

# Background

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## Empowering Patients as Key Decision Makers in the Face of Rising Health Care Costs

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**Abstract:** *The current trend of rapidly rising health care costs is unsustainable. Many proposed reforms to curb spending rely on some type of rationing imposed by an unaccountable government body. A better alternative would be to allow individual consumers to make their own decisions about care, including the self-rationing of medical services, based on cost and their own desires. Such a policy is compatible with American values of limited government and individual liberty and responsibility. State and federal policymakers should adopt measures to facilitate personal control of health care decisions.*

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Health care costs are consuming ever larger portions of the gross domestic product (GDP). There is broad bipartisan agreement on the need to control these rising costs and to control federal entitlement spending in general, including spending on the giant health care entitlements Medicare and Medicaid. However, the standard approach to limiting federal health care spending is to limit federal payments for medical goods and services. This limitation, in itself, is a form of health care rationing. In fact, rationing of one form or another is already a routine feature of public and private health insurance arrangements, although it is often covert, opaque, or subtle in its implementation.

For policymakers and the public, the basic question is not whether there should be rationing in health care: It already exists. Economics itself is an exercise

### Talking Points

- High and rising health care costs necessitate action to bring them under control.
- Patients should be in the driver's seat to make decisions about cost and benefit for their own health care.
- In the current U.S. health care system, barriers make it difficult for patients to participate effectively in these decisions.
- These barriers create problems for patients at all stages of life, but the problems become more pronounced at the end of life.
- To remove these barriers, policymakers should promote a free market for health insurance coverage and a free-market clearinghouse for health care information. They should also take steps, including medical liability reform, to increase provider comfort with patient empowerment.

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in rationing among goods and services because limited resources cannot purchase unlimited goods. The crucial question is: Who should make the rationing decisions?

Americans value personal liberty and self-rule—classical liberal values at the heart of American political culture. Given these values, Americans have consistently resisted any health care proposals that threaten to undermine these principles as they understand them. Although they acknowledge the problem of health care spending, including rising government spending, Americans are unlikely to accept rationing decisions made by a European-style “independent” body or an unaccountable government agency. Instead, policymakers should seek an American solution that enables individual patients to make the key decisions about their care in accordance with their own preferences, beliefs, and values. This is especially important in decisions relating to end-of-life care.

To achieve this level of patient engagement, policymakers must reduce or eliminate barriers to patient decision making, including patient ignorance of and insulation from the true costs of care, the lack of information on medical prices and options, and medical malpractice and inadequate skills among doctors and nurses and other medical professionals in dealing with an engaged patient. Policymakers need to make the health care sector far more transparent. They can do this by promoting a free market for health insurance coverage in which prices and the content of insurance are clear and transparent; creating an information-driven system of choice to enable patients to better understand the range of available benefits and services; enacting medical malpractice reform in

the states where it is sorely needed; and encouraging better education of medical professionals to prepare them to communicate more effectively and clearly with all patients, including those facing a long illness or the end of life itself.

## The Health Care Cost Explosion and Its Casualties

In 2000, the U.S. spent 13.8 percent of GDP on health care. By 2009, 17.6 percent of GDP went to health care costs.<sup>1</sup> By 2020, health care spending will consume an estimated 19.8 percent of GDP.<sup>2</sup> This is a conservative projection, which does not allow for a permanent or temporary imposition of a Medicare “doc fix,” the now traditional measure by which Congress reverses the scheduled reductions in Medicare physician payments required by current law. Any such adjustment will likely cost taxpayers hundreds of billions of dollars over the next two decades. Together, Medicare and Medicaid account for roughly one-half of all health care spending.<sup>3</sup>

Researchers have recently studied the effect of rising costs on a hypothetical average American family. Their findings show that health care costs are gradually eroding family take-home pay to the point that the discretionary portion of take-home pay rose only \$95 over the past decade.<sup>4</sup> If health care costs had risen only 1 percent more than GDP each year, discretionary take-home pay would have increased by \$355. This difference of \$260 was consumed by health care costs rising much faster than GDP.<sup>5</sup> According to one observer, “In effect, employees have been giving their pay raises to the health care system for the last 7 years.”<sup>6</sup> From another perspec-

1. Centers for Medicare and Medicaid Services, NHE tables, Table 1, at <https://www.cms.gov/NationalHealthExpendData/downloads/tables.pdf> (December 13, 2011).
2. Centers for Medicare and Medicaid Services, “National Health Expenditure Projections 2010–2020,” p. 4, at <https://www.cms.gov/NationalHealthExpendData/downloads/proj2010.pdf> (November 3, 2011).
3. Centers for Medicare and Medicaid Services, NHE tables, Table 1.
4. The authors ran this analysis without taking into consideration the portion of health care costs that contributed to the national debt. They explain that if they had included these unpaid costs, discretionary pay would have been reduced by \$390, thus requiring the family to reduce other expenditures by \$295.
5. David I. Auerbach and Arthur L. Kellermann, “A Decade of Health Care Cost Growth Has Wiped Out Real Income Gains for an Average US Family,” *Health Affairs*, Vol. 30, No. 9 (September 2011), pp. 1632–1633, at <http://content.healthaffairs.org/content/30/9/1630.full.pdf> (September 28, 2011; subscription required).
6. Helen Darling, “Control Health Care Costs and Improve Quality: We Have to Act Now,” Institute on Health Care Costs and Solutions, November 14, 2008, at <http://www.rwjf.org/files/research/101508.helendarlingpresentation.pdf> (October 4, 2011).

tive, the U.S. spends twice as much on health care as on food.<sup>7</sup>

Even if the current level of spending on health care were deemed acceptable, future increases in projected spending are clearly unsustainable because they would crowd out other priorities, particularly those funded by the federal government. According to the Congressional Budget Office (CBO), if public health care costs continue to expand as they have over the past 40 years and if additional funding were brought in only through increased income taxes, the situation would be unsustainable beyond 2050. By 2082 (roughly when people born this year would retire), public and private health care costs would consume the entire U.S. GDP. Clearly, policy-makers need to find a way to “bend the cost curve,” particularly in federal health care programs.

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**The Spectre of Government Rationing.** The recent focus on rationing has been intensified by rising costs and the congressional deliberations on key provisions of the Patient Protection and Affordable Care Act of 2010 (PPACA).

Explicit rationing occurs when decision makers deliberately set limits on care, generally utilizing some form of cost-benefit analysis. Such rationing occurs in Britain, which has a government-run national health plan that covers all citizens. Faced with the need to control costs, the U.K. established the National Institute for Clinical Excellence (NICE). NICE provides guidance on the treatment of medical conditions. When new technologies and drugs are released, NICE determines whether the benefits that they offer outweigh their costs. The national health plan covers the new therapy or drugs only if NICE approves.<sup>8</sup> Some prominent health policy specialists, such as former Senator Tom Daschle (D-SD), consider NICE a model rationing body to be emulated.<sup>9</sup>

In general, the British people seem satisfied with their health care system. Nevertheless, the system can be ruthless. Individual patients have made headlines in Britain when they have fought to receive effective treatments that NICE had deemed not cost-effective. Examples have included drugs to treat cancer<sup>10</sup> and Alzheimer’s disease.<sup>11</sup>

In the U.S. there are examples of explicit government rationing. States attempting to balance their budgets have rationed care offered through Medicaid. Most notably, under the Oregon Medicaid reform plan the state created “a prioritized list of health services (ranked according to clinical effectiveness and social value)” whereby “the scope of benefits would be tied explicitly to the budget process. Services above the cut-off line would be funded; those below the line would not be covered.”<sup>12</sup> More recently, Arizona’s

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7. Huma Khan, “Why Health Care Costs Keep Rising: What You Need to Know,” ABC News, March 9, 2010, at <http://abcnews.go.com/Politics/HealthCare/health-care-costs-biggest-drivers/story?id=10044091> (October 4, 2011).
  8. Amanda Owen-Smith, Joanna Coast, and Jenny Donovan, “Are Patients Receiving Enough Information About Healthcare Rationing? A Qualitative Study,” *Journal of Medical Ethics*, Vol. 36, No. 2 (February 2010), p. 88, at <http://jme.bmj.com/content/36/2/88.full.pdf> (September 30, 2011).
  9. Conn Carroll, “Nailing Down Daschle’s Direction on Health Care,” The Heritage Foundation, The Foundry, January 8, 2009, at <http://blog.heritage.org/2009/01/08/morning-bell-nailing-down-daschles-direction-on-health-care/> (December 18, 2011).
  10. BBC News, “Woman Loses Herceptin Court Bid,” February 15, 2006, at <http://news.bbc.co.uk/2/hi/health/4715430.stm> (October 7, 2011).
  11. Associated Press, “Alzheimer’s Patients Sue U.K. for Drugs,” CBS News, May 18, 2009, at <http://www.cbsnews.com/stories/2007/06/27/health/main2985997.shtml> (October 7, 2011).
  12. Margo L. Rosenbach, A. James Lee, Constance Hwang, Steven A. Garfinkel, and Nancy Swigonski, *The Evolution of the Oregon Health Plan: First Interim Report*, Centers for Medicare and Medicaid Services, December 12, 1997, p. ES-2, at [http://www4a.cms.gov/DemonstrProjectsEvalRepts/downloads/OMR\\_First\\_Interim\\_Report.pdf](http://www4a.cms.gov/DemonstrProjectsEvalRepts/downloads/OMR_First_Interim_Report.pdf) (December 18, 2011).

