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# ECONOMIC PARAMETERS OF END-OF-LIFE CARE: SOME POLICY IMPLICATIONS IN AN ERA OF HEALTH CARE REFORM

MICHAEL ASH\* & STEPHEN ARONS\*\*

Decisions about patient care at the end of life are perhaps the most complex, emotionally wrenching, and difficult—yet among the least avoidable—of all of life's decisions. Although the dilemmas of end-of-life care decision-making have many common threads, each situation is inherently unique to the patient and his family. These decisions reflect health care resources; personal, cultural, and religious values; family relationships and life experience; and a bewildering variety of understandings of the meaning of life and death. The choice between palliative care and the continuation of curative effort—or treatment—is among the most difficult of these end-of-life decisions.

Factors external to the relationships among patient, family, and physician sometimes influence the choice between treatment and palliative care. Cultural, religious, and political pressures, as well as media attention and legal complications may arise that can transform the intimate uniqueness of an end-of-life decision into a state, national, or even international *cause célèbre*.<sup>1</sup> Less familiar per-

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1. The tragic case of Terri Schiavo received an embarrassing level of national and international attention as the United States Congress and President George W. Bush sought to intervene and manipulate the decisions of the Florida state courts. A thoughtful and useful discussion of the lessons to be learned from this legal and policy debacle can be found in a special issue of *Palliative and Supportive Care: The Lessons of*

haps, are the economic and policy parameters of end-of-life care decisions, and the impact that economic incentives or disincentives may have on the availability and quality of end-of-life care. Some people find it unpleasant, even morally offensive, to contemplate how the economics of health care policy might affect end-of-life care, holding that money should not matter when life and death are on the line and that any form of health care “rationing” may convey a disrespect for human life. Others may propose changes in end-of-life care as a way to reduce low-productivity, “futile” or “wasteful” health care spending, or to transfer scarce health care dollars to preventive medicine or to younger patients with longer life expectancies.<sup>2</sup> Outside of the conflicts sometimes generated between these two competing agendas,<sup>3</sup> the majority of citizens are probably unaware of the existence and effect of economic incentives built into such things as the Medicare hospice benefit or the provision of palliative care in hospitals or nursing homes.

In this Article, we introduce and briefly explore some of what is known, as well as what is not known, about the economics of end-of-life care and its policy implications. We attempt to stay largely in the realm of positive analysis, describing the policy parameters and what is known about behavioral responses to those parameters. We attempt to identify areas in which further economic research might be important, and we suggest that the health care reform that Americans are demanding and that politicians have been promising

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*the Terri Schiavo Case.* See 4 PALLIATIVE & SUPPORTIVE CARE 111 (2006). This volume was guest edited by Lewis Cohen, MD. The earlier case of Nancy Cruzan was no less painful for the family involved, and it received national media attention for years; however, its handling by the courts was not the subject of such overt political and ideological warfare. For the best source of the personal, medical, and legal facts of that case, see WILLIAM COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN (2002). For a discussion of the culture wars as they are affecting end-of-life care issues more generally, see Stephen Arons, *Palliative Care in the U.S. Healthcare System: Constitutional Right or Criminal Act*, 29 W. NEW ENG. L. REV. 309, 338-55 (2007) [hereinafter Arons, *Palliative Care in the U.S.*].

2. For a discussion on “medical futility,” a term that may be more conclusive than descriptive, see Zita Lazzarini, Stephen Arons & Alice Wisniewski, *Legal and Policy Lessons from the Schiavo Case: Is Our Right to Choose the Medical Care We Want Seriously at Risk?*, 4 PALLIATIVE AND SUPPORTIVE CARE 145 (2006).

3. Some health care personnel regard the economics of end-of-life care as a virtually radioactive topic. This is apparently because of the fear that any suggestion that palliative care might be less expensive than the full pursuit of medical treatment—no matter how much that may extend the suffering of a dying person—amounts to an incentive to disregard the value of human life. The issue has obvious religious and ideological overtones. One intention of this Article is to provide some facts and suggestions for further research in the hope that palliative care can be considered on its medical rather than ideological merits in individual cases and in policymaking.

should include changes in the economics of end-of-life care designed to make palliative care more readily and equally available to all. We set our exploration in the context of a particular legal and policy issue—whether the availability of quality palliative care at the end of life is unduly and unfairly restricted by individual or aggregate economic policies of government at the state or federal levels. To put the matter bluntly, we ask whether some Americans die in unnecessary pain and suffering, robbed of dignity and separated from the comfort of their families, because of economic incentives and disincentives built into particular government regulations of end-of-life care. We ask these questions at a time when national attention and increasing resources are being trained on health care reform. In general, we address ourselves to two broad sets of questions.

The first set of questions includes: What are the costs and benefits associated with the choice between palliative care to increase the quality of remaining life and curative treatment designed to increase time spent living? How are the costs and benefits distributed institutionally; for example, how do they accrue to hospitals, hospices, other health care providers, public and private insurers, and patients? How are costs and benefits distributed socially? How are they distributed across age groups, social classes, and ethnic and racial groups?

These are followed by the next set of questions: How would alternative policies affect the choices made by consumers and suppliers of different forms of end-of-life care? Would the gross costs and benefits of health care change with alternative policies, and how will the distribution of those costs and benefits change?

After an initial statement about the legal and policy context of our questions, we have organized these general areas of inquiry into four parts. In each of those four parts we combine some description of how Medicare or other rules operate with discussion of the existing evidence on the effects or implications of those rules and incentives.

Part I provides a brief discussion of the legal and policy issues surrounding end-of-life care in the United States. In Part II, we describe briefly some of the major institutions and structures for delivery of end-of-life care. In Part III, we discuss whether the utilization of palliative care at the end of life produces significant cost savings over advanced medical treatment, potentially distorting the judgment of doctors or other health care providers or making it

more difficult for terminal patients and their families to make informed choices about care. In Part IV, we examine policies that segregate end-of-life care from the other parts of the health care system, exploring the discontinuities between aggressive treatment in a hospital and palliative care in a hospice setting. We focus on the all-or-nothing nature of the choices that patients or their doctors may have to make because of reimbursement regulations affecting health care institutions. Finally, in Part V, we examine some of the consequences of the underdeveloped and understructured end-of-life care system, suggesting demographic distortions in the availability and quality of palliative care based on race and poverty as possible results of the economics of end-of-life care.

### I. THE LEGAL AND POLICY CONTEXTS OF PALLIATIVE CARE

Before examining the economics of end-of-life care, it is useful to understand the legal and policy issues surrounding the end-of-life debate. The question whether any government can constitutionally deny a patient access to palliative care received national attention in the Supreme Court's 1997 decisions in *Washington v. Glucksberg*<sup>4</sup> and *Vacco v. Quill*.<sup>5</sup> The central question in these joined cases concerned whether there was any constitutional impediment—in either the Due Process or Equal Protection clauses of the Fourteenth Amendment<sup>6</sup>—to Washington or New York's criminalization of what was then referred to as "physician-assisted suicide."<sup>7</sup> A unanimous Court decided that there were no such impediments, that there is no fundamental right for a terminally ill person in intractable pain to hasten her own death with the aid of a physician. But in five of the six opinions written in support of that decision, there was ample reasoning to suggest, as Justice Breyer did, that

the laws of New York and of Washington do not prohibit doctors from providing patients with drugs sufficient to control pain despite the risk that those drugs themselves will kill. . . .

. . . .

Were the legal circumstances different—for example, were state law to prevent the provision of palliative care, including the

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4. *Washington v. Glucksberg*, 521 U.S. 702 (1997).

5. *Vacco v. Quill*, 521 U.S. 793 (1997).

