Family Practice Grand Rounds

The Living Will

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DR. PETER RIZZOLO (*Director, Family Practice Residency Program*): Welcome to our fourth Grand Rounds Conference. Our religious and philosophical beliefs have evolved over a long period of time when life events were relatively unchanging. Life and death were part of a recurring cycle over which man had little control. Today man can intervene in many ways and this new technology has raised many ethical, philosophical, and theological questions. Unless we can integrate these technical advances with our cultural backgrounds we will increasingly face legal dilemmas. Law, medicine, philosophy, and religion enter into discussion of these vital issues.

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This morning we want to focus our discussion on the living will or, as some people define it, the right to die with dignity. On our panel we have many distinguished people from both inside and outside the institution.

Dr. John Brewer, third year family practice resident, will present the patient.

Mr. Edmund Bernhard, local attorney, will discuss legal implications of the death with dignity, especially in view of the Quinlan decision, and also possible impact of the California law on what we do here in New Jersey.

Mrs. Ellie Claus, Vice President for Patient Services, will talk about the hospital's responsibility and nursing involvement in this particular problem.

Dr. M.W. Looloian, family physician, will talk about his own attitudes and his approach to the patient and family.

Dr. Kenneth Tuttle, internist and member of the Hunterdon Medical Center full-time staff, will speak on the subject from his particular perspective.

Reverend Bruce Upsahl, a local minister, will present philosophical and religious aspects of the question.

DR. BREWER: The patient providing background for this discussion was Mrs. P.B., a 75-year-old white, widowed woman admitted via the Emergency Room with an acute myocardial infarction. She had a history of atherosclerotic vascular disease with congestive heart failure, hypertension, diabetes, and hyperlipidemia. She saw her physician infrequently (last seen three years ago) and took her prescribed medications irregularly.

According to her daughter with whom she lived, Mrs. P.B. for the previous two months had been having episodes of chest pain which had become more frequent and more severe; these pains the patient attributed to indigestion. On the day of admission, she experienced a severe episode which, that evening, led to shortness of breath. En route to the hospital she sustained cardiac arrest. Rescue squad personnel immediately began cardiopulmonary resuscitation. Upon her arrival at the Emergency Room (11:15 PM), she was intubated and resuscitative measures were continued with extensive pharmacological manipulations resulting in her going from asystole to ventricular fibrillations, and finally to sinus rhythm. Within an hour, she was transferred to the intensive care unit where her blood gases were monitored; results showed she was able to maintain adequate levels through her own respiratory effort.

By 1:15 AM, two hours after admission, Mrs. P.B. had developed pulmonary edema and ventricular irritability; she was begun on the MAI respirator. During this treatment, the patient's pupils were noted to be reactive. Ten hours later (11:00 AM), Mrs. P.B.'s cardiovascular signs had stabilized and her pulmonary edema improved, but she was totally unresponsive to any stimuli. She then began to have seizure-like activity which was controlled with intravenous valium.

On her second hospital day, Mrs. P.B. had a fever of 102 F, her sputum revealed gram-positive diplococci, and a chest film was suggestive of pneumonia; intravenous antibiotics were begun immediately. Her enzymes and cardiograms this day confirmed that she had suffered a large myocardial infarction.

During the evening of the second day, Mrs. P.B.'s children were presented with the facts of her illness. They disagreed as to the wisest action to take: the sons felt too much already had been done; the daughters favored the staff's doing everything possible. None would agree to discontinuing the respirator.

During her third, fourth, and fifth hospital days, the patient continued in deep coma. On the third day, an electroencephalogram done at the highest amplification possible revealed some activity and was read as representing severe encephalopathic changes and damage. After intravenous feeding was discontinued, she was hydrated via nasogastric feedings, which were partially successful at best, due to her poor peristalsis.

Mrs. P.B.'s blood pressure began falling and on the morning of her fifth hospital day, she had no pulse, no blood pressure, and a urine output of 1 to 2 cc. She continued in this condition for 24 hours until the morning of her sixth day when the cardiac monitor showed ventricular fibrillation and finally, asystole; she was pronounced dead.

After a postmortem examination, Mrs. P.B.'s final diagnoses were determined to be atherosclerotic cardiovascular disease with an acute myocardial infarction, submyocardial infarction, bronchopneumonia, and massive early cerebral encephalomyelitis.

DR. RIZZOLO: What I would like to do is discuss the case itself and the ways you would have proceeded, and have you comment on how you would have handled the family. As obviously there was no communication with the patient at that point, it was really a question of dealing with the family.

DR. TUTTLE: I would like to summarize the problem medically for the attorney and the minister, as I think they will need that. The cardiopulmonary resuscitation was somewhat prolonged and apparently successful because the physician said that when the patient arrived at the Emergency Room she was stabilized, her pupils were reactive, her irregular heart had been regularized, and she had a PO_2 of greater than 50 percent which means there was circulation at that point. They did document that she was perfusing adequate oxygen and as far as we know the reacting pupils connote a live brain. We could not weigh whether she had had a stroke or severe irreversible damage to the brain and she may indeed have had impaired function. Later, use of the respirator was a valid medical decision in my opinion because all indications were that resuscitation had been successful.

