

-A TUFTSCOPE COMMENTARY-

THE RIGHT TO REFUSE

by Kathryn Reiser

The rights and duties of the patient and the physician regarding the option of life-sustaining treatment is a hotly contested issue in American healthcare. When a patient suffers from severe disability or terminal illness, the patient's quality of life may be so far reduced as to drive him or her to decide against such treatment. This scenario is not uncommon and it presents an ethical dilemma to the physician, who may be torn between his sympathy for the patient, his moral obligations as a healthcare professional, and his own personal beliefs. In this article, Kathryn Reiser explores arguments for and against the patient's autonomy in this matter, arguing that with very few exceptions, the patient is entitled to refuse life-sustaining medical treatment and is not obligated to justify his or her decision.

The relationship between patient and healthcare professional is often defined by the common goal of sustaining the life of the patient. However, this may not be the case when a patient suffers severe disability or terminal illness and requires life-sustaining treatment to live. In this situation, the patient's quality of life may be so far reduced as to drive him or her to decide against further treatment. This scenario is not uncommon and it presents an ethical dilemma to the physician, who may be torn between his sympathy for the patient, his moral obligations as a healthcare professional, and his own personal beliefs. Here I argue that with very few exceptions, the patient is entitled to refuse life-sustaining medical treatment and is not obligated to justify his or her decision in order to have and exercise that right.

Refusal of treatment on the part of a severely ill or disabled person is not unreasonable because many complicated and deeply personal issues may factor into the patient's decision; this decision should be respected regardless of his or her personal grounds for reaching it. Some reasons for refusal of life-sustaining medical treatment are decay in quality of life, both for the patient and other involved parties; the artificiality of medically sustained life; and the value of patient autonomy both during and after a decision regarding treatment. I will explore these three reasons in detail, but first I will address two arguments against the right to refuse, and show that they are inadequate grounds for forbidding a severely disabled or terminally ill patient to refuse life-sustaining treatment.

Many have argued against the patient's right to refuse treatment, but these arguments are not strong enough to force the patient to justify his or her refusal. First, Ackerman¹ makes the case that the duty of the physician should be to restore autonomy to the patient, which may be compromised during times of acute disability or illness. He suggests that the "transforming effects of illness" cloud the judgment of the patient and prevent him or her from making a truly informed and rational decision about pursuing further treatment. Ac-

ording to this argument, the patient may be unable to make the choice he or she would make under less compromising conditions. Ackerman seems to view the severely disabled or ill patient as incompetent. I argue, however, that neither the desire to refuse treatment nor the illness or disability itself should serve as grounds for classifying a patient as incompetent. Powell and Lowenstein⁴ agree that "the competence of patients with recent traumatic injuries may be questioned," but they endorse careful evaluations of capacity before overriding the patient's wishes. If, after competency has been proven and options for rehabilitation discussed, the patient still wishes to refuse treatment, it is his or her right to do so. The patient is not obligated to justify this decision.

Second, Michel³ objects to the notion that refusal of treatment by severely handicapped, but otherwise competent, people amounts to suicide. For this reason, she argues that the Court should not readily grant disabled persons the right to refuse life-sustaining treatment, and that "it is not the disability itself that makes life so unbearable that suicide seems a reasonable solution, but rather the conditions that people with disabilities have to contend with".³ Disabled persons unquestionably deserve equal respect in court, but it is simply unreasonable to treat such persons as ordinary patients in every regard; their situations constitute a special case. Michel's call for the "eradication of social barriers"² for handicapped people is unfortunately a very idealistic goal, as there is little hope that most patients on life support will return to normal, independent, or autonomous lives if they remain on treatment. For this reason, refusing treatment cannot be considered suicide in the same sense as other suicide cases. Michel's argument against the right to refuse life-sustaining treatment cannot override the motives for permitting it.

The basis for a patient's right to refuse life-sustaining medical treatment outweighs Ackerman's and Michel's arguments. The patient does not have to justify his or her refusal because there are many reasons for arriving at such a

decision, the nature of which may be deeply personal. I will consider the quality, artificiality, and autonomy of life during life-sustaining medical treatment as reasons for refusal, and then give an example of a rare exception to the right to refuse.