6. U.S. CONST. amend. XIV, § 1.

7. A more accurate and neutral term, and the one used in this Article, is "physician-aided dying." See KATHRYN L. TUCKER, AM. CONSTITUTION SOC'Y FOR LAW & POLICY, CHOICE AT THE END OF LIFE: LESSONS FROM OREGON 2 (2008), <http://www.acslaw.org/files/Kathryn%20L.%20Tucker%20Issue%20Brief.pdf>.

administration of drugs as needed to avoid pain at the end of life—then the law’s impact upon serious and otherwise unavoidable physical pain (accompanying death) would be more directly at issue. And as Justice O’Connor suggests, the Court might have to revisit its conclusions in these cases.<sup>8</sup>

A number of commentators have observed that although the *Glucksberg* court found no constitutional right to physician-aided dying, it did suggest that a right to palliative care might be discovered in the Fourteenth Amendment if the facts in a future case demonstrated that any state’s laws “obstruct the provision of adequate palliative care, especially for the alleviation of pain and other physical symptoms of people facing death.”<sup>9</sup> The question then becomes, “what kind of state laws or state action should be surveyed to find out whether a government has placed an undue burden upon the provision or receipt of adequate palliative care?”

There are many overt ways that a state or the federal government might create burdens on palliative care that could be found to be constitutionally unacceptable. A number of these were discussed in a previous *Western New England Law Review* article on the politics of health law.<sup>10</sup> For example, the National Right to Life Committee has produced a model act for state legislatures aimed at restricting the right to refuse certain medical treatments when that

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8. *Glucksberg*, 521 U.S. at 791-92. There is great irony—no doubt satisfying to the plaintiffs in *Glucksberg*—that in November of 2008 the voters of Washington State approved a physician-aided dying law nearly identical to Oregon’s Death with Dignity Act by a fifty-nine to forty-one percent vote. See Washington Death with Dignity Act, WASH. REV. CODE ANN. § 70.245.020 (West 2009); John Iwasaki, *State Second in Nation to Allow Lethal Prescriptions*, SEATTLE POST-INTELLIGENCER, Nov. 5, 2008, available at [http://seattlepi.nwsourc.com/local/386450\\_initiatives05.html](http://seattlepi.nwsourc.com/local/386450_initiatives05.html); see also Initiative Measure No. 1000: The Washington Death with Dignity Act (Jan. 24, 2008), <http://www.secstate.wa.gov/elections/initiatives/text/i1000.pdf>. The State of Montana has also moved towards creating a right to physician aid in dying. See Kathryn L. Tucker, *Privacy and Dignity at the End of Life: Protecting the Right of Montanans to Choose Aid in Dying*, 68 MONTANA L. REV. 317 (2007); see also *Baxter v. State*, No. ADV-2007-787, 2008 Mont. Dist. LEXIS 482 (Mont. Dist. Ct. Dec. 5, 2008) (finding this right in the state constitution).

9. Robert A. Burt, *The Supreme Court Speaks: Not Assisted Suicide but a Constitutional Right to Palliative Care*, 337 NEW ENG. J. MED. 1234 (1997); see also TUCKER, *supra* note 7, at 3-4 & n.18. It is worth noting that although palliative care and physician-aided dying are often portrayed as alternative, competing end-of-life policies, the nine-year experience of Oregon has been that the legalization and regulation of physician-aided dying has brought with it a substantial increase in the availability and quality of palliative care in Oregon. TUCKER, *supra* note 7, at 9.

10. See Arons, *Palliative Care in the U.S.*, *supra* note 1, at 338-55.

refusal might hasten a patient's death.<sup>11</sup> On the federal level, former Attorney General John Ashcroft attempted to cripple Oregon's Death with Dignity Act by issuing an order that would have cast a chill over every palliative care physician in the nation by threatening to revoke any doctor's license to prescribe drugs listed in the Controlled Substances Act, Schedule II if such opiates were prescribed with the intent to hasten the death of a terminally ill patient.<sup>12</sup> That order was found by the Supreme Court to have exceeded the authority given the attorney general under the Controlled Substances Act.<sup>13</sup> As is appropriate, the Court in *Gonzales v. Oregon* interpreted the reach of the statute, rather than the constitutional issue suggested by the five Justices in *Glucksberg*. But the facts nevertheless could have supported a constitutional ruling on a putative right to palliative care as Justices Breyer and O'Connor had suggested might be found.<sup>14</sup> Other examples of overt placement of government obstacles to palliative care include the conduct of the War on Drugs at the federal level, the regulation of medical practice at the state level,<sup>15</sup> and criminal prosecutions of physicians and nurses for practicing palliative care in line with accepted medical standards.<sup>16</sup>

It is possible that any of these examples of overt state action directed against the provision of palliative care might constitute part of a fact pattern capable of sustaining a claim for a constitutional right to palliative care. But it is also possible, and more important, that an aggregate of many smaller state actions—especially the reimbursement regulations and economic structuring of Medicare or Medicaid end-of-life care benefits, or the regulation of private health insurers and the reimbursement of private nursing homes—could contribute to an overall systemic burdening of pallia-

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11. MODEL STARVATION & DEHYDRATION OF PERS. WITH DISABILITIES PREVENTION ACT (2006), available at <http://www.nrlc.org/euthanasia/MODELN&HStateLaw.pdf>.

12. Controlled Substances Act, 21 U.S.C. §§ 801-971 (2000).

13. *Gonzales v. Oregon*, 546 U.S. 243, 262 (2006).

14. *Id.* at 249; see *supra* text accompanying note 8.

15. See, e.g., Charles Wilson, *Establishing a Right to Palliative Care at the End of Life*, 2 J. PALLIATIVE MED. 15 (1999), available at <http://www.umass.edu/legal/Arons/Spring2007/397N/397N-bazelon-pall-care.pdf>.

16. See Lewis Cohen et al., *Accusations of Murder and Euthanasia in End-of-Life Care*, 8 J. PALLIATIVE MED. 1096, 1096-104 (2005). The study referred to in the article is still in progress. See Arons, *Palliative Care in the U.S.*, *supra* note 1, at 346-50; Ben A. Rich, *Overcoming Legal Barriers to Competent and Compassionate Pain Relief for the Dying Patient*, AM. PAIN SOC'Y BULL., Winter 2005, available at <http://www.ampainsoc.org/pub/bulletin/win05/law1.htm>.

tive care by state action. That would open a more subtle but significant analysis of how states might, whether wittingly or not, be discouraging or obstructing the provision of quality palliative care to the terminally ill.

Finally, and most important for purposes of this Article, it is possible that this same aggregate of economic regulations, reimbursement practices, and palliative care policies—if discovered to discourage the provision of palliative care—might constitute the basis for designing and demanding legislative reform of certain aspects of the health care system. Since the nation is in the midst of once again launching an attempt at health care reform, knowledge of and expanded research into the economic parameters of palliative care for end-of-life patients could be extremely important. It is this inquiry about the economics of palliative care that we hope to help stimulate with this Article.

## II. THE INSTITUTIONS OF END-OF-LIFE CARE

The main manifest functions of end-of-life care are to respect patient and family preferences regarding the end of life and to provide the highest possible quality of life to people with conditions that make death imminent. A recent consideration in end-of-life care is on the election of palliative care and the foregoing of efforts at curative treatment. Two key structures of end-of-life care in the United States are hospice, which embodies the election for palliative care, and advance directives, which govern the expression of intent regarding choice among treatments, or choice between treatment and palliation, in light of the possibility that the individual may later lose the capacity for either expression or intent.

Hospice refers to a care process whose aim is to provide comfort and cogency during the process of dying for the dying person and her family. Hospice does not have a specified location; hospice can be provided in dedicated hospice facilities, nursing homes, hospitals, and in homes. In hospice, the dying person is provided with access to symptom relief and pain management, counseling, and emotional and material support, such as housekeeping.<sup>17</sup>

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17. COMM. ON CARE AT THE END OF LIFE, INST. OF MED., *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 30-32 (Marilyn J. Field & Christine K. Cassel eds., 1997) [hereinafter *APPROACHING DEATH*]; see also NAT'L CONSENSUS PROJECT, *CLINICAL PRACTICE GUIDELINES FOR QUALITY PALLIATIVE CARE* 57-61 (2004), <http://www.nationalconsensusproject.org/Guideline.pdf>.



