



UNC
SCHOOL OF LAW

NORTH CAROLINA LAW REVIEW

Volume 92

Number 5 *Health Care Decisions in the New Era of
Health Care Reform*

Article 10

6-1-2014

Can Patients in the United States Become Savvy Health Care Consumers

Peter A. Ubel

Follow this and additional works at: <http://scholarship.law.unc.edu/nclr>



Part of the [Law Commons](#)

Recommended Citation

Peter A. Ubel, *Can Patients in the United States Become Savvy Health Care Consumers*, 92 N.C. L. REV. 1749 (2014).

Available at: <http://scholarship.law.unc.edu/nclr/vol92/iss5/10>

This Article is brought to you for free and open access by Carolina Law Scholarship Repository. It has been accepted for inclusion in North Carolina Law Review by an authorized administrator of Carolina Law Scholarship Repository. For more information, please contact law_repository@unc.edu.

CAN PATIENTS IN THE UNITED STATES
BECOME SAVVY HEALTH CARE
CONSUMERS?*

PETER A. UBEL **

INTRODUCTION1750

I. THE COST OF U.S. HEALTHCARE: A BRIEF AND BROAD HISTORY1751

II. THE RISING BURDEN OF U.S. HEALTHCARE EXPENDITURES1756

III. HOW “SKIN IN THE GAME” OUGHT TO WORK1761

IV. LACK OF PRICE TRANSPARENCY1763

V. THE CHALLENGE OF GETTING PRICE INFORMATION IN TIME TO INFLUENCE HEALTHCARE DECISIONS1766

 A. *Not Enough Time to Decide*1766

 B. *Unpredictable Trajectories of Care*1768

 C. *The Challenge of Determining Patient-Specific Costs*1769

VI. THE CHALLENGE OF DISCUSSING PATIENT OUT-OF-POCKET COSTS DURING CLINICAL ENCOUNTERS1770

 A. *Reluctance to Discuss Costs of Care*1770

 B. *Difficulties Sharing in Clinical Decisions*1773

 C. *What We Talk About When We Talk About Money*1777

VII. IMPROVING THE HEALTHCARE MARKET PLACE1782

 A. *Price Transparency*1783

 B. *Improving Communication About Out-of-Pocket Costs During Clinical Encounters*1784

 C. *Designing Smarter Incentives*1786

CONCLUSION1787

* © 2014 Peter A. Ubel.

** I want to thank the many members of the *North Carolina Law Review* who helped with this article, especially Caroline Cress and Dawn Milam. I don't know if they knew what they were getting into when they asked a “big picture”—a.k.a. get all the little details wrong—person like me to contribute an article to this collection. Even now, as I add these thanks, I wonder if I have defined “big picture” incorrectly, but relax in the knowledge that the *North Carolina Law Review* members are on the job, and will not only correct my mistakes, but gently suggest a rewritten version of this footnote that actually makes me look semi-eloquent.

INTRODUCTION

In the U.S. healthcare market, patients are being asked to bear an increasing proportion of their healthcare expenses.¹ Not only are people paying more out of pocket for their health insurance,² but once they purchase this insurance they find themselves facing higher deductibles, larger co-pays, and steeper coinsurance rates.³ Evidence is already accumulating that these higher out-of-pocket costs—this greater amount of “skin in the game”—are reducing healthcare expenditures.⁴ But does it lead to better decision making? Does it turn patients into savvy healthcare consumers?

Ideally, the financial cost of care would be treated as one of many factors that patients consider when weighing the pros and cons of their healthcare alternatives. In the same way that physicians inform patients about treatment side effects before prescribing a given treatment, they would also inform patients about the costs of these treatments.⁵ But many barriers stand in the way of making out-of-pocket costs a part of clinical conversations.⁶ This Article identifies these barriers and discusses what would need to be done, both clinically and from a policy perspective, to overcome some of these barriers. Parts I and II explain how the U.S. healthcare system has

1. See HA T. TU & GENNA R. COHEN, CTR. FOR STUDYING HEALTH SYS. CHANGE, FIN. AND HEALTH BURDENS OF CHRONIC CONDITIONS GROW 1 (2009) (“In 2007, 28 percent of working-age adults with chronic conditions . . . reported that their families had problems paying medical bills in the past year—a significant increase from 21 percent in 2003 . . .”).