First and foremost, the quality of life of an individual is dramatically reduced following the incurrence of sickness or injury. The patient may become depressed, suffer physical as well as emotional and psychological trauma, or develop a feeling of worthlessness. Additionally, a patient on life support places great burdens on family members or other caretakers, causing their qualities of life to decrease as well. Both the patient and family members may wish to remember the patient's healthy days and forgo the pain and suffering that further treatment entails. The patient may even feel embarrassed and ashamed of his or her last days, carrying the sentiment that "I don't want them to see me like this." When quality of life is thus compromised, it is the patient's right to refuse further life-sustaining treatment. Neither the physician nor the law has the authority to impose treatment or to require justification for refusal of treatment, even in an effort to prolong life. The goal should not always be to preserve life, but rather to preserve happiness, comfort, quality of life, and the interests of the patient and his or her family.

Second, the life of a patient who is dependent on life-sustaining treatment is artificial to a certain degree. Some patients may find this state depressing or unacceptable. Cancer patients have the right to refuse chemotherapy; Powell and Lowenstein explain, "We accept this refusal more readily [than refusal of life-sustaining treatment] because we can say that the illness kills the patient, who has merely let nature take its course." It seems that refusal of life-sustaining treatment certainly allows nature to take its course. Dependence on life support is, in fact, quite unnatural from this point of view. Although a large number of patients are unbothered in this regard and choose to remain on life-support, others may find the artificiality of this type of life undesirable; it is the right of the patient to choose between these two options. As we have seen, dependence on life-sustaining treatment may cause great suffering, much in the same way as chemotherapy. Patients with severe disabilities should be given the same rights as cancer patients in this respect.

Finally, the value of patient autonomy confers his or her right to refuse life-sustaining treatment. If the patient is competent and understands the ramifications of potential treatment as well as the prospect of death without treatment, he or she should not be required to justify a decision whether or not to accept that treatment. It is also worth noting that if the patient does decide to remain on life support, his or her

autonomy will be diminished simply due to reliance on constant care and technology. To some, this constitutes a loss of individuality and dignity and may serve as a reason to forgo treatment. Additionally, religious and cultural beliefs may serve as grounds for refusing treatment. Whatever the reason for a patient's decision to refuse life-sustaining treatment, the decision should be respected and carried out regardless of the personal reasons for reaching it.

Thus far we have considered severely disabled or ill patients whose lives would be significantly shortened if they were to refuse further treatment, and it has been argued that they always deserve the autonomy to make decisions regarding their continued dependence on life-sustaining treatment. Michel raises one case that nicely illustrates an exception to this rule when she introduces Howard Andrews³, who sustained paralyzing injuries when he attempted to commit suicide. In this unusual case, the patient acquired the need for life-sustaining treatment as a direct result of intentional action, leading the refusal of treatment to equate itself with the fruition of his suicide attempt. Here, the Court can rationally treat the patient as if he were non-handicapped and suicidal. Other patients who sustain injuries via illness or debilitating accidents do not fall into this very specific category, and should be able to refuse medical treatment without providing justification.

Life-sustaining treatments may prove to be the best solution for many patients with severe handicaps or illnesses. For others, such treatment may lead to depression, misery, feelings of worthlessness or artificiality, and undermined autonomy. It is the right of the patient to decide whether or not to pursue medical treatment, and he or she should not be required to justify that decision due to its deeply personal nature. This is not to say that all patients will withhold their reasons for refusing treatment; to the contrary, many patients will want to discuss the possible options with their doctors and families. The right to choose, however, and the right to choose for whatever reasons the patient sees fit, should be inalienable except in very rare and specific circumstances.

References

1. Ackerman, Terrence F. "Why Doctors Should Intervene." *Biomedical Ethics*. Comp. Thomas A. Mappes and David Degrazia. New York: McGraw Hill, 1982. 85-89.
2. Mappes, Thomas A., and David Degrazia, eds. *Biomedical Ethics*. New York: McGraw Hill, 2006.
3. Michel, Vicki. "Suicide by Persons with Disabilities Disguised as the Refusal of Life-Sustaining Treatment." *Biomedical Ethics*. Comp. Thomas A. Mappes and David Degrazia. New York: McGraw Hill, 1995. 335-340.
4. Powell, Tia, and Bruce Lowenstein. "Refusing Life-Sustaining Treatment After Catastrophic Injury: Ethical Implications." *Biomedical Ethics*. Comp. Thomas H. Mappes and David Degrazia. New York: McGraw Hill, 1996. 330-334.