The Function of Medicine

by ERIC J. CASSELL

A thirty-eight-year-old man who had a mild upper respiratory infection suddenly developed severe headache, stiff neck, and a high fever. He went to a local hospital emergency room for help. Based on the progress of the illness and the age of the patient, the physician believed that the most likely diagnosis was pneumococcal meningitis, which was confirmed by examination. This kind of bacterial meningitis is almost uniformly fatal if not treated, but curable by simple antibiotic treatment. If treatment is delayed, although cure will result, permanent neurological damage is likely. The doctor told the patient that urgent treatment was needed to save his life and forestall brain damage. The patient refused consent for treatment saying that he wanted to be allowed to die.

Treatment Refusal and Allowing to Die

Does such a patient have a right to be allowed to die? On the face of it the answer must be yes, because the patient cannot be legally treated without his consent. But I believe that it would be a rare hospital where such a patient would not be treated against his will. The physicians would ask for a psychiatric consultation to declare the patient incompetent and then start therapy. Since penicillin works equally well against the bacteria whether the patient wants to die or not, he would recover.

Why do I expect (and sincerely hope) that such a patient would be treated despite his declared wish to be allowed to die? When a patient enters the hospital (or doctor's office) for help, he enters into a relationship with the treating physicians—and by extension with the hospital itself. While the nature of that relationship is still obscure, we know that when the physician enters the relationship he acquires a responsibility for the patient that *cannot* be morally relieved merely by the patient's refusal to consent for treatment. But more simply, the physician could not stand aside and allow the patient to die from a disease otherwise easily treated without feeling that he, the doctor, was responsible for the death.

The patient also has obligations. In giving himself into the responsibility of another, he is obligated not to injure the other morally or legally by making it impossible for the physician to act on the responsibility. In coming into the emergency room for help (he could have stayed home), he caused the physician and the hospital to become responsible for him without beforehand limiting the nature and degree of their responsibility. Although not meaningful in this case, such antecedent limits might allow the physician to refuse to enter the relationship.

In the situation I have described, by refusing treatment, the patient appears to be committing suicide. If he jumped out a high window, he would accomplish his goal alone; here he is enlisting the aid of others. On the other hand, if he is not committing suicide, his motives are not clear. Therefore, if he resists treatment, the doctors might reasonably believe that the patient does not know what he is doing. The element of time appears to play a part. But time for what? A different but similar situation may make clear the function of time and what is lacking in this case of the man with meningitis.

A Jehovah's Witness, injured in an accident, comes to the hospital bleeding profusely. Blood transfusions are necessary to save the patient's life. The Jehovah's Witness refuses transfusions. While there will probably be much agonizing over the decision, or even recourse to the courts, the patient's right to refuse treatment (even though death will follow) may be, indeed has been, acknowledged. The situations are similar. The condition is curable, but without treatment death results. What is very different is that the patient's motive is well known and has been expressed and defended by an established institution, his church, over time. Further, the patient's decision is consistent with a set of beliefs that are well known, whatever we may think about them.

In addition to highlighting the element of time, the case makes another important point. The Jehovah's Witness did not ask to be allowed to die, he asked to be permitted to refuse treatment. That the decision may result in his death is not relevant. It is not death that is chosen. It is treatment (and its effects—religious in this instance) that is being refused. Most, if not all, instances chosen to highlight the discussion of the right to die, in medical cases, are really instances of the right to refuse the *consequences* of treatment of which death may be only one, and the least important at that.

For the first group of patients, those whose disease is curable but who will die without treatment, I conclude from my experience of how medicine is practiced in the United States that the patient's right to be allowed to die will not be honored. At least one reason the request will not be granted is that insufficient time is present to assess the patient's motives if they are not otherwise clear.

Treatment Refusal in Chronic Cases

I believe the issues will be clarified by considering the second class of patients, those whose disease is not curable but for whom continued treatment will provide functional life over a long period. This class of patients is daily enlarged by medical advances, as chronic diseases from cancer to emphysema are more successfully treated. Instead of the man with bacterial meningitis, consider the case of a patient with sickle cell anemia requiring repeated transfusions, or a patient with chronic renal failure who needs dialysis several times weekly. If such a patient were to refuse treatment, could the same course be followed as with the man in the emergency room? It seems unlikely. A patient who refused further artificial kidney dialysis could

be declared incompetent on the basis of the fact that his refusal constituted suicide. But what would happen then? Would the doctors in that kidney unit tie him down on the dialysis couch week after week? If it was a patient with anemia who required continued transfusions, would the doctors force the transfusions on the patient? Again and again and again? That does not seem reasonable. But, why not?

