

PROFESSION

End-of-life care: Pain control carries risk of being called a killer

Accusations of euthanasia are common as patients, families and even other health professionals struggle to adjust to the new realities of end-of-life care.

By **KEVIN B. O'REILLY**, amednews staff. Posted April 16, 2012.

Three decades after hospice emerged as the standard of care for terminally ill patients, the end-of-life treatments that palliative medicine physicians provide are frequently referred to as murder, euthanasia and killing.

More than half of hospice and palliative medicine physicians say patients, family members and even other health professionals have used those terms to describe care they recommended or implemented within the last five years, according to a nationwide survey of 663 palliative care doctors in the March *Journal of Palliative Medicine*.

Common palliative care treatments such as the use of opiates, sedatives and barbiturates to control pain and other symptoms are enough to draw accusations of murder and euthanasia, the study said. The troubling survey results come nearly six years after the American Board of Medical Specialties approved the hospice and palliative medicine subspecialty certification, and 30 years after the creation of the Medicare hospice benefit.

Nearly 1.6 million Americans received hospice care in 2010, up from about 25,000 in 1982, said the National Hospice and Palliative Care Organization. And palliative medicine has made its presence felt in hospitals, with 85% of 300-plus bed hospitals boasting palliative care teams, according to the New York City-based Center to Advance Palliative Care.

Yet the growing use of hospice and palliative care is creating more opportunities for misunderstandings, experts said. New developments in end-of-life care — aggressive pain and symptom management (even to the point of unconsciousness), along with a greater willingness to withdraw advanced, life-sustaining treatments such as mechanical ventilation, dialysis, and artificial hydration and nutrition — still strike many people as wrong.

The survey's findings highlight the gap between the well-established ethical and legal boundaries that demarcate acceptable end-of-life care and the understanding of patients, families and other members of the health care team, experts said.

"It's alarming," said H. Rex Greene, MD, a practicing oncologist and palliative medicine specialist in Lima, Ohio. "To accuse legitimate palliative care physicians of euthanasia and murder is a horrible mischaracterization of what's done to relieve symptoms at the end of life."

Twenty-five of the physicians surveyed said they were formally investigated by their institutions, state medical boards or prosecutors, with about half of those cases related to the use of opiates to manage dying patients' pain. Nearly a quarter of the investigations were related to the use of palliative and sedative medications when discontinuing mechanical ventilation. An additional 8% of the investigations were for palliative sedation — the practice of sedating to unconsciousness terminally ill patients who have severe, refractory pain.

All of these treatments — when conducted with the consent of patients or surrogate decision-makers and implemented with the intent of alleviating pain or other symptoms in terminally ill patients — are broadly accepted as ethically and legally appropriate, even if they have the secondary effect of speeding the dying process.

"Physicians have an obligation to relieve pain and suffering and to promote the dignity and autonomy of dying patients in their care," says the American Medical Association Code of Medical Ethics. "This includes providing effective palliative treatment even though it may foreseeably hasten death."

Hard-wired misperceptions

Although none of the physicians investigated was found at fault, most reported worry, anger, anxiety, isolation, depression and difficulty working as a result of the ordeal. Euthanasia accusations — whether voiced in the patient's room or in the courtroom — could have a chilling effect on physicians' treatment of dying patients' symptoms, said John G. Carney, CEO of the Center for Practical Bioethics, a Kansas City, Mo., think tank that works to improve end-of-life care.

"I'm deeply concerned that if we don't pay attention to the message in this article, we are going to be dealing with this issue of physicians who are reluctant to do what they know to be right because they are afraid of what people will say or that someone's going to investigate," said Carney, a former hospice executive director.

The distinction between aggressive pain control or the withdrawal of life-sustaining treatments and euthanasia is still lost on many patients and families, physicians said.

"These misperceptions are really pretty hard-wired and difficult to eliminate," said David Casarett, MD, chief medical officer of the University of Pennsylvania Health System's hospice program in the Philadelphia area. "Believe me, if there were an easy way to communicate these issues, then we wouldn't have highly qualified physicians called before medical boards to explain

their actions. To some degree, this is a cultural change. We're far ahead of where we used to be 20 years ago. On the other hand, we can't wait another 20 years for these things to go away."

Transformation in end-of-life care

Doctors who care for dying patients should take into account the public's lagging understanding of end-of-life treatments, take time to explain their intricacies and make use of ethics consultation services, said Porter Storey, MD, executive vice president of the American Academy of Hospice and Palliative Medicine.

"When I started training in this area 30 years ago, it was a rare thing to remove a feeding tube because nobody lived long enough to get that sick," said Dr. Storey, who practices outpatient palliative care in Boulder, Colo. "Now many people are living until they are extremely debilitated on life support. And if you work in an ICU, you want to sit down and take time and talk to people, but when it's happening every day, it's hard to remember sometimes that the public didn't get informed that things have changed."

Yet confusion about end-of-life care is not limited to patients and families. A majority of the doctors surveyed said that other physicians or health professionals at times characterized their palliative care treatments as murder, euthanasia or killing.

As end-of-life care has become more specialized, the gap between what palliative care specialists see as appropriate care and other doctors' perception of those treatments has grown, physicians said.

"Those of us in palliative care and hospice don't think that much about putting a patient on a large dose of an opioid like morphine. We do it all the time, and we see patients do well," said Dr. Casarett, associate professor of medicine at the Perelman School of Medicine at the University of Pennsylvania.

Recently, a patient dying of cancer enrolled in Dr. Casarett's hospice program after deciding to stop chemotherapy treatment. The oncologist caring for the patient was upset and talked with Dr. Casarett, saying that the combination of stopping curative treatment and using high doses of opiates was wrong.

"He said, 'We might as well just be walking away, and we might as well just shoot [the patient] now,'" Dr. Casarett recalled.

"It still stings to hear that," he said. But Dr. Casarett takes solace in knowing that he is doing right by his patients. "I tell other physicians that this is the standard of care, and that these sorts of medications and interventions are safe and effective."

ADDITIONAL INFORMATION:

Who's calling palliative care "euthanasia"

More than half of palliative care doctors have been told the care they recommended or provided is "murder," "euthanasia" or "killing." The frequency of such accusations varies by source and at times includes other doctors.

- Patient:** 25%
- Patient's friend or relative:** 59%
- Physician's friend or relative:** 25%
- Another physician:** 56%
- Another health professional:** 57%

Source: "Prevalence of Formal Accusations of Murder and Euthanasia against Physicians," *Journal of Palliative Medicine*, March ([ncbi.nlm.nih.gov/pubmed/22401355](http://www.ncbi.nlm.nih.gov/pubmed/22401355))

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"Prevalence of Formal Accusations of Murder and Euthanasia against Physicians," *Journal of Palliative Medicine*, March (www.ncbi.nlm.nih.gov/pubmed/22401355)

"Opinion 2.201 — Sedation to Unconsciousness in End-of-Life Care," American Medical Association Code of Medical Ethics, adopted June 2008 (www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2201.page)

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