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Symposium Articles

SYMPOSIUM
**Cost and
End-of-
Life Care**

Guest Edited by
Thaddeus M. Pope,
Robert M. Arnold,
and
Amber E. Barnato

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*Letter from
the Editor*

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Introduction

*Thaddeus M. Pope, Robert M. Arnold,
and Amber E. Barnato*

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End-of-Life Care: A Philosophical or Management Problem?

Daniel Callahan

End-of-life care became an important issue in the late 1960s and early 1970s. It was in great part driven by complaints about the care of the dying: lack of patient autonomy, indifferent or insensitive physicians, and inadequate pain control. The main task of those who worked to improve the situation centered on changing each of those variables, assuming that would do the job. But it has worked to a moderate extent only and the problem is not fully solved. The main omission has been a failure to confront the medical enterprise itself, which believes in endless progress and conducts a war against death. Only a change in those underlying values can bring about further significant change.

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The Ethical Implications of Health Spending: Death and Other Expensive Conditions

Dan Crippen and Amber E. Barnato

The cost of health care in the United States has important generational considerations whether analyzed at a point in time, or over many years. The budgets of governments contain important information about the funding of public services, including health care, and the intra- and inter-generational implications of both the inherent tradeoffs, and the particular means of funding the services. End-of-life expenditures, while a significant component of the cost of health care, are not the primary consideration in the ethical or moral questions raised.

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Care, Compassion, or Cost: Redefining the Basis of Treatment in Ethics and Law

Tom Koch

There are in two assumptions inherent in this issue's theme, both inimical to the traditional goals of medicine and to the standards of care it proposed. First, the idea

that treatment must be limited for some (but not others) on the basis of cost was born in the early literature of bioethics. Second, that there is a quantifiable and diagnostically predictable period at the "end-of-life" where treatment is "futile," and therefore not worth supporting in a context of scarcity grew out of bioethics's construction of allocative protocols in the 1990s. This paper traces the history of these ideas as constructs grounded in neither natural scarcity nor in firm diagnostic categories. Their relation to issues of care is therefore suspect.

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Health Care Accessibility for Chronic Illness Management and End-of-Life Care: A View from Rural America

*Kathryn E. Artnak, Richard M. McGraw,
and Vayden F. Stanley*

Nearly \$2 trillion is spent annually in the U.S. treating chronic illness — yet accessibility to quality health care services in rural communities for the chronically ill and dying remains problematic. Unique barriers present special challenges to a meaningful discussion of and subsequent strategies for addressing these issues in the context of increasingly scarce resources.

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Just Caring: Health Care Rationing, Terminal Illness, and the Medically Least Well Off

Leonard M. Fleck

What does it mean to be a "just" and "caring" society in meeting the health care needs of the terminally ill when we have only limited resources to meet virtually unlimited health care needs? That question is the focus of this essay. Put another way: relative to all the other health care needs in our society, especially the need for lifesaving or life-prolonging health care, how high a priority ought the health care needs of persons who are terminally ill have? On the one hand, we might see the terminally ill as being among the "medically least well off" and therefore deserving very high priority. On the other hand, we might see them as squandering vast medical resources for marginal medical benefits, thereby denying needed resources to others who would benefit much more. We begin the essay by making a number of morally relevant distinctions with regard to the category of "being terminally ill." We note, given contemporary medicine, that individuals may be terminally ill several times in the course of a life. Not all such circumstances make equal just claims to needed health care. We also note that our conceptions of health care justice are ultimately incapable of making very fine-grained, morally

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justified rationing judgments in complex medical circumstances. We conclude that we must finally rely upon fair processes of rational democratic deliberation to articulate such judgments for our own future, possibly terminally ill selves, thereby undercutting the rhetoric of “death panels.”