These patients also presented themselves for treatment and entered into a relationship with a physician and hospital. That relationship involved the doctor's responsibility and the patient's obligation. However, there are several crucial differences. In this instance, when the patient refuses treatment and asks to be allowed to die, can we claim that he does not know what he is doing? Obviously not. Patients with chronic diseases requiring long-term therapy are usually very knowledgeable. They have had plenty of time to learn about the disease, its treatment, and the consequences of both. Such patients learn from books, from physicians and nurses, and perhaps most important, from other patients. The patient has also had time to test his beliefs against the arguments of others. Certainly by the time he refuses further therapy, the patient will have been exposed to considerable argument. Discussion, however, is two-sided. Just as the patient has had time to acquire knowledge and test his beliefs, his doctors have had time to know the patient. During the weeks, months, or years that they have been treating him, the staff has an opportunity to know whether the patient's refusal of treatment and desire to die is consonant with all the other things they know of him.

When the man with meningitis refuses treatment and asks to be allowed to die, it does not appear to me to be a truly autonomous act. However, when a dialysand refuses further dialysis, his action appear to me to be much more the exercise of his autonomy. As the emphasis has shifted in the critical and theoretical examination of medicine, from the doctor's obligations to the patient's rights, there has been increasing discussion of the importance of the patient's autonomy. Autonomy appears to be the basis for the demand for informed consent. Patients' autonomy is also, it seems to me, the basis of the move to demystify medicine and make the patient a partner in his or her care. But what is autonomy?

Autonomy and Illness

Gerald Dworkin argues that autonomy requires both *authenticity* and *independence* (*Hastings Center Report*, February 1976, pp. 23-28). Authenticity is the true selfness of a person, the degree to which a person's beliefs, ideas or actions are truly unique despite their source.

The central question raised by the issue of the patient's right to be allowed to die or right to refuse the consequences of treatment: is the function of medicine to preserve biological life or to preserve the person as he defines himself? I believe that the function of medicine is to preserve autonomy and that preservation of life is subservient to the primary goal.

Independence is above all freedom of choice. Freedom of choice requires three things: first, knowledge about the area where choice is to be made. One cannot make a free choice if he does not know what the choices are. Knowledge alone is not sufficient. To have freedom of choice one must also be able to reason, to think clearly, otherwise the knowledge is of little use. Finally, one must have the ability to act on one's choice, otherwise freedom of choice is meaningless.

When philosophers and lawyers (and many others) talk about rights they often speak as though the body does not exist. When they discuss the rights of patients they act as if a sick person is simply a well person with an illness appended. Like putting on a knapsack, the illness is added but nothing else changes. That is simply a wrong view of the sick. The sick are different from the well to a degree dependent on the person, the disease, and the circumstances in which they are sick and/or are treated.

Consider what autonomy means to a sick person, or conversely what illness does to autonomy. Let me start with authenticity. Am I my authentic self as I writhe in pain? When I am foul-smelling lying in the mess of my illness? In the first days after a mastectomy, it seems reasonable when the patient questions her authenticity — after all, our body image is part of our authentic self. It is common to hear patients say that they do not want visitors "to see me like this." Is that my authentic father lying there, weak and powerless, hooked up to tubes and wires? It is clear that illness can impair authenticity.

Authenticity and Independence

But if illness has an effect on authenticity, what does it do to independence? The sick do not have the same freedom of choice as the well. Knowledge for the sick person is incomplete and (for the very sick) never can be complete even if the patient is a physician. For even the best-understood disease there are large gaps in understanding. Causes may be obscure and outcomes vary in probability. But the sick person cannot deal in percentages when what is wanted is certainty. For the doctor, these gaps are of less importance and uncertainty is his constant companion. Besides, as my colleague Jeremiah Barondess has pointed out, it is vastly easier for a physician to know what to do than to know what is the matter.

Not only is knowledge lacking for the sick person but reason is also impaired. In the simplest terms, it is difficult to be clear-headed in pain or suffering. The very sick may have impairment in the ability to reason abstractly even when their mental function is seemingly intact. Illness so obviously interferes with the ability to act as to require almost no comment. It should be pointed out, however, that a patient does not have to be bedridden to be unable to act; the fear of action born of uncertainty may be just as disabling.

Illness interferes with autonomy to a degree dependent on the nature and severity of the illness, the person involved, and the setting. What helps restore wholeness? Autonomy is exercised in relation to others; it is encouraged or defeated by the action of others as well