2. See Alexander J. Ryu et al., *The Slowdown in Health Care Spending in 2009–11 Reflected Factors Other than the Weak Economy and Thus May Persist*, 32 HEALTH AFF. 835, 837 (2013).

3. See *id.* at 836 (finding increased healthcare spending defined as “all reimbursements made to the provider of care—copayments, deductibles, insurance payments, and third-party payments”).

4. See *id.* at 837–38 (“These differences suggest that a change in benefit design that resulted in higher out-of-pocket expenses for enrollees partially accounted for slower spending growth.”).

5. See, e.g., Peter A. Ubel, Amy P. Abernethy & S. Yousuf Zafar, *Full Disclosure—Out-of-Pocket Costs as Side Effects*, 369 NEW ENG. J. MED. 1484, 1486 (2013) (arguing that physicians should discuss out-of-pocket costs with their patients).

6. See *id.* at 1484 (“The current reality is that it is very difficult, and often impossible, for the clinician to know the actual out-of-pocket costs for each patient, since costs vary by intervention, insurer, location of care, choice of pharmacy or radiology service, and so on . . .”). Other studies show that barriers to discussing cost may include patient discomfort in discussing cost, insufficient time, a belief that the physician would not have a solution, and concerns that discussing cost would impact the quality of care. See G. Caleb Alexander et al., *Barriers to Patient-Physician Communication About Out-of-Pocket Costs*, 19 J. GEN. INTERNAL MED. 856, 856 (2004). Barriers to discussing costs for physicians include “insufficient time . . . and a belief that they [do] not have a solution to offer . . .” *Id.*

evolved to the point where many people suffer financial burdens from the cost of their medical care. Part III lays out how patient out-of-pocket costs ideally ought to be factored into healthcare decisions. Parts IV, V, and VI describe a number of ways in which the U.S. healthcare system falls far short of this ideal. And Part VII discusses several clinical and policy interventions that could move us closer to the ideal.

I. THE COST OF U.S. HEALTHCARE: A BRIEF AND BROAD HISTORY

For much of history, healthcare costs have not been a great burden to patients and society for two main reasons: the lack of effective healthcare on which to spend money and the abundance of inexpensive healthcare.⁷ In the nineteenth century, surgical operations took place in rudimentary “theatres” without expensive anesthetics or even perioperative antibiotics.⁸ The few medications in existence were plant-based remedies and a wide range of questionable cure-all concoctions.⁹ The physician’s job during this era in medical history was to comfort patients with opiates and comfort families with information on whether the patient would survive.¹⁰ The goal for physicians (especially non-surgeons) was to comfort and

7. See ROY PORTER, *THE GREATEST BENEFIT TO MANKIND: A MEDICAL HISTORY OF HUMANITY* 595–96, 675 (1998) (stating that unlike today, patients of the past notoriously self-dosed, “drugging themselves with a diet of home-brew kitchen physic, shop-bought nostrums, [and] quacks’ mixtures” and that physicians were plagued by “[t]oo many worthless medicines [and] too few remedies”; today’s medicine is marked by a “spiralling [sic] cost of health care” brought on by “increasingly expensive . . . patch-up procedures”).

8. See *id.* at 360. Hospitals in London and Paris in the early 1800s served as “theatres for virtuoso surgeons” who performed operations attended by students, colleagues, and spectators. *Id.* Most commonly, these shows involved amputations, and the only solution to the excruciating pain was the surgeon’s skill and speed. *Id.* The lack of anesthetics during surgery led to almost unbearable pain in some patients. In 1809, a Kentucky physician removed a fifteen-pound tumour from a fully-conscious woman who “sang hymns to drown the pain.” *Id.* at 363. In 1810, novelist Fanny Burney had a mastectomy without anaesthetic, later writing that the agony was “excruciating.” *Id.* at 364.

9. *Id.* at 365 (stating that early doctors attempted to dull pain with mandrake root steeped in wine, sponges soaked in opium, and henbane (the “poor man’s opium”).

