

Virtual Mentor

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FROM THE EDITOR

Clinical Cures, Ethical Questions

Cancer. The disease that has touched so many of us, in one way or another, immediately commands attention and engenders questions of life, death, values, and meaning.

Each passing year brings a vast array of new drugs, technologies, and guidelines that introduce new dimensions to age-old questions of ethics and caregiving that medicine—and society at large—are still grappling with. As is increasingly being recognized, cancer is not a single disease, but rather a diverse collection of diseases differing in pace, expression, and challenges. The way in which it is experienced, then, varies dramatically from patient to patient and caregiver to caregiver, setting the stage for a clinical environment rife with particularly complex ethical situations.

Navigating these dilemmas to ensure the best possible outcomes for patients requires direct, empathic communication on the part of caregivers. But initiating such difficult conversations has not always been the norm—and is something that the medical community continues to struggle with today. Thomas P. Duffy, MD, describes how the culture of American medicine—devoted to conquering disease at all costs and still uncomfortable with death and dying—often prevents physicians from having vitally important end-of-life discussions with their patients.

These emotionally trying discussions are layered with additional complexity when there is a disconnect between doctor and patient about realistic goals of treatment and appropriate courses of action. If initial treatment regimens fail and disease progresses, patients and families may request increasingly risky and unproven treatments. When physicians believe a drug is likely to do more harm than good, are they obligated to refuse treatment or should they strive to maintain patient autonomy? In their case commentary, Laura L. Tenner, MD, and Paul R. Helft, MD, explore strategies for preserving the therapeutic relationship and promoting the patient's best interests near the end of life. At times, these issues expand beyond the clinic and into the courtroom. Valarie Blake, JD, MA, discusses landmark judicial cases questioning patients' constitutional right to experimental therapies and current FDA regulations.

Doctors confront different aspects of autonomy, beneficence, and shared decision making when caring for children. In their case commentary, Cristie M. Cole, JD, and Eric Kodish, MD, explore the ethics of withholding terminal diagnoses from pediatric patients, weighing a minor's right to know against the possible psychological and physiological harms of disclosure.

Patient and physician experiences are also inextricably linked to the larger health care delivery system. This connection becomes acutely apparent when doctors confront difficult treatment decisions precipitated by scarce resources. Over the past decade, cancer drug shortages have become an increasingly problematic and unpredictable component of providing oncologic care. Liza-Marie Johnson, MD, MPH, MSB, and Deena Levine, MD, discuss a challenging clinical case created by drug shortfalls and the criteria for ethical allocation of scarce resources.

At the same time that shortages of proven generic drugs threaten to compromise effective cancer care, the medical system has been flooded with expensive—and often only marginally effective—new cancer treatments. This situation is heightened during an era in which the exorbitant cost of health care is seen as unsustainable. In her discussion of Tito Fojo’s and Christine Grady’s thought-provoking article, “How much is life worth: Cetuximab, non-small cell lung cancer, and the \$440 billion question,” Nancy Berlinger, PhD, explores the high and growing cost of cancer care and the physician’s role in helping patients recognize and understand value.

The unsustainable cost of medical care, and wide disparities in quantity and quality of care delivered, were in part the impetus for the health care reform measures introduced by the Affordable Care Act (ACA). In their op-ed, Thomas W. LeBlanc, MD, MA, and Amy P. Abernethy, MD, PhD, explore the factors contributing to substantial variations in cancer treatment across the United States, and offer a promising path forward. Michael K. Gusmano, PhD, examines the ACA’s potential to reduce disparities in cancer screening and treatment through comparative effectiveness research. And James F. Thrasher, PhD, Amira Osman, MPH, and Dien Anshari, MS, describe a recent public health effort to reduce the burden of cancer: the FDA mandate that cigarette packaging carry graphic images of the negative health consequences of smoking. The authors summarize existing evidence regarding the effectiveness of pictorial warnings, as well as the tobacco industry’s arguments and legal challenges against the mandate.

As we enter the age of personalized medicine, advances in genomic sequencing hold great promise for tailored, sophisticated diagnosis and anti-cancer therapy. Erin Hofstatter, MD, and Allen Bale, MD, explore the science of whole-genome sequencing for real-time oncologic diagnosis, challenges of implementation, and ethical issues going forward. The past several decades have seen great advancements in cancer care, and many patients today enjoy longer, richer lives than they did in the past. In her essay, Gayle Sulik, PhD, discusses what it really means to be a cancer survivor and the positive and problematic aspects of the survivorship culture.

The issue closes with a podcast interview with Ronald DePinho, MD, president of MD Anderson Cancer Center, who discusses the future of cancer research and treatment, as well as the powerful, symbolic message of striking a red line through the word “cancer” on the center’s logo (click on the podcast tab).

From prevention to treatment, patient to doctor, the lab bench to Capitol Hill, every component of cancer care brings its own set of promises and dilemmas. The widespread and deadly nature of the disease makes finding and adopting ethically responsible solutions of the utmost importance. In a field in which the rate of new technologies often exceeds society's capacity to fully comprehend their consequences, frequent and robust discussions of ethics, empathy, and equity will be required. This issue of *Virtual Mentor* seeks to extend and strengthen that conversation.

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