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Mrs. G. was a beautiful, vivacious lady with a wonderful family. One day, she developed a splitting headache. She had had headaches before, but nothing like this. She called her husband who immedicately came home and found her unconscious on the floor in the kitchen, next to the phone. He called paramedics, and within minutes, his wife was rushed to the emergency room of the community hospital. Hasty examination showed that she was in deep coma with a dilated pupil on the right, rigid extremities and a Babinski sign on the left.

Because of respiratory distress, she was intubated, given oxygen, and taken to Radiology where a computerized tomographic (CT) scan of the brain revealed a massive intracerebral hemorrhage in the right hemisphere.

During the next 72 hours, the patient stabilized and she could be extubated, although she remained in a coma. Tube feeding was begun and intravenous infusions were discontinued. Physical therapy was instituted and appropriate nursing care continued. After three weeks of continued coma, it was obvious that nursing home placement was in order, and she was transferred to the appropriate facility where she resides to this day.

Fortunately, the financial resources and insurance of the family are more than adequate for the care of the patient. Her husband has visited her every day and continues to hope for her recovery. Her children have likewise been most supportive of their father and pray daily for their mother to recover.

However, the grim prospect of no chance for recovery has begun to dawn upon the husband, for it has been many months since this catastrophe occurred. He asks himself, "What is my obligation to my wife?" The doctors give him no encouragement in regard to his wife's prognosis. He is grateful that insurance is lightening the financial burden, but when the insurance runs out, what is he to do? What are the obligations which must be fulfilled? In short, what does a good man do in this morally perplexing situation?

If this scenario seems familiar, it can be repeated many times over in these United States. Generally speaking, a patient is under no obligation to use extraordinary means to take care of his health, but he must use ordinary means. A crucial distinction is important to make here: it is the patient who determines what is extraordinary for him or her, and not his physician. What may be ordinary for the physician may be extraordinary for the patient. For example, a physician might think that renal dialysis in this day and age is very ordinary treatment for a patient in renal failure. For the patient it may represent quite an extraordinary route to follow. The patient's perception must be followed, assuming that the patient's judgment and mental facilities are intact.

In the application of the ordinary/extraordinary approach to clinical decision-making, it is vital for us to determine what is extraordinary.

The usual distinctions are: (1) excessive pain and/or disability; (2) economic considerations, *eg*, cost of care which would impoverish a family; and (3) benefits outweighed by the risks.

While the outlining of these ethical rules is clear enough, the application of them is sometimes very difficult. This is so because sometimes the clinical facts are not yet clear. Sometimes the patient is so confused and upset that rational, coherent, logical thought is impossible. Nevertheless, having a clear set of ethical criteria is essential for the physician if he is to behave ethically.

By far, one of the best helps to the physician in doing his job is a knowledge of the patient and the family. There is no substitute for this, as he brings profound insight to the wishes of the patient and the family. The relationships which he has forged over the years with the patient will serve him well when he is faced with having to make difficult clinical decisions on whether to institute or withhold extraordinary measures. How often have we been faced with decisions that house staff have made for our patients at a time of crisis, with which decisions we disagree? Many times, the house staff, acting in good faith, did what they thought was correct. But we know that, had we been there, we might have done things differently, based upon our knowledge of the patient and his wishes.

I vividly recall a patient who entered the hospital emergency room comatose and in a state of seizure. I had known him for years. His whole life had been one of tremendous activity and accomplishment. The CT scan showed a massive intracerebral hemorrhage and his prognosis was zero. The family was informed and very supportive. At that time we decided that no extraordinary means would be used, as it was obvious that they would be of no avail and would simply prolong the process of dying. Despite orders to the contrary, a resident inserted an endotracheal tube when the patient exhibited respiratory distress. I was informed and ordered it removed, after talking to the family again. The patient died shortly thereafter. Knowing this patient and the family so well made the decision easy. Had the resident been aware or made himself aware of the entire situation, he probably would not have embarked upon the extraordinary procedure.

