A Question of Life or Death

How does one decide to stop life support for a dying patient?

By KATHY FACKELMANN

"Late one night I was called to a ward by a nurse to see a patient breathing his last. My knee-jerk reaction was to do a tracheotomy. Immediately he began to breathe again and signaled for a note pad lying on a nearby table. He wrote: 'Why did you do this to me?'"

George R. Dunlop, a surgery professor at the University of Massachusetts Medical School, told this story to members of the President's Commission for the Study of Ethical Problems — a group of medical, legal and ethics experts who met in Washington, D.C., this summer to discuss problems doctors face when making decisions to stop medical treatment for dying patients. Dunlop, disturbed by the incident, which occurred fifty years ago in a Cincinnati hospital, said he felt it was wrong to save this patient's life because it merely prolonged the man's suffering.

Dunlop expressed what many people intuitively feel — that many times aggressive medical care for dying patients is futile and inhumane. Proponents of "death with dignity" argue that ending treatment for patients with no hope of recovery is justified because it spares them further pain.

But that's only one side of a complex issue. There are also those who are concerned that mounting social pressure to allow patients a "dignified death" will push doctors too far. Some doctors fear that other doctors might start to make hasty decisions, based more on social concerns than on what is really best for the patient and that patients who might truly benefit from aggressive medical care will be allowed to die.

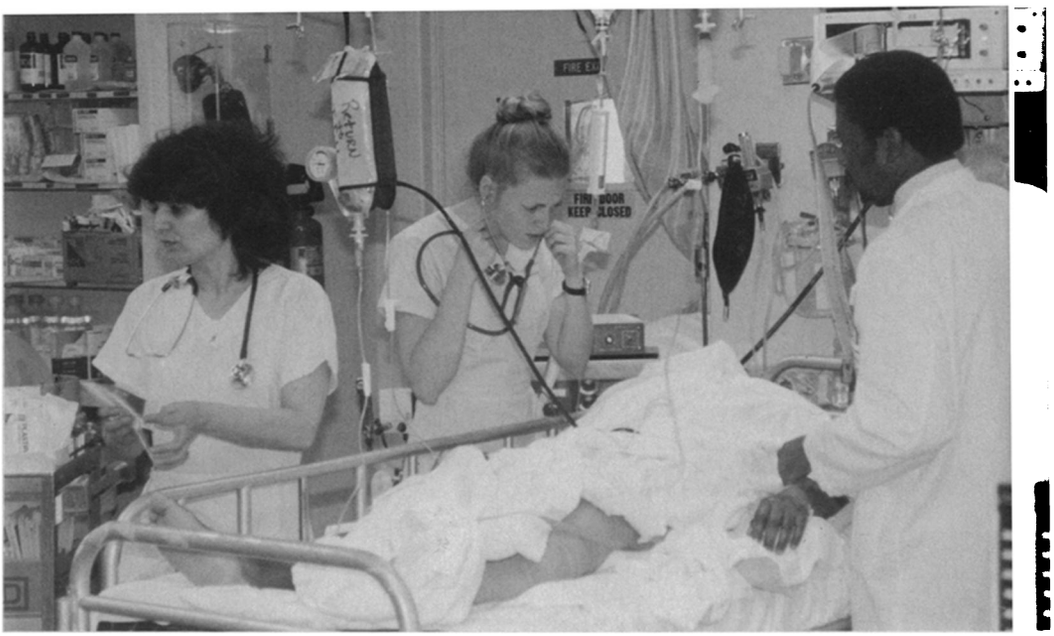
But this story really begins with a loosely organized social movement called "death with dignity" that started about twenty years ago by people who began to realize that some aspects to the new life-saving technology were not as beneficial as they seemed. "My perception of the whole business is that it is an outgrowth of the efficient life-support systems and emergency teams that can be summoned quickly," says Paul B. Beeson, professor of medicine emeritus at the University of Washington in Seattle. More sophisticated machines and better drugs allow doctors to save or resuscitate patients who would certainly have died ten or twenty years ago. While the benefits to our new abilities are enormous, there are many disadvantages — epitomized by coma patients like Karen Ann Quinlan who are saved from death only to exist indefinitely on hold.

Joel Feinberg, a University of Arizona philosopher, told commission members another story about the dark side of medical technology. His 89-year-old mother's heart had stopped, and the hospital emergency team broke her ribs during resuscitation. "She never said another word, but moaned in pain the whole time. I think this was a moral abomination." What happened to Feinberg's mother is not an uncommon occurrence. Patients in intensive care units often "die" ten and twelve times in a night — only to die again hours, days or months later. Often these patients are revived just enough to be conscious of pain. Other times, patients never regain consciousness but simply deterioriate until they die.

"People believe it is objectionable to go through the unpleasant ritual of trying to make the heart beat one more time," says Beeson. In fact, much of the impetus for "death with dignity" may spring from private experiences with death. Beeson says family members are often upset by the frantic commotion and turmoil that surround a dying patient. Unfortunately for people who are unfamiliar with hospital settings, the machines, monitors and tubes all resemble some kind of modern torture — especially when patients don't improve.