Medicaid program stopped covering some organ transplants,<sup>13</sup> and Hawaii plans to cut inpatient hospital coverage to 10 days per year.<sup>14</sup> Medicare also places some stark limits on coverage: Patients are responsible for all inpatient costs after 150 days in a hospital,<sup>15</sup> and there is a 190-day lifetime limit on inpatient psychiatric care.<sup>16</sup>

Implicit rationing is more subtle than a formal payment decision to deny coverage for a particular service, such as a treatment, test, or medication. Rather, implicit rationing occurs when a payer agrees to cover all services, but sets a limit on the price to be paid for each. In theory, covered members can access the service, but problems arise when providers stop offering the service after determining that the allowed payment is inadequate to cover their costs. As providers stop offering the service, availability drops, and patients are forced to wait longer for treatment.

For example, the Canadian system controls health care costs through budgetary and payment restrictions.<sup>17</sup> In Saskatchewan, patients diagnosed with cancer must wait to see an oncologist and then wait

again for each phase of treatment because there is a shortage of oncologists. Moreover, patients wishing to seek treatment elsewhere in Canada are advised that there are waits throughout the country.<sup>18</sup> Indeed, some Canadian patients cross the border into the U.S. to obtain care, paying for their care out of their own pockets—an option they may not have in Canada, where private health care is technically illegal.<sup>19</sup>

American patients with Medicaid, which pays less than other payers, also have difficulties accessing care. Researchers have found that children with Medicaid have difficulty accessing specialists. Even when they are able to make an appointment, they will likely wait an average of 22 days longer than children covered by other payers.<sup>20</sup> Medicare patients can also experience access problems, as doctors and other medical professionals facing reduced Medicare payments are increasingly refusing to accept new Medicare patients.<sup>21</sup> Additionally, providers who accept Medicare are not allowed to bill patients extra for care or services which Medicare inadequately reimburses. This may mean that Medicare patients cannot access care for which they would be willing to pay out of pocket.<sup>22</sup> Of course,

13. Kevin Sack, "Arizona Medicaid Cuts Seen as a Sign of the Times," *The New York Times*, December 4, 2010, at <http://www.nytimes.com/2010/12/05/us/05transplant.html> (October 7, 2011).
14. Phil Galewitz, "States Are Limiting Medicaid Hospital Coverage in Search for Savings," Kaiser Health News, October 24, 2011, at <http://www.kaiserhealthnews.org/Stories/2011/October/24/States-Are-Limiting-Medicaid-Hospital-Coverage-In-Search-For-Savings.aspx> (October 24, 2011).
15. U.S. Department of Health and Human Services, "Medicare Premiums and Coinsurance Rates for 2011," November 2010, at [https://questions.medicare.gov/app/answers/detail/a\\_id/2305/-/medicare-premiums-and-coinsurance-rates-for-2011](https://questions.medicare.gov/app/answers/detail/a_id/2305/-/medicare-premiums-and-coinsurance-rates-for-2011) (September 30, 2011).
16. Centers for Medicare and Medicaid Services, "Medicare and Your Mental Health Benefits," December 2009, p. 11, at <http://www.medicare.gov/publications/pubs/pdf/10184.pdf> (September 30, 2011).
17. Theodor Marmor, Jonathan Oberlander, and Joseph White, "The Obama Administration's Options for Health Care Cost Control: Hope Versus Reality," *Annals of Internal Medicine*, Vol. 150, No. 7 (April 7, 2009), p. 487, at <http://www.annals.org/content/150/7/485.full.pdf> (December 18, 2011).
18. Saskatchewan Cancer Agency, "Frequently Asked Questions," 2011, at <http://www.saskcancer.ca/Default.aspx?DN=832aa54e-b999-4241-bd70-27c7f447cf6e> (September 30, 2011).
19. Kim Murphy, "In Canada, a Move Toward a Private Healthcare Option," *The Los Angeles Times*, September 27, 2009, at <http://articles.latimes.com/2009/sep/27/nation/na-healthcare-canada27> (October 6, 2011).
20. Joanna Bisgaier and Karin V. Rhodes, "Auditing Access to Specialty Care for Children with Public Insurance," *The New England Journal of Medicine*, Vol. 364, No. 24 (June 16, 2011), p. 2324, at <http://www.nejm.org/doi/pdf/10.1056/NEJMs1013285> (September 30, 2011).
21. Richard Wolf, "Doctors Limit New Medicare Patients," *USA Today*, June 21, 2010, at [http://www.usatoday.com/news/washington/2010-06-20-medicare\\_N.htm](http://www.usatoday.com/news/washington/2010-06-20-medicare_N.htm) (September 30, 2011).
22. Victoria Stagg Elliott, "Physicians Seek Right to Balance-Bill Under Medicare," *American Medical News*, January 6, 2003, at <http://www.ama-assn.org/amednews/2003/01/06/gvsb0106.htm> (October 28, 2011).

patients with no insurance coverage also have difficulty accessing care.

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**Doctors and other medical professionals facing reduced Medicare payments are increasingly refusing to accept new Medicare patients.**

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Dr. Donald Berwick, former administrator of the Centers for Medicare and Medicaid Services (CMS), indicated that he would like to move the U.S. toward a more explicit and centralized system of rationing. An admirer of NICE, he said of rationing in America, “The decision is not whether or not we will ration care—the decision is whether we will ration with our eyes open. And right now, we are doing it blindly.”<sup>23</sup>

Acknowledging the public relations nightmare of trying to impose a system of explicit rationing on the American people, the Obama Administration and the congressional sponsors of the PPACA chose instead the path of implicit rationing through price controls and progressive payment reductions for medical services. Most notably, the Independent Payment Advisory Board (IPAB) is tasked with bending the cost curve of Medicare, but is not allowed to recommend any reduction in services or explicit rationing. However, it is specifically authorized to reduce payments to doctors and other medical professionals to meet budget or statutorily ordained spending targets. This opens up an avenue for rationing through reimbursement reductions and threatens reduced access for Medicare beneficiaries. Moreover, IPAB’s recommendations automatically

go into effect unless Congress enacts legislation achieving equal cuts by other means.<sup>24</sup>

**A Conflicted Country.** Americans appear to be uncertain over how to control health care spending. Seventy-six percent of Americans are “dissatisfied with the total cost of health care in this country,” and 83 percent say that they personally worry about “the availability and affordability of healthcare” a fair amount or quite a lot.<sup>25</sup> Nevertheless, Americans are divided on the concept of making decisions based on cost:

When asked if it is better to keep a terminally ill person alive as long as possible, regardless of the expense, or to make a judgment as to whether it’s worth the expense, 48 percent said it’s better to weigh the costs, compared with 40 percent who said to keep the person alive as long as possible, regardless of the cost.<sup>26</sup>

### The Big Drivers of Health Care Costs

Any discussion of how to reduce health care costs must include a discussion of the drivers of health care costs. In a health care economy as complex as that of the United States, the answer is also complex.

Health policy analysts generally agree that innovative technologies—including pharmaceuticals, diagnostic tests, and treatments—are an important and initial driver of health care costs.<sup>27</sup> Many new technologies are expensive. Some experts say this reflects the cost of the development and approval process.<sup>28</sup> Even if a new technology is less expensive than the option it replaces, it may increase overall costs if more people use it. For example, the development of tech-

23. “Rethinking Comparative Effectiveness Research,” *Biotechnology Healthcare*, June 2009, p. 36, at <http://www.biotechnologyhealthcare.com/journal/fulltext/6/2/BH0602035.pdf> (October 3, 2011).

24. Grace-Marie Turner, James C. Capretta, Thomas P. Miller, and Robert E. Moffit, *Why Obamacare Is Wrong for America* (New York: HarperCollins, 2011), p. 33.

25. Gallup, “Healthcare System,” 2011, at <http://www.gallup.com/poll/4708/Healthcare-System.aspx> (October 3, 2011).

26. Julie Appleby, “Debate Surrounds End-of-Life Health Care Costs,” *USA Today*, October 19, 2006, at [http://www.usatoday.com/money/industries/health/2006-10-18-end-of-life-costs\\_x.htm](http://www.usatoday.com/money/industries/health/2006-10-18-end-of-life-costs_x.htm) (October 25, 2011).

27. Congressional Budget Office, “Technological Change and the Growth of Health Care Spending,” January 2008, p. 1, at <http://www.cbo.gov/ftpdocs/89xx/doc8947/01-31-TechHealth.pdf> (October 6, 2011).

