

From *Death + Decision*
Edited by Ernan McMullin
AAAS Selected Symposium 2 #18
1978 Westview Press, Inc
Boulder, Colorado

What Is the Function of Medicine?¹

Eric J. Cassell

Thought about the care of dying patients has changed over the past several decades. The questions raised initially concerned physicians' obligations towards the dying. As the technical power of medical practice increased, thought was given as to whether "ordinary" or "extraordinary" means must be used to keep the terminally ill alive. In more recent times, the emphasis has shifted from the obligations of physicians, to the patient as a possessor of rights. A glance at bibliographies of bioethics will show the same increasing preoccupation with the rights of the sick in all areas of medical care. Whether one sees the topic of the dying patient from the point of view of physicians' obligations or patients' rights, it is clearly concerned with the doctor-patient relationship. I am going to examine the issue of the patient's right to be allowed to die to see what it can tell us about the doctor-patient relationship and equally what it can reveal about the intimately related question - what is the function of medicine?

It is reasonable to start by seeing what universe of patients we are talking about. It seems to me that we are talking about three classes of patients. First are those patients whose disease is completely curable but if untreated will probably be fatal. The serious infectious diseases such as the bacterial meningitides or septicemias come to mind as examples. But also included would be surgical emergencies such as hemorrhage, shock, head injuries or perforated ulcers.

A second group of patients are those whose disease is not curable but who will, with continued treatment, live in functional health for a variable but meaningful time. In this class are patients with heart failure, certain malignancies such as Hodgkins' disease, patients with end-stage renal disease who require regular dialysis with the artifi-

cial kidney, and persons with certain chronic anemias who need repeated transfusions. This class of patients is expanding as more cancers become responsive to chemotherapy and other diseases are controlled by newer therapy. The key characteristics of these patients is not simply that they live longer but that they require continuing treatment to remain alive.

The final group are the terminally ill. Their disease is not curable, and treatment offers nothing beyond the prolongation of their dying.

Although it is the contributions of technology and physicians to the sufferings of this latter group, paradoxically, that initially raised the issues I am examining, the question of the patient's right to be allowed to die was gradually extended to the former two groups in both theory and practice.

An example from each of the first two groups should help unpack the issues.

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 emergency room for help. Brief examination confirmed the physician's suspicion that the man had meningitis. Based on the story of the illness and the age of the patient, the most likely diagnosis was pneumococcal meningitis. This kind of bacterial meningitis is almost uniformly fatal if not treated, and if simple antibiotic treatment is delayed, although cure will result, permanent neurological damage is likely. The doctor told the patient the problem and how important urgent treatment was to save his life and forestall brain damage. The patient refused consent for treatment saying that he wanted to be allowed to die.

Does such a patient have a right to be allowed to die? On the face of it the answer must be yes. That is because the patient cannot be legally treated without his consent. But I would guess 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 is my expectation (and sincere hope) that such a patient would be treated despite his declared wish to be allowed to die? When a patient enters the hospital (or doc-

tor's office) for help, he enters into a relationship with the treating physicians -- and by extension 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. Much is said of the patient's rights in the doctor-patient relationship, but 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 not come at all) 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 is effectively committing suicide. As opposed to going out a high window, here he is enlisting the aid of others in his suicide. 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 what function time serves 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 before surgery can be done to stop the bleeding. 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 to us and has been expressed by a durable agent, his church, over time. Further, the patient's decision is consistent with a set of beliefs well known to us, whatever we may think about them.

In addition to highlighting the element of time in

allowing the reason for the decision to be expressed over time, time to be durable and time to be known to us, 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. We do not say that the soldier on a hazardous mission chose death, we say that he was courageous. On reflection, I think that you will see that most, if not all, instances chosen to highlight the discussion of patients' rights to die in medical care are instances of the right to refuse the consequences of treatment of which death may be only one, and the least important at that.

From the first group of patients, those whose disease is curable but who will die without treatment, I must 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 and that the thing truly being requested is the right to refuse treatment. Further, 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.

