

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 sim-

ply, 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

as by the actor. For this reason wholeness can be restored to the sick (in the terms of autonomy) in part by family and friends. However, there are limits to the capacity of family or friends in returning autonomy to the sick, particularly in acute illness. Even the most loving well may turn aside from the ugliness, foulness, pain, and suffering of sickness. Merely the smell of illness and its mess are difficult for most people to overcome. They may be unable to see the sick person completely apart from the illness. Visitors in intensive care areas commonly cannot decide where to look and often end up staring more at the monitors and the equipment than at the patient. That person on the bed is simply not the authentic loved one, friend, or relative. These things are especially true during acute illness, although when sickness lasts longer the family may successfully overcome their distaste.

The family is also injured by the damaged authenticity of the beloved sick person. As the sick person is not whole, neither are they. Similarly, family and friends cannot usually restore independence to the sick person. They too do not have the knowledge of the illness and although they can supply the ability to reason, their thinking is also clouded by emotion—by fear, concern, and doubt. Finally, while the family and friends can (and usually do) provide some surrogate ability to act for the sick person, they, like he or she cannot act against the most important thief of autonomy, the illness.

The Physician as Restorer of Autonomy

The doctor-patient relationship can be the source from which both authenticity and independence can be returned to the patient. The degree of restoration will depend on both patient and doctor and is subject to the limits imposed by the disease. I am also well aware that by his actions or lack of them, the physician can further destroy rather than repair the patient's autonomy. But here I am not speaking of what harm can be done but what good can be done. In the same manner, when I speak of the use of a good and potent drug, I would not focus on its misuse even though it may often be misused, nor concentrate pri-

marily on its side effects, but speak rather of how it can and should be employed.

The mess of illness does not repel the physician and through training he is protected from defensiveness at the pain of others. For these reasons, he can see a parent where there is a father or a craftsman, attorney, or mother, aside from the sickness surrounding them. If he has known the patient for a long time, he knows the past or can construct it from conversation. He can talk of the future if he chooses. He helps restore authenticity by teaching the sick person how to reassert himself above his disability, by teaching how to be whole when the body is not whole.

The physician can also help return independence to the patient. He has knowledge of the disease and circumstances that the patient and family lack and he can search out the knowledge of the person necessary to make his medical knowledge meaningful to the patient. He can supply the ability to reason and help bridge the gaps in the patient's ability to reason. Finally, he can provide surrogate ability to act, against the illness if nowhere else. In so doing, the patient can be shown how to act in his own behalf and by that means reach a measure of control over his circumstances.

The Function of Medicine

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. However, this issue is confused by several factors. First, it is obvious that the best way to preserve autonomy is to cure the patient of the disease that impairs autonomy and return him to his normal life. Second, the threats to life and well-being, and therefore autonomy, have been organized into a system of knowledge and a mode of thought called medical science which concentrate on disease and enlarging the system of thought, often forgetting the origins of the system in the human condition. That body of medical science

and its derivative technology have acquired an existence now independent of their original function—understanding the sicknesses which rob persons of their independence and authenticity.

The issue is further confused because the underlying focus of medicine has increasingly become the preservation of the body and biological life. But until the last two generations it did not matter what the philosophy was, the tools of medical practice were so poor that medical care (although perhaps not surgery) had to function through the agency of the patient. The major tool of medicine was the doctor-patient relationship itself. Where that is the case, preserving the relationship and keeping it functioning requires the active participation of the patient. Where the patient's function is necessary, so is some measure of his autonomy represented. And it does not matter here whether the patient's autonomy was expressed primarily by the patient or primarily by the physician, so long as the actions and outcome were authentic to the patient, or at least perceived by the patient as authentic to himself. But, in an era of technological effectiveness, life at all costs seems to be a slogan and becomes a reality in the face of which autonomy is easily destroyed. The last thirty or forty years of medical history should not be allowed to eclipse the goals of the previous two thousand years.