10. See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 7, 17–19 (1984) (discussing the methods of medieval physicians and their focus on offering the patient “comfort, reassurance and hope”; this sense of duty led many early doctors to advocate for lying to fatally ill patients if knowledge of their impending death might seriously injure the patient’s mental state).

prognosticate, since there was little they could do to cure their patients.¹¹

With the advent of antibiotics in the 1940s, medical practice evolved into a therapeutic profession.¹² Wonder pills now killed bacteria, lowered blood pressure, and dissolved blood clots.¹³ Chemicals promised to mask the pain of what could then become increasingly elaborate surgical procedures.¹⁴ X-rays enabled doctors to diagnose previously mysterious ailments.¹⁵ Amidst this burgeoning technology, the modern hospital industry began to arise,¹⁶ building imposing structures substantial enough to house all this new medical equipment, and filled with enough beds to care for the many patients whose previously fatal diagnoses were now transformed into lengthy hospital stays.¹⁷

11. See, e.g., NICHOLAS A. CHRISTAKIS, *DEATH FORETOLD: PROPHECY AND PROGNOSIS IN MEDICAL CARE* 5 (1999) (stating that in the early twentieth century, “when effective treatment . . . was unavailable, prognosis played a key role”).

12. See *id.* at 3 (stating that today, “diagnosis and therapy receive much more attention than prognosis”). For example, pneumonia was the leading killer in the United States in 1900. *Id.* at 5. After antibiotic therapy for pneumonia was discovered in the 1930s, the prognosis for pneumonia “improved substantially.” *Id.* Simultaneously, prognosis for pneumonia was neglected, and physicians turned their attention to diagnosis and therapy. *Id.* For another description of the development of therapy in the medical profession, see PORTER, *supra* note 7, at 457–58 (describing how the flow of new drugs, including penicillin, brought about the “long anticipated therapeutic revolution”).

13. See, e.g., Eric Kades, *Preserving a Precious Resource: Rationalizing the Use of Antibiotics*, 99 NW. U. L. REV. 611, 614 (2005) (stating that “antibiotics have had a dramatic positive impact on human health,” including treating bacterial infections); P.M. Esunge, *From Blood Pressure to Hypertension: The History of Research*, 84 J. ROYAL SOC’Y OF MED. 621, 621 (1991) (stating that the first orally effective treatment for hypertension was invented in 1957); *Best Practice Guidelines: Warfarin*, MT. DPHHS 1, (2010), <http://www.dphhs.mt.gov/dsd/ddp/documents/Warfarin.pdf> (stating that Warfarin was developed in 1948).

14. See PORTER, *supra* note 7, at 597 (“[T]he combination of anesthesia and asepsis offered the unprecedented prospect of safe and virtually unlimited surgical intervention.”); *id.* at 610 (“Stimulated by technical innovations and driven by outside pressures, not least the appalling wounds of two world wars, surgery moved stage-centre in the twentieth century.”).

15. See *id.* at 606–08 (stating that radiographs have been used in a clinical setting since 1896 and even aided in scanning for bullets during the Spanish-American War; early use was often misguided, however, such as in the 1940s when benign menstrual bleeding was sometimes treated with X-rays and radium).

16. See ROSEMARY STEVENS, *IN SICKNESS AND IN WEALTH: AMERICAN HOSPITALS IN THE TWENTIETH CENTURY* 206 (1999) (describing the importance of American medical centers as research hubs after World War II, correlating with a rise in both medical office practices and in medical incomes).

17. *Id.* at 105 (stating that “hospitalization became an accepted consumption good” and hospitals became “stations for the diffusion of medical technique”); see also PORTER, *supra* note 7, at 380 (asserting that by World War I, the hospital had become “the headquarters of medicine”).

This increase in medical interventions was inevitably accompanied by an increase in healthcare expenditures. In the United States, for example, healthcare expenditures rose 10.6% during the 1960s, 13.1% during the 1970s, and 11% during the 1980s.¹⁸ Most developed countries have constructed their health care systems to minimize out-of-pocket costs.¹⁹ During the same period, the United Kingdom, for example, created its National Health Service in the aftermath of World War II, a system that has largely protected the British population from out-of-pocket costs ever since.²⁰ In Germany, the government created its own national health system in the 1880s, one built around non-profit insurance companies.²¹ Of note, Otto von Bismark established this system not to protect German workers from healthcare costs, but instead to protect them from the economic impact of lost wages.²² Thus, only workers qualified for government sickness funds, because only they stood to lose significant money by becoming ill.²³

In contrast to programs established by other developed countries, the United States failed to set up a national health system during this period of burgeoning health costs. Instead, the New Deal created Social Security and unemployment benefits.²⁴ The complexities of health insurance prevented FDR's administration

18. See CTRS. FOR MEDICARE & MEDICAID SERVS., NAT'L HEALTH EXPENDITURES DATA TABLES 2012, available at <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/NationalHealthExpendData/Downloads/tables.pdf> (last visited Mar. 2, 2014) (showing a rise in healthcare expenditures from the 1960s–1980s).

