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THE CONFLICT BETWEEN THE DESIRE TO KNOW
AND THE NEED TO CARE FOR THE PATIENT

There was a symposium about the moratorium on recombinant DNA research. Someone said that the research would start up again, that it had to. Hans Jonas asked the simple question — "why?". A scientist answered that if we did not do it, someone else would. Therefore we had to. Again Hans Jonas asked "why?". Others may move you to examine your dearest unquestioned assumptions by the persuasiveness and complexity of their reasoning; but such is the force of Hans Jonas' intellect and moral authority that his simple question — "why?" can be more provoking of reflection and inner questioning than longer and more complicated arguments. Certainly, he has had this effect on me and this essay is a small acknowledgement of what I have learned from him. I would not think as I do were it not for him.

In the art of medicine, knowledge about the body is used in the service of the sick. That knowledge varies from a vast theoretical structure of human biology through ever more practical and less generalizable facts used in the care of the ill. The profession of medicine would appear at times to love its knowledge more than its practice. Thus, the modern ideal of medicine is the research center not the clinic, and young physicians are more often taught by researchers than practitioners. (Although that is less true of surgeons.) Yet, doctors are, ultimately, the caretakers of the sick and their knowledge is meant to be used for the good of their patients. It seems to me, therefore, that medicine and physicians may be in relation to their patients as science and scientists are in relation to nature — if Hans Jonas is correct, that man is caretaker of his world. I believe he is correct and that therefore the relation of the doctor to knowledge in medicine provides an opportunity to explore the problem of the double agent — caretaker versus knower.

In an attempt to explore this conflict in medicine, it seems helpful to describe a case that lends itself to an examination of the dilemma. A thirty-three years old woman who had always been healthy was finishing her doctoral dissertation in sociology, when a nagging pain in the upper right side of her abdomen forced her to see her doctor. The pain, after coming on suddenly, became progressively worse for two weeks. In addition, she was aware of loss of appetite, weight loss and weakness. Her lack of desire to do anything distressed her greatly, because it prevented her from working, despite the

approaching deadline. Finally, she developed a fever. She was obviously ill when her doctor examined her. The abdomen in the region of the liver was quite tender. The doctor explained that the story of the illness, the examination and office laboratory tests all seemed to indicate that she had had an attack of gall bladder disease with gallstones. He told her that she had probably developed an inflammation or infection of the bile ducts of the liver (cholangitis). She was advised to enter the hospital where tests could be done which should prove the diagnosis.

Within the first few days, the blood tests and X-rays suggested by the diagnosis had been done. They had caused the young woman some, but not much, discomfort. The tests were, however, all normal. There was no apparent gall-bladder disease and the blood tests showed no evidence of liver infection. Although she was aware of the possibility that the diagnosis would not be substantiated, she was disconsolate because her weakness and fever persisted, and she continued to lose weight. The pain and tenderness over her liver were less, but still distressing. Other tests, although not pointing to a diagnosis, continued to show that her illness was serious.

The doctors' (for by now interns and residents were active in her care) concern for her future heightened. Increasingly, it was suggested (although not to her) that malignant disease, probably lymphoma, was the cause of her illness. The pressure to make a diagnosis increased as the days passed and illness deepened. Although apparently obvious, it seems reasonable to inquire into the source of the pressure.

The case was mystifying. There could be no question of the seriousness of the illness. To doctors that means an active disease process which threatens death or which would significantly impair or interfere with normal life; a situation in which the disease or its effects dominate the patient's life. It is in the nature of the physician-patient relationship that what threatens the life of the patient in some sense threatens the physician. It seems reasonable that the threat to the physician inherent in the threat to the patient, is one source of the sense of responsibility the physician feels for the patient.¹ The responsibility of the doctor for the patient is central to the conflict between the desire to know and the need to care for the patient.

The evidence in the case suggested infection except for one small but important test which was normal (white blood count). But infection of what? The pain and tenderness in the upper right side of the abdomen pointed to an infection of the liver or something near the liver. The adjacent kidney was normal and no abscess could be found (negative scans and sonogram). The very absence of any concrete evidence for a specific disease entity in this sick

young woman did not calm the physicians' fears, but rather increased them.

The most obvious reason for pressing on toward the diagnosis — the medical equivalent of knowledge — was to make the patient better. In fact, however, as the diagnosis became more and more obscure, the probability diminished that a treatable disease would ever be found. Instead, experience suggests that such patients usually either get well without specific treatment or are ultimately found to have a malignancy. But further, the need (in terms of the patient's physical well being) to press for a diagnosis recedes, because the necessity for *urgent* treatment becomes extremely unlikely. In terms simply of the patient's body, it could be argued that the best course might be to wait and allow further events to unfold. In other words, to allow the diagnosis or lack of necessity for it, the patient having become well, to express itself through time.

I. THE PATIENT'S NEED TO KNOW

Such a course seemed most difficult for both the patient and her doctors. The young woman had a need to know what was the matter with her. But what is the nature of the knowledge that the patient desired? Clearly, it is not abstract but rather very concrete. The focus of her desire to know is primarily the patient herself rather than that which is making her sick. What the illness is doing to her is her concern. The young woman's knowledge of her disease is experiential and whatever she knows of patients in similar positions is regarded in relation to her own situation. It is, if you will, a kind of "I" knowledge, a knowing in which the central position from which perception will come can only be herself, her well-being, pain or suffering. The label that will ultimately be attached to her illness will be (to her) symbolic of her suffering rather than of the thing apart from her. And so it must be of all knowledge to the degree that the knowing of anything has an experiential component. But where others can to one degree or another move their knowledge and manipulate it as a thing apart from both themselves and their experience of it, such ability to abstract is denied the sick. So the limits on this young woman's desire to know are set by the price in pain and suffering that further knowledge may cost. She has competing needs. She is caretaker of her body and must protect its integrity and her dignity not only from the disease and from her doctors but from her own desire to know.

In fact, however, the patient did know *what* was the matter: she had pain, weakness, no appetite, and she knew these things better than anyone. But what she did not know was *why*. The symptoms were events that had