Medicare Part A, which provides hospital insurance to almost everyone age sixty-five and over, as well as to some categories of disabled nonelderly, includes a hospice benefit.<sup>18</sup> The benefit requires a physician's diagnosis that the patient has less than six months to live, and the discontinuation of curative treatment for the terminal illness. All other appropriate medical care provided under Medicare Part A (and Part B if the patient is covered) continues for treatment of health problems unrelated to the terminal illness. The hospice benefit includes physician and nursing care for the relief of symptoms and for pain management; medical appliances, equipment, and supplies; outpatient drugs for symptom management; and pain relief. Access to prescription drugs for pain relief, including opiates and palliative chemotherapy agents, is substantially expanded and cheaper for patients using the hospice benefit than for those in the standard Medicare program. The benefit includes significantly more availability of home care than is offered under the standard Medicare benefit, including the services of a home health aide and homemaker services. In fact, provision of home health aides is highly constrained under Medicare, and homemaker services are entirely unavailable.<sup>19</sup>

The patient may use the benefit essentially indefinitely, even if she lives beyond the initial six-month diagnosis, as long as a physician will recertify the diagnosis of less than six months to live. Medicare sometimes investigates providers whose patients have substantial incidence of survival in hospice beyond six months. The patient retains the right to discontinue hospice care and return to standard Medicare coverage and may also reenter hospice with recertification of terminal illness.

Although almost one-quarter of Medicare beneficiaries are now enrolled in private managed care organizations under the Medicare Part C (Advantage) program, the hospice benefit is administered and funded through traditional Medicare. Patients revert to traditional Medicare when they enter Medicare-funded hospice. Medicare covered 78.6% of hospice discharges in 2000,

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18. See MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: NEW APPROACHES IN MEDICARE 140-41 (2004), available at [http://www.medpac.gov/documents/June04\\_Entire\\_Report.pdf](http://www.medpac.gov/documents/June04_Entire_Report.pdf) [hereinafter NEW APPROACHES IN MEDICARE].

19. MARILYN MOON & CRISTINA BOCCUTI, THE URBAN INST., MEDICARE AND END-OF-LIFE CARE (2002), available at [http://www.urban.org/UploadedPDF/1000442\\_Medicare.pdf](http://www.urban.org/UploadedPDF/1000442_Medicare.pdf); see also Carol Raphael, Joann Ahrens & Nicole Fowler, *Financing End-of-Life Care in the USA*, 94 J. ROYAL SOC'Y MED. 458 (2001).

with the remaining fifth covered largely by private insurers or by the Medicaid hospice benefit.<sup>20</sup>

Medicaid, a shared state and federal health insurance program, provides health care to elderly and nonelderly persons who meet income and family-structure eligibility criteria. As Medicaid is subject to both federal and state regulation and funding, there is variation across states in the range and generosity of the benefits, with the federal government requiring states to offer some mandatory benefits. Hospice care is not among the mandated Medicaid benefits. However, forty-seven states and the District of Columbia currently include a hospice benefit in Medicaid.<sup>21</sup> Among people jointly covered by Medicare and Medicaid, Medicare reimburses hospice providers more generously than does Medicaid. Medicaid covered only 5.1% of hospice discharges in 2000.<sup>22</sup>

Private insurance is the primary source of health care coverage for the non-elderly, and employment-based health insurance is the most common form of insurance in this category. Private insurance covered thirteen percent of hospice discharges in 2000.<sup>23</sup> The central role of Medicare in hospice is not surprising because the elderly constitute a high share of all deaths as well as deaths in hospice.

Medicare, furthermore, plays an important institutional role in the structure of hospice care both because hospices, like hospitals, require certification by the Medicare system to be eligible for funds and because other insurance systems piggyback on the Medicare hospice system. Medicare licensing is required for participation in Medicaid and most private hospice programs.<sup>24</sup> As an example of employment-based health insurance reliance on the Medicare-created structure of the hospice system, the Massachusetts state employees' health insurance plan covers hospice care with much the same restrictions and benefits as Medicare in any Medicare-licensed

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20. Barbara J. Haupt, U.S. DEP'T OF HEALTH & HUMAN SERVS., CHARACTERISTICS OF HOSPICE CARE DISCHARGES AND THEIR LENGTH OF SERVICE: UNITED STATES, 2000, at 10 tbl.1 (2003), [http://www.cdc.gov/nchs/data/series/sr\\_13/sr13\\_154.pdf](http://www.cdc.gov/nchs/data/series/sr_13/sr13_154.pdf) [hereinafter CHARACTERISTICS OF HOSPICE CARE DISCHARGES]. Almost all hospice discharges are associated with the death of the patient. A small fraction may represent a return to conventional care. *Id.* at 4.

21. Lainie Rutkow, *Optional or Optimal?: The Medicaid Hospice Benefit at Twenty*, 22 J. CONTEMP. HEALTH L. & POL'Y 107, 123-24, n.102 (2005) (listing the rules and regulations of participating states, as well as noting that Connecticut, New Hampshire, and Oklahoma do not provide Medicaid hospice benefit rules).

22. CHARACTERISTICS OF HOSPICE CARE DISCHARGES, *supra* note 20, at 10 tbl.1.

23. *Id.*

24. Chester A. Robinson, Thomas Hoyer & Carol Blackford, *The Continuing Evolution of Medicare Hospice Policy*, PUB. ADMIN. REV., Jan.-Feb 2007, at 127, 128.

hospice program.<sup>25</sup> Some private insurers have experimented with more flexible access to the hospice benefit, in particular with the rule regarding the six-month limitation.<sup>26</sup>

Advance directives are an important part of the end-of-life decision-making process for the approximately twenty percent of Americans who have them.<sup>27</sup> Advance directives may be living wills, designation of health care proxies, do-not-resuscitate (DNR) orders, or other forms authorized by state law. They express the treatment intentions of the patient—made while competent—in the event that he loses the capacity to continue to participate in treatment decisions.<sup>28</sup> Although the reach and limitations of advance directives vary from state to state, they all express the principle of patient autonomy and the right of incompetent as well as competent patients to refuse unwanted medical treatment or have it withdrawn.<sup>29</sup> Federal law requires that federally aided health care institutions in each state inform patients of state policies regarding advance directives.<sup>30</sup> Advance directives do not solve all problems that might arise concerning the choice between treatment and palliative care, but they do create parameters within which economic and other incentives apply.<sup>31</sup>

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25. See, e.g., UNICARE, UNICARE STATE INDEMNITY PLAN BASIC: MEMBER HANDBOOK FOR ACTIVE EMPLOYEES AND NON-MEDICARE-ELIGIBLE RETIREES 30, 42 (2008), <http://www.unicare-cip.com/PDF/series1hndbk0608.pdf>.

26. See *infra* note 57 and accompanying text.

27. The SUPPORT Principal Investigators, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 JAMA 1591 (1995); see also LAST ACTS, MEANS TO A BETTER END: A REPORT ON DYING IN AMERICA (2002), <http://www.rwjf.org/files/publications/other/meansbetterend.pdf>.

28. The decision-making process for treatment of legally incompetent patients without advance directives is regulated by state law, but that law may be constrained by constitutional rights of privacy or substantive due process liberty. See Stephen Arons, *Current Legal Issues in End-of-Life Care*, in LIVING WITH DYING: A HANDBOOK FOR END-OF-LIFE HEALTHCARE PRACTITIONERS 730, 732-42 (Joan Berzoff & Phyllis R. Silverman eds., 2004) [hereinafter Arons, *Current Legal Issues in End-of-Life Care*].

29. The right to refuse medical treatment, or to have it withdrawn, has both common law and constitutional dimensions, and, therefore, its regulation by state law has some limitations. *Id.* at 738-42.

30. Patient Self Determination Act of 1990, 42 U.S.C. § 1395 (2000).

31. See Arons, *Current Legal Issues in End-of-Life Care*, *supra* note 28, at 734-38; see also Ben A. Rich, *Advance Directives: The Next Generation*, 19 J. LEGAL MED. 1 (1998); Rich, *supra* note 16. The utility and appropriateness of advance directives, especially living wills, have been contested by some conservatives who contend that an aging and dying patient has lost much of the autonomy that justifies the making of living wills in the first place. This view was expressed by the President's Council on Bioethics during the administration of George W. Bush. PRESIDENT'S COUNCIL ON BIOETHICS, TAKING CARE: ETHICAL CAREGIVING IN OUR AGING SOCIETY 53-91

We examine several aspects of advance directives, including their adoption before or at the onset of illness as well as their application in the event of loss of decision-making capacity. There is variation across states in the regulation of advance directives and other decision making about end-of-life care. Two important policy dimensions are the incentives for provider compliance with advance directives and alternative appointment of a proxy or surrogate decision maker in the absence of an advance directive.<sup>32</sup> Some incentives for compliance are as mild as the legislative requirement that properly executed advance treatment directives are legally binding. More specific incentives include the specification of civil or criminal penalties for physicians who disregard advance directives. Some regulations include the specification of conditions under which a physician can refuse to comply with an advance directive, which could either reduce or increase the incentive for providers to comply.<sup>33</sup> Still other regulations provide a liability waiver for actions arising out of good-faith compliance with an advance directive.