19. See T.R. REID, *THE HEALING OF AMERICA: A GLOBAL QUEST FOR BETTER, CHEAPER, AND FAIRER HEALTH CARE* 19–20 (2009) (stating that Britain's out-of-pocket costs are around three percent, while the United States ranks fairly high among wealthy countries with seventeen percent of health care costs funded by out-of-pocket payment).

20. *Id.* at 107–08, 110 (detailing Britain's government-run National Health Service which is funded by general taxation, as compared to the small three percent of out-of-pocket cost associated with private British medicine).

21. *See id.* at 67.

22. *See id.* at 67, 72–73.

23. See PAUL STARR, *THE SOCIAL TRANSFORMATION OF AMERICAN MEDICINE* 237–38 (1982) (explaining that Germany's "first national system of compulsory sickness insurance" only applied to wage earners to account for wages lost during sickness; the program provided "insurance against the chief risks that interrupted continuity of income").

24. See DAVID BLUMENTHAL & JAMES A. MORONE, *THE HEART OF POWER: HEALTH AND POLITICS IN THE OVAL OFFICE* 53 (2009) (explaining why historians have "largely granted FDR a bye on universal health coverage" because of the tangled politics of Depression-era America, other reforms passed such as Social Security, his waning political fortunes, World War II, and his ill health).

from attempting to pass federal health insurance legislation.²⁵ As a result, the U.S. healthcare system evolved to be largely employer-based, with companies offering private health insurance as a way to attract good employees at a time when the American economy was booming.²⁶ American health insurance companies largely adopted a fee-for-service model of payment as opposed to a more centralized and structured system seen in health management organizations (HMOs).²⁷ The fee-for-service model consisted of hospitals and healthcare providers directly billing insurance companies, which largely passed these costs on to enrollees through hikes in their annual premiums.²⁸

Medicare, enacted in 1965, perpetuated the American fee-for-service model.²⁹ This law enabled elderly patients (many of whom no longer had access to employer-based insurance) to receive the same kind of generous, first-dollar coverage³⁰ they had gotten used to before retirement, because like insurance companies, Medicare also adopted a fee-for-service payment system.³¹ Thus, the enactment of Medicare created a huge influx of government money, allowing hospitals and physicians in the United States to spend freely on

25. See *id.* at 53–54.

26. See STARR, *supra* note 23, at 200 (“Employers had a practical interest in using medical services for recruiting and selecting workers, maintaining their capacity and motivation to work, keeping down liability and insurance costs, and gaining good will from their employees and the public.”).

27. See Lalena J. Turchi, *Health Insurance: Paying the Premium, or Paying the Price?—ERISA Preemption and RICO’s Recourse*, 5 RUTGERS J.L. & PUB. POL’Y 526, 534 (2008) (“The traditional health insurance model is fee-for-service, where a physician provides services and submits the bill to the insurer for payment subject to negotiated payment terms under the contract.”).

28. See *id.* (outlining the billing procedure for fee-for-service model); Susan Adler Channick, *Health Care Cost Containment: No Longer an Option but a Mandate*, 13 NEV. L.J. 792, 794 (2013) (describing how, in recent years, rising health care costs result in private insurers raising premium rates, shifting the burden to employers, who then shift the burden again to employees).

29. Medicare Prescription Drug, Improvement, and Modernization Act, Pub. L. No. 108-173, 117 Stat. 2066 (2003) (codified in scattered sections of 26 U.S.C. and 42 U.S.C.).

30. First dollar coverage is a term used to describe “a plan that pays deductibles and co-payments so that the beneficiary has no out-of-pocket costs.” *What Is “First Dollar” Coverage?*, MEDICARE NEWSGROUP, <http://www.medicarenewsgroup.com/news/medicare-faqs/individual-faq?faqId=630d590d-d09b-4cb0-8b9a-43e2c74f1ee7> (last visited Mar. 1, 2014).

