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## **Weighed in the Balance: Ethical Decisions at the End of Life**

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Among the wide range of ethical issues encountered in VHA, end-of-life issues are among the most common. The provision of high quality clinical care for patients at the end of their lives has always involved difficult choices. Rapidly developing medical technology has increased the number and complicated the nature of decisions facing dying patients, families, surrogates, and health care providers. What kinds of ethical issues arise in end-of-life care? How can VHA staff better identify and deal with these ethical dilemmas?

One of the first places VHA staff look for guidance is official VHA policy. Policy, however, cannot answer all questions, and is subject to change. As societal expectations of end-of-life care evolve, so too must policies that provide the framework for care of the dying. For example, current VHA policy on Do-Not-Resuscitate (DNR) orders provides that patients must be "terminally ill" in order for their physicians to write a DNR order for them. Although many clinicians and ethics committees interpret the standard broadly, there are times when this requirement can complicate care and even restrict patients' options with respect to DNR instructions. As Paul Rousseau, MD, Associate Chief of Staff for Geriatrics and Extended Care and head of the palliative care program at the VAMC in Phoenix, AZ explains, "If an elderly patient in poor health comes in for a hip repair, despite the uncertainty of the surgical outcome and the real possibility of devastating complications, you still can't write a DNR order for that patient, even if he wants one."

"Ethics policies need to be regularly reviewed and updated to reflect changing circumstances and practices," says Ellen Fox, MD, Director of the National Center for Ethics. "In the next year we will be reexamining several VHA national policies, including the one relating to DNR orders. I anticipate that significant revisions will be made."

Dr. Michael Cantor of the National Center for Ethics staff agrees. "We are in the process of getting input on needed changes in our DNR, informed consent, and advance care planning policies. We expect to convene working groups to begin rewriting policies by the end of this year. Revising policies can take a long time, since the concurrence process is designed to assure that all those affected by the policy have input into its design. We may also need to seek changes in regulations, and that process is also lengthy. However, we are committed to moving forward as rapidly as possible."

VHA staff also look to their local ethics advisory committees for guidance in handling the ethical dilemmas that arise at the end of life. The members of the

committee can help to identify and resolve ethical dilemmas in patient care. According to George Flanagan, chaplain and chairman of the ethics committee at the Kansas City VAMC, ethical difficulties often arise because of communication problems between doctors and patients, or among family members. "Many seemingly ethical difficulties are really about inadequate or failed communication," Flanagan says. "The family often does not have the information it needs to make a decision. Most of the time, either there is no information, or not enough time to gather pertinent information as the patient's status changes." Because Chaplain Flanagan understands that this is often the case, his ethics committee members invest time educating a wide range of health care providers on how to communicate successfully with families, as well as educating families and patients about what their options may be in terms of end-of-life care.

"Sometimes the case will appear as an ethics consult, but when we spend time with the family we recognize that it is about failed communication. We get someone to sit down with them and help people reason through the process using their own value system," he explains. Ethics consults can help resolve communication problems by facilitating shared decision making among patients, families, surrogates, and the health care team. This can only happen when everyone is actively listening to the others, and honestly sharing what they know and feel, as well as what they do not know.

Margaret Berrio, RN, co-chair of the ethics advisory committee at the Boston VAMC, also notes that effective communication often is critical in ethics consults. "As ethics consultants, we provide 'just-in-time' education for patients and families," she says. At Boston anyone may request an ethics consult, including patients or family members or any member of a health care professional team. According to Berrio, health care professionals often request an ethics consult, "when they have a problem getting on the same wavelength as the family."

In such cases, the ethics team can identify the issues that appear to be in dispute, and help to clarify what each party really means or intends. "The great contribution of this process is to assure that communications provide a way to understand exactly what is being said, and to allow each view to be clearly stated. Talking about an issue with every person who has a stake in the outcome is a critical element of the successful ethics consult," Berrio says.

The type of care itself that patients, families, or surrogates decide upon can lead to ethical difficulties. A good example is palliative sedation, the practice in which dying patients are deeply sedated to alleviate pain and suffering. Because the patient's condition is so tenuous, in such circumstances death sometimes may occur naturally while the patient is sedated, but other times the sedation enables the patient to survive without discomfort. Recently, Rousseau, an expert in palliative sedation, sedated a patient who was expected to die within days—instead, he lived for five more weeks.

"Everyone began to question whether we were doing the right thing," he says, "the patients' three adult children, and the staff. Even I wasn't sure if we had done the right thing. There was a lot of dissension among the family. But his daughter insisted that this is what her father had wanted, and so we continued."

Ethics committees continue working to educate clinical colleagues and their patients. The Phoenix ethics committee sponsors a journal club and monthly education sessions. To promote patient awareness of end-of-life and other ethical issues, it also maintains a bulletin board in the main lobby of the medical center. The Boston VAMC sponsors biennial education conferences which in the past have focused on issues such as informed consent, end-of-life decision making, and medical futility. At the Kansas City VAMC, the ethics committee sponsors a monthly meeting where staff discuss topical issues and as well as basic principles of bioethics.

As health professionals and patients together continue to pursue opportunities for better end-of-life care, they face difficult ethical decisions. With the guidance of experienced and well-informed ethics committees and staff, many feel more secure that they have done the right thing for the right reasons.