead" in which there is irreversible cessation of the heartbeat and respiration. There are those of us who would choose to be kept "alive" by any standard or definition and who would seek all possible means to avoid the unknown. The choice now exists: to continue on in whatever possible form even after we have lost consciousness, or to pass away. We get to decide in the form of advanced directives and verbal communications to our peers and health care workers. Before the modern age of medicine there was little we could do to resuscitate our patients once the heart or lungs stopped. Now the possibility to push our lives beyond our natural means is readily available to us.

The nature of medicine and the goals of the physician have changed. Until the 20th century, the role of the physician was, if not to cure, then to care for the patient and promote the patient's comfort. Now physicians make value judgments concerning their patients' lives, actively aid in the extension of human life, and even sometimes help to promote the cessation of certain lives. Many issues affecting our lives have commonly become medicalized and fall under the purview of the physician or other practitioners because physicians and practitioners can be "expected to have developed special sensitivity and skills regarding the judgments to be made, and are an identifiable group that can be readily held accountable for serious error."[3] For example, in *Belchertown v. Saikewicz*, the Probate Court largely deferred to the doctors' expert opinion. In this case, sixty-seven-year-old Joseph Saikewicz, a mentally retarded patient who has been diagnosed with a particularly lethal version of leukemia, must have his future decided for him. The Court explicitly inquired of Dr. Mying Cho whether, given the nature of the Mr. Saikewicz's illness and the risks and benefits which treatment would incur, it was his opinion that treatment should be administered at the present time.[4] When both Dr. Cho and Dr. Melnick stated that they would not give the treatment at the present time in light of the discomfort Mr. Saikewicz would be likely to experience and his inability to understand the situation, the Probate Court deferred to their opinion and held that life-saving treatment would not be given.

Mr. Saikewicz passed away without pain or discomfort due to a complication of the leukemia.[5] In this case, no attempt was made to solicit an opinion that would most closely confer with that of someone in Mr. Saikewicz's condition. Instead, Judge Jekamonksi reflected on what he himself would want, which is to go ahead with any treatment if it had any chance of prolonging his life. In presenting their evidence and stating what they believed the average rational person would want, the doctors had almost total determination over the results of this case, and therefore Mr. Saikewicz's life. Before the invention of life-saving treatments such as chemotherapy, the doctor would not be put in the position of having to decide whether to treat a mentally retarded, terminally ill person. The patient would simply die as an effect of the disease.

The problem becomes identifying when medicine should no longer be employed in the effort to extend a person's life. In

Atul Gawande's piece, "Letting Go," we learned about the consequences of continuing treatment in spite of the futility of the intervention. In the case of Sara Moore, who had been diagnosed with terminal cancer, the benefits that were to be derived from treatment would be very slight (only a few extra added days of life); however, after it became clear that remission was not likely, she was given not one or two, but three rounds of additional chemotherapy. In this case, the data showed that after the failure of second-line chemotherapy, lung cancer patients rarely gain any additional survival time from further treatments, and instead often suffer significant side effects.[6] Sara's last days were spent in a hospital when she could have been enjoying her young family in the comfort of her home. The problem that our society faces is recognizing when it is time to let go. It is often only after we have extended millions of thousands of dollars in health care, and we have exhausted every available treatment option, that we stop trying to save the lives of our loved ones. Much like the Common in Hassam's painting, we have clipped and boxed nature into one remote area of our lives while medical technology courses on ahead.