31. See Benjamin M. Zegarelli, Note, *Terminating Beyond the Limits: CMS Is Overreaching in Its Attempt to Regulate ACOs According to Antitrust Standards*, 34 CARDOZO L. REV. 781, 785 n.34 (2012) (citing 42 U.S.C. § 1395g(a) (2006)) (“Fee-for-service is the default model of Medicare payments to health care providers, whereby a patient receives a certain treatment and the Medicare program compensates ‘each provider of services with respect to the services furnished by it.’”).

constructing new buildings and clinics, confident that there would be plenty of paying customers to recoup these investments.³² As a consequence of this system, U.S. healthcare quickly became more expensive than most other developed countries. By 1970, the United States spent 7.4% of its GDP on healthcare versus only 4.5% in the United Kingdom.³³

More importantly for the purposes of this Article, the U.S. fee-for-service model created a system of price insensitivity.³⁴ The country was so wealthy, such a dominant economic force, that employers could provide generous benefits to employees and the government could afford to pay off its population's rapidly growing medical bills. Healthcare consumers, too, were given little reason to pay attention to healthcare prices. Employees paid only a small portion of their health insurance premiums, with employers picking up the bulk of the tab.³⁵ In addition, the U.S. government subsidized these health insurance premiums, which allowed Americans to pay their premiums out of pre-tax dollars.³⁶ Medicare, too, proved artificially inexpensive for its recipients, who did not pay the full cost of their coverage; they were subsidized by younger Americans.³⁷ In effect, American healthcare consumers were raised in a culture of false affordability.

32. See STEVENS, *supra* note 16, at 284 (“Medicare gave hospitals a license to spend.”).

33. Howard Oxley & Maitland MacFarlan, *Health Care Reform: Controlling Spending and Increasing Efficiency* 60 tbl.1 (OECD Econ. Dep’t, Working Paper No. 149, 1994).

34. See *id.* (manuscript at 54).

35. See THE KAISER FAMILY FOUND. & HEALTH RESEARCH & EDUC. TRUST, EMPLOYER HEALTH BENEFITS: 2013 ANNUAL SURVEY 70 exhibit 6.1 (2013), available at <http://kaiserfamilyfoundation.files.wordpress.com/2013/08/8465-employer-health-benefits-20131.pdf>. Although healthcare costs continue to rise, it remains true that employers pay the bulk of an employee’s health insurance premium. Since 1999, employers have paid, on average, between 70–74% of a covered family’s premium and between 81–86% of a single employee’s premium. See *id.*

36. See Amy B. Monahan, *Health Insurance Risk Pooling and Social Solidarity: A Response to Professor David Hyman*, 14 CONN. INS. L.J. 325, 331 (2008) (citing I.R.C. §§ 106, 125, 162(l)(1)(b) (2006)) (“[O]nly self-employed individuals and those who receive coverage through their employer may pay health insurance premiums on a pre-tax basis.”).

37. See STARR, *supra* note 23, at 385 (“As third parties, both private insurers and government programs effectively insulate patients and providers from the true cost of treatment decisions”); see also DAVID GOLDHILL, CATASTROPHIC CARE 143 (2013) (pointing out that Medicare is primarily funded by payroll taxes and general government revenues).

II. THE RISING BURDEN OF U.S. HEALTHCARE EXPENDITURES

Eventually, the cost of healthcare began to burden Americans. Health insurance premiums rose so quickly that they put American companies at a competitive disadvantage.³⁸ By one estimate, the price of a typical U.S. automobile includes \$1,200 to pay for employee health insurance, versus only \$215 for a vehicle made in Japan.³⁹ Indeed, an argument can be made that U.S. healthcare costs have sped the process of economic globalization and outsourcing.⁴⁰ In addition, employees eventually began to feel the burden of their healthcare costs. Employee contributions to annual health insurance premiums almost doubled between 1999 and 2013, from \$1,543 per employee to over \$4,500.⁴¹ Less noticed, but perhaps more importantly, the rise in health insurance premiums limited U.S. wage growth, since money spent on health benefits was thereby not available as wages.⁴² In the absence of rising healthcare costs, U.S. workers would have seen significantly more take-home pay over this period.⁴³