28. U.S. Department of Commerce, International Trade Administration, *Pharmaceutical Price Controls in OECD Countries: Implications for U.S. Consumers, Pricing, Research and Development, and Innovation*, December 2004, p. 25, at <http://www.trade.gov/td/health/drugpricingstudy.pdf> (October 7, 2011).

nology to remove gallbladders laparoscopically has led to a 60 percent increase in the number of people having their gallbladders removed.<sup>29</sup>

New technologies fall along a spectrum from the most beneficial to the least, and medical professionals widely agree that overuse of some technologies contributes to waste in the health care system. For example, health care expenditures vary significantly among different regions of the United States. Further examination reveals that regions with higher expenditures use expensive therapies more frequently without a corresponding improvement in health outcomes.<sup>30</sup> International comparisons of outcomes reveal that “even if the difference between a very parsimonious and a moderately generous country (in terms of procedure use) is substantial, the difference between a moderately generous country and a very generous one is not.”<sup>31</sup> This suggests that there is a point on the health care spending curve beyond which further spending does not lead to better outcomes. Treatments beyond that point would be obvious targets for spending limitations and thus rationing.

End-of-life care is perhaps the most controversial topic in discussions of costs and rationing. Care for patients at the end of life does *not* drive growth in health care spending, but it does represent a significant portion of spending, especially among the Medi-

care population. Although only 5 percent of Medicare beneficiaries die each year, one-quarter of Medicare expenditures are for care of beneficiaries in their last year of life and one-tenth are for care in the last 30 days.<sup>32</sup> Some believe that 20 percent to 30 percent of this money does not yield beneficial results.<sup>33</sup> For another perspective, 77 percent of an average patient’s Medicare expenditures will occur in his last year, and 40 percent in his last month of life.<sup>34</sup> At the end of life, as for health care costs generally, health care spending varies widely by region. In 2006, it cost 3.5 times more to die in Manhattan than in Wichita Falls, Texas.<sup>35</sup>

The problem is that “productive care and wasteful care are not so easy to tell apart.”<sup>36</sup> For example, one study found that hospitals that spend the most on caring for patients at the end of life do not show measurably better results than those that spend the least. Yet a later study using a different methodology found that patients may indeed live longer when treated at the more aggressive medical centers. Dr. David T. Feinberg, chief executive officer of the “high-spending” Ronald Reagan UCLA Medical Center, says, “If you come into this hospital, we’re not going to let you die.” While Feinberg and his colleagues are seeking to reduce waste in the care that they provide, they are proud of their accomplishments in keeping very sick people alive.<sup>37</sup>

29. Thomas Bodenheimer, “High and Rising Health Care Costs. Part 2: Technologic Innovation,” *Annals of Internal Medicine*, Vol. 142, No. 11 (June 7, 2005), p. 932, at [http://dms.dartmouth.edu/cfm/education/PDF/health\\_care\\_costs\\_2.pdf](http://dms.dartmouth.edu/cfm/education/PDF/health_care_costs_2.pdf) (October 5, 2011).
30. Brenda Sirovich, Patricia M. Gallagher, David E. Wennberg, and Elliott S. Fisher, “Discretionary Decision Making by Primary Care Physicians and the Cost of U.S. Health Care,” *Health Affairs*, Vol. 27, No. 3 (May/June 2008), pp. 813–823, at <http://content.healthaffairs.org/content/27/3/813.full.pdf> (October 5, 2011).
31. John F. Cogan, R. Glenn Hubbard, and Daniel P. Kessler, *Healthy, Wealthy, and Wise: 5 Steps to a Better Health Care System*, 2nd ed. (Washington, D.C.: AEI Press, 2011), p. 15.
32. Christopher Hogan, June Lunney, Jon Gabel, and Joanne Lynn, “Medicare Beneficiaries’ Costs of Care in the Last Year of Life,” *Health Affairs*, Vol. 20, No. 4 (July/August 2001), p. 188, at <http://content.healthaffairs.org/content/20/4/188.full.pdf> (October 5, 2011).
33. CBS News, “The Cost of Dying: End-of-Life Care,” August 8, 2010, at <http://www.cbsnews.com/stories/2010/08/05/60minutes/main6747002.shtml> (October 5, 2011).
34. John M. Luce and Gordon D. Rubenfeld, “Can Health Care Costs Be Reduced by Limiting Intensive Care at the End of Life?” *American Journal of Respiratory Critical Care Medicine*, Vol. 165, No. 6 (March 2002), p. 750, at <http://ajrccm.atsjournals.org/cgi/reprint/165/6/750> (October 18, 2011).
35. Appleby, “Debate Surrounds End-of-Life Health Care Costs.”
36. Cogan *et al.*, *Healthy, Wealthy, and Wise*, p. 15.
37. Reed Abelson, “Months to Live: Weighing Medical Costs of End-of-Life Care,” *The New York Times*, December 22, 2009, at <http://www.nytimes.com/2009/12/23/health/23ucla.html> (October 5, 2011).

Here again is an area where many consider rationing would be an obvious move, yet in no area of health care is the fear of rationing more visceral, as the discussions of “death panels” revealed. On one side are those who decry spending large amounts of money to pursue care that is likely futile. This group believes that it would be more ethical to spend this money in other ways. On the other side are those who believe that patients and families should be allowed or even encouraged to pursue every available treatment option while life exists. For them, the idea of limiting care to reduce cost is morally unacceptable. Because the two views are intrinsically related to the moral, ethical, and religious beliefs of those who hold them, the two sides seem unlikely to agree about decisions on rationing health care.

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**The Wrong Question.** The conflict may arise from attempts to answer the wrong question. Instead of discussing *how* government can ration care or reduce costs, perhaps leaders should be asking *who* should ration care. The American ethos has always valued individual liberty and responsibility. It should not be surprising that Americans resist outside attempts to restrict their ability to make their own decisions about their health care. Instead of imposing rationing from the top down, the U.S. should empower individual Americans to ration their own care, each according to his own beliefs and preferences.

### **Barriers to Patient Decision Making**

There are several barriers to patient decision making over care, and many are structural and a direct result of government policy.

**Ignorance of True Cost.** Various components of the U.S. health care system reduce incentives for consumers to control the costs of their own care. Structurally, the third-party payer system, especially when there is low cost-sharing, largely insulates patients and providers from the costs of their decisions. They have few incentives to pursue low-cost health care options, even when those options might be just as effective, if not more so. Thus, for many patients the value in health care is completely divorced from the financial cost to them.

By giving almost exclusive preference to employer-provided insurance, the U.S. tax code discourages an employee from purchasing a policy on the individual market that may better meet his needs and preferences. In 2005, Americans with private insurance were eight times more likely to obtain their coverage through their employers than through the individual market (64.1 percent versus 8.3 percent of all Americans).<sup>38</sup>

Unlike other sectors of the economy, the provision of health care benefits and services is often divorced from consumers’ specific wants and needs. Moreover, the pre-tax exemption on health insurance premiums provides an incentive for employees to prefer more expensive plans with lower out-of-pocket costs. As already noted, this in turn encourages increased utilization. Once an employee has the expensive health insurance plan, he feels driven to use it to get his money’s worth,<sup>39</sup> much as a consumer at an all-you-can-eat buffet will eat more than if he were paying by the item.<sup>40</sup>

Medicare beneficiaries with supplemental coverage (90 percent of all Medicare beneficiaries<sup>41</sup>) experience a similar lack of incentive to reduce expenses because many supplemental plans reduce out-of-pocket costs to near zero. Once the con-

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38. Richard L. Kaplan, “Who’s Afraid of Personal Responsibility? Health Savings Accounts and the Future of American Health Care,” University of Illinois College of Law *Law and Economics Working Paper* No. 40, 2005, pp. 438 and 542, at <http://law.bepress.com/cgi/viewcontent.cgi?article=1039&context=uiucwps> (November 3, 2011).

39. *Ibid.*, p. 548.

40. David R. Just and Brian Wansink, “The Fixed Price Paradox: Conflicting Effects of ‘All-You-Can-Eat’ Pricing,” June 9, 2008, at <http://agnr.umd.edu/departments/AREC/Department/Seminars/2008-2009/AYCE%206-13-08.pdf> (November 3, 2011).

41. Henry J. Kaiser Family Foundation, “Supplemental Coverage Among Medicare Beneficiaries, by Income, 2008,” January 18, 2011, at <http://facts.kff.org/chart.aspx?ch=1931> (October 20, 2011).

sumer has purchased the coverage—frequently at his own expense—he has no reason not to use it. Moreover, traditional Medicare does not include even the cost controls used by private insurance, such as utilization review or preferred provider networks.<sup>42</sup> Instead, under its fee-for-service structure, providers have incentives to order more tests and treatments while patients have few incentives to question the benefits of these recommendations. Finally, tight legislative control of Medicare makes the program susceptible to lobbying by special-interest organizations.<sup>43</sup> For most of these organizations, their mission is to expand benefits and increase costs, shifting even more of the costs onto the taxpayers.

