END-OF-LIFE CARE

A JAMA THEME ISSUE

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A Piece of My Mind

"Al had received the kind of care that I worked hard to deliver to my own patients. Why then were his dying and death so horrible for Al and his family?" From "Sometimes Dying Still Stings."

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Contempo Updates

Etiology, diagnosis, and treatment of delirium at the end of life.

SEE PAGE 2427

Medical News & Perspectives

In the United States, local coalitions dedicated to palliative care and the creation of programs for children with terminal illness are growing.

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Broader Provision of Palliative Care

Addressing barriers to palliative care for patients in nursing homes and in the African American community.

SEE PAGES 2489 AND 2518

Legally Permissible End-of-Life Care

A consensus panel from the American College of Physicians-American Society of Internal Medicine discusses current myths about legal barriers to end-of-life care.

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New JAMA Series

Care at the Close of Life

The first article in a new series of case-based discussions explores initiating end-of-life discussions with seriously ill patients.

SEE PAGES 2502 AND 2512

JAMA Patient Page

For your patients: Information about decisions about care at the end of life.

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Limiting Neonatal Intensive Care: Beliefs and Decisions

Physicians who care for high-risk newborns often face decisions about starting or continuing life-sustaining treatment when the long-term prognosis is known to be very poor. To study the relationship between attitudes toward limiting intensive care and actual clinical decision making, Rebagliato and colleagues surveyed physicians regularly employed in neonatal intensive care units in 10 European countries. Physicians with beliefs valuing quality of life were more likely to report having set limits to intensive neonatal interventions in cases of poor neurological prognosis than physicians with beliefs valuing sanctity of life at any cost. Of several factors associated with physicians' attitudes and practices, including religious background and professional experience, country was the most important.

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Patient Attitudes About Euthanasia and PAS

Emanuel and colleagues interviewed terminally ill patients and their caregivers to determine their attitudes toward euthanasia or physician-assisted suicide (PAS). Almost two thirds of terminally ill patients supported euthanasia or PAS in a scenario-based hypothetical situation, but only a small proportion of terminally ill patients seriously considered euthanasia or PAS for themselves, and about half of those changed their preference when interviewed again 2 to 6 months later.

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Understanding of Prognosis and Influence on Care

Little is known about the association between parental understanding of prognosis in children with cancer and decisions about treatment goals and palliative care. Wolfe and colleagues interviewed the parents of children who had died of cancer and the child's primary oncologist, and reviewed the medical records. At diagnosis, concordance between parents' and physicians' beliefs about the likelihood of cure was fairly good, but parents' recognition that their child had no realistic chance for cure lagged behind medical record documentation of this prognosis by the primary oncologist by more than 3 months. When both physician and parent recognized earlier that the child had no realistic chance for cure, cancer therapy with the goal to lessen suffering and provide elements of palliative care were more likely to be integrated into the child's care.

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Defining a Good Death

Understanding what patients, families, and clinicians consider important at the end of life is necessary to improve end-of-life care. Steinhauser and colleagues conducted a survey of seriously ill patients, recently bereaved family members, and physicians and other care providers. Twenty-six of 44 attributes of quality at the end of life were rated as being important across all 4 groups, but 10 items varied broadly, including decisions about life-sustaining treatments, dying at home, and talking about the meaning of death. Among 9 major attributes, participants ranked freedom from pain as most important and dying at home least important. In a commentary, Daaleman and VandeCreek discuss religion and spirituality in end-of-life care.

SEE PAGE 2476 AND COMMENTARY ON PAGE 2514

Patient Knowledge About Legal Options at End of Life

The effectiveness of legislation promoting advance directives and legalizing physician-assisted suicide depends on patients' understanding of their legal options about care at the end of life. In this survey of 728 adult outpatients in Oregon, Silveira and colleagues found that a notable proportion of respondents appeared to misunderstand what end-of-life care is legally permissible based on their responses to a series of questions posed in a vignette about a patient who eventually dies from cancer. Sixty-nine percent of respondents answered correctly about refusal of treatment, 46% for withdrawal of treatment, 23% for assisted suicide, 32% for active euthanasia, and 41% for double effect.

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