Ethical Decision-Making at the End of Life

March 10, 2008 : 2:00 p.m. - 5:00 p.m.

Event Summary

Dr. Edmund Pellegrino, Chairman, President's Council on Bioethics; Dr. K. Eric De Jonge, Director of Geriatrics, Washington Hospital Center; Jennifer L. Crawley, Senior Social Worker, Washington Hospital Center; Raphael Cohen-Almagor, Chair in Politics, Department of Politics and International Studies, University of Hull, and Fellow, Wilson Center. Moderated by Marie T. Connolly, former coordinator of the U.S. Department of Justice's Elder Justice and Nursing Home Initiative, and Fellow, Wilson Center. Co-sponsored by the Center's Global Health Initiative

In recent decades, the question of when to withhold or withdraw life-sustaining treatment from a patient has become the most frequently encountered issue in medicine. For medical personnel, patients, and patients' loved ones, making such a decision can be extremely difficult, even under ideal circumstances. A program organized by the Division of United States Studies and the Global Health Initiative enabled scholars and medical professionals to discuss the process that should lie behind the decision-making.

Keynote speaker Dr. Edmund Pellegrino said that analysis of the decision-making process includes the questions of who is the decision-maker, what the criteria are for selecting the decision-maker, how conflicts about the decision should be resolved, and how such conflicts might be prevented. A patient with mental capacity is the default decision-maker. If a patient is mentally incapacitated, an advance directive (an oral or written statement of end-of-life preferences) becomes the surrogate decision-maker. If there is no advance directive, the decision-making responsibility passes to a legally valid surrogate. However, Dr. Pellegrino cautioned, the legally valid surrogate sometimes does not have the best interests of the patient at heart. He prefers for the decision-maker to be a morally valid surrogate – someone close to the patient who knows his or her values, and has no vested interest in a particular outcome. If there is persistent disagreement, either because family members disagree, or because medical personnel believe that family members are not following the wishes of the patient, the decision may have to be taken to a hospital ethics committee.

The words that are used by medical professionals in end-of-life situations, Raphael Cohen-Almagor noted, may save medical professionals' time but can shape the decision-making process at the expense of a patient's best interests. Words categorize phenomena and thereby necessarily affect that process. A physician's use of "terminal," for example, might suggest to the patient that the medical staff has given up. Similarly, the phrase "persistent vegetative state" has negative connotations for family or other decision-makers, and Cohen-Almagor suggested that terminology such as "prolonged unawareness" or "post-coma unawareness" would be more neutral and less frightening. He recommended that more ethics courses be included in medical school curricula, that physicians spend more time speaking with patients and elaborating on medical terms, and that the law be made clearer with respect to treatment guidelines.

Medical professionals have found that ethical theory rarely anticipates clinical reality. Dr. K. Eric De Jonge noted that end-of-life care is fraught with uncertainty and the kinds of strong emotions that are not taken into account by ethical theory. He told the audience that advance directives may not be of use when the prospect of death is imminent, as the decisions a person makes in fashioning a living will cannot possibly cover all clinical situations and often change as death nears. One such situation, for example, might involve a patient who checked off "I do not want a feeding tube" on an advance directive. The physician is then confronted with the problem of whether that means no feeding tube, even if it will be no more than a temporary measure, or no feeding tube only if its use will be permanent. As advance directives therefore cannot always be relied upon, a power of attorney given to a trusted person may be more important. Most important of all, however, is the creation of a trusting relationship among the clinicians, the patients, and the families (or other loved ones involved in the decision-making process).

Dr. De Jonge and Jennifer Crawley illustrated the ethical dilemmas involved in end-of-life decisions by presenting two case studies, noting the many moments at which decisions that were difficult for the patient, the family, and clinicians had to be made. They went on to suggest tools to help guide clinicians and families. Clinicians must build trust and an alliance with patients and their families, maintain that alliance until the end, help families make difficult decisions, and help them prepare emotionally for the end. Doctors should anticipate and lay out clearly the decisions that will have to be made at each step in the process. Families, for their part, must demand answers from medical staff, agree upon the person who has the power of attorney, create a loving system of care, and prepare themselves emotionally for the patient's death. Most importantly, as Dr. Pellegrino insisted, everyone involved in the process must remember that the overriding criterion is the best interests of the patient – hopefully, as that is defined by the patient himself or herself.

Drafted by Acacia Reed

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