### III. CAN PALLIATIVE CARE REDUCE THE COST OF U.S. HEALTH CARE?

There is substantial debate in the policy literature on the possibility of controlling the economic costs of end-of-life care. The hope for cost savings in changing patterns of end-of-life care from life extension to palliative care emerges from the observation that end-of-life Medicare spending, defined as Medicare spending in the 365 days preceding death, constitutes about one-quarter of all Medicare spending. In 1988, Medicare spent \$13,316 per elderly decedent in the last year of life, and total health care costs per decedent ran approximately \$29,300. Spending on an average Medicare beneficiary was slightly more than \$1900. Although all amounts have increased, the share spent on decedents has remained stable.<sup>34</sup> The underlying facts concern the large share (and level) of Medicare expenditure on patients in their last year of life. The widely

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(2005), available at [http://www.bioethics.gov/reports/taking\\_care/taking\\_care.pdf](http://www.bioethics.gov/reports/taking_care/taking_care.pdf). But the anti-autonomy view has long been contested by leading bioethics experts such as George Annas. See, e.g., George Annas, Book Review, *The Practice of Autonomy: Patients, Doctors, and Medical Decisions*, 283 JAMA 930 (2000).

32. See generally Daniel P. Kessler & Mark B. McClellan, *Advance Directives and Medical Treatment at the End of Life*, 23 J. HEALTH ECON. 111 (2004).

33. *Id.* at 113. It is not specified if such provisions are modeled as increasing or decreasing incentives for compliance. See *id.*

34. Ezekiel J. Emanuel & Linda L. Emanuel, *The Economics of Dying—The Illusion of Cost Savings at the End of Life*, 330 NEW ENG. J. MED. 540 (1994).

quoted, stylized fact is that twenty-seven percent of Medicare expenditure pays for care for the five percent of recipients who die during the year.<sup>35</sup> Extrapolations to the general population and the social construction of much of this care as “futile care” suggests that large cost savings are possible by containing expenditure on end-of-life care.

The case for cost savings in end-of-life care that focused on palliative rather than curative intervention may have been adopted strategically by early advocates of the adoption of hospice policy.<sup>36</sup> Hospice, which advocates saw as a substantial improvement on the medicalized and—in their estimation—degrading way of death, could be pitched more broadly as a cost-effective health care solution. There may be an important analogy here.<sup>37</sup> While the appeal to efficiency may have attracted some cost-cutters to the hospice movement, the same appeal may have also cost support among those repelled by the prospect of reducing medical effort for dying people based on economic reasons.

Regardless of the moral dilemmas posed by introducing cost considerations in the allocation of care, a central positive consideration is whether there are substantial cost savings in reallocating the care effort. Emanuel and Emanuel offer five criticisms of optimistic cost-containment scenarios: (1) the straightforward error of extrapolating the twenty-seven to thirty percent of Medicare to a similar share of all medical expenditure; (2) selection bias in observational demonstrations of the low cost of alternative end-of-life care; (3) the high cost of high-quality alternatives (e.g., hospice-based end-of-life care); (4) the unpredictability of death and the difficulty in advance identification of “futile” care—in particular using retrospective data; and (5) the widespread adoption of DNR orders, which limit the application of futile but highly expensive services at the very end of life, may mean that the low-hanging fruit of end-of-life cost savings has already been picked and marginal

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35. This stylized fact is reviewed at many places in the literature, both in studies that see opportunities for cost reduction and in second-generation literature critiquing the earlier studies. For examples of second-generation literature, see Ezekiel J. Emanuel, *Cost Savings at the End of Life: What Do the Data Show?*, 275 JAMA 1908 (1996); Emanuel & Emanuel, *supra* note 34, at 540; Anna A. Scitovsky, “*The High Cost of Dying*” Revisited, 72 MILBANK Q. 561 (1994).

36. Robinson, Hoyer & Blackford, *supra* note 24, at 128.

37. In the 1960s and 1970s, the social movement on behalf of the mentally ill favored deinstitutionalization to combat medicalization and to empower sufferers from mental illness. In some cases, this movement joined forces with cost cutters who saw deinstitutionalization as a way to relieve strained public sector budgets.

switching from aggressive to palliative care will yield smaller savings.<sup>38</sup>

The potential cost savings aside, the actual cost savings of replacing aggressive curative treatment until death with a palliative model appear to be small relative to national health care expenditure. A reasonable estimate is that 3.3% of total national health care expenditure might be saved by a conversion away from aggressive curative treatment, and more importantly, that the growth rate of health care expenditure would be unaffected.<sup>39</sup> Furthermore, end-of-life care has not been a site of disproportionate growth of health care expenditure, so changes only to this component of health care cannot reduce the rapid growth that has been the focus of cost-control efforts. It is possible that improving the management of end-of-life care could significantly reduce end-of-life care costs, even if it is not a feasible approach to reducing the growth in national expenditure on health care. There is some variation across studies in the extent of cost reduction possible through alternative management of end-of-life care.

Despite the common sense of the assumption that replacing futile, high-intensity curative care for dying patients with palliative care would reduce health care costs, a consensus has developed that such cost reductions are illusory. There are two critical points in this somewhat unexpected finding: first, high quality hospice care is itself expensive; and second, identification of dying patients, for whom additional curative efforts would be futile, is not easily done in advance.

Emanuel and Emanuel observe that the after-the-fact definition of end-of-life spending creates the illusion of high end-of-life expenditure. People in the last year of life have high medical costs because they have faced grave health crises to which life-saving care attempts were applied. Well-matched survivors would be people who faced similarly grave health crises but for whom life-saving care was successful. A comparison of decedents to all survivors, rather than to well-matched survivors, overstates the expenditure on decedents.<sup>40</sup> Since survival or death is not foreseeable in ad-

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38. Emanuel & Emanuel, *supra* note 34, at 542.

39. *Id.* at 544.

40. Christopher Hogan et al., *Medicare Beneficiaries' Costs of Care in the Last Year of Life*, 20 HEALTH AFF. 188, 193-94 (2001). The actual subtitle of the article is "End-of-life costs are only slightly higher for persons who died than for survivors with similar characteristics." *Id.* While this analysis does not in fact appear in the article, it does appear in a final report to Medpac by the same authors. See C. Hogan et al.,

vance in many cases, the potential cost savings are significantly overstated. There is little reason to believe that health care providers can effectively distinguish future decedents from survivors in time to make decisions about reducing the cost of care.

Although end-of-life care represents approximately a quarter of Medicare spending and overall Medicare spending has grown sharply over time, the end-of-life share of Medicare spending has been remarkably stable.<sup>41</sup> New developments or applications of expensive interventions have not been disproportionately focused on end-of-life care.

Emanuel and Emanuel also note that the figure has been inflated by the casual and inaccurate extension of the end-of-life twenty-seven percent share of Medicare spending to the share of end-of-life spending in all health expenditure.<sup>42</sup> Medicare enrollees die at much higher rates than do the general population, and the overall share of end-of-life expenditure in the national health care bill is substantially below twenty-seven percent.

Micro studies of changing the organization of end-of-life care have yielded mixed results with respect to cost savings. Some studies have even shown higher Medicare cost for hospice users than for nonusers.<sup>43</sup> Medicare does not pay for long-term nursing home care, which composes a significant portion of end-of-life care for elderly patients. Thus, for the most elderly decedents, Medicare costs are somewhat lower relative to younger decedents even if overall health care costs increase.

