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## **Clinical Experience for Teaching Medical Ethics**

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Ethical principles give permanent expression to what life has taught us about the dignity of the human person and the moral values that ought to be realized in his relations with other human beings and with his environment. It is through experience of the ways in which these values disclose themselves that we can best appreciate the principles that have been formulated to protect them.

In order to be better able to offer courses in bioethics to college students, particularly student nurses, I found it helpful to acquire clinical experience that would clarify for me how these moral principles function in the actual giving and receiving of health care. Early in the sabbatical year which I spent at the Kennedy Institute for Bioethics, Georgetown University, Washington, D.C., I was introduced by the director of social work in a Washington hospital to some doctors and nurses who invited me to join them in their staff sessions and medical rounds and to audit some courses with medical students. I participated in these meetings from 12 to 15 hours a week throughout the year, and came to better appreciate the needs and concerns of the patients as well as the problems they pose for the doctors and nurses who are caring for them. I would like to summarize this experience and consider some of the moral issues raised in the course of providing treatment and care for patients.

Among the staff sessions I attended were the weekly meetings in the adult hemodialysis unit, where the nurses and a staff psychiatrist discussed the condition of some of the patients and the problems they

presented with regard to dialysis. The doctor helped them to understand why some of the patients reacted in unexpected ways, and advised them in particular how to deal with those who were mentally disturbed.

### Patient Autonomy and Consent

At one meeting in the dialysis unit, we considered whether or not it would be right to employ a placebo dialysis to help find out why an elderly woman experienced retching and distress every time she underwent dialysis. Was it due to psychological reasons or to a particular chemical agent used in the procedure? It was determined that no harm would be done to the patient by the omission of one session on dialysis because the number of hours per week that she was on dialysis was about to be reduced anyway. After being informed of the purpose and nature of the placebo dialysis, she gave her consent to have it take place sometime during the ensuing weeks. When it was administered, she did not suffer the usual distress. This provided added evidence that it was indeed a chemical agent—a certain one suspected by the staff—which caused her trouble during dialysis.

During this test, respect was shown for the patient as a person, as one capable of self-determination and responsibility for her own future well-being. She was provided with the information needed to make an intelligent decision, and was not prevented by deception from freely deciding whether or not she would undergo the experiment.

Can a patient waive the right to receive full information about the risks involved before giving consent for a surgical procedure? This problem arose in the dialysis unit in the case of a young woman who did not want to be told the potential consequences of the operation she would undergo in donating one of her kidneys to a friend. Does her right of self-determination mean also that she may waive her right to this information? The psychiatrist in charge, impressed by her apparent intelligence and emotional stability, seemed to think that it does. To compel the patient to hear unwanted information would seem to show great disregard for her just claims to autonomy. On the other hand, by deliberately refusing the possibility of a fully-informed consent, she leaves the full responsibility for her physical well-being to the physician. Does his assumption of a decision-making role which is properly hers show a greater lack of regard for her independence than requiring her to give a fully-informed consent before undergoing the operation? Some anxiety might have resulted from her consideration of the possible results of a kidney donation. But it is questionable whether the prevention of anxiety is a sufficient reason for taking over from her the kind of responsibility that defines her as a person.

At another meeting in the dialysis unit, the issue of internally free consent came under consideration in regard to a young man who had

been given medical approval for becoming a kidney donor for his brother. He had expressed the desire to do something generous for his family, and his brother's need provided the opportunity. However, just before the scheduled removal of his kidney, while waiting outside the operating room, he suddenly decided not to have the surgery because he was afraid of it. It was learned that a nurse had earlier shown him a picture of the wound that results from the removal of a kidney. Some weeks later, however, when he returned and asked to be allowed to donate a kidney to his brother, the staff psychiatrist refused to give him the required approval, considering him an unsuitable donor.

The real possibility that one who offers himself as a kidney donor may not be a genuine volunteer is widely recognized. Family members, in particular, can exert undue psychological pressure on a relative to have him offer to donate a kidney to one of their own in need. And, if he should refuse, there is the threat of a burden of guilt or lifelong condemnation. One can easily understand, therefore, why the danger of family blackmail and involuntary consent is sufficient to render suspect, in many instances, the freedom of a decision made by the potential donor. For this reason, it has become a typical practice to advise him that no one will find out if he should express his unwillingness to be a donor, because the physician will protect his confidence by simply stating that he is unsuitable to be a donor.

