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# End-of-life Care: An Interdisciplinary Perspective

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The Institute of Medicine has described the “death-denying character of American society” and surely, there is an opportunity to change this character. Despite our understandable concern with costs, end-of-life care options must be variously considered from economic, ethical, and legislative perspectives. We consider these multiple perspectives of end-of-life care in an attempt to inform current thinking on the part of legislators, policy makers, providers, patients, families/

caregivers, and insurers on the issue of end-of-life care. Society must be educated to understand that death can be peaceful and that end-of-life planning and care is an integral part of society’s continuum of care. Enabling affordability, expanding availability, and ensuring access are the only ways of realizing that outcome.

**Keywords:** end-of-life care; palliative care; cost of dying

## Introduction

In all health care systems, there is a struggle to decide how end-of-life care should be provided to patients. Criteria such as affordability, availability, and access are used in this selection process. These struggles in decision making are often compounded by a lack of understanding or commitment to end-of-life care as part of the natural continuum of care over an individual’s life cycle. Just as there are choices concerning quality of life, so too are there choices regarding quality of death.

Medicare’s coverage of hospice care began in 1983 and literally transformed society’s view of dying. Based upon normative or professional guidance and financial considerations, it helped establish the principal that hospice can improve the quality of death and might even do so at lower cost.

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Implicitly assumed were the availability, affordability, and accessibility of hospice. The Medicare benefit was specifically designed to provide nursing and homemaker services, counseling, pharmaceuticals, and medical supplies for the terminally ill. It was not designed to include curative care. It did, however, provide options to family, friends, and communities for care that eased the transition from life to death. The wishes of the dying were given legislative and financial support. A choice could be made between aggressive, continual treatment and relief from suffering and comfort in death.

The cost of caring for patients with advanced disease in their last year of life has remained fairly constant over the past 30 years at roughly 28% of Medicare’s annual expenses for the 5% of beneficiaries who die each year. Estimates of cost savings for hospice and advance directives have been less definitive ranging from 10% to 20% over the last 6 months of life.<sup>1</sup> Placing an economic value on dying has propelled end-of-life care as a public policy issue. As a result, other options for end-of-life care beyond hospice have been met with renewed attention and have broadened the consideration of death as something that occurs not only to the frail elderly population but to the entire population from the moment of birth onward.

Palliative care initiatives to improve the care of the sickest and most vulnerable patients, young or old, as well as their families and caretakers, came into prominence. The expansion of palliative care options paralleled and supported the expansion of hospice care, but its emphasis is on symptom relief during any stage of disease. Hospital-based palliative care units (PCU) were developed to expand beyond treatment of terminal illness to support acute and chronic care models. Currently, 25% of hospitals have PCU or programs.<sup>2</sup> There is some evidence that symptom improvement with respect to pain, fatigue, and depression in patients and improved well-being of caregivers results from the use of palliation. Financial successes have also been documented as well, although they remain a source of further scrutiny.<sup>3,4</sup> In particular, specialist palliative care for cancer patients has been proven to improve health outcomes of patients and improve satisfaction and identify needs of families and caretakers when compared to conventional care.<sup>5</sup>

The Institute of Medicine has described the “death-denying character of American society,” and surely, there is an opportunity to change this character. Despite our understandable concern with costs, end-of-life care options must be variously considered from economic, ethical, and legislative perspectives. Our intent is to do just that and move beyond the “tyranny of numbers over generous feelings...”<sup>6</sup> This forum is based on an invited presentation for the Westchester Region Second Interdisciplinary and Inter-faith End-of-life Conference for Professionals, Caregivers, and Families (4 April 2008; Valhalla, New York). We consider multiple perspectives of end-of-life care in an attempt to inform current thinking on the part of legislators, policy makers, providers, patients, families/caregivers, and insurers on the issue of end-of-life care.

## **The Economic Perspective: The Tyranny of Numbers**

Given that American society considers death an option, choices need to be made. Choices, by implication, require further decision making about resource use and allocation. It is therefore inevitable that the cost of dying, like all healthcare, be subject to some form of economic evaluation.

The changing demographics contribute to this concern; the number of people aged  $\geq 65$  years

represented 12.4% of the total population in 2000.<sup>7</sup> Approximately 90% of Medicare beneficiaries have a chronic condition in the year before death. Fully, 73% of beneficiaries report 2 or more chronic conditions.<sup>8</sup> Perhaps more startling, more than 440 000 children live with a life-threatening condition.<sup>9</sup>

Recent evidence on the cost-effectiveness of palliative care is sparse, although some compelling arguments remain. Zimmermann et al reviewed 396 reports of randomized controlled trials for effectiveness of palliative care. They found evidence of cost savings in only 1 of 7 studies that evaluated cost data, but noted that the studies under consideration had not evaluated the impact of personal costs to families and caretakers.<sup>10</sup> This omission is critical—for patients needing substantial care, 10% of household income was spent on direct health care-related costs.<sup>11</sup> In addition, as much as 30% of direct costs for hospice are not even reimbursed by Medicare.<sup>12</sup> Just as importantly, indirect costs to families and caretakers, such as the impact of lost time at work, impact to their own health, and quality of life, have been omitted as well. Surely, these “invisible” costs serve to bias the savings downward.<sup>13</sup>