Other studies have shown decreased costs associated with hospice use. A case-control study found that hospital-based hospice services substantially reduced end-of-life costs, with savings of almost \$5000 among decedents who died in the hospital. The savings were largely determined by lower intensive care unit (ICU) costs for the hospice participants, although reduced pharmacy and lab costs were substantial as well. Savings were smaller for participants who were discharged alive from the hospital, largely based on the reduced use of ICU for both hospice users and nonusers.<sup>44</sup>

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Medicare Beneficiaries' Costs and Use of Care in the Last Year of Life, Contractor Research Series Report No. 00-1 (Washington: Medicare Payment Advisory Commission, May 2000).

41. Raphael, Ahrens & Fowler, *supra* note 19, at 458.

42. Emanuel & Emanuel, *supra* note 34, at 542-43.

43. Raphael, Ahrens & Fowler, *supra* note 19, at 459.

44. R. Sean Morrison et al., *Cost Savings Associated with US Hospital Palliative Care Consultation Programs*, 168 ARCHIVES INTERNAL MED. 1783 (2002).

Emanuel and Emanuel are critical of nonexperimental studies for two reasons. First, hospice participants are self selected and may likely have used fewer resources in the conventional care setting had they not opted for hospice.<sup>45</sup> This selection bias leads to overestimates of the savings from hospice care. Second, entrance into hospice may be associated with the realization that further curative efforts are futile, while the hospice nonusers had the potential for realizing gains from continuing curative effort.<sup>46</sup>

There have been only limited experimental evaluations of hospice as a cost-saving institution, and these have suffered from significant design flaws.<sup>47</sup> High quality end-of-life care is quite intensive in labor costs as well as in costs for pharmaceuticals.<sup>48</sup> Far from constituting a cheap way out, as the withdrawal of high-cost curative methods would imply, hospice requires time from physicians and nurses as well as aides and social workers. Furthermore, the pain-relief medications and other symptom-alleviating interventions can be high tech and expensive, e.g., chemotherapy or radiation therapy to limit or reverse functional impairment from tumors. In a simple tabulation subject to all of the caveats described above, hospice-using and non-using decedents had similar Medicare spending (\$17,790 for nonusers, \$19,950 for users) and total health care spending (\$26,047 for nonusers and \$27,202 for users).<sup>49</sup> Hospice care alone cost \$4186 per hospice user, which was offset by modestly lower hospital inpatient and other care for users.<sup>50</sup>

For these fundamental reasons, changing end-of-life care practice is unlikely to have a significant effect on the global cost of health care. However, while the macro picture may suggest that changing end-of-life care policy is not the panacea for high health care costs, there are likely micro policy changes that can significantly increase the quality of care at small or even negative cost. The micro policy changes concern the environment in which physicians make decisions regarding the application of palliative care, the reimbursement of different health care providers at different phases of the end-of-life process, and the potential for unfair or

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45. Emanuel & Emanuel, *supra* note 34, at 541.

46. *Id.* at 541-42.

47. *Id.* (assessing multiple studies in a review table).

48. See generally Vincent Mor & David Kidder, *Cost Savings in Hospice: Final Results of the National Hospice Study*, 20 HEALTH SERVS. RES. 407 (1985).

49. MOON & BOCCUTI, *supra* note 19, at 17.

50. *Id.* at 17 tbl.4.



inefficient cost shifting among paid providers, informal caregivers, and patients.

Although gross costs may not be easily addressed by end-of-life policy, it is clear that policy exerts significant control over the distribution of the costs of end-of-life care. Policies should be examined for their impact on current and potential cost shifting among providers, caregivers, patients, and the public sector. Some of the cost shifting is explicit in the regulation of the hospice system. As noted above, Medicare Advantage (Medicare HMO) patients revert to the traditional Medicare system for the funding of hospice care. There is anecdotal evidence that skilled nursing facilities and nursing homes sometimes discharge dying patients to hospitals to avoid the cost of care for the dying.<sup>51</sup> Hospitals can also operate hospices and change the mix of Medicare-reimbursable and nonreimbursable care.<sup>52</sup>

#### IV. PROVIDERS, PAYERS, AND PATIENTS: THE DISTRIBUTION OF COSTS OF END-OF-LIFE CARE

In the absence of net systemic savings, there may still be important cost savings to some parties. However, without net savings—the finding that broadly characterizes the review of the literature in Part III—cost savings to one party imply increased costs to other parties. Some changes in who faces the cost of end-of-life care may encourage more careful decision making; other changes may burden parties who are unable to pay, unable to resist, or unable to respond in beneficial ways. Particular uses of hospice may be differentially attractive to providers in the current health

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51. Melinda Beeuwkes Buntin & Haiden Huskamp, *What is Known About the Economics of End-of-Life Care for Medicare Beneficiaries?*, 42 THE GERONTOLOGIST (SPECIAL ISSUE III) at 40, 40-43 (2002). The challenging cost of end-of-life care for nursing homes is discussed at greater length in Diane E. Hoffmann & Anita J. Tarzian, *Dying in America—An Examination of Policies that Deter Adequate End-of-Life Care in Nursing Homes*, 33 J.L. MED. & ETHICS 294 (2005).

52. The distribution of the full costs of health care across providers requires significant new research. Basics of use, such as the rates of use of hospice and other palliative care—within hospitals, in freestanding facilities, or at home—and the sociodemographic distribution of care, are unknown. Similar questions remain about rates of creation and application of advance directives. These basics need to be examined before we can move to policy-analytic questions such as the economic factors or disincentives that account for low rates of utilizing palliative care in these hospice settings, or whether changes in the incentive structure (Medicare, private insurers, hospitals) would change the use or quality of palliative or hospice care. For an excellent survey of economic issues in end-of-life care, see APPROACHING DEATH, *supra* note 17, at 155-87.

care system. Hospitals may, for example, register savings in their curative activities if terminally ill patients are transferred to external or hospital-based hospice care. Similarly, nursing homes and Medicare HMOs see their costs directly affected by the use or non-use of hospice for terminally ill patients. However, changes in taxpayer costs, in financial and time costs for patients and families, and in resource needs for the hospice system are less well catalogued. The distribution of the burden needs to be more carefully tracked.<sup>53</sup>

On the demand side, a significant barrier to patients' use of palliative care is the construction of the Medicare hospice benefit. In this section we examine policies that segregate end-of-life care from the other parts of the health care system that are most relevant to people with grave and possibly terminal illness. We discuss the functional and dysfunctional components of these segregating policies.

The required certification of six-month life expectancy for eligibility for the hospice benefit is the most explicit segregation of end-of-life care from other forms of care. The full set of care available under the hospice benefit, including palliative medication, housekeeping, family support, and counseling are simply unavailable to people who lack the terminal certification. Lack of access to personal care at home is a significant shortcoming of the Medicare program.<sup>54</sup> There is insufficient palliative care and pain relief reimbursement under standard Medicare.

Medicare Part A—hospital insurance—includes coverage for intravenous opiates but not orally administered opiates, which greatly facilitate self-regulated, noninvasive pain relief. Orally administered opiates are now, in principle, covered under Medicare Part D, but the deductible, copayment, and “doughnut hole”<sup>55</sup> significantly raise the price to patients.

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53. Advocates of palliative care have flagged the potential for single-institution cost saving. *See, e.g.,* Morrison et al., *supra* note 44. This is indeed relevant to individual decision makers, for example, hospital administrators. We would encourage more systemic analysis of the incentives for and costs of providing palliative care.

54. CTRS. FOR MEDICARE & MEDICAID SERVS., DEP'T OF HEALTH & HUMAN SERVS., MEDICARE AND HOME HEALTH CARE (2007), <http://www.medicare.gov/publications/pubs/pdf/10969.pdf>. In a section entitled “What isn't covered by the Original Medicare Plan,” the booklet explains that Medicare does not pay for “24-hour-a-day care at home”; delivered meals; “[h]omemaker services like shopping, cleaning, and laundry when this is the only care . . . need[ed], and when these services aren't related to the plan of care”; or “[p]ersonal care given by home health aides like bathing, dressing, and using the bathroom when this is the only care . . . need[ed].” *Id.* at 7.