MR. BERNHARD: The Quinlan case, as you know, is the main precedent-setting case on which

death with dignity decisions are now based. In that case, the family and church were unified in their desire to have life-sustaining measures removed. Without such unification, it seems the best approach is to determine the hospital's responsibility in using its human and mechanical resources.

One of the basic questions in the Quinlan case was, with the patient unable to make a decision, what function do the family, state, and judiciary have when medical standards are at odds with family wishes. Chief Justice Hughes, in his opinion, discussed ordinary and extraordinary life-prolonging measures. The nature of the intervention depends not only on the measure itself, but on the context in which it is applied. Life-prolonging measures, with the potential of sustaining life almost indefinitely in an otherwise hopeless situation, must be considered extraordinary.

In considering the given hypothetical situation, the question to be resolved is whether the patient definitely is curable, possibly is curable, or is beyond hope of being cured. The most appropriate portion of the Quinlan decision in addressing this question is the discussion of who is to participate in the decision-making process when life-sustaining measures are to be abated. The New Jersey Supreme Court ruled that life-support equipment used to keep Karen Ann alive could be terminated by a joint decision of Karen's family and physicians in consultation with that hospital's ethics committee.

Certain factors need to be added to the given hypothesis. The question of terminating life-support measures would have to be raised. At the risk of sounding crass, it only seems logical that the family would raise this question on the basis of cost. If the family is in agreement and the patient is terminal, the physician, in consultation with the ethics committee, may decide to discontinue extraordinary measures. This legally sound decision is based on the fact that to continue the measures would be an inappropriate use of limited resources in a hopeless situation.

Having the family divided opens the way for dangerous complications to emerge, such as the possibility of criminal charges. Without judicial sanction, removal of the life-support devices is extremely unwise.

DR. RIZZOLO: The ordinary/extraordinary nature of intervention only can be determined as it applies to an individual situation. At just a glance, the law appears quite simple: the patient affirms he/she wants to die with dignity, and without use of extraordinary measures. However, it is not that simple, as there are shades of differences in almost every situation. With these variables involved in every decision, the legal complexities will grow until there exists a honeycomb of rules and regulations similar to this country's tax structure.

Mrs. Claus, will you address the topic of the position of this hospital and this state on the living will.

MRS. CLAUS: It would first be helpful to give you a legal update from the hospital's point of view. In January 1975, our Medical Board sent a letter of inquiry to the hospital's attorney on the question of informed refusal of treatment. In reviewing pertinent legal opinions, counsel cited the case of Heston vs JFK Hospital in which a young Jehovah's Witness needed a blood transfusion to survive an automobile accident. Her mother refused to give approval, so the consultant appointed a guardian to give the necessary consent.

Several statements clearly are made through the decision of this case:

1. The state strongly favors the preservation of life, regardless of the patient's family's moral or religious convictions;
2. life-saving measures for a minor are rendered uniformly regardless of the parent's beliefs;
3. an adult or parents of a child may refuse approval of a non-life-saving treatment; and
4. for an adult who is unable to give/refuse consent, the nearest relative or guardian of that adult may act in behalf of the patient.

In September 1975, a form for informed refusal of treatment was presented to this hospital's Medical Board for approval, but was rejected.

New Jersey, at the present time, is operating under the decision of the Quinlan court. Sixteen states, including New Jersey, have proposed death with dignity laws. Most seem to have in common four basic provisions: definition of terminal illness as one which will result in death regardless of medical intervention; execution of a written document directing the withholding/withdrawal of extraordinary life-sustaining measures; determination of terminal illness being made by one or more physicians; relief of physician and health-care facility of liability.

RESIDENT: Does the proposed New Jersey law give consideration to the healthy person who

wishes to make a long-term living will?

MRS. CLAUS: Yes, it is proposed that with no threat of death, a person may prepare a living will. With the exception of New Jersey, all state proposals include a provision for a formal document to this effect. At this time, in New Jersey, such a will is not legally binding.

I would like to comment on nursing attitudes towards death, the role of the nurse in that context, and the nursing viewpoint of the right-to-live issue here at Hunterdon Medical Center. In school today, the nurse is taught the stages of dying and begins to examine her own feelings about death. Obstetrics, psychiatry, and pediatrics present to the nurse a lower exposure to dying patients, and the nurses in these situations are likely to be more uncomfortable with this contact. However, more or less contact with dying patients does not help in dealing with the concept of one's own death, and this is necessary in order for the nurse to be therapeutic with a dying patient.

Most nurses feel that a patient should be told as soon as possible, but always be given hope. The manner of telling is most important. And it seems it is easier to care for a patient who knows the diagnosis and its terminal nature.

In these cases that part of the management is a nursing function. Nurses do not have the responsibility of telling or not telling the patient but because they are usually near to the patient they may be faced with searching questions without warning. The role of the nurse is to be supportive and this can only be effective if she is involved with the physician and the other team members in the management of the patient in a meaningful way. Part of this management is the capacity to listen—this is vital.