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**Lack of Information.** To weigh costs and benefits appropriately, a patient must know both to some degree. Yet even a consumer motivated to be cost-conscious might find the lack of necessary information to be a barrier.

*Lack of medical information.* As the culture of medical paternalism evolved to acknowledge the

importance of patient autonomy, the concept of informed consent emerged. The American Medical Association defines informed consent as “a process of communication between a patient and physician that results in the patient’s authorization or agreement to undergo a specific medical intervention.”<sup>44</sup> Although the informed consent process includes discussion of alternative treatments, it generally occurs in the context of the provider’s “proposed treatment.”<sup>45</sup> Ultimately, the patient just says “yes” or “no” to the treatment the doctor offers.<sup>46</sup>

In recent years, this has led to calls for broader patient involvement emphasizing “meaningful dialogue between physician and patient instead of a unidirectional, dutiful disclosure of alternatives, risks, and benefits by the physician.”<sup>47</sup> There is room for improvement. A 1999 analysis of 3,552 decisions ranging from minor to serious in the outpatient clinic setting showed that only 9 percent fully met the criteria for informed decision making. Even for serious decisions, physicians informed patients of pros and cons of the recommended treatment and other alternatives less than 30 percent of the time. Physicians also elicited patient preferences less than 30 percent of the time.<sup>48</sup> In a survey of patients who had discussed cancer screenings (e.g., breast, prostate, and colon) with their providers, 90 percent reported that the provider had discussed the pros of the screen, but only 19 percent to 30 percent reported discussing the cons.<sup>49</sup>

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42. Francis Walton, *Putting Medicare Consumers in Charge: Lessons from the FEHBP* (Washington, D.C.: AEI Press, 2009), pp. 18 and 27.

43. *Ibid.*, p. 60.

44. American Medical Association, “Informed Consent,” at <http://www.ama-assn.org/ama/pub/physician-resources/legal-topics/patient-physician-relationship-topics/informed-consent.page> (October 20, 2011).

45. *Ibid.*

46. American Cancer Society, “How Is Shared Decision-Making Different from Informed Consent?” August 10, 2010, at <http://www.cancer.org/Treatment/FindingandPayingforTreatment/UnderstandingFinancialandLegalMatters/InformedConsent/informed-consent-shared-decision-making> (October 20, 2011).

47. Clarence H. Braddock III, Kelly A. Edwards, Nicole M. Hasenberg, Tracy L. Laidley, and Wendy Levinson, “Informed Decision Making in Outpatient Practice: Time to Get Back to Basics,” *JAMA*, Vol. 282, No. 24 (December 22/29, 1999), p. 2313, at <http://jama.ama-assn.org/content/282/24/2313.full.pdf> (October 20, 2011).

48. *Ibid.*, p. 2313.

49. Richard M. Hoffman, Carmen L. Lewis, Michael P. Pignone, Mick P. Couper, Michael J. Barry, Joann G. Elmore, Carrie A. Levin, John Van Hoewyk, and Brian J. Zikmund-Fisher, “Decision-Making Processes for Breast, Colorectal, and Prostate Cancer Screening: The DECISIONS Survey,” *Medical Decision Making*, Vol. 30, No. 5 (September/October 2010).

Patients who have used decision aids, which can include booklets and DVDs, and participated in shared decision making expressed a preference for being involved in their care. A majority of patients want to make their own medical decisions, with a significant minority preferring to share decision making with their doctor. Only 2 percent to 4 percent want their medical decisions to be made mainly by their doctor.<sup>50</sup>

The development and use of decision aids have shown potential to improve patients' participation in decisions about their care. Moreover, a review of evidence suggests that patients who are more involved in their own care may choose less expensive options, including 20 percent fewer elective surgeries.<sup>51</sup> One analysis projects that use of decision aids and shared decision making for patients with 11 specific conditions would save the U.S. health care system \$9.2 billion over 10 years.<sup>52</sup>

Decision aids can also help patients who are planning for end-of-life care. One study divided patients with advanced cancer into two groups. Clinicians talked with both groups about different types of care: aggressive, including intensive care (ICU) and CPR; limited including hospitalization, but not ICU; and comfort care. One group also watched a video of real patients receiving each of

the three levels. After the intervention, patients who saw the video showed better understanding of the options and were dramatically more likely (92 percent versus 22 percent) to choose comfort care. One hundred percent of patients who viewed the video said that they would recommend the video to other patients in their situation.<sup>53</sup>

**Lack of Price Information.** Although many decision aids provide excellent information in an easily understood format, most do not include explicit cost information. Indeed, finding information about the costs of health care can be extremely difficult, especially before the care is provided. Even providers are often unaware of how much care costs individual patients, and payers may not be able to predict costs accurately in advance.<sup>54</sup> One factor confounding efforts to publish prices is the variability of pricing with providers charging different prices to different payers.<sup>55</sup> Other factors include lack of price availability due to contractual prohibitions or concerns about breaching anti-trust laws and the difficulty of determining total cost for services involving more than one provider. For example, multiple physicians and the hospital may submit separate bills for the same surgery.<sup>56</sup>

A poll in 2006 revealed that 84 percent of consumers would like to see health care prices pub-

50. Lyn Paget, "Shared Decision Making," in slideshow at the conference on "Saving Money and Improving Patient Care in Medicare: Ideas For the Joint Select Committee," Washington, D.C., October 19, 2011, slide 53, at [http://www.healthaffairs.org/events/2011\\_10\\_19\\_saving\\_money\\_and\\_improving\\_patient\\_care\\_in\\_medicare/media/slides.pdf](http://www.healthaffairs.org/events/2011_10_19_saving_money_and_improving_patient_care_in_medicare/media/slides.pdf) (October 20, 2011).
51. Dawn Stacey *et al.*, "Decision Aids for People Facing Health Treatment or Screening Decisions," Cochrane Database of Systematic Reviews, No. 10, 2011, at <http://www2.cochrane.org/reviews/en/ab001431.html> (October 20, 2011).
52. Cathy Schoen, Stuart Guterman, Anthony Shih, Jennifer Lau, Sophie Kasimow, Anne Gauthier, and Karen Davis, *Bending the Curve: Options for Achieving Savings and Improving Value in U.S. Health Spending*, Commonwealth Fund, December 2007, p. 20, at [http://www.commonwealthfund.org/usr\\_doc/Schoen\\_bendingthecurve\\_1080.pdf](http://www.commonwealthfund.org/usr_doc/Schoen_bendingthecurve_1080.pdf) (October 20, 2011).
53. Angelo E. Volandes, "Improving the Quality of End-of-Life Care Using Videos," presentation at the conference on "Saving Money and Improving Patient Care in Medicare," MP3 audio, Washington, D.C., at [http://www.healthaffairs.org/events/2011\\_10\\_19\\_saving\\_money\\_and\\_improving\\_patient\\_care\\_in\\_medicare/](http://www.healthaffairs.org/events/2011_10_19_saving_money_and_improving_patient_care_in_medicare/) (December 19, 2011).
54. Government Accountability Office, *Health Care Price Transparency: Meaningful Price Information Is Difficult for Consumers to Obtain Prior to Receiving Care*, GAO-11-791, September 2011, p. 14, at <http://www.gao.gov/new.items/d11791.pdf> (December 15, 2011).
55. Anna D. Sinaiko and Meredith B. Rosenthal, "Increased Price Transparency in Health Care—Challenges and Potential Effects," *The New England Journal of Medicine*, Vol. 364, No. 10 (March 10, 2011), pp. 891–892, at <http://www.nejm.org/doi/pdf/10.1056/NEJMp1100041> (October 20, 2011).
56. Government Accountability Office, *Health Care Price Transparency*, p. 14.

lished, and 79 percent said they would use this information to “shop for the best price.”<sup>57</sup> As more consumers find themselves in high-deductible consumer-driven health plans (CDHPs), interest in cost may rise.<sup>58</sup> One study showed that individuals enrolled in CDHPs with higher deductibles than traditional preferred-provider organization (PPO) plans are more likely to seek out information about health and cost of health care.<sup>59</sup> In Indiana, introduction of CDHPs with health savings accounts has saved the state an estimated 10.7 percent on the cost of care for enrollees. Enrollees themselves have also saved substantial amounts of money, and there is no evidence that enrollees are avoiding necessary care.<sup>60</sup>

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***In Indiana, introduction of CDHPs with health savings accounts has saved the state an estimated 10.7 percent on the cost of care for enrollees.***

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The federal government has called for more transparency and availability of pricing information.<sup>61</sup> More than 30 states are moving toward greater price transparency by publishing average or median pricing information by provider and procedure, and some attempt to provide quality information as well.<sup>62</sup> Although ease of navigation and comparison on these Web sites varies from state to state, comparing both price and quality is generally

difficult. The federal government provides quality and pricing information based on Medicare payment rates at Hospital Compare, but has deliberately not linked quality and pricing or promoted the availability of pricing information out of concern that consumers might “select high-priced providers due to an assumption that price indicates quality.”<sup>63</sup> This concern is valid, although cost information in the absence of corresponding quality data can be even more problematic for initiatives that do not link the two:

Timely and salient comparative quality information is often unavailable, so patients may rely on cost as a proxy for quality. The belief that higher-cost care must be better is so strongly held that higher price tags have been shown to improve patients’ responses to treatments through the placebo effect.<sup>64</sup>

In 2007, New Hampshire became one of the first states to provide online health care cost information. According to a recent Government Accountability Office report, the state is a model in demonstrating “that while providing complete cost information presents challenges, it can be done.”<sup>65</sup> Anecdotally, some lower-cost facilities in New Hampshire report that patients have reported choosing them for cost reasons, but overall results have been mixed. High-cost hospitals have not moved to reduce their costs, although in negotiations with insurers, they may have demanded lower increases than previously.