38. See Toni Johnson, *Healthcare Costs and U.S. Competitiveness*, COUNCIL ON FOREIGN REL. (Mar. 26, 2012), <http://www.cfr.org/competitiveness/healthcare-costs-us-competitiveness/p13325> (noting that some economists believe rapidly rising health care costs “can put [U.S. companies] at a substantial competitive disadvantage in the international marketplace”); James Sherk, *Auto Bailout Ignores Excessive Labor Costs*, HERITAGE FOUND. (Nov. 19, 2008), <http://www.heritage.org/research/reports/2008/11/auto-bailout-ignores-excessive-labor-costs>. Other commentators, however, have indicated that American companies are more likely to pass along increasing costs to their employees rather than to consumers. See, e.g., GOLDHILL, *supra* note 37, at 56 (“Many [employers] are cutting back on their benefits packages and increasing deductibles, co-pays, or employee shares of premiums. In other words, to avoid cutting pay, they are passing on more costs to their employees.”). Of course, despite scholars’ disagreement on the “degree to which health care affects U.S. industries,” the two courses of action are not mutually exclusive. See Johnson, *supra*.

39. Sherk, *supra* note 38, at 2.

40. See, e.g., Robert S. Galvin & Suzanne Delbanco, *Perspective: Why Employers Need to Rethink How They Buy Health Care*, 24 HEALTH AFF. 1549, 1550 (2005) (“The growth in global outsourcing of labor [has been] driven at least in part by the high cost of health care . . .”).

41. See THE KAISER FAMILY FOUND. & HEALTH RESEARCH & EDUC. TRUST, *supra* note 35, at 70 Ex. 6.4.

42. See GOLDHILL, *supra* note 37, at 55 (“With health care expenses increasing faster than inflation . . . [and] overall economic growth . . . we’ve clearly seen the impact of higher health insurance premiums in slower wage growth.”). Goldhill gives the simple example of a worker whose total value to her employer is \$40,000, of which \$5,000 comes to her in the form of health care benefits and \$35,000 as wages. *Id.* at 54–55. When the growth of health care expenses outpaces the growth of inflation and economic growth, health care takes a greater proportion of her total compensation, thereby crowding out wage growth. *Id.* at 55–56.

43. See *id.* at 55.

Meanwhile, healthcare costs eventually burdened the U.S. government, as an increasing proportion of the federal budget began to be spent on healthcare.⁴⁴ In 1970, five years after Medicare and Medicaid were established, healthcare accounted for 7.1% of federal expenditures.⁴⁵ By 2012, that amount had risen to 26.1%.⁴⁶ The same goes for state governments, which share the cost of administering Medicaid, a program which pays healthcare expenses for some low-income populations.⁴⁷

But the financial burden most relevant for the purposes of this Article is the increasing cost of healthcare borne by patients as a result of the specific healthcare services they receive—the “out-of-pocket costs” associated with their healthcare. To be clear on what I am referring to by out-of-pocket costs, I distinguish between two kinds of direct healthcare expenses that patients owe: (1) patients’ portion of their *health insurance premiums*; and (2) the *post-insurance costs* patients pay for healthcare services which are not covered by their insurance. These latter costs typically fall into one of three categories:

(A) deductibles—the amount of money a given patient or family spends before their health insurance “kicks in” to reduce additional expenses;

(B) co-pays—flat fees patients are responsible for paying when receiving specific services (e.g., “\$45 for a physician appointment”); and

(C) co-insurance—a percentage of costs for which a patient is responsible (e.g., “10% of hospital costs”).

In recent years, all three of these post-insurance costs have increased.⁴⁸ The number of patients choosing high deductible

44. See OFFICE OF MGMT. & BUDGET, EXEC. OFFICE OF THE PRESIDENT, FISCAL YEAR 2014 HISTORICAL TABLES: BUDGET OF THE U.S. GOVERNMENT 360 tbl.16.1 (2013), available at <http://www.whitehouse.gov/sites/default/files/omb/budget/fy2014/assets/hist.pdf>.

45. *Id.*

46. *Id.*

47. See generally *About Us*, MEDICAID.GOV, <http://www.medicaid.gov/About-Us/About-Us.html> (last visited April 7, 2014) (describing a partnership between the Center for Medicaid and CHIP Services and states to provide “effective, innovative, and high quality health coverage programs”).

48. See TU & COHEN, *supra* note 1, at 3–4 (noting that employers are “increasing patient cost sharing in the form of larger deductibles and copayments” and “have pared benefits and moved from fixed-dollar copayments to percentage coinsurance”).

insurance plans is growing, typically because those plans are associated with lower monthly premiums.⁴⁹ Co-pays and co-insurance rates are also rising.⁵⁰ As a result, insurance no longer protects people as thoroughly from the costs of their medical care as it used to.