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Futility, Autonomy, and Cost in End-of-Life Care

Mary Ann Baily

This paper uses the controversy over the denial of care on futility grounds as a window into the broader issue of the role of cost in decisions about treatment near the end of life. The focus is on a topic that has not received the attention it deserves: the difference between refusing medical treatment and demanding it. The author discusses health care reform and the ethics of cost control, arguing that we cannot achieve universal access to quality care at affordable care without better public understanding of the moral legitimacy of taking cost into account in health care decisions, even decisions at the end of life.

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Making the Case for Talking to Patients about the Costs of End-of-Life Care

Greer Donley and Marion Danis

Costs at the end of life disproportionately contribute to health care costs in the United States. Addressing these costs will therefore be an important component in making the U.S. health care system more financially sustainable. In this paper, we explore the moral justifications for having discussions of end-of-life costs in the doctor-patient encounter as part of an effort to control costs. As health care costs are partly shared through pooled resources, such as insurance and taxation, and partly borne by individuals through out-of-pocket expenses, we separate our defense for, and approach to, discussing both pooled and individual aspects of cost. We argue that there needs to be a shift away from formulating the options as a dichotomous choice of paying attention to end-of-life costs versus ignoring such costs. The question should be how personal costs will be managed and how societal expenditures should be allocated. These are issues that we believe patients care about and need to have addressed in a manner with which they are comfortable. Conversations about how money will be spent at the end of life should begin before the end is near. We propose discussing costs from the onset of chronic illness and incorporating financial issues in advance care planning. Through these approaches one can avoid abruptly and insensitively introducing financial issues at the very conclusion of a person's life when one would prefer to address the painful and important issues of spiritual and existential loss that are appropriately the focus when a person is dying.

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Costs and End-of-Life Care in the NICU: Lessons for the MICU?

John D. Lantos and William L. Meadow

Neonatal intensive care units (NICUs) and medical intensive care units (MICUs) are both very expensive. The cost-effectiveness of NICUs has been extensively evaluated, as has

the long-term outcomes of subpopulations of NICU patients. NICU treatment is among the most cost-effective of high-tech interventions. And most patients do well. There are fewer evaluations of cost-effectiveness in the MICU and almost no long-term outcome studies. Policymakers who scrutinize expensive high-tech interventions would do well to study the examples found in the NICU.

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End-of-Life Decision Making across Cultures

Robert H. Blank

Even more so than in other areas of medicine, issues at the end of life elucidate the importance of religion and culture, as well as the role of the family and other social structures, in how these issues are framed. This article presents an overview of the variation in end-of-life treatment issues across 12 highly disparate countries. It finds that many assumptions held in the western bioethics literature are not easily transferred to other cultural settings.

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The Value of Life at the End of Life: A Critical Assessment of Hope and Other Factors

Paul T. Menzel

Low opportunity cost, weak influence of quality of life in the face of death, the social value of life extension to others, shifting psychological reference points, and hope have been proposed as factors to explain why people apparently perceive marginal life extension at the end of life to have disproportionately greater value than its length. Such value may help to explain why medical spending to extend life at the end of life is as high as it is, and the various factors behind this value might provide normative rationale for that spending. Upon critical analysis, however, most of these factors turn out to be questionable or incompletely conceived; this includes hope, which is examined here in special detail. These factors help to explain complexity and nuance in the normative issues, but they do not provide adequate justification for spending as high as it often is. In any case, two additional factors must be added to the descriptive explanation of high spending, and they throw its normative justification into further doubt: the “insurance effect” and provider-created demand. Overall, the perception of especially high value of life at the end of life provides some normative justification for high spending, but seldom strong justification, and not for spending as high as it often is.