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57. Council for Affordable Health Insurance, “CAHI Releases Poll Showing Health Care Consumers Want to Know Prices,” May 1, 2006, at <http://www.cahi.org/article.asp?id=795> (October 20, 2011).
58. Parija B. Kavilanz, “Biggest Medical Mystery: The Bill,” CNN Money, April 22, 2009, at [http://money.cnn.com/2009/04/22/news/economy/doctors\\_pricing/](http://money.cnn.com/2009/04/22/news/economy/doctors_pricing/) (October 20, 2011).
59. Anna Dixon, Jessica Greene, and Judith Hibbard, “Do Consumer-Directed Health Plans Drive Change in Enrollees’ Health Care Behavior?” *Health Affairs*, Vol. 27, No. 4 (July/August 2008). p. 1129, at <http://content.healthaffairs.org/content/27/4/1120.full.pdf> (October 21, 2011).
60. Cory Gusland, Tyler Harshey, Nick Schram, and Todd Swim, “Consumer-Driven Health Plan Effectiveness—Case Study: State of Indiana,” Mercer, May 20, 2010, pp. 1–3, at [http://www.in.gov/spd/files/CDHP\\_case\\_study.pdf](http://www.in.gov/spd/files/CDHP_case_study.pdf) (October 21, 2011).
61. Madeline Kreischer, Andrew Thangasamy, Richard Cauchi, and Katie Mason, “State Legislation Relating to Transparency and Disclosure of Health and Hospital Charges,” National Conference of State Legislatures, October 2011, at <http://www.ncsl.org/default.aspx?tabid=14512> (October 21, 2011).
62. Sinaiko and Rosenthal, “Increased Price Transparency,” pp. 891–892.
63. Government Accountability Office, *Health Care Price Transparency*, p. 23.
64. Sinaiko and Rosenthal, “Increased Price Transparency,” p. 892.
65. Government Accountability Office, *Health Care Price Transparency*, p. 25.

One explanation may be that only 5.3 percent of insured patients in New Hampshire in 2007 had significant exposure to cost through high-deductible plans, so they had no incentive to seek a lower-cost alternative.<sup>66</sup>

Like the states, the private sector is seeking ways to provide consumers with improved pricing information. For example, Castlight is an organization that contracts with employers and health plans to provide members with information that allows them to compare prices and available patient satisfaction and quality measures. Other private companies and insurers are offering similar services with varying degrees of detail.<sup>67</sup> Aetna's initiative has addressed the "price as proxy for quality" issue by providing "information to educate consumers that high quality and low price are not mutually exclusive."<sup>68</sup> Like New Hampshire, Aetna has developed an initiative to provide "complete cost information."<sup>69</sup>

Retail walk-in clinics, which are typically staffed by nurse practitioners and conveniently located in large stores such as Wal-Mart and CVS, offer treatment for common acute illnesses and certain preventive services. These clinics are taking another approach to transparency by publicly posting price lists so consumers know up front exactly what they will be charged.<sup>70</sup> One study looked at three common conditions and found that patients who sought care for these conditions at a retail clinic paid 30 percent to 40 percent less than they would have at a physician's office or urgent care center and 80 per-

cent less than in an emergency department. Other studies have also shown cost savings.<sup>71</sup> Although patients most commonly cite convenience when asked why they chose to seek care in a retail clinic, 48 percent of patients in one survey identified lower cost as their reason. Patients listed lower cost and price transparency as contributing to their decision to use a retail clinic.<sup>72</sup> Physician groups have expressed concern about the quality of care provided in these clinics, but studies have shown that care is as good across several measures of quality as that provided in traditional settings.<sup>73</sup>

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**Systemic Barriers.** The structure of the medical system can also serve as a barrier. Achieving the desired outcome of consumer-driven health care requires health care providers who are skilled in communication and who are able and willing to discuss the relative benefits of given treatment options in light of a specific patient's condition and values.

**Systems and structures.** The most common payment structure for providers in the U.S. is fee for service (FFS), although some plans and systems have

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66. Ha T. Tu and Johanna R. Lauer, "Impact of Health Care Price Transparency on Price Variation: The New Hampshire Experience," Center for Studying Health System Change *Issue Brief* No. 128, November 2009, at <http://www.hschange.com/CONTENT/1095/1095.pdf> (October 20, 2011).

67. Anna Wilde Matthews, "Get Informed on Prices," *The Wall Street Journal*, August 21, 2011, at <http://online.wsj.com/article/SB10001424053111903639404576521010640869454.html> (October 21, 2011).

68. Government Accountability Office, *Health Care Price Transparency*, p. 24.

69. *Ibid.*, p. 25.

70. Robin M. Weinick, Craig Evan Pollack, Michael P. Fisher, Emily Meredith Gillen, and Ateev Mehrotra, "Policy Implications of the Use of Retail Clinics," RAND Corporation, 2010, pp. vii and 1, at [http://www.rand.org/content/dam/rand/pubs/technical\\_reports/2010/RAND\\_TR810.pdf](http://www.rand.org/content/dam/rand/pubs/technical_reports/2010/RAND_TR810.pdf) (October 21, 2011). See also, Devon Herrick, "Retail Clinics: Convenient and Affordable Care," National Center for Policy Analysis *Brief Analyses* No. 686, January 14, 2010, at <http://www.ncpa.org/pub/ba686> (December 21, 2011).

71. *Ibid.*, p. 23.

72. Weinick *et al.*, "Policy Implications of the Use of Retail Clinics," pp. 9–10.

73. *Ibid.*, p. x; Jeffrey Kluger, "Drive-Thru Medical: Retail Health Clinics' Good Marks," *Time*, September 1, 2009, at <http://www.time.com/time/health/article/0,8599,1919754,00.html> (October 21, 2011).

experimented successfully with alternate structures. On its face, this payment structure gives providers an incentive to order more tests and treatments. As a compounding feature, most FFS plans do not pay for provider time spent talking with patients: “Time pressures and limited reimbursement in contemporary medical practice have been cited as serious constraints” to shared decision making.<sup>74</sup> In a recent study, 40 percent of physicians reported that they ordered tests and consultations because they did not have enough time to spend talking with their patients to determine what was wrong with them.<sup>75</sup>

Fear of malpractice suits is an additional incentive for providers to order unnecessary care. Although it is difficult to identify exactly what percentage of health care costs could be eliminated by tort reform, one study estimated savings of 5 percent to 9 percent.<sup>76</sup> In another study, 76 percent of physicians reported practicing more aggressively because they feared being sued. These physicians were substantially more concerned about being sued for failing to order a test (83 percent) than for ordering an unnecessary test (21 percent).<sup>77</sup>

Some providers may also fear participating with their patients in shared decision making, believing that patients who experience an adverse outcome of their decision may sue. Indeed, a patient sued successfully in just such a scenario.<sup>78</sup> Washington state, in developing a demonstration project requiring

shared decision making, chose to include as part of the legislation “increased legal protection to physicians whose patients sign an acknowledgement that patient decision aids were used during informed consent.”<sup>79</sup>

At times, even quality measures can create a conveyor-belt approach that may impede individualized care and shared decision making. In one study, 52 percent of physicians believed that one cause of excess care is “the use of clinical performance measures that are used to judge whether doctors are doing their jobs correctly,”<sup>80</sup> such as preventive care standards and guidelines. These will indeed benefit the majority of the population, but the benefits are less pronounced for some segments of the population. For example, one physician observes that “the side effects of early detection efforts—overdiagnosis and overtreatment—are even more pronounced as [patients] age (simply because there is less time for abnormalities to become important problems).”<sup>81</sup>

*Attitudes and Skills of Medical Professionals.* Clinician attitudes and training can affect patients’ ability to participate effectively in decisions about their health care. In 1999, Dr. Ellen Fox wrote:

When the curative model dominates medical education, as it does today, its inherent assumptions, attitudes, and values tend to define the culture of academic medical centers. Trainees who are thoroughly immersed

74. Barbara K. Rimer, Peter A. Briss, Paula K. Zeller, Evelyn C. Y. Chan, and Steven H. Woolf, “Informed Decision Making: What Is Its Role in Cancer Screening?” *Cancer*, Vol. 101, Issue Supplement S5 (September 1, 2004), at <http://onlinelibrary.wiley.com/doi/10.1002/cncr.20512/pdf> (December 15, 2011).
75. Karen Kaplan, “Some Doctors Blame Themselves for Rising Healthcare Costs,” *The Los Angeles Times*, September 27, 2011, at <http://www.latimes.com/health/boostershots/la-heb-doctors-aggressive-medicine-20110927,0,7603341.story> (October 25, 2011).
76. Paul Ginsburg, “High and Rising Health Care Costs: Demystifying U.S. Health Care Spending,” Robert Wood Johnson Foundation, October 2008, p. 19, at <http://www.rwjf.org/files/research/35368.highrisingcosts.rpt.pdf> (October 25, 2011).
77. Kaplan, “Some Doctors Blame Themselves for Rising Healthcare Costs.”
78. Alex H. Krist, Steven H. Woolf, and Robert E. Johnson, “How Physicians Approach Prostate Cancer Screening Before and After Losing a Lawsuit,” *Annals of Family Medicine*, Vol. 5, No. 2 (March/April 2007), at <http://www.annfammed.org/content/5/2/120.full.pdf> (October 25, 2011).
79. David Arterburn, “Lessons Learned from Washington State,” Research and Policy Forum 2010, January 28, 2009, at <http://informedmedicaldecisions.org/forum-summaries/D.ArterburnForumSummary2010-2.pdf> (October 25, 2011).
80. Kaplan, “Some Doctors Blame Themselves for Rising Healthcare Costs.”
81. H. Gilbert Welch, “A Doctor’s Vision for Medicare,” *The Los Angeles Times*, October 16, 2011, at <http://www.latimes.com/news/opinion/commentary/la-oe-welch-medicare-20111016,0,4689958.story> (October 25, 2011).

in such a cure-oriented milieu can hardly avoid being influenced by it.<sup>82</sup>

Part of the problem is that although only 13 percent of patient-physician encounters occur in hospitals, medical education takes place primarily in the hospital setting, which is inherently and structurally focused on cure. The curative model “assumes not only that diagnosis and treatment are possible, but that they are also necessary and desired.”<sup>83</sup> The effects of the curative model on health care are pervasive.

The curative model elevates the decision-making role of the physician at the expense of all other health care participants, including the patient.<sup>84</sup> Thus, physicians may be accustomed to prescribing tests and treatments as they see fit with little reference to patient preference.<sup>85</sup> A recent study revealed that for many physicians other considerations, including their own judgment and clinical protocols, may be equally or more important than patient autonomy. Younger physicians valued patient autonomy more than their older colleagues. One possible explanation is that the older physicians were exposed to more paternalistic ideas on patient care during their training.<sup>86</sup>

In 2005, the President’s Council on Bioethics observed, “Acute causes of death (such as pneumonia, influenza, and septicemia) are in decline; prolonged causes of death from age-related degener-

ative diseases (such as Alzheimer’s, Parkinson’s, and emphysema) are on the rise.”<sup>87</sup> Among the Medicare population, 90 percent will “live with a serious, chronic condition before death.”<sup>88</sup> This change in disease trajectory calls for a corresponding change in the education of care providers. So far, however, medical education has been slow to respond.

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**Among the Medicare population, 90 percent will “live with a serious, chronic condition before death.”**

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In June 2009, the Medicare Payment Advisory Commission (MedPAC) stated, “Reforming medical education will be a key component in transforming the nation’s health care delivery system from one that historically has focused on care for acute illness—at the expense of chronic condition management...—to one that values patient-centered care.”<sup>89</sup> In June 2010, MedPAC went on to say, “Although experience in caring for hospital inpatients is an indispensable part of a physician’s education, greater focus on providing ambulatory care for chronically ill patients with complex health care needs is essential for preventing avoidable hospitalizations and improving overall care delivery.”<sup>90</sup>

82. Ellen Fox, “Predominance of the Curative Model of Medical Care: A Residual Problem,” *Journal of the American Medical Association*, Vol. 278, No. 9 (September 3, 1997), at <http://www.fammed.washington.edu/palliativecare/requirements/FOV1-00015079/PCvCC.htm> (November 3, 2011).

83. *Ibid.*

84. *Ibid.*

85. Joseph E. Scherger, “Future Vision: Is Family Medicine Ready for Patient-Directed Care?” *Family Medicine*, Vol. 41, No. 4 (April 2009), p. 287, at <http://www.stfm.org/fmhub/fm2009/april/joseph285.pdf> (October 24, 2011).

86. R. E. Lawrence and F. A. Curlin, “Autonomy, Religion and Clinical Decisions: Findings from a National Physician Survey,” *Journal of Medical Ethics*, Vol. 35, No. 4 (April 2009), p. 5, at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2867468/pdf/nihms194537.pdf> (October 21, 2011).

87. President’s Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society*, September 2005, p. 12, at [http://bioethics.georgetown.edu/pcbe/reports/taking\\_care/taking\\_care.pdf](http://bioethics.georgetown.edu/pcbe/reports/taking_care/taking_care.pdf) (December 15, 2011).

88. RAND Corporation, Southern California Evidence-Based Practice Center, “End-of-Life Care and Outcomes,” U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality *Evidence Report/Technology Assessment* No. 110, December 2004, p. v, at <http://www.ahrq.gov/downloads/pub/evidence/pdf/eolcare/eolcare.pdf> (October 31, 2011).

89. Medicare Payment Advisory Commission, *Improving Incentives in the Medicare Program*, June 2009, p. 3, at [http://www.medpac.gov/documents/Jun09\\_EntireReport.pdf](http://www.medpac.gov/documents/Jun09_EntireReport.pdf) (October 28, 2011).

90. Medicare Payment Advisory Commission, *Aligning Incentives in Medicare*, June 2010, p. 108, at [http://www.medpac.gov/documents/Jun10\\_EntireReport.pdf](http://www.medpac.gov/documents/Jun10_EntireReport.pdf) (December 15, 2011).

Nurses also play a key role in providing care to patients who are chronically ill or at the end of life. A recent Institute of Medicine report observed, “Nurse-led initiatives are at the forefront of the management of chronic diseases,”<sup>91</sup> yet nursing education has also lagged in meeting this challenge. According to the report, “Primary nursing education is still largely located in the acute care domain, with students mastering the care of the acute manifestations of chronic disease rather than care management of complex chronic illness.”<sup>92</sup>

The focus of clinical education on acute and curative care has particular implications for patients at the end of life, where another barrier is the frequent failure of clinicians to recognize how close patients are to death. This may be especially true in patients with nonmalignant conditions, such as congestive heart failure, chronic obstructive pulmonary disease, and dementia, which often have less predictable disease trajectories than the various types of cancer.<sup>93</sup> Studies suggest that physicians frequently overestimate a patient’s prognosis. Indeed, one study found that physicians are overly optimistic about prognosis even when referring patients to hospice.<sup>94</sup> As a result, patients may not be given the

opportunity to make fully informed decisions, and referrals to hospice are frequently delayed. This is one reason why many patients enter hospice programs when they have less than one month to live.<sup>95</sup>

As already noted, excellent provider communication is an important piece of consumer-driven care. Evidence suggests that medical students and practicing physicians can improve their communication skills,<sup>96</sup> yet there is widespread acknowledgement that many current medical training programs teach such skills inadequately. Students learn communication skills during their first two years of medical school, but these lessons might be more appropriately taught during the third and fourth years, when they actually begin to see patients.<sup>97</sup> Moreover, a recent study of 26 medical residency programs revealed that only half included education on shared decision making.<sup>98</sup>

If communication about routine health decisions can be difficult, discussions about end-of-life care are even more so. An AARP survey of members in Massachusetts found that, while 84 percent would be “at least somewhat comfortable talking about death,” only 17 percent had actually discussed their wishes