55. The “doughnut hole” is the range of gross pharmaceutical payments for which the patient bears full responsibility, from \$2250 to \$5100 per year. *See* DEAN BAKER,

At the same time, patients who are enrolled in Medicare hospice face limited access to those high-tech medical resources that are appropriate for hospice-based end-of-life care. Such interventions, while high tech and potentially expensive, are intended to improve the quality of life, not necessarily to extend the duration of life. Per diem reimbursement, which provides incentives for cost control by transferring the cost to the hospice providers, also provides a disincentive for additional expenditures, even those that benefit the terminal patient. The per diem reimbursement of hospice creates a significant disincentive for hospices to provide potentially expensive, high-tech palliative care, such as palliative chemotherapy or surgery.

The incentive problems with access to high-tech palliative care in hospice is compounded by widespread confusion among both patients and providers regarding access of hospice patients to curative care unrelated to the terminal illness. For example, hospice patients are eligible for treatment of infection by antibiotics under the standard Medicare benefit, but patients and family may incorrectly worry that enrollment in hospice eliminates access to basic health care for unrelated or painful conditions.

There are benefits claimed for segregating treatment from hospice care. Segregating palliative and curative health care is based on concern that per diem reimbursement, which provides valuable flexibility in the types of care provided as well as incentives for cost control, also creates an incentive to enroll low-maintenance patients for long periods of time.<sup>56</sup> The six-month rule creates an arbitrary line between the dying and others, which defines the availability of the per diem hospice benefit. If the line governing the availability of the benefit were relaxed with respect to the six-month prognosis, then some other mechanism for allocating hospice reimbursement only to terminal patients would have to be implemented.

The costs of segregating care are significant. Segregation of care denies important forms of relief both to the dying and to the not-yet-dying. Indeed, there is substantial evidence that the dying

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CTR. FOR ECON. POLICY RESEARCH, THE ORIGINS OF THE DOUGHNUT HOLE: EXCESS PROFITS ON PRESCRIPTION DRUGS 1 (2006), [http://www.cepr.net/documents/part\\_d\\_drug\\_profits\\_2006\\_08.pdf](http://www.cepr.net/documents/part_d_drug_profits_2006_08.pdf).

56. Interviews with end-of-life care providers have provided a basis for discussing the costs and benefits of the reimbursement system. See Haiden A. Huskamp et al., *Providing Care At the End of Life: Do Medicare Rules Impede Good Care?*, 20 HEALTH AFF. 204 (2001).

and surviving are not *ex ante* recognizable, at least not with the type of predictive precision that the six-month rule would require. Reducing segregation would create the opportunity to provide high-quality palliative care both to dying patients for whom curative efforts have been ended and to patients also receiving curative treatment.<sup>57</sup>

The benefit requires a physician's prognosis of life expectancy less than six months. Uptake of the benefit requires explicit acknowledgment that death is near. In fact, Medicare recipients may exit the hospice program at any time, and the benefit may be indefinitely extended in the case of patients who outlive the six-month prognosis. The six-month rule, then, is effective only insofar as it discourages uptake by patients who are uncomfortable with explicitly agreeing to the designation. Several pilot programs have tested the uptake of the hospice benefit with the relaxation of the six-month prognosis rule, and these programs have demonstrated some additional uptake, such as the SUPPORT program.<sup>58</sup>

Also on the demand side, qualification for the hospice benefit is a requirement for Medicare-funded access to pain relief medications. There are forms of palliative care that should be available and funded without initiating the hospice benefit. There is substantial evidence that pain is undertreated throughout the U.S. health care system.<sup>59</sup> Furthermore, qualification for the Medicare hospice benefit requires the discontinuation of curative treatment for the disease causing impending death.<sup>60</sup> However, the Medicare benefit

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57. While six-month prognoses are clinically unreliable, identifying markers of functional status that could supplant the six-month rule is a significant clinical challenge. See Ellen Fox et al., *Evaluation of Prognostic Criteria for Determining Hospice Eligibility in Patients with Advanced Lung, Heart, or Liver Disease*, 282 JAMA 1638 (1999) (demonstrating the extraordinary difficulty in establishing six-month survival prognoses in noncancer patients in a reanalysis of SUPPORT data); see also *supra* note 27. The Medicaring project is examining alternative eligibility criteria in multiple clinical trials. See Palliative Care Policy Center, <http://www.medicaring.org/> (last visited Apr. 15, 2009); see also BARBARA GAGE ET AL., U.S. DEP'T OF HEALTH & HUMAN SERVS., *IMPORTANT QUESTIONS FOR HOSPICE IN THE NEXT CENTURY* (2000), <http://aspe.hhs.gov/daltcp/reports/impques.htm> (discussing the six-month eligibility rule and alternatives).

58. See, e.g., The SUPPORT Principal Investigators, *supra* note 27.

59. See Wilson, *supra* note 15.

60. Medicare may be revising some of these regulations for illnesses such as cancer, in which some aspects of traditional treatment may be usefully continued after admission to hospice because those treatments alleviate suffering even though they may not extend life. Patients with other illnesses, however, such as end-stage renal failure, may likewise benefit from treatments such as dialysis but find that these treatments are not available in hospice even though they reduce suffering.

is in fact ambiguous about the availability of curative treatment for other disorders. There is a lack of clarity about coverage for related disorders, unrelated disorders, and interventions that pertain to the specific disorder but are intended to relieve symptoms and improve the quality of life.

The restrictive structure of the hospice benefit likely suppresses demand for palliative health care. A greater emphasis on continuity between care at the end of life and care at other stages would increase demand. The six-month prognosis for hospice-benefit eligibility and the unavailability of pain relief to patients outside the hospice benefit construct a potentially unnecessary division between the dying and the merely ill. The division has the logic of bureaucratic monitoring behind it; namely, the hospice benefit is fairly generous for providers, and Medicare fears overuse if components of the benefit were available without strict rules subject to monitoring.

Another demand-side barrier is lack of information about end-of-life care opportunities. The evidence on the provision of care changing the demand for hospice is mixed. There is a new California law that provides such information guarantees, and evaluation of it would be useful for future research.<sup>61</sup> Cost-conscious payers prefer to focus on measurable processes (e.g., numbers of mammograms conducted, chemo doses administered) and outcomes.<sup>62</sup> Medical care providers can increase productivity in the dimensions of quality (e.g., via better scanning technology) or quantity (e.g., via electronic medical records) with the application of new technology. In contrast, it is hard to realize productivity increases in the area of meaningful communication, which requires scarce face-time between a care provider and the recipients of care. Economists have observed that areas with low productivity increases are subject to neglect and disinvestment as they are expensive relative to high-productivity areas.<sup>63</sup>

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61. Right to Know Act of 2009, H.R. 2747, 2008 Assem., Reg. Sess. (Cal. 2008), available at [http://www.leginfo.ca.gov/pub/07-08/bill/asm/ab\\_2701-2750/ab\\_2747\\_bill\\_20080930\\_chaptered.pdf](http://www.leginfo.ca.gov/pub/07-08/bill/asm/ab_2701-2750/ab_2747_bill_20080930_chaptered.pdf).

62. Non-measurable, "soft" activities are often overlooked by highly scrutinized cost-conscious systems that involve public payment, a concept elaborated on at some length by Paula England and Nancy Folbre. See Paula England & Nancy Folbre, *Contracting for Care*, in *FEMINIST ECONOMICS TODAY: BEYOND ECONOMIC MAN* 61 (Marianne A. Ferber & Julie A. Nelson eds., 2003).

63. This observation regarding the stresses on sectors with low-productivity growth, sometimes referred to as the "cost disease of the service sector," is due to New York University economist William J. Baumol. See WILLIAM J. BAUMOL & ALAN S.

Some analyses focus on the implicit discontinuity of care in hospice to explain why a relatively generous benefit has rather low utilization. Hospice enrollment requires a physician's diagnosis that the patient has less than six months to live. The break from patient to dying person may discourage enrollment in hospice. Some experiments with more flexible, continuous transition from curative to end-of-life palliative care have made palliative care available immediately following a poor prognosis rather than requiring the six-month trigger.<sup>64</sup> As with other dimensions of health care services, there is evidence that health care providers can induce demand for available or profitable services. For example, it is well established that regions with high densities of hospital beds have a disproportionate number of in-hospital deaths.<sup>65</sup> Demand for hospice care may lack an advocate among providers in the health care system.