Cost savings from PCU may be the longer term trend. In a longitudinal study of patients in the Virginia Commonwealth University Health System, half of the 1744 adult admissions were diagnosed with cancer. Patients who died in the PCU had expenditures 66% less than those who received usual care. Structured ethics reviews of those most likely to die in the intensive care unit (ICU) assured that the “right patients” were linked to the PCU at the “right time”.<sup>14</sup> Just as importantly, evidence for specific treatments for pain management have suggested additional benefits of palliation.<sup>15</sup> In fact, these considerations rather conveniently move us away from the absolutes of economic data or the tyranny that could result if decision making relied only upon the numbers as documented. An additional perspective might be warranted if we are motivated toward a more comprehensive review of end-of-life care.

## **The Ethical Perspective: Generous Feelings**

In 1999, the Journal of the American Medical Association (JAMA) considered “how economics and bioethics can reconcile in order to generate strategies for delivering care at the end of life”.<sup>16</sup> The call

was made to medical students and doctors to “examine death more broadly.” An editorial in the *British Medical Journal* (BMJ) USA noted that the variation in clinical practice of end-of-life care suggests a “strong influence on local practice patterns of opinion leaders, market forces, local medical culture, hospital and ICU bed availability, and access to specialists.”<sup>17</sup> This has certainly contributed to the difficulty of developing evidence-based standards for end-of-life care. In a comprehensive review of bioethics practices in decision making, Drought and Koenig found little evidence of patient choice. Barriers included “the incommensurability” of patient, family/caretaker knowledge, and the complexities of planning end-of-life care. The role of the informed patient was considerably diminished and was not helped by consults with physicians.<sup>18</sup> Given that palliative care curricula in undergraduate medical education are often inadequate, this came as no surprise.<sup>19</sup> Furthermore, limited availability of hospice and PCU, especially for children and racial minorities, makes planning even more difficult. A recent study examined hospice availability and concluded that gaps in service availability may explain underuse of hospice care, not just for minority groups, but surprisingly, for the elderly group as well.<sup>20</sup>

To help eliminate these disparities, there is a need for legislation to protect patients and expand their rights regarding end-of-life care and decision making.

## The Legislative Perspective: Peace of Mind

High-quality, end-of-life care where people have reasonably good deaths and their wishes are respected is important for those who are dying and their loved ones. This can be accomplished at both the national and the state levels.

At the federal level, Congress passed the Patient Self Determination Act<sup>21</sup> in 1990 requiring Medicare and Medicaid to give adult individuals, at the time of inpatient admission or enrollment, certain information about their rights under state laws governing advance directives, including: (1) the right to participate in and direct their own health care decisions; (2) the right to accept or refuse medical or surgical treatment; (3) the right to prepare an advance directive; (4) information on the provider’s policies that govern the use of these rights. The act

also prohibits institutions from discriminating against a patient who does not have an advance directive.

At the state level, several progressive initiatives have extended the reach of federal legislation. The Palliative Care Education and Training Act<sup>22</sup> was enacted in New York in 2007 and is the first bill of its kind in the nation. The legislation addresses the urgent public health care crisis of the undertreatment of pain and the need for better end-of-life care. The legislation accomplishes, among other things, the establishment of a statewide advisory council on palliation, training programs for undergraduate and graduate students; Department of Health (DOH), Centers for Palliative Care Excellence and DOH-approved resource centers to assist physicians in pain management. Last year another bill was enacted in New York<sup>23</sup> that requires the state’s DOH to conduct education and outreach programs for consumer, patients, and health care providers relating to an advance directive, particularly a health care proxy; it emphasizes the need and importance for health care providers to play a leadership role in discussing end-of-life care preferences and values with patients and to provide patients with health care proxy forms.

Additional considerations for legislation include safe harbor bills that protect physicians from discipline who appropriately treat their patients’ pain and subjects them to discipline for failing to do so; and allowing people to indicate on their drivers’ licenses who their health care agent is, thus making it more likely that someone will be contacted who knows what the individual’s wishes are with respect to end-of-life care.

## Conclusion

Jacques Barzun, when describing 19th-century economic progress, discussed the tension between “the tyranny of numbers over generous feelings, peace of mind, moral conscience and religious faith.” Today, in our consideration for end-of-life care, we are similarly asked to reconcile these same tensions. Our recommendation is that we consider end-of-life care from multiple perspectives and that this interdisciplinary focus (economic, ethical, and legislative) should be broadened to address the implicit, erroneous assumptions that options are affordable, available, and accessible to all. Society must be educated

to understand that death can be peaceful; that end-of-life planning and care is an integral part of society's continuum of care. Enabling affordability, expanding availability, and ensuring access are the only ways of realizing that outcome.

## Acknowledgments

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