Doctors, especially in the past, exacerbated the problem because they were unlikely to honor a request to stop treatment even when dying patients had no real hope of recovery. Sociologists suggest physicians were reluctant to stop or withhold treatment because individual doctors viewed patient death as a personal failure. And evidence further indicates the high-tech atmosphere in most hospital intensive care units added to the physician's feeling of failure: death in the "can do" atmosphere of most hospitals was, and still is, sometimes seen as an unacceptable outcome of medical therapy.

David L. Jackson, director of the Center for the Critically Ill at University Hospitals in Cleveland, Ohio, says that some doctors won't stop treatment because they are afraid of legal problems. He tells the story of one amyotrophic lateral sclerosis victim in Akron, Ohio, who knew there was no treatment for her chronic debilitating condition. "She had a living will and repeatedly said she did not want to go on a



In the past doctors could offer only care and solice to dying patients, but today doctors using modern technology routinely save lives. George Washington Univ Med Ctr

ventilator," Jackson says. "She ended up in the emergency room on a ventilator and they wouldn't take her off until they got a court order." Lawyers say existing laws about decisions to stop treatment are hopelessly ambiguous. While doctors are implicitly required to treat patients to the best of their ability, laws are unclear about the extent of treatment required. Morris B. Abram, commission chairman and a New York City attorney, says any attempt to rigidly legislate these decisions would probably make things worse. Each case brought before the court would result in a new precedent and doctors, already unsure about their legal obligations, would be even more confused. Abram says he can imagine a future horror scene in which a dying patient looks up from his deathbed to see the doctor flipping through a thick docket of legal cases.

Jackson suggests hospitals need to set up ethics committees to help doctors and family members who are often burdened by intense emotions about the impending death and can't always make good decisions. Jackson says ethics committees — usually groups of religious, medical and community leaders — often help because they can offer an objective viewpoint. Yet he says unpublished research indicates that most hospitals nationwide do not have such committees.

Despite the lack of guidance and the consequences of such decisions, evidence suggests doctors, perhaps sensitized by social concerns to allow patients a dignified death, are much more likely to stop treatment today.

A 1970 survey published in the JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION revealed that 87 percent of doctors queried said they agreed with the principle of passive euthanasia (stopping or withholding medical treatment for dying patients). Eighty percent said they practiced this type of euthanasia in varying degrees and another 15 percent said they favored actively ending certain patients' lives by injecting them with a poison.

And Beeson says he notices a growing trend nationwide to put more "no code" orders on older patients' charts. A no code order tells the doctor on duty not to start the patient's heart if it stops.

Beeson says he is afraid house staff will start to write no code orders out of habit and that such practices could lead doctors to what ethicists term the "slippery slope." The slippery slope theory says that common acceptance of one action — like no code orders — will inevitably lead to other less morally desirable actions. The theory assumes that people will "slip down the slope" from actions that might be acceptable in their own right to those that are not acceptable.

There is some concern among physicians that decisions to stop treatment will become increasingly socially acceptable and that doctors, especially inexperienced interns, will begin to make hasty decisions. Jackson says doctors, influenced by the social movement toward "death with dignity," are now much more willing to listen when their patients want treatment stopped.

But Jackson and co-worker Stuart Youngner report in a 1979 NEW ENGLAND JOURNAL OF MEDICINE article that certain patients have temporarily altered judgment and may not be able to make good decisions. The authors report that patients suffering from pain, severe symptoms like nausea or depression often say they want treatment stopped — but if pain or the depression can be controlled these same patients often want to live again and tell doctors to continue with treatment.

Jackson and Youngner warn doctors against siding too quickly with a decision to stop treatment simply because it is a decision the doctor personally agrees with. They say there is greater danger of that happening when an individual patient's decision vacillates from day to day.

Decisions to stop treatment might also be an "easy way out" for doctors and staff who continually must face the emotional drain of caring for dying patients, says Willard Gaylin, a psychiatrist at the Hastings Center in Hastings-on-Hudson, N.Y. He says staff members often have difficulty coping with the emotional anguish that accompanies each downturn in a patient's progress.

"I don't want anyone making an easy decision. I want that decision to be made with sweaty palms. I want that person to have at least one sleepless night," Gaylin told the ethics commission.

These decisions are anything but easy. Despite the strides in knowledge and technology, doctors are still grappling with intangibles and unknowns; many facets of the decision are emotional and not easily analyzed. Gaylin says, "This is not a logical decision. It is not one that you can make by a computer model."

And Beeson says doctors can never be completely certain of any diagnosis. Even when doctors are relatively certain of the disease, they can't always predict how quickly the disease will progress or how painful the symptoms will be.

"I guest what I'm trying to stumble through is a hell of a complex situation — there are down sides to each way of making the decision," says Jackson. Doctors are placed in the unenviable position of balancing risks. On one hand, they must avoid reviving patients who will simply suffer more and die anyway. On the other hand, doctors feel that a decision to continue treatment buys the patient and the doctor more time. They feel there is always the possibility that a new drug or treatment might reverse the patient's situation.

"If I have to make a mistake I would rather tilt slightly to the side of preserving life because to tilt the other way is irrevocable," Jackson says. "If I'm not sure that the patient wants to be taken off the respirator, but I go ahead and do it, I'll never know whether the patient meant that or not — because the patient will die." □