The core of the Medicare hospice benefit pays providers a per diem rate, which varies by the intensity of the health care activity: \$110 for routine home care; \$644 for continuous home care; \$114 for inpatient respite care; and \$491 for general inpatient care.<sup>66</sup> Hospice operators report adequate reimbursement except during initial intake, when extensive counseling and diagnosis is required; during inpatient crises when the per diem must cover the full cost of provided care; and in the final stages of death, when highly attendant care is required. Because hospice reimbursement is constant, while costs generally follow a u-shaped trajectory (costs are high at the beginning and end of hospice use), there is a disincentive for hospices to accept patients for short stays. Indeed, there is some evidence that hospices incur financial loss for shorter stays and that private for-profit hospices are strategic in their enrollment of long-stay patients. There is significant variation among hospices regarding financial viability. Nursing homes may face financial barriers to

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BLINDER, *ECONOMICS: PRINCIPLES AND POLICIES* 623 (5th ed. 1991); ENGLAND & FOLBRE, *supra* note 62 (discussing the implications for care services in particular); *see also* Nancy Folbre, *When a Commodity Is Not Exactly a Commodity*, 319 *SCIENCE* 1769 (2008).

64. LARRY BERESFORD, IRA BYOCK & JEANNE SHEILS, ROBERT WOOD JOHNSON FOUND., *FINANCIAL IMPLICATIONS OF PROMOTING EXCELLENCE IN END-OF-LIFE CARE* 19 (2002), *available at* [http://www.promotingexcellence.org/files/public/finance\\_monograph.pdf](http://www.promotingexcellence.org/files/public/finance_monograph.pdf); *see also* MOON & BOCCUTI, *supra* note 19, at 14 (discussing the Program of All-inclusive Care for the Elderly (PACE)).

65. *See* Ezekiel J. Emanuel et al., *Managed Care, Hospice Use, Site of Death, and Medical Expenditures in the Last Year of Life*, 162 *ARCHIVES INTERNAL MED.* 1722, 1727 (2002).

66. MOON & BOCCUTI, *supra* note 19, at 12 tbl.3.

providing palliative care or hospice care, and these barriers may reduce the incentives to develop and provide high-quality palliative care systems, which would in turn attract more dying patients.

The six-month rule provides the Medicare administration with an opportunity to audit strategic enrollment of long-staying patients.<sup>67</sup> A straightforward alternative would be to change the structure of the hospice benefit by increasing the reimbursement for enrollment and for the intensive support immediately preceding death. The Medicare hospice benefit also interacts in a complex manner with Medicare managed care (Medicare Advantage). Medicare Advantage enrollees who enter hospice have the hospice benefit covered by the traditional Medicare program. The hospice care benefit thus releases the Medicare Advantage program from the cost of hospice care for patients who enter hospice, the only Medicare benefit that so reverts from Medicare Advantage to traditional Medicare. Medicare Advantage thus has an outlet to avoid the high cost of care for dying patients by transferring them to hospice.<sup>68</sup>

The high cost of care for patients who are predicted to have a high likelihood of death is not fully compensated by the risk-adjustment system (DCG-PIP) used to adjust Medicare Advantage payments. Medicare Advantage plans have, in general, avoided patients likely to die despite the possibility of releasing such patients into the care of hospice under the Medicare hospice benefit. Because several reconfigurations of care are possible, including hospice enrollment and Medicare Advantage disenrollment, the implications of the program interactions have not been fully explored. It is clear that Medicare Advantage beneficiaries are more likely to use hospice (twenty-six percent versus fifteen percent among patients in traditional Medicare), but joint enrollment statuses may reflect decisions made in the lead-up to death. If there are savings from hospice care compared to aggressive curative treatment until death, whose savings are they? The parties that could potentially benefit include the patient; her family, survivors, or estate; care providers, with possibly different savings to hospitals and physi-

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67. See *NEW APPROACHES IN MEDICARE*, *supra* note 18, at 139; see also *MEDICARE PAYMENT ADVISORY COMM'N, REPORT TO THE CONGRESS: REFORMING THE DELIVERY SYSTEM* 203 (2008), [http://www.medpac.gov/documents/Jun08\\_EntireReport.pdf](http://www.medpac.gov/documents/Jun08_EntireReport.pdf) [hereinafter *REFORMING THE DELIVERY SYSTEM*].

68. Melinda Beeuwkes Buntin et al., *The Costs of Decedents in the Medicare Program: Implications for Payments to the Medicare+Choice Plans*, 39 *HEALTH SERVICES RES.* 111, 114 (2004).

cians; and insurers, with possibly different implications for private and public insurers on ultimate savings.

On the supply side, excellent end-of-life care requires providers to communicate with patients and their families. Communication needs to begin early, with the negotiation of desires, needs, and intentions and their inscription in an advance directive, which is best completed before loss of capacity or even the onset of critical illness. Only thirty percent of Americans report having a living will, including a mere fifty percent of those with terminal illness, and more than sixty percent of patients with living wills do not give copies to their physicians.<sup>69</sup> Furthermore, advance directives do not appear to be the last word, with frequent disputes and misinterpretations of intentions by proxies and providers. Communication among the people involved clearly needs to continue beyond the sealing of the advance directive through the process of treatment and the approach of death.<sup>70</sup>

Communication is chronically undervalued and underfunded by the public and private health care finance systems. Communication is hard to monitor, hard to justify in measurable terms, and does not leave a clearly defined material trail for accountants. Excellent end-of-life care can benefit from communication in the advance directive process, through the difficult decisions around the discontinuation of curative efforts and the adoption of exclusively palliative care, through counseling and comfort for the dying person, and through solace and processing for the bereaved. The United States health care system is ill-equipped to finance the type of communication required to improve end-of-life care, and the pressures on this type of care are likely to increase over time. Physicians can bill Medicare for “advance care planning sessions,” but there is some evidence that the coverage is not widely known among physicians.<sup>71</sup>

Physician reimbursement for conversations with patients, for example, to discuss advance directives, is quite limited under some care arrangements. The current Resource-Based Relative Value Scale (RBRVS) for Medicare directs resources towards specialty rather than general practice and towards expensive technological

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69. Kevin B. O'Reilly, *Defective Directives? Struggling with End-of-Life Care*, AM. MED. NEWS, Jan. 5, 2009, <http://www.ama-assn.org/amednews/2009/01/05/prsa0105.htm>.

70. The apparently impending national drive to create electronic medical records may have a significant effect on this communication.

71. MOON & BOCCUTI, *supra* note 19, at 1.



interventions rather than office visits.<sup>72</sup> Capitated fees also reduce the physician's incentive to engage in discussion about long-term planning, such as presenting and discussing advance directives. Yet, there is some evidence that physician discussion of advance directives does increase uptake by patients. However, one component of the SUPPORT study, a randomized controlled trial of incentives to participate in conversations about care directives, failed to demonstrate an impact of physician-initiated discussion on patient willingness to express preferences regarding end-of-life care.<sup>73</sup>

The Kessler and McClellan study found mixed results with respect to the effect of interstate variation on advance directive policy on the structure of care and the use of health resources at the end of life.<sup>74</sup> As with palliative care, the use of advance directives seems to have little relationship to the cost of treatment.<sup>75</sup> States that provide greater incentives for following the dictates of advance directives have a modestly lower share of deaths occurring in acute-care hospitals, but a slightly higher rate of nonacute hospital stays.<sup>76</sup> States that provide for the appointment of a surrogate decision maker in the absence of advance directives have a slightly higher share of deaths occurring in the hospital, but a slightly lower rate of nonacute hospital stays.<sup>77</sup> The nondefinitive results suggest the possibility of imprecise coding of the state institutional environment or a limited impact that is swamped by other factors.<sup>78</sup>

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72. See Paul B. Ginsburg & Robert A. Berenson, *Revising Medicare's Physician Fee Schedule—Much Activity, Little Change*, 356 *NEW ENG. J. MED.* 1201 (2007) (discussing the possible shortcomings of the RBRVS); John D. Goodson, *Unintended Consequences of Resource-Based Relative Value Scale Reimbursement*, 298 *JAMA* 2308 (2007) (same).