In recent years, healthcare spending has continued to grow in the United States, but at a much slower pace than historical averages, no longer growing at the rates it grew in the last three decades.⁵¹ Instead, it has recently grown at an annual rate of closer to 3%.⁵² Experts have argued that the current slowdown in U.S. healthcare inflation is partially attributable to this cost sharing⁵³ and have advocated that policy makers expand such cost shifting to further control costs.⁵⁴ However, as a consequence of these increasing out-of-pocket costs, patients are experiencing a corresponding increase in financial burden from their healthcare expenses.⁵⁵ Due in part to out-of-pocket costs, the Centers for Disease Control (“CDC”) estimated that in 2011, approximately one-third of U.S. citizens lived in families that were

49. See THE KAISER FAMILY FOUND. & HEALTH RESEARCH & EDUC. TRUST, *supra* note 35, at 149 exhibit 8.5 (showing that between 2006 and 2013, the number of workers enrolled in high-deductible plans has roughly quadrupled).

50. See TU & COHEN, *supra* note 1, at 3–4 (noting that employers are now requiring covered employees to make “larger . . . copayments” and pay “percentage coinsurance” for their health care needs).

51. See Ryu et al., *supra* note 2, at 835. Between 1980 and 2009, total health care spending in the United States grew at a rate of 7.4%. *Id.*

52. *Id.* (“In 2009–11 the spending growth rate was down to 3.1 percent.”).

53. See *id.* at 838 (“Rising out-of-pocket payments appear to have played a major role in [the decline in spending growth from 2009–11], accounting for approximately 20 percent of the observed slowdown.”); Larry Levitt et al., *Assessing the Effects of the Economy on the Recent Slowdown in Health Spending*, HENRY J. KAISER FAMILY FOUND. (Apr. 22, 2013), <http://kff.org/health-costs/issue-brief/assessing-the-effects-of-the-economy-on-the-recent-slowdown-in-health-spending-2/> (attributing some of the recent decrease in health spending to “rising levels of patient cost-sharing in private insurance plans that discourage use of services”); Andrew Pollack, *Health Care Costs Climb Moderately, Survey Says*, N.Y. TIMES (Aug. 20, 2013), http://www.nytimes.com/2013/08/21/business/survey-finds-modest-rise-in-health-insurance-premiums.html?_r=1& (“Premiums have been held in check partly by increasing out-of-pocket costs that workers pay through co-payments and deductibles.”).

54. Michael E. Chernew, *Additional Reductions in Medicare Spending Growth Will Likely Require Shifting Costs to Beneficiaries*, 32 HEALTH AFF. 859, 862 (2013) (noting that the growth of public health spending could be limited “by shifting costs to beneficiaries via higher beneficiary premium contributions (overall or via means testing), changes in eligibility, or greater cost sharing at the point of service”).

55. See ROBIN A. COHEN, RENEE M. GINDI & WHITNEY K. KIRZINGER, CTR. FOR DISEASE CONTROL, FINANCIAL BURDEN OF MEDICAL CARE: EARLY RELEASE OF ESTIMATES FROM THE NATIONAL HEALTH INTERVIEW SURVEY, JANUARY–JUNE 2011, at 1 (2012), available at http://www.cdc.gov/nchs/data/nhis/earlyrelease/financial_burden_of_medical_care_032012.pdf.

experiencing financial burdens due to healthcare.⁵⁶ Indeed, out-of-pocket costs can cause patients to experience financial distress⁵⁷ and can cause them to skip important medical treatments.⁵⁸ The Center for American Progress estimated that in Massachusetts, out-of-pocket costs for breast cancer treatment could reach over \$55,000 for women with high-deductible insurance plans.⁵⁹ Moreover, out-of-pocket costs for patients with uncomplicated diabetes could amount to more than \$4,000 per year, a figure that rises to \$40,000 per year for a diabetic patient with a heart attack requiring hospitalization.⁶⁰

A recent study from the State of Washington demonstrates just how serious the burden of healthcare costs can be for people with serious illnesses.⁶¹ The researchers discovered that people with cancer diagnoses were approximately two and one-half times more likely to file for bankruptcy than their age-matched peers.⁶² If anything, the Washington study underestimates the financial impact of health problems. For starters, many of the people who file for bankruptcy and did not have cancer suffered from other serious illnesses.⁶³ In addition, many of the people with cancer diagnoses did not have advanced disease.⁶⁴ It is likely that people with lower burden of disease experience lower healthcare costs and a smaller reduction in their income, meaning that people with more advanced cancer likely

56. *Id.*

57. See S. Yousuf Zafar et al., *The Financial Toxicity of Cancer Treatment: A Pilot Study Assessing Out-of-Pocket Expenses and the Insured Cancer Patient's Experience*, 18 ONCOLOGIST 381, 382 (2013) (discussing how cancer treatments can cause even the insured to need nonprofit or government assistance).