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In the Business of Dying: Questioning the Commercialization of Hospice

Joshua E. Perry and Robert C. Stone

This article critically questions the commercialization of hospice care and the ethical concerns associated with the industry's movement toward “market-driven medicine” at the end of life. For example, the article examines issues raised by an influx of for-profit hospice providers whose business model appears at its core to have an ethical conflict of inter-

est between shareholders doing well and terminal patients dying well. Yet, empirical data analyzing the experience of patients across the hospice industry are limited, and general claims that end-of-life patient care is inferior among for-profit providers or even that their business practices are somehow unseemly when compared to nonprofit providers cannot be substantiated. In fact, non-profit providers are not immune to potentially conflicting concerns regarding financial viability (i.e., “no margin, no mission”). Given the limitations of existing empirical data and contrasting ideological commitments of for-profit versus non-profit providers, the questions raised by this article highlight important areas for reflection and further study. Policymakers and regulators are cautioned to keep ethical concerns in the fore as an increasingly commercialized hospice industry continues to emerge as a dominant component of the U.S. health care system. Both practitioners and researchers are encouraged to expand their efforts to better understand how business practices and commercial interests may compromise the death process of the patient and patient's family — a process premised upon a philosophy and ethical tradition that earlier generations of hospice providers and proponents established as a trusted, end-of-life alternative.

Independents

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Fetal Pain, Abortion, Viability and the Constitution

I. Glenn Cohen and Sadath Sayeed

In early 2010, the Nebraska state legislature passed a new abortion restricting law asserting a new, compelling state interest in preventing fetal pain. In this article, we review existing constitutional abortion doctrine and note difficulties presented by persistent legal attention to a socially derived viability construct. We then offer a substantive biological, ethical, and legal critique of the new fetal pain rationale.

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A Living Wage for Research Subjects

Trisha B. Phillips

Offering cash payments to research subjects is a common recruiting method, but this practice continues to be controversial because of its potential to compromise the protection of human subjects. Federal regulations and guidelines currently allow researchers to pay subjects for participation, but they say very little about how much researchers can pay their subjects. This paper argues that the federal regulations and guidelines should implement a standard payment formula. It argues for a wage payment model, and critically examines three candidates for a base wage: the nonfarm production wage, the FLSA minimum wage, and a living wage. After showing that the nonfarm production wage is too high to satisfy ethical criteria, and the minimum wage is too low, this paper concludes that the wage payment model with a base wage equivalent to a living wage is the best candidate for a standard payment formula in human subjects research.

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Multi-Professional Recommendations for Access and Utilization of Critical Care Services: Towards Consistency in Practice and Ethical Decision-Making Processes

Laura Hawryluck, Redouane Bouali, and Nathalie Danjoux Meth

Multiprofessional guidelines for fair access to and use of adult critical care services are desperately needed to define a consistent transparent standard of care: when such therapies have the potential to benefit and help a patient as they journey with illness and when they cannot.

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Testing Public Health Ethics: Why the CDC's HIV Screening Recommendations May Violate the Least Infringement Principle

Matthew W. Pierce, Suzanne Maman, Allison K. Groves, Elizabeth J. King, and Sarah C. Wyckoff

The CDC's HIV screening recommendations for health care settings advocate abandoning two important autonomy protections: (1) pretest counseling and (2) the requirement that providers obtain affirmative agreement from patients prior to testing. The recommendations may violate the least infringement principle because there is insufficient evidence to conclude that abandoning pretest counseling or affirmative agreement requirements will further the CDC's stated public health goals.

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Reining In the Pharmacological Enhancement Train: We Should Remain Vigilant about Regulatory Standards for Prescribing Controlled Substances

Katherine Drabiak-Syed

This article challenges recent assumptions that physicians may ethically and legally prescribe psychopharmacological enhancement drugs to patients and the counterintuitive notion that in some cases ingesting an enhancement drug constitutes the more ethical choice than forgoing this option. Enhancement proponents have touted modafinil as an ideal mechanism to improve concentration, alertness, and forgo sleep and keep pace with our society's demands. However, patients who use modafinil for these reasons risk potentially severe side effects and addiction, and face unintended consequences related to their cognitive, emotive, and physiological functioning. Importantly, prescribing a controlled substance such as modafinil for performance enhancement and sleep avoidance runs contrary to a physician's ethical duty to the patient and the standard of practice set forth in legal requirements governing the prescription of controlled substances.

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articles are essays unrelated to the symposium topic, and can cover a wide variety of subjects within the larger medical and legal ethics fields. These articles are peer reviewed.

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