At the present time a nurse or physician who ends the life of a terminally ill patient in a painless way, even at the patient's request, may be charged with murder. The new California law allows the patient to prepare a living will which literally permits removal of life support equipment if death is imminent.[1-3]

DR. RIZZOLO: Usually theologians and philosophers have centuries during which to formulate ideas. Within the past 20 years, technology has been progressing so rapidly that this time has been abruptly shortened, so that philosophers and theologians are being pushed. The Reverend Mr. Upsahl now will address some of the theological aspects of the living will.

THE REVEREND MR. UPSAHL: The key in discussing the living will, or death with dignity, is to be aware constantly of treating the patient as a whole person. From the theological standpoint, promotion of life is mandatory. Inherent in the commandment "Thou shall not kill" is the idea that life neither shall be destroyed nor hindered. After all, life is a gift from God.

DR. RIZZOLO: Thank you, Reverend. This certainly strikes a resonant note within me when you talk about treating the whole patient. In family medicine, in the literature, we repeatedly come across the admonition to treat the dis-ease of the patient rather than the disease, and I believe this is what we are trying to imbue our residents with, looking at the entire patient. At this point, I would like to introduce Dr. Looloian.

DR. LOOLOIAN: A few questions more directly related to the case at hand: Was it appropriate to start cardiopulmonary resuscitation (CPR) in this chronically ill, elderly woman although she was self-sufficient until the onset of this fatal illness? Is it reasonable for rescue squads to be put into the position of having to initiate CPR considering the patient's age, chronic ill health, and exceedingly remote likelihood of returning to a high quality of life? In my view it is necessary for us to consider the benefit-risk relationship in starting CPR and as far as this particular patient is concerned, was it reasonable to continue CPR after her arrival at the hospital since she already had not responded?

Perhaps an alternative way of stating the question is, "Did the family and family physician really maintain close contact?" The family were divided in their ideas of appropriate treatment. Was there a family physician involved?

DR. BREWER: Yes, however, the patient's last office visit was three years ago.

DR. LOOLOIAN: So, she had no close contact with a family physician. A family cannot be given the responsibility of deciding to permit a patient to die; neither should a committee have to make this decision. This is the job of the physician. The family must confer with the physician, but not be expected to make the final decision. How, specifically, was the case presented to the family?

DR. BREWER: The family simply was told there was little chance that Mrs. P.B. would awaken and that, if she did, the chances of her func-

tioning normally were minimal. Their response to this information was divided, with certain family members laboring under a great amount of guilt concerning their relationship with the patient. In this, as with similar cases, with no preexisting physician-patient relationship, these decisions are excrutiatingly difficult.

DR. TUTTLE: When I came on this case, as a consultant, Mrs. P.B. already was on the respirator. At that time, I suggested the case be referred to the nonexisting ethics committee in an effort to bring this issue to a head.

Basically, the problem comes down to the physician-patient relationship. Until recently, the physician has been regarded as an authority figure who, like the father, instructed the patient in what was right for him/her. That feeling persisted too long and we now are feeling the results in the form of the patient's bill of rights and the concept of consumerism. The patient expects and has the right to be informed. The conflict comes in deciding if the patient's right extends to determining the time and method of his death. Another issue to be resolved is the rights of the family in making such a decision.

In a situation in which death is the likely outcome, the physician's actions and reactions need to be predictable as the patient and family both may have a confused approach to this vital issue. In the physician-patient relationship, the ultimate concern is the outcome of the illness and the potentiality of death. Throughout this relationship, it is necessary to keep the patient informed of the diagnosis, or medical expectations, and a projected outcome for that diagnosis. A second and vital part of the physician-patient interaction must include therapeutic options and their risks. If the patient is unable to make the necessary decisions, then the family must be consulted. In a particularly difficult situation, an ethics committee could act as a consultant by gathering data and offering an opinion.

In addressing the living will, it is necessary to consider the right to life. In the acute situation, as with Mrs. P.B., the decision by the rescue squad en route to the hospital must be to sustain life until it is proven unsustainable and until medical staff is sure that the patient is in a vegetative process, rather than a viable one. To make that decision at the time of arrest would be premature and, therefore, cannot be done.

The living will through which a patient leaves directions to medical personnel not to use extraordinary means to save his/her life must be scrutinized thoroughly. If such a patient were to be an automobile accident victim and found hung in the seat belt, only needing the seat belt cut to save life, this contract then would seem to be a broachable one.

For the physician, the answer to each situation is to be found through communication with the patient and family and understanding of his own fears of death and rejection. In maintaining a moving dialogue with the patient about his/her progress and the physician's expectations as to the outcome, and in listening to the patient's fears and concerns, the physician will be meeting the needs of the whole patient and will be much more qualified to make life/death decisions. In so doing, the physician also allows the patient the right to formulate and react to his/her own expectations as to outcome. In the end, it is the professional with the patient's/family's participation who will make the decision. The only successful way is through communication.

References

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2. Goldberg JH: The extraordinary confusion over "the right to die." Med Econ 54:121, 1977
3. Doyle A: Medical ethics: Fact or fantasy? AORN J 23:227, 1976