The right to refuse life-saving treatment came up for discussion in the case of a patient who refused to continue with the dialysis he needed in order to survive. One nurse considered it "horrendous" that a constant stream of "white-coated people" entered his room to try persuading him to change his mind. He remained obstinate in his refusal, however, and even told his doctor that he did not wish to be resuscitated if he should lapse into unconsciousness. The doctor had told him that if resuscitated, he might wake up to find himself attached to a dialysis machine. Eventually, the patient, who feared to die, did consent to having the dialysis resumed, but after undergoing the procedure several times, he became strangely quiet and appeared very depressed. The possibility that he might attempt suicide was considered real.

It is important to identify the underlying meaning of a patient's request to have life-saving treatment discontinued. He may be saying that he wants to be rid of the burdens of his existence without implying a fixed determination to die. Perhaps what is needed to make his life again worth living for him is a more appropriate management of his depression and other problems. This might include a better-regulated regime of anti-depressant drugs, as well as a greater effort to have his relatives and friends provide him with more company and support.

If, however, a patient who is competent remains steadfast in his

refusal to accept life-saving therapy, his decision must be respected. Not to allow him normally to so choose, or to badger him until he changes his mind, would violate his right of self-determination. It is on the basis of this right that the courts in recent years have more readily allowed patients whose competence is evident to refuse life-saving therapy.

### Patient-Doctor Relationship

A class for fourth year medical students, which I attended on a weekly basis throughout the year, was concerned particularly with the emotional and social needs of the patient. One of the students, after first presenting for discussion the medical history of a patient in the hospital, would bring him to the class to be interviewed by two doctors who were teaching medicine and psychiatry. Each patient had agreed beforehand, for the benefit of the students, to discuss with them the way in which he understood his illness and the manner in which it had affected his life. In response to the gentle and friendly questions of the doctors, the patients spoke freely and candidly, giving us valuable insights into their concerns and complaints, particularly with regard to the medical care they had been receiving. Their personal histories gave striking evidence to show why medical care must also take into account the psychological, social, and emotional needs of the patient, if it is to really succeed in achieving its healing purpose. After each patient was taken back to his hospital room, a discussion followed in which the students made their observations relative to the patient's condition and treatment.

One issue which came up for consideration in these meetings was that of the patient's right to know the truth about his illness. One patient complained about his doctor, who was otherwise competent and caring, for not explaining to him what was wrong. He discovered the truth about his condition by reading the report which he brought from the doctor to the hospital. He thought that every patient should be told the full truth provided that he is stable.

A poor doctor-patient relationship was revealed also by a young woman who seemed to be unaware of the nature and effects of the dialysis that she was about to undergo that very morning for the first time. The doctor interviewing her in class made up for her own doctor's negligence by explaining the procedure to her in a clear and simple manner.

The American Hospital Association presents a Patient's Bill of Rights which includes the right of the patient "to obtain from his physician complete information concerning his diagnosis, treatment and prognosis in terms the patient can be reasonably expected to understand." Nevertheless, the duty of being truthful is not an absolute one, and the best interests of the patient can require, in some instances, that the truth not be fully disclosed to him. A physician

would seem to be justified, for example, in delaying telling a patient of a diagnosis of cancer if he has good reason for believing that overwhelming anxiety might thereby be prevented. The patient may become better able to live with his serious condition if it is made known to him only gradually. However, in most cases it is difficult to predict the consequences of telling the truth to the patient, and a paternalistic approach risks denying him information that may be vitally important for setting in order his personal affairs. Concern for the patient's reaction to bad news should not normally result in keeping from him the truth about his health unless it is evident that overriding reasons dictate a different course of action.

In another session, an elderly and well-educated patient talked about what he saw as the depersonalizing process that takes place during the x-ray and test procedures he was undergoing during his hospital stay. He had refused at one point to allow the taking of additional x-rays when the technician requested that he return for them. He contrasted the "impersonal" manner of contemporary medical care with the "more personal" attention given in earlier times by doctors who were "less narrowly scientific" and "more truly educated and learned" because of their scholarly interest in some field other than that of medicine. Many students saw this man's anger regarding the taking of necessary hospital tests and x-rays as an indication of his denial of the serious nature of his illness. It was made evident to me how important it is to try to understand the serious psychological effects that newly acquired awareness of his condition can have on a patient. A lack of compassion can easily lead one to misjudge his words and actions and to react to them in a way that would only aggravate his suffering.

