Doctors and Death

In this issue of The Journal, Dr. Ebrahim summarizes our responsibilities as individuals in facing the process of death. In addition, we physicians have a special role to play at the end of life. Traditionally, this role has included relieving pain, advising when death is near, and comforting emotionally those who are dying and those whom they love.

Sadly, few of us can expect to peacefully die surrounded by family and guided by a wise physician who knows us and knows death. Instead, most of us will die in the hands of strangers, in sterile intensive care units, where wisdom is sacrificed to technology. This is because physicians no longer understand dying and no longer accept their critical role and its unfolding.

What do we know about dying in America? Many Americans fear that they will have no control over their death and that it will be prolonged, painful, and impersonal. Physicians often fail to communicate with the dying patient or their family. Instead, they prescribe invasive and aggressive treatments that are often more expensive than they would choose for themselves.

A recent study of 9,000 terminally ill patients cared for in five of the country’s best academic medical centers showed that the average patient spent eight days on mechanical ventilation in an ICU and most experienced moderate to severe pain for the last three days of life. DNR orders were written in only half of the cases where the patients themselves wished them, and they were usually written within only two days of death. In effect, DNR orders prevent only the last violent and hopeless treatment provided by “code” teams at these large hospitals.

One of my roles as medical director of a large skilled nursing home has been to protect patients from the pain, fear and loneliness of a hospital death. Certain management tools have been useful in this regard:

1) “Do not hospitalize” - Most patients who know that death is near want to avoid the needle sticks, sleeplessness, multiple transports, and the depersonalization of being a hospitalized patient. A majority of my terminal patients and their families have agreed to a clear plan not to rehospitalize. This is useful in organizing the end of life decisions and makes it possible to focus on quality of life rather than quantity of life issues.

2) “No tube feedings” - Until very recently, when a person could no longer eat, they died. With the advent of enteral feedings, NG tubes, and PEG tubes, we can now continue the lives of comatose patients for years. Families often misunderstand the process by which death occurs in someone who can no longer eat. When it is described and families are given permission to avoid tube feedings, peace often comes to the dying process. A shift occurs from worrying about “appropriate hydration” to comforting with ice chips, sips, and touch.

3) “No antibiotics” - Sometimes the only thing separating life and death is recurring courses of antibiotics to treat pneumonias, skin infections, or pyelonephritis. In such cases, the infection usually wins, but only after an escalating battle between increasingly resistant organisms and increasingly aggressive antibiotic therapy. In such cases, I will often ask the patient or their family how they want to treat “the next infection.” A common answer is “I’ve had enough.”

As physicians we have focused so much on the physiology of dying (i.e., PEEP, pressor agents, and cardiac output) that we have lost sight of the critical role that will-to-live plays in the timing of death. In most patients there is a critical moment when the acceptance of death occurs. It is essential that physicians recognize this moment in their patient’s lives and not violate it with physiologic imperatives. (“We’ve got to get the urine output up.”) At that moment, death is no longer the enemy.

Finally, we must reexamine our communication about death. Many families say that communication with the physician does not occur or is limited to the impersonal techno-jargon of the DNR order (“If the heart stops, do you want us to try to shock it back to life?”) Our failure in this area has resulted in lawyers drafting documents such as the Patient Self Determination Act and living wills, which attempt to protect patients from medical interventions. No law can prescribe the communication needed to achieve a

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good death. Lawyers use complex written words for their communication. Effective physicians often use silence, a held hand, and a look deep into the dying person's eyes.

It is sad that physicians have forsaken their role as a trusted guide at the end of life. Not until we can again be trusted with death will we be completely trusted with life.

References

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