In the United States, a great portion of our GDP goes to paying for expensive medical care. Between 1960 and 1983, private and public expenditures on health care rose from 5 to 11 percent of the GDP. The greatest amount of our health care expenditures goes to end-of-life care, and specifically treatment for those with terminal illnesses.[7] Five percent of Americans account for half the total we spend on health care. A ten-day visit to the ICU can cost as much as $326,000.[8] It is clear that expenditures have to be cut.Unfortunately, with the transition of autonomy to patients such as Sara Moore, who cling desperately to their lives, doctors often fall prey to ill-advised courses of action. Doctors who know full well that medicine cannot fend off death forever and that at some point the "letting go" process becomes far more beneficial to the patient in question than allowing him or her to continue treatment. However, our society continues to hold fast to the notion that John Stuart Mill expressed so eloquently one hundred years ago: "Over himself, over his own body and mind, the individual is sovereign."[9] With notions of freedom and self-determination pervading the medical ethos, doctors find it hard to say no to the dying patient, such as 11-year-old David Stewart. The demands of the desperate, terminally ill population is changing how medicine operates because the more money that is expended on futile care, the more our premiums are raised and the more expensive health insurance becomes.

Modern medicine has the power to sustain a person's body long beyond what the average person can bear. In the effort to extend life, we destroy it. It is with horror that Karen Ann Quinlan's family regarded her withered body,

> "They had her uncovered, because of this new machine, and Mama could see what I never thought she would have to see—Karen's little figure, shrunken and twisted in a position that seems inhuman, with a blanket stuck between the legs so the bones don't cut into the flesh, and the gauze pads between her toes to keep them from bruising each other, and the bedsores that go so deep you can see the hipbone exposed."[10]

In seeking to gain control over the medical realm, we expose our own humanity, our limitations, our mortal boundaries, and trudge forward with an unseeing eye. The photograph I chose represents this curious phenomenon of erasure. Though

the photographer intended to capture the likeness of the subjects, for they clearly looked posed and artfully arranged (the couple's feet is angled towards each other and theirs touch carefully at their sides), there is a crucial part missing from the frame: The couple's heads have been cut from view. The camera is not level with their faces; it is instead pointed at the couple's bodies and the surrounding space of the sidewalk. I think this photograph does an extraordinary job of representing what happens when a human person enters a medical establishment and falls under the medical gaze. People cease to be human beings and instead are viewed simply as bodies—without souls. A person becomes an injured limb, a faltering heart, or a cancer-riddled pair of lungs. Though the object of medicine is to promote healing, we often destroy ourselves by removing the person from the life we are attempting to save.

I included the quote at the beginning of this paper because it accurately captures the preoccupation of our society with personal choice. We believe that to be a person is to have the freedom to design our own lives. In the popular Harry Potter series, the protagonist is even able to choose whether he would like to return from the dead and rejoin the living or continue on into the afterlife. Daniel Callahan writes, "to be self is to live with perpetual tension of dependence and independence. The former is as much a part of us as the latter…it still remains only half the story of our lives, however."[11] Human beings do not exist in a vacuum. Though we may emphasize individualism and self-determination, we do not operate as singular machines in the cosmos. Because we live with others, and we come from others before us, we cannot keep choosing courses that are detrimental to us all. If Americans do not stop the ridiculous expenditure on health care costs, America will bleed to death, both figuratively and literally. Furthermore, if we continue to push the boundaries of death with no regard for the destruction of the natural body, we risk changing the face of humanity to the point where it is no longer recognizable.

At Dusk (Boston Common at Twilight)[12]

Untitled[13]

ENDNOTES

1. Introduction, 389.

2. "At Dusk (Boston Common at Twilight)," Museum of Fine Arts, Boston. Web.

3. "President's Commission," *Deciding to Forgo Life-Sustaining Treatment*, 406.

4. Belchertown v. Saikewicz, 467.

5. Superintendent of Belchertown v. Saikewicz (Supreme Judicial Court), 473.

6. "Letting Go," 30.

7. "Lester Thurow," Learning to Say No, 537.

8. Lisa M. Krieger, "The Cost of Dying: Its Hard to Reject Care Even as Costs Soar."

9. John Stuart Mill, "On Liberty," 151-A.

10. Joseph Quinlan and Karen Ann, 486-496.

11. McCormick, 22.

12. Childe Hassam, *At Dusk (Boston Common at Twilight)*, 1885-86. Oil on Canvas. Museum of Fine Arts, Boston.

13. Unidentified photographer, Untitled, 1950's. Photograph, gelatin silver print. Museum of Fine Arts, Boston.