Let us return to the cases. The patient with pneumococcal meningitis is treated against his will (correctly, I think) because the physicians have not had time to know whether his desire to avoid treatment is authentic while they do know it to be suicidal. Further, the only consequences of treatment that can be perceived are a return to health. It appears reasonable to me that *where doubt exists* doctors should always err on the side of preserving life. While there may not always be hope where there is life, there are usually more options. Indeed, in this instance, after he is well again the patient can, if he wishes, commit suicide.

The patient with end-stage renal disease presents a different problem. We allow him to refuse treatment and thus die because in his knowledge of the disease and its treatment and in our knowledge of him acquired during his treat-

ment, we know his actions to be authentic. Further, allowing him to act on his desire preserves his independence. Here it is clear that the patient is not choosing death but rather avoiding the consequences of treatment. The issue is sharpened in the case of the terminally ill. If biological life is medicine's goal, then the patient should be kept alive as long as possible. If the preservation of autonomy is the goal of medicine, then one

must do everything possible to maintain the integrity of the person in the face of death.

To medicine, as to mankind, death should not matter, life matters.

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LAW AND THE LIFE SCIENCES

Legalizing Laetrile for the Terminally Ill

by GEORGE J. ANNAS

During 1977 Laetrile was the subject of a dozen or more state statutes, a day of Senate hearings, a major Food and Drug Administration report, a number of lawsuits, and a series of Doonesbury cartoons by Gary Trudeau. Yet no consensus has emerged. This column will focus on one lawsuit and the solution to the Laetrile problem it proposes: making Laetrile legally available only to terminally ill patients.

In 1971, Glen L. Rutherford developed cancer of the colon. Upset about the potential risks of surgery, Rutherford traveled to Tijuana, Mexico, where he was treated with Laetrile. His symptoms disappeared, and he continued using Laetrile until 1975 when his supplier was arrested. Rutherford brought suit to enjoin the FDA from interfering with his procurement of Laetrile. The case was heard in U.S. District Court in Oklahoma by Judge Luther Bohanon, who found that the FDA had refused to "make a clear determination of whether the drug Laetrile should or should not be placed in commerce" even though thousands of patients had been using it for years. The judge ruled that individuals like Rutherford were being "denied freedom of

choice" as guaranteed by the United States Constitution. Accordingly, he entered an order granting the injunction. *Rutherford v. U.S.*, 339 F. Supp. 1208 (W.D. Okla. 1975). (This case is discussed in "Laetrile: Cancer Cure or Quack Remedy?" *Hastings Center Report*, December 1976, pp. 18-20.)

Laetrile and the FDA

The U.S. Court of Appeals for the Tenth Circuit affirmed the decision, but remanded the case to District Court to determine if Laetrile was exempted from the "new drug" provisions of the Food, Drug and Cosmetic Act by virtue of the "grandfather" clauses of the 1962 amendments. To qualify for the exemption it would have had to have been marketed on October 9, 1962, as a cancer drug and generally recognized as "safe," or used as a cancer drug under the same conditions as its current use sometime during the period June 30, 1906, to June 25, 1938. The FDA presented no evidence on these questions, and therefore the court could make no decision regarding them. *Rutherford v. U.S.*, 542 F. 2d 1137 (1976).

On remand, Judge Bohanon directed the FDA to hold an administrative hear-

ing to answer these questions. He also certified the suit as a "class action" so that it would apply to all patients like Rutherford. *Rutherford v. U.S.*, 424 F. Supp. 105 (1977).

An Affidavit for Terminal Illness

This was in January. In April Rutherford's attorneys sought a clarification of the class which had been characterized as including all "terminally ill cancer patients." The judge ruled that a practicing physician must determine that the patient is terminally ill and sign an affidavit certifying:

1. that there is histologic evidence of a rapidly progressive malignancy in the patient possessive of a high and predictable mortality rate; and
2. (a) that further orthodox treatment would not reasonably be expected to benefit the patient; or
(b) that Laetrile will be administered only in conjunction with established and recognized forms of cancer treatment; or
(c) that the patient has made a knowing and intelligent election to take Laetrile after being fully apprised of the full range of recognized treatments available and of the fact that