In regard to patients who are in the process of dying, when their demise is only days or weeks away, it is obvious that extraordinary means are out of the question. Our principal duty is to support the patient and the family. Pain control is essential. With the continuous morphine infusion pumps which even the patients can regulate, pain can be alleviated or certainly ameliorated to a great degree. Even if the dosage of analgesia contributes to the demise of the patient, a physician or nurse should not feel culpable, as the intent was to relieve pain, and not to cause the death of the patient.

In regard to fluids and nutrition in the imminently dying patient, problems can be found. When the intravenous fluid infiltrates, or the patient runs out of veins, or the vein becomes infected, what is one to do? Consultation with the family is in order. If it is not feasible to use intravenous fluids, they should be discontinued. What about nasogastric tubes, and/or gastronomy tubes? Again, if in consultation with this family these modalities are not feasible, they should be discontinued; and the patient should be taken care of with the usual nursing care until he or she dies. Emotional care and support are the keystone for the imminently dying patient.

What does one do for the patient who is not dying, but who is permanently comatose and probably on intravenous fluids or tube feeding and in a nursing home? This is a most difficult and perplexing question. As long as the patient receives nutrition and water, he or she will live. If the patient does not receive these, he or she will surely die. What is our obligation in these circumstances? Food and water are ordinary requirements for life. To deprive a person of these requirements is morally wrong. However, suppose that, in virtue of the fact that food and water are artificially given, *ie,* via feeding or gastronomy tubes or intravenous feedings, we have created an extraordinary means to keep this patient alive? Suppose the cost of these artificial modalities, with the attendant nursing care, becomes a tremendous financial burden on the family—must this obligation continue to be fulfilled?

In light of the previous distinction, I think not, as excessive financial burden certainly puts this into the extraordinary means realm. As pointed out before, extraordinary means are never obligatory to the patient, physician, or relatives.

In a very finely nuanced ethical analysis of the above ethical question, Thomas J. O'Donnell, S.J., in the *Medical-Moral Newsletter* of February 1987, states that it is "inappropriate, however, to refer to 'feeding' without distinguishing between natural and artificial nutrition and hydration.

"The difference between normal eating and drinking and the artificial (intravenous, nasogastric, etc.) delivery of nutrition and hydration is clearly evident in the difference between eating in a restaurant and being nourished in intensive care. The question is: How morally significant is this difference? Or more specifically: Are both natural and artificial nutrition and hydration to be considered as always ordinary means of prolonging life, and therefore obligatory (unless their burden to the patient, or even to

others, would clearly outweigh their benefit)? NOTE: The last parentheses are included because it would seem that all moral theologians would admit that the burden-benefit calculus in a particular case could render the means extraordinary; certainly in the case of artificial feeding and even in the case of natural feeding when that would be extremely painful and/or even dangerous to the patient, as it could be in some cases.

". . . we would hold that, at least in the case of incurable pathology accompanied by definitely established irreversible coma and the attendant inability to take food and water normally, artificial provision of nutrition and hydration could be withheld or withdrawn either because the burden of continuing treatment would be disproportionate to the benefit, or because their continuation would be judged not to be clinically significant or therapeutic.

"It is important to note that in the situation of incurable pathology accompanied by irreversible coma, the purpose (*intention*) to cause death by withdrawal of artificial nutrition and hydration is unacceptable since that would be 'euthanasia by intention.' Nor is withdrawal of artificial nutrition and hydration the cause of death. The cause of death is the irreversible disease, which has caused both the terminal coma and the inability to eat and drink. Since death would occur in the same way and from the same cause if artificial nutrition and hydration were unavailable or had never been started, they might be seen as an intervention that is artificially interrupting an independently occurring process. Thus, rather than causing death, their withdrawal accurately could be viewed as letting inchoative death occur.

"In any discussion of ordinary and extraordinary means of prolonging life in terminal illness, it seems reasonable and necessary to introduce a category of 'minimal means' which must **always** be used, because to withhold them when they can be received is equivalent to a positive act of destruction. By these we mean food and water taken normally as distinct from the clinical modalities of IV needles, gastric tubes, hyperalimentation formulae, etc. Much of the current confusion in the discussion of withholding nutrition and hydration results from the failure to make this distinction."