91. Institute of Medicine, Committee on the Robert Wood Johnson Foundation Initiative on the Future of Nursing, *The Future of Nursing: Leading Change, Advancing Health* (Washington, D.C.: The National Academies Press, 2011), p. 418, at [https://download.nap.edu/catalog.php?record\\_id=12956](https://download.nap.edu/catalog.php?record_id=12956) (October 31, 2011).
92. *Ibid.*, p. 395.
93. Diane E. Hoffmann and Anita J. Tarzian, “Dying in America: An Examination of Policies That Deter Adequate End-of-Life Care in Nursing Homes,” University of Maryland *Legal Studies Research Paper* No. 2005–40, June 2, 2005, at [http://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=733625&download=yes](http://papers.ssrn.com/sol3/papers.cfm?abstract_id=733625&download=yes) (October 25, 2011).
94. Marcus Alexander and Nicholas A. Christakis, “Bias and Asymmetric Loss in Expert Forecasts: A Study of Physician Prognostic Behavior with Respect to Patient Survival,” *Journal of Health Economics*, Vol. 27, No. 4 (July 2008), pp. 1095–1108, at <http://christakis.med.harvard.edu/pdf/publications/articles/086.pdf> (October 25, 2011).
95. Jennifer Shin and David Casarett, “Facilitating Hospice Discussions: A Six-Step Roadmap,” *Journal of Supportive Oncology*, Vol. 9, No. 3 (May/June 2011), p. 97, at <http://www.supportiveoncology.net/jso/journal/articles/0903097.pdf> (October 31, 2011).
96. Michael J. Yedidia *et al.*, “Effect of Communications Training on Medical Student Performance,” *JAMA*, Vol. 290, No. 9 (September 3, 2003), p. 1157, at <http://jama.ama-assn.org/content/290/9/1157.full.pdf> (October 24, 2011), and Wendy Levinson and Debra Roter, “The Effects of Two Continuing Medical Education Programs on Communication Skills of Practicing Primary Care Physicians,” *Journal of General Internal Medicine*, Vol. 8, No. 6 (June 1993), at <http://www.springerlink.com/content/6381gn2234053qk2/> (October 24, 2011).
97. Wendy Levinson, Cara S. Lesser, and Ronald M. Epstein, “Developing Physician Communication Skills For Patient-Centered Care,” *Health Affairs*, Vol. 29, No. 7 (July 2010), p. 1314.
98. Medicare Payment Advisory Commission, “Medical Education in the United States: Supporting Long-Term Delivery System Reforms,” in *Report to the Congress: Improving Incentives in the Medicare Program*, June 2009, p. 24, at [http://www.medpac.gov/documents/Jun09\\_EntireReport.pdf](http://www.medpac.gov/documents/Jun09_EntireReport.pdf) (October 28, 2011).

with their physicians.<sup>99</sup> In a study of patients with metastatic lung cancer, only 53 percent of patients who died within two months had discussed hospice with their providers.<sup>100</sup> Another study found that “more than 60% of dying patients do not recall having end-of-life discussions with their physicians.”<sup>101</sup> This study found significant variation by region.<sup>102</sup> Another study found that physicians in areas with higher medical costs are less likely to discuss palliative care with a patient admitted to the hospital for end-stage heart failure than are their colleagues in areas where costs are lower.<sup>103</sup>

Part of the problem may be that “the curative model conflicts with the notion of a good death. Where cure is the ultimate goal, death is the ultimate failure.”<sup>104</sup> Therefore, “[p]hysicians...avoid these conversations, communicate euphemistically, are overly optimistic, or delay discussions until patients are close to death, perhaps because [of] their own feelings of failure or loss.”<sup>105</sup>

Physicians worry that discussing end-of-life care may cause patients psychological distress, although one study found no evidence of this.<sup>106</sup> On the contrary, studies suggest that patients who discuss their end-of-life preferences with their providers have lower health care costs in the last week of

life (\$1,041 less) and better quality of death than patients who do not.<sup>107</sup> Such conversations also correlate with improved bereavement outcomes for family members and caregivers.<sup>108</sup>

### The Critical Lessons of Palliative Care

The field of palliative care offers lessons on involving patients in decisions about their own care:

Palliative care focuses on achieving the best-possible quality of life for patients and their family caregivers, based on patient and family needs and goals and independent of prognosis. Interdisciplinary palliative care teams assess and treat symptoms, support decision making and help match treatments to informed patient and family goals.<sup>109</sup>

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***“Palliative care focuses on achieving the best-possible quality of life for patients and their family caregivers, based on patient and family needs and goals and independent of prognosis.”***

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Palliative care differs from both curative care and hospice care. The fundamental difference between the palliative and curative models is that in the palliative

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99. Erica Dinger, “AARP Massachusetts End of Life Survey,” AARP, 2005, p. 1, at [http://assets.aarp.org/rgcenter/health/ma\\_eol.pdf](http://assets.aarp.org/rgcenter/health/ma_eol.pdf) (December 15, 2011).
100. Haiden A. Huskamp *et al.*, “Discussions with Physicians About Hospice Among Patients with Metastatic Lung Cancer,” *Archives of Internal Medicine*, Vol. 169, No. 10 (May 25, 2009), p. 954, at <http://archinte.ama-assn.org/cgi/reprint/169/10/954> (December 15, 2011).
101. Alexi A. Wright *et al.*, “Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care near Death, and Caregiver Bereavement Adjustment,” *JAMA*, Vol. 300, No. 14 (October 8, 2008), p. 1672, at <http://jama.ama-assn.org/content/300/14/1665.full.pdf> (October 24, 2011).
102. *Ibid.*, p. 1668.
103. Sirovich *et al.*, “Discretionary Decision Making by Primary Care Physicians,” p. 819.
104. Fox, “Predominance of the Curative Model of Medical Care.”
105. Wright *et al.*, “Associations Between End-of-Life Discussions,” p. 1672.
106. *Ibid.*, p. 1670.
107. Zhang *et al.*, “Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations,” *Archives of Internal Medicine*, Vol. 169, No. 5 (March 9, 2009), p. 480, at <http://archinte.ama-assn.org/cgi/reprint/169/5/480> (October 24, 2011).
108. Wright *et al.*, “Associations Between End-of-Life Discussions,” pp. 1665–1666.
109. Diane E. Meier, “Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care,” *The Milbank Quarterly*, Vol. 89, No. 3 (September 2011), p. 344, at <http://www.milbank.org/quarterly/8903feat.pdf> (December 15, 2011).

setting “cure is not a goal.”<sup>110</sup> Other differences flow from this one:

Perhaps the most important difference...is that in palliative care, the management plan is tailored specifically to each patient, according to the patient’s personal values and preferences. This approach contrasts with the curative model, in which the appropriate treatment is considered a scientific question that is best decided by the physician.<sup>111</sup>

The ethos of palliative care is similar to that of hospice, but unlike hospice (as defined in the United States by Medicare), palliative care “is offered *independent of the patient’s prognosis and simultaneously with life-prolonging and curative therapies* for persons living with serious, complex, and life-threatening illness.”<sup>112</sup>

The core competencies for palliative care medicine are instructive. Among other skills, the palliative care physician needs to develop the skills to ensure that “[p]atients and families obtain the information they need in order to understand their condition and treatment options. Their values and goals are elicited over time, with sensitivity to relevant cultural issues; the benefits and burdens of treatment are regularly reassessed; and the decision-making process about the care plan is sensitive to changes in the patient’s condition.”<sup>113</sup>

Research shows that patients participating in palliative care have improved quality of life and are satisfied with their care.<sup>114</sup> Surprisingly, the effects of palliative care on life expectancy are difficult to predict. As one might suppose, some studies show that patients receiving palliative care do not live as long as those receiving usual care alone. This is attributed at least partly to patients choosing not to undergo futile aggressive care at the end of life.<sup>115</sup> However, other studies have found that patients receiving palliative care may actually live longer. Experts hypothesize that one factor contributing to this unexpected outcome may be “avoidance of the hazards of hospitalization and high-risk medical interventions.”<sup>116</sup>

Multiple studies have also shown that palliative care reduces health care utilization and costs. One study of a palliative care initiative led by an advanced practice nurse in an outpatient oncology practice found decreased hospitalizations among the palliative care group with no increase in mortality.<sup>117</sup> Overall, the evidence suggests that palliative care reduces health care utilization across a variety of measures.<sup>118</sup> A study of an inpatient palliative care program found significant cost savings for palliative care patients in the hospital.<sup>119</sup> A study of participants in an outpatient palliative care program

110. Fox, “Predominance of the Curative Model of Medical Care.”

111. Meier, “Increased Access to Palliative Care,” p. 345.

112. *Ibid.* (emphasis added.)

113. Accreditation Council for Graduate Medical Education, “Hospice and Palliative Medicine Core Competencies,” January 5, 2007, p. 1.

114. Richard Brumley *et al.*, “Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care,” *Journal of the American Geriatrics Society*, Vol. 55, No. 7 (July 2007), p. 993, at [http://geriatrics.medicine.ucsf.edu/files/in\\_home\\_palliative\\_care\\_JAGS\\_0208.pdf](http://geriatrics.medicine.ucsf.edu/files/in_home_palliative_care_JAGS_0208.pdf) (December 15, 2011), and Areej El-Jawahri, Joseph A. Greer, and Jennifer S. Temel, “Does Palliative Care Improve Outcomes for Patients with Incurable Illness? A Review of the Evidence,” *Journal of Supportive Oncology*, Vol. 9, No. 3 (May/June 2011), p. 87, at <http://www.supportiveoncology.net/jso/journal/articles/0903087.pdf> (December 15, 2011).