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. As I noted earlier, 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, let us pose the case of a patient with sickle cell anemia requiring repeated transfusions, or a patient with chronic renal failure who needs dialysis with an artificial kidney 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. It has been the case that a patient who refused further artificial kidney dialysis was declared incompetent on the basis of the fact that his refusal constituted suicide. But what happened then? Did the doctors in that kidney unit tie him down on the dialysis couch time after time and 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 seems counter-intuitive. But if it is not reasonable, 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 between situations like this and those represented by the man with meningitis. 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 disease and treatment. Such patients learn from books, from physicians and nurses, and perhaps most importantly from other patients. Not only is the information available, but, the patient has time to test his beliefs against time and the arguments of others. Certainly at the point of refusing further therapy the patient will be exposed to considerable argument and discussion that can test his reasons and reasoning. The process is two-sided. 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 dialysand refuses further dialysis, his action appears to me to be much more the exercise of his autonomy. To clarify my reasoning it is necessary to look more closely at the concept of autonomy as it applies to medical care. As these last decades have seen the emphasis shift, 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. As a society we have come to place increasing value on autonomy. Indeed we often mark ourselves in part by our autonomy. But what is autonomy?

Gerald Dworkin argues (2) that autonomy requires both authenticity and independence. Authenticity is the true selfness of a person. The degree to which their beliefs, ideas or actions are truly their ideas, beliefs or actions despite whatever source they may have had. Someone is authentic to the degree that they are uniquely themselves.

Independence, it appears to me, 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 be considered to be making 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 than the well (3) to a degree dependent on the person, the disease, and the circumstances in which they are sick and/or are treated.

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

But if illness has an effect on authenticity, what does it do to independence? If freedom of choice requires knowledge, then 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 caring for the patient, these gaps are of less importance and uncertainty is his constant companion. Besides, as Jerimiah Berondess 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. I have said previously that the very sick may have impairment in the ability to reason abstractly even when their mental function is seemingly intact (4). Thus not only is knowledge incomplete for the ill, but the capacity to operate on the knowledge is disturbed. The final element necessary for meaningful free choice is the ability to act. 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.

It is reasonable to conclude that illness interferes with autonomy to a degree dependent on the nature and severity of the illness, the person involved, and the setting. The sick person is deprived of wholeness by the loss of complete independence and by the loss of complete authenticity. What helps restore wholeness? It should first be pointed out that autonomy is a relational term. 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. This is true of both terms of autonomy, authenticity and independence. This is because the well, even the most loving well, are forced to turn aside from the ugliness, foulness, pain and suffering of sickness. Merely the smell of illness and its mess is difficult to surmount for most people. They are unable to see the sick person in the bed completely apart from the illness and when sickness itself does not turn them aside, the setting will. 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. But further the family is also injured by 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 surro-

gate ability to act for the sick person, they, like he, cannot act against the most important thief of autonomy, the illness.

There is one relationship from which wholeness can be returned to the patient and that is the relationship with the doctor. 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 primarily on its side effects, but speak rather of how it can and should be employed.

The physician, in his relationship with the patient, can help restore authenticity. The mess of illness does not repel him and through training he is protected from defensiveness at the pain of others. For these reasons, he can see the person amidst and within the illness. He can see a parent where there is a father or a craftsman, attorney or mother, all aside from the sickness surrounding them. If he has known the patient for a long time he knows the person has a history or he can construct that history from conversation. He has the ability to talk of the future if he chooses (as in all of this) to use that ability. 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 the knowledge of the disease and the circumstances that the patient and family lack and he can search out the knowledge of the person that is 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.

I must stop now and ask 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 is the function of medicine 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 neither primary nor secondary but rather subservient to the primary goal. 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. In normal life, doctors and medical care are irrelevant. The second thing that confuses the issue is that 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 centers around concepts of disease. Doctors are trained to concentrate on disease and the system of thought, often forgetting the origins of the system in the human condition. That body of medical science and the derivative technology has acquired an existence now independent of its original function - understanding the sicknesses which rob persons of their independence and authenticity. The issue is further confused because in the last few centuries of the history of medicine, the underlying focus of medicine has been 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 patient did or did not follow the regimen or work with the physician. The major tool of medicine was the doctor-patient relationship itself. Where that is the case, to preserve the relationship, to keep 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. That may be difficult to conceive in this era of "I can do it myself" but is, I believe, supportable from the perspective of previous eras. But, in this time 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. This last thirty or forty years of medical history should not be allowed to eclipse the goals of the previous two thousand years. For me, and I believe, for most of the history of medicine, the function of medicine is the preservation of autonomy.

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 treatment, 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 which to the patient means a life the living of which is un-supportable. 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.

References

¹With the assistance of Nancy McKenzie. This work was supported in part by grants from the Henry Blum Research Fund and the Robert Wood Johnson Foundation.

²Gerald Dworkin. "Autonomy and Behavior Control," Hastings Center Report, 6 (February 1976), 23-28.

³Eric J. Cassell. The Healer's Art. New York: Lippincott, 1976, 47-83.

⁴Eric J. Cassell. The Healer's Art, p. 38.