Perhaps this is the stance of the AMA's Council on Ethical and Judicial Affairs' Opinion of 1986, in which it is stated that artificial hydration and nutrition may be discontinued in the permanently comatose patient along with other medical intervention. In issuing this Opinion, it would have avoided much confusion if the proper distinction alluded to above had been published along with the Opinion.

While the above ethical distinctions of ordinary/extraordinary means are quite clear in regard to nutrition and hydration, Mark Siegler, MD and Alan J. Weisbard JD[1] pointed out in 1984 that the "powerful rhetoric of death with dignity has gained intellectual currency and practical importance in recent years." They stated in their article that "the death with dignity movement advanced to a new frontier: the termination or withdrawal of fluids and nutritional support."

Siegler felt that this was an unexpected development and ran contrary to the traditions of medical care, and he called for further debate on the subject. After describing current thinking on the subject, he alludes to a *New England Journal of Medicine* article in which a group of distinguished clinicians advocated the withholding of parenteral fluids and nutritional support from severely and irreversibly demented patients and perhaps, at times, from elderly patients with permanent mild impairment of competence (a group to which they refer as "pleasantly senile").[2]

Siegler offers several arguments against this stream of opinions to discontinue fluids. He feels that patients will be protected against diagnostic errors, inadequate treatment, and unscrupulous care for financial or other reasons.

Furthermore, he states that physicians would not be forced to make ad hoc, value-laden decisions nor would they be forced to act in violation of their conscience in regard to standards of care. "Physicians also would be spared the direct causal responsibility for the death of the patient and the inevitable psychological association of this practice with active euthanasia."

He warns that the "primary commitment of physicians to patients might be compromised and the image of physicians tarnished at precisely the time when physicians must establish the primacy of quality of care and not become overwhelmed by cost-containment efforts which run contrary to good clinical medicine."

Siegler states that "society's larger interest would be preserved by rejecting the movement toward discontinuation of fluids in the dying patient because it sows the seeds of unacceptable consequences." We have witnessed too much history to disregard how easily society may disvalue the lives of the "unproductive." The "angel of mercy" can become the fanatic, bringing the "comfort" of death to some who do not clearly want it, then to others who "would really be better off dead," and finally, to undesirable persons, "which might involve the terminally ill, the permanently unconscious, the severely senile, the retarded, the incurably and chronically ill, and, perhaps, the aged." While the allusions are to Nazi Germany, Siegler's concerns are reinforced by the "coming together of the emerging stream of medical and ethical opinion with the torrent of public and governmental concern with the cost of medical care. Cost containment strategies may impose significant financial penalties on those who provide prolonged care for the impaired elderly. In the current environment it may well prove convenient—all too easy—to move from an individual's "right to die" to a climate enforcing a "duty to die."

As we move into the waning years of the 20th century and look over the medical environment and the direction in which it is heading, in my estimation, Siegler's apprehensions seem to be justified. As he concludes his article, he avows that this issue of withdrawing fluids and hydration is most complicated, "the tradition of medicine to do no harm is long, and a slow, conservative approach is most advisable." He feels that "compassionate calls for withdrawing of fluids in a few selected cases bears the

seeds of great potential abuse. Little is to be lost and much to be gained by slowing down the process, by taking stock of where we have come from and where we are going, by improving our methods of comforting and caring for the dying without necessarily hurrying to dispatch them on their way, and by deferring any premature legal, ethical, or professional approval and legitimization of this new course. Continuing to administer fluids, even to dying patients, provides an important clinical, psychological, and social barrier that should be retained."

Does Siegler's approach seem viable in these times? With the continued barrage from government, business, and industry on cost containment, the medical profession is on the defensive. As Siegler points out, there is a growing acceptance for this among physicians, ethicians, philosophers and, of course, the Euthanasia Society of America. It behooves us all to ponder the implications of Siegler's arguments, to hone our ethical skills, to use the ethical guidelines of the AMA with great caution, and to remain close to the patient and his or her family.