115. Brumley *et al.*, “Increased Satisfaction with Care and Lower Costs,” p. 993.

116. Meier, “Increased Access to Palliative Care,” p. 349.

117. Maryjo Prince-Paul, Christopher J. Burant, Joel N. Saltzman, Lois J. Teston, and Carol R. Matthews, “The Effects of Integrating an Advanced Practice Palliative Care Nurse in a Community Oncology Center: A Pilot Study,” *The Journal of Supportive Oncology*, Vol. 8, No. 1 (January/February 2010), p. 21, at <http://www.supportiveoncology.net/jso/journal/articles/0801021.pdf> (December 15, 2011).

118. El-Jawahri *et al.*, “Does Palliative Care Improve Outcomes for Patients with Incurable Illness?” p. 93.

119. Institute of Medicine, *The Future of Nursing*, p. 425.

found cost savings of 33 percent compared with those receiving standard care.<sup>120</sup>

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***A study of participants in an outpatient palliative care program found cost savings of 33 percent compared with those receiving standard care.***

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These impressive outcomes from palliative care have led to calls for expansion of the concept. First, proponents would like to see a loosening of the six-month prognosis required by Medicare for hospice services so that more patients could enjoy the benefits of palliative care. Private initiatives designed as transitions to hospice, in which terminally ill patients receive palliative care and curative care simultaneously, have shown promise. One found that patients who participated in the program, but did not elect hospice care, still realized savings of \$2,000 per month.<sup>121</sup> Another achieved an average savings of 22 percent per patient through a combination of an “increase in hospice election and decrease in acute care services.”<sup>122</sup>

Others have called for the expansion of the concepts of palliative care into the area of chronic illness:

One antidote to the burgeoning crisis in health care is to reconceptualize our care delivery model from episodic disease management to living with chronic and life-limiting diseases and injuries. Palliative care, which includes hospice care at the end of life, offers a promising method for actualizing this focus.

...Although contemporary models of palliative care include end-of-life and bereavement care, they are broadly applicable for all people who are experiencing acute, chronic, or debilitating conditions from the time of diagnosis.<sup>123</sup>

Perhaps the answer lies in the middle:

Between the curative model and the palliative model lies an unnamed approach that supports all legitimate goals of medicine—health promotion, prevention, rehabilitation, life preservation, comfort, and care—and is willing to combine them in whatever manner best reflects the values of an individual patient. The flexibility of this approach makes it appropriate for all cases in which neither the curative model nor the palliative care model alone will do.<sup>124</sup>

### **Removing Barriers to Patient Decision Making**

Moving the U.S. health care system in the direction of greater patient awareness of cost and involvement in decisions will require involvement at each level of government as well as the private sector. Policymakers should have an overall goal of reducing centralization by reducing the role of the federal government as a direct payer. Traditional Medicare and Medicaid neither encourage consumer involvement nor allow for rapid innovation. Although the new Center for Medicare Innovation seeks to remedy the latter problem, it will still be difficult for a large government program to be as nimbly innovative as private plans are. Moreover, government programs tend to take a one-size-fits-all approach, which is directly at odds with intensely individualized health care.

To remove the barriers to patient decision making, all levels of government should work with the private sector to implement a series of reforms:

**Reform #1: Focus patient interest on cost by promoting a free market for health coverage.**

Consumers will become interested in the cost of health only when they are directly exposed to those costs at the point of care and through a con-

120. Brumley *et al.*, “Increased Satisfaction with Care and Lower Costs,” p. 998.

121. Harris Meyer, “Changing the Conversation in California About Care near the End of Life,” *Health Affairs*, Vol. 30, No. 3 (March 2011), p. 392.

122. Randall Krakauer, Claire M. Spettell, Lonny Reisman, and Marcia J. Wade, “Opportunities to Improve the Quality of Care for Advanced Illness,” *Health Affairs*, Vol. 28, No.5 (September/October 2009), p. 1358.

123. Institute of Medicine, *The Future of Nursing*, p. 423.

124. Fox, “Predominance of the Curative Model of Medical Care.”

sumer-driven insurance market. While individuals are patients of doctors or other medical professionals, they are also consumers of the health plans that reimburse their doctors and such professionals. Good policy would erode the artificial separation of the individual's roles as patient and consumer. Individuals need to be aware of and sensitive to costs before they can begin to participate effectively in weighing the costs and benefits of particular health care choices in their own lives.

The first step to empowering individuals is therefore to involve them more directly in choosing their own health care plan.<sup>125</sup> This would require both federal tax and federal and state regulatory reform. These consumers would be more aware of formerly "hidden" costs and, depending on their situation and values, might choose less expensive plans with less comprehensive coverage. One author describes this as "prospective self-denial" in which consumers voluntarily "economize by accepting substantial restrictions on their freedom to draw upon a common fund for future medical needs."<sup>126</sup>

In fact, people do this today by voluntarily choosing a managed care plan that requires gatekeeping for the use of specialists. The trade-off would be payment of lower premiums than for fee for service or PPO plans. These less expensive plans could also take the form of high-deductible plans with health savings accounts. In certain markets, options could include plans that provide "first-dollar coverage but only over a limited range of medicine.... For instance, they [consumers] might choose not to cover high-cost organ transplants at all, or they may decide that it is not worth the extra premium expense to cover high-tech life-support when they are terminally ill or in a permanent coma."<sup>127</sup> With-

in a rapidly evolving health care system, in which individuals directly control the money and make the decisions about the plans they want, all sorts of new delivery options and payment arrangements could develop in the freer market. All of them would have one thing in common: They would compete to offer more specialized products designed to meet consumers' demands for quality and cost-effectiveness.

The policy goal is for Americans to have access to insurance coverage that they take with them throughout their life, from early adulthood through middle age to old age and end of life. Individuals should be able to select the plans that best match their personal goals and values. Plans would then have incentives to provide customer satisfaction and to optimize health throughout the customer's life span.

### **Reform #2: Expand patient knowledge through a free market clearinghouse of information.**

Consumers shopping for a computer have access to vast quantities of information, from technical specifications to pricing to reviews from fellow consumers about both the product and the seller. Health care consumers do not yet have access to similar information, but early initiatives at the state level and in the private sector promise an information revolution. Individuals will have access to reliable sources of information about health care cost, quality (outcomes), and patient satisfaction as well as scientific evidence and expert opinion in an easily understandable format at their fingertips before they make decisions.

### **Reform #3: Improve physician comfort with patient empowerment.**

Sensible state medical liability reform<sup>128</sup> is necessary if doctors and other medical professionals

125. Stuart M. Butler, Alison Acosta Fraser, and William W. Beach, eds., *Saving the American Dream: The Heritage Plan to Fix the Debt, Cut Spending, and Restore Prosperity*, The Heritage Foundation, 2011, at <http://savingthedream.org/about-the-plan/plan-details/>.
126. Clark C. Havighurst, "Prospective Self-Denial: Can Consumers Contract Today to Accept Health Care Rationing Tomorrow?" *University of Pennsylvania Law Review*, Vol. 140, No. 5 (May 1992), p. 1757, at [http://scholarship.law.duke.edu/cgi/viewcontent.cgi?article=1357&context=faculty\\_scholarship](http://scholarship.law.duke.edu/cgi/viewcontent.cgi?article=1357&context=faculty_scholarship) (October 27, 2011).
127. Mark A. Hall, *Making Medical Spending Decisions: The Law, Ethics, and Economics of Rationing Mechanisms* (New York: Oxford University Press, 1997), p. 30.
128. Randolph W. Pate and Derek Hunter, "Code Blue: The Case for Serious State Medical Liability Reform," Heritage Foundation *Background* No. 1908, January 17, 2006, at <http://www.heritage.org/research/reports/2006/01/code-blue-the-case-for-serious-state-medical-liability-reform>.

are to feel comfortable fully engaging patients as partners in decision making. Beyond this, the current education and training systems for health care providers frequently leave clinicians unprepared to provide care in an environment where empowered patients seek greater involvement in care decisions. This is especially apparent in the end-of-life setting, in which the sensitive nature of the discussions make communication and decision making especially difficult. Ultimately, education systems need to teach providers to value patient involvement in health care decisions, and techniques to facilitate shared decision making need to become an integral part of clinician training.

### Conclusion

The rapid increase in health care spending in both the public and the private sectors makes it imperative for policymakers to find a solution. The recent concern over “death panels” in the health legisla-

tion, although no such explicit panels were created in law, nonetheless revealed Americans’ reluctance to surrender such sensitive decision making to any external entity, especially a governmental body.

The better approach would be to allow individual consumers to make their own decisions about care, including the self-rationing of medical services, by engaging patients in the decisions about their care and its cost throughout their life span and at the end of life. Because such a policy is compatible with American values of limited government and individual liberty and responsibility, state and federal policymakers should adopt measures that would facilitate personal control as they reconsider current law and propose new legislation to reform health care.

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