### Doctor-Family Relationships

By taking part each week throughout the year in a staff meeting in the neonatal unit, where specialized care is given to babies born prematurely or with serious birth defects, I gained a deeper understanding of the concerns and problems that challenge not only the skill and compassion, but also the ability of doctors, nurses, and social workers to deal with unresponsive or overly anxious parents. I also came to realize how much the future well-being of the infant depends on the psychic health and inner strength of his mother and how much, in turn, her capacity for mothering is conditioned by her relationship with her own mother and the support she receives from her husband or some other close friend.

At one of our meetings in the neonatal unit we discussed the problem created by the mother of an infant who had been born prematurely. She rarely came to visit him during his stay in the nursery and answered each telephone call from the nurse by saying that she

would come the following day. Invariably, however, she would fail to appear. The psychiatrist suggested that the social worker visit her at home and try to persuade her to come, lest the lack of parental bonding with the child from the first days of his life make future attachment to him weaker.

On another occasion, the members of the unit considered whether or not a baby should be released from the nursery in the care of a mother whose very poor health and lack of family support raised serious questions about her capacity to provide for the basic needs of the child. She had earlier inquired about the possibility of giving him up for adoption. Not married, she appeared to want to bring the child home only because her boyfriend was telling her to do so. Consideration was given to the legal and financial problems which might arise if the baby were kept a few days longer until the situation was clarified.

At two of our meetings, we discussed the trouble raised in the unit by the intelligent young parents of a baby who was ill from birth and whose prospects were poor. One day they would relate well with one of the nurses caring for the child, only to avoid her the next day and seek out another nurse, while openly criticizing the first. They followed a similar pattern with regard to the resident doctors, asking that one after another of them not be allowed to tend their child, and so making it very difficult for all concerned.

The doctor in charge of the unit arranged to have an interview with the couple and set down for them in a courteous but forceful manner the guidelines: if the baby were to remain in the hospital, she must be under the care of the nurses and doctors who are approved by the attending doctor. Otherwise, the parents should take the baby to another hospital. This meeting helped to solve the problems caused for the staff by the anxious couple, but it left unrelieved the pain they suffered in being unable to adjust to having a child who was born defective. Evidently in need of psychiatric assistance, they were unwilling to accept it and chose instead not to face up to their problem.

My experience of sharing the concerns of the health care personnel in the neonatal unit made me keenly aware of their determination not only to tend to, with great skill, the immediate needs of the baby, but also to insure that the parents be helped in every way possible to properly care for their child after he left the hospital.

### Sharing the Doctor's Experience

In many other ways the hospital experience enabled me to acquire a deeper understanding of the work performed by those who care for the sick, as well as of the methods they employ to provide that care as humanely and efficiently as possible. For several months in the department of obstetrics, for example, I attended a weekly review of the

more difficult cases of prenatal care and of childbirth that had presented themselves. Under the direction of the professor of obstetrics, the discussions were conducted in technical language often beyond my comprehension. Nevertheless, they did make evident to me why early and competent prenatal care is essential for the health of mother and child, and how difficult can be the problems in pregnancy and childbirth which challenge the ability and compassion of doctors and nurses.

Attendance at the preceptor rounds in differential diagnosis with a small number of medical students was helpful in showing me how doctors go about determining the causes of a patient's ailment, and why x-rays and laboratory tests are effective aids to this end. The course raised the question of the morality of performing expensive and unnecessary hospital tests as well as that of truth-telling in terminal illness.

Joining several medical students on preceptor rounds with a neurosurgeon many times, I visited young patients in the intensive care nursery and in other sections of the hospital. We observed the doctor as he tested the patients for important neurological signs, studied brain scans, and conferred with parents visiting the patients. The respect and sensitivity he manifested in honestly and gently informing them of the current condition of their children and their prospects for the future, were remarkable and gave eloquent testimony to his deep compassion.

### Conclusion

This hospital experience has given me not only a better understanding of the many claims put upon the skills and the humanity of doctors and nurses, but also a greater awareness of the value judgments and moral issues which are present in the medical decisions they must constantly make or implement. I was made cognizant of the singular circumstances which make each of these decisions different from every other. The experience served as a good testing ground for the principles of bioethics which, for the most part, I had understood previously only in theoretical and academic form. By sharing the concerns of the patients and of those caring for them, I acquired greater insight into what takes place in the care of the sick and a deeper appreciation of the sensitivity which health care personnel generally have for the dignity and rights of their patients. For these reasons, I consider my clinical experience a valuable preparation for the teaching of medical ethics.