73. See Laura C. Hanson, James A. Tulsky & Marion Danis, *Can Clinical Interventions Change Care at the End of Life?*, 126 *ANNALS INTERNAL MED.* 381 (1997), available at <http://www.annals.org/cgi/content/full/126/5/381>; see also *supra* note 17. However, Emanuel and Emanuel criticize the design of the communication intervention in the SUPPORT study because it involved indirect communication from the patient to the physician via a nurse facilitator. See Emanuel & Emanuel, *supra* note 34, at 1908.

74. See Kessler & McClellan, *supra* note 32, at 20.

75. *Id.*

76. *Id.* at 19-20.

77. *Id.* at 20.

78. *Id.* at 4.

## V. WHO RECEIVES HIGH-QUALITY END-OF-LIFE CARE? THE DISTRIBUTION OF CARE BY RACE AND INCOME

So far we have suggested that there are weak incentives for high-quality end-of-life care and substantial incentives for inefficient cost shifting. Market and institutional factors disempower patients from demanding high-quality care, and inhibit providers from supplying high-quality care to many dying people. Discontinuous care systems and sharp resource shifts among providers, and between providers and payers, depending on the organization of care, are examples of these incentives and large cost shifts. In this closing section, we examine some of the consequences of the underdeveloped and understructured end-of-life care system. Shortcomings in care are often most apparent among the least empowered people. We examine the racial and economic distribution of care as markers of how care is, or is not, made available.

African Americans are significantly more likely to die in hospitals and less likely to die in hospice care than are whites.<sup>79</sup> African Americans constituted 8% of deaths in hospice care, although they constituted 11% of the population and 11.4% of deaths from heart attack, cancer, and stroke.<sup>80</sup> African Americans were also more likely to spend less time in hospice care. Of hospice deaths for whites, 37.4% involved care for more than one month, while for African Americans, only 31.5% involved hospice care for more than one month.<sup>81</sup> Furthermore, the cost of care in the last year of life is actually higher for African Americans than for whites.<sup>82</sup>

One interpretation of these observations is that African Americans and other minorities, fearing hospice as a form of warehousing and a site in which the medical needs of minority patients can be systematically ignored, eschew hospice and insist on more aggressive, hospital-based intervention.<sup>83</sup> For example, one health

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79. The National Center for Health Statistics reports general statistics on the use of hospice care. See FASTSTATS – Hospice Care, Center for Disease Control and Prevention, <http://www.cdc.gov/nchs/fastats/hospicecare.htm> (last visited Apr. 15, 2009).

80. See MELONIE HERON, U.S. DEP'T OF HEALTH & HUMAN SERVS., DEATHS: LEADING CAUSES FOR 2004, at 12 tbl.E, 95 tbl.I (2007), [http://www.cdc.gov/nchs/data/nvsr/nvsr56/nvsr56\\_05.pdf](http://www.cdc.gov/nchs/data/nvsr/nvsr56/nvsr56_05.pdf).

81. CHARACTERISTICS OF HOSPICE CARE DISCHARGES, *supra* note 20, at 10.

82. Amresh Hanchate et al., *Racial and Ethical Differences in End-of-Life Costs: Why Do Minorities Cost More Than Whites?*, 169 ARCHIVES INTERNAL MED. 493 (2009).

83. See, e.g., LAVERA CRAWLEY & MARJORIE KAGAWA SINGER, CALIFORNIA HEALTHCARE FOUNDATION, RACIAL, CULTURAL, AND ETHNIC FACTORS AFFECTING THE QUALITY OF END-OF-LIFE CARE IN CALIFORNIA: FINDINGS AND RECOMMENDA-

care provider opined, “[p]eople who have been fighting for access to that healthcare system are likely to be suspicious that we’re just looking for a reason to not give them all these goodies they’ve been trying to get.”<sup>84</sup>

There is, however, another explanation of the racial disparity that does not require attribution of ethnically specific tastes. A myriad of studies regarding the many dimensions of health care, including preventive care, cardiovascular care, and cancer, find that in the United States, African Americans and other minorities receive worse health care. There is no reason to believe that end-of-life care is different. The minority-white hospice gap provides indirect evidence that hospice-based end-of-life care is good care that is offered to and accepted by patients who generally receive higher quality health care.

Further evidence that hospice care, along with other forms of high-quality health care, is disproportionately available to people of higher socioeconomic status comes from the 1995-1998 Medicare Current Beneficiary Survey.<sup>85</sup> Of decedents with incomes above 300% of the Federal Poverty Level (FPL), 20% used hospice; of those with incomes between the FPL and 300%, 16% used hospice; of those with income below the FPL, only 14% used hospice.<sup>86</sup> In another analysis without access to individual income data, studies have shown that the cost of care in the last year of life is higher for decedents residing in high-poverty ZIP codes.<sup>87</sup> The gradient between education and hospice use is present but less pronounced: more-educated patients are slightly more likely to use hospice services.<sup>88</sup>

Another indicator of socioeconomic discrepancy in the distribution of hospice care is its use by the Medicare population at large and by the Medicaid population. Concerning the length of care, 38.5% of Medicare hospice users and only 26.3% of Medicaid hospice users received more than one month of hospice service with Medicare median length of service at 16.7 days and Medicaid at only 5.4 days.<sup>89</sup> The comparison may be imperfect because Medi-

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TIONS 20 (2007), <http://www.chcf.org/documents/chronicdisease/CulturalFactorsEOL.pdf> (for this view and supporting evidence from attitudinal surveys).

84. Mary Engel, *Whites Use a Hospice Most*, L.A. TIMES, Mar. 16, 2007, <http://articles.latimes.com/2007/mar/16/local/me-healthcare16>.

85. MOON & BOCCUTI, *supra* note 19, at 9.

86. *Id.*

87. Hogan et al., *supra* note 40, at 192.

88. *Id.*

89. CHARACTERISTICS OF HOSPICE CARE DISCHARGES, *supra* note 20, at 10 tbl.1.

care users are almost entirely over age sixty-five, while Medicaid users of hospice include a wider range of ages and a potentially different mix of diagnoses and reasons for hospice use.<sup>90</sup>

To the extent that the insurer difference, neighborhood income, and poverty characteristics are proxies for social class, the comparison contributes to the picture of palliative care as disproportionately available to people from higher social classes and aggressive, yet futile, treatment as disproportionately applied to people from lower social classes.

### CONCLUSION

This is very much an introduction to, rather than a definitive statement about, economic issues in the provision of the quality palliative care to which we believe every American should be entitled. Several things stand out clearly. We have been convinced by our review of the literature that substitution of palliative care for curative treatment offers little opportunity for *overall* savings in the health care system. But we have identified two main areas in which current economic policy inhibits access to high-quality palliative care: discontinuities for patients and reimbursement for providers.

Not enough information is available about the use and experience of palliative care, and this is an important area for future research. The evidence of the chilling effects of economics on access to care is observed indirectly, through the social and demographic characteristics of users. Far from being a cheap disposal of the poor and minorities, palliative care appears to be disproportionately used by the well-off and white. Additional research could profitably be done in the economic dimensions of several other areas of end-of-life care, as identified throughout the Article. These include, for example, the impact of policies on cost shifting,<sup>91</sup> a systemic analysis of costs and incentives of palliative care,<sup>92</sup> the effect of Medicare regulations preventing most treatments in hospice even if those treatments are palliative in effect, and the effect of the new California law requiring that patients be fully informed of numerous alternative forms of end-of-life care.<sup>93</sup>

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90. MOON & BOCCUTI, *supra* note 19, at 1; see also REFORMING THE DELIVERY SYSTEM, *supra* note 67.

91. See *supra* note 52 and accompanying text.

92. See *supra* note 53 and accompanying text.

93. See *supra* notes 60-61 and accompanying text.

The context of this and other additional research—the need for some kind of legal guarantee that palliative care will be readily available so that it can be freely chosen by any dying person—lends increased importance to doing additional research on the economic dimensions of end-of-life care. In particular, the reform of health care in the United States, which we hope is imminent, should take into account the ways in which economic parameters of end-of-life care influence the availability and quality of palliative care. Adding the economic perspective to the other, more overt forms of discouraging access to palliative care identified early in this Article may suggest the outline of an approach to litigation regarding the putative right to palliative care. It certainly suggests important considerations for creating a legislative right to palliative care as part of the general reform of health care being undertaken nationally and in each state.