When all is said and done in ethical matters, this is where the action is. If the physician treats his patient as he himself would like to be treated, if he does no harm, then he has fulfilled his obligation to his patient with a clear conscience. Continued discussion and debate are essential to further clarify this most difficult and perplexing ethical question.

The reason that the food and water element is so important in the comatose patient is because it isolates a problem upon which we can focus to make some telling points. We know that the patient, although comatose, will live if fed, even though it is artificially done. Assuming that this is ordinary means, the patient will continue to live until some other pathological process supervenes. If nutrition is withdrawn, the patient will surely die in a short time. If a family or physician wishes to dispense with these ordinary means, the intent of the family or physician must be examined. Do they wish the patient to die and accomplish this by removing the only things which keep him living, namely food and water? Or do they simply want to let him die? If we assume that fluids and nutrition, artificially given, are ordinary means, and these supports are withdrawn, then we are talking about euthanasia by omission. On the other hand, if they can be categorized as extraordinary, then no obligation exists.

In a larger context, however, it would be well for us to ponder history and what it is warning us about when we consider the above. There have been and are various movements in this century and in our own time which are very disturbing to physicians who cherish their medical ethic, to do no harm. When we contemplate what happened to people in the Third Reich in the 1930s and 1940s, where mental defectives were eliminated as being unfit to live, and have this escalated to include the Jews and political dissidents; when we see where these euthanasia programs were begun by elements in the German medical professions and brought to terrifying proportions by that evil man, Hitler; when we see that life is being devalued in our society by the sickening statistics which come in each year on

elective abortions (20,000,000 since 1972), it must be obvious to even the most insensitive that we, as physicians, should be on guard. We should not be lulled into complacency by bland words or by double-talk. There is a drive for euthanasia going on in this country—euthanasia not simply by omission but by commission. If you doubt it, I would remind you that such legislation has been introduced into the California Legislature. The various courts have not been very supportive of us and some opinions have a most chilling impact on us and our medical ethics; *eg*, the Compton decision in the Bouvia case. Elizabeth Bouvia wished to die by starvation and wished the physicians and hospital to help her accomplish this. The hospital refused and the case came to court. Judge Compton in denying the hospital position stated the following:

"Elizabeth apparently has made a conscious and informed choice that she prefers death to continued existence in her helpless and, to her, intolerable condition. I believe she has an absolute right to effectuate that decision. The state and the medical profession instead of frustrating her desire, should be attempting to relieve her suffering by permitting and in fact assisting her to die with ease and dignity. The fact that she is forced to suffer the ordeal of self-starvation to achieve her objective is in itself inhumane.

"The right to die is an integral part of our right to control our own destinies so long as the rights of others are not affected. That right should, in my opinion, include the ability to enlist assistance from others, including the medical profession in making death as painless and quick as possible.

"That ability should not be hampered by the state's threat to impose legal sanctions on those who might be disposed to lend assistance.

"The medical profession, freed of the threat of governmental or legal reprisal, would, I am sure, have no difficulty in accommodating an individual in Elizabeth's situation."

In short, Judge Compton wishes that the medical profession would forsake its medical ethic and kill the patient if she so desires. What a perversion of legal thought and abasement of judicial prudence!

In summing up, the good physician must be the patient advocate to the end, even until death, do no harm and be aware of those who are trying to manipulate and corrupt his medical ethic. We are living in hard times for the medical profession, but when all is said and done, all we have left is our dedication and unswerving adherence to our Hippocratic Oath. How much money we made, how well our family has done, how many papers we have written, how many deliveries we have made, how many surgeries we have performed, will be as nothing if we have compromised on our solemn oath to do no harm. For it is on this oath and our adherence to it that we find our identity, our reason for being, and our worth as a physician.

It is upon our adherence to our oath that we will be judged. Let us hope that we of this generation will not be found wanting!

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