58. See John D. Piette, Michele Heisler & Todd H. Wagner, *Cost-Related Medication Underuse Among Chronically Ill Adults: The Treatments People Forgo, How Often, and Who Is at Risk*, 94 AM. J. PUB. HEALTH 1782, 1782, 1786 (2004) ("Many chronically ill adults frequently cut back on medications owing to cost.").

59. KAREN POLLITZ ET AL., CTR. FOR AM. PROGRESS ACTION FUND, *COVERAGE WHEN IT COUNTS: HOW MUCH PROTECTION DOES HEALTH INSURANCE OFFER AND HOW CAN CONSUMERS KNOW?* 8 (2009) (discussing the out of pocket costs to young adult women on the lowest cost, highest deductible plan in Massachusetts).

60. *Id.*

61. See Scott Ramsey et al., *Washington State Cancer Patients Found to be at Greater Risk for Bankruptcy than People Without a Cancer Diagnosis*, 32 HEALTH AFF. 1143, 1143 (2013).

62. *Id.* at 1147.

63. Medical debt is a factor in 53% to 62% of bankruptcies. *Id.* at 1144; see also Melissa B. Jacoby & Mirya Holman, *Managing Medical Bills on the Brink of Bankruptcy*, 10 YALE J. HEALTH POL'Y L. & ETHICS 239, 273 (2010) (finding bankruptcy filers often underreport the effects of financial stress from their medical expenses).

64. See Ramsey et al., *supra* note 61, at 1145 (finding that cancer patients who filed for bankruptcy were more likely to have localized, treatable cancers).

experience bankruptcy rates more than two and one-half times greater than the population at large.

One final note on financial burden before discussing the challenge of improving the system: the burdens discussed so far are largely borne by people with health insurance.⁶⁵ For those without health insurance, the burdens are even greater.⁶⁶ Although the proportion of Americans without health insurance should decline as the Affordable Care Act (“ACA”)⁶⁷ takes effect, many will still be uninsured.⁶⁸ That means that a large number of Americans will still

65. See James C. Robinson, *Reinvention of Health Insurance in the Consumer Era*, 291 JAMA 1880, 1881 (2004) (detailing contemporary trends in health insurance that have increased co-payments for everyday medical services and increased the average employee’s monthly contribution to family insurance coverage); GOLDHILL, *supra* note 37, at 56–58 (discussing the negative impact of the recession on increasing employee costs for their health insurance plans and the aggregate effect on their wages).

66. See, e.g., Steven Brill, *Why Medical Bills Are Killing Us*, TIME, Mar. 4, 2013, at 22 (detailing the misfortune of one uninsured person, “Janice,” who was billed \$21,000 for an ambulance ride after experiencing chest pains—one line item of her bill was marked up fourteen times over what Medicare estimates a similar test should cost).

67. Patient Protection and Affordable Care Act, Pub. L. No. 111-148, 124 Stat. 119 (2010) (codified in scattered sections of the U.S. Code).

68. See CONG. BUDGET OFFICE, ESTIMATES FOR THE INSURANCE COVERAGE PROVISIONS OF THE AFFORDABLE CARE ACT UPDATED FOR THE RECENT SUPREME COURT DECISION 12–13 tbl.3 (2012), available at <http://www.cbo.gov/sites/default/files/cbofiles/attachments/43472-07-24-2012-CoverageEstimates.pdf> (noting that coverage for the uninsured will increase under the ACA by 2022, but because of several states’ decisions not to expand Medicaid immediately after the Supreme Court’s decision in *National Federation of Independent Business v. Sebelius*, 132 S. Ct. 2566 (2012), six million people who are otherwise eligible will not have Medicaid coverage); Jaime A. Rosenthal, Xin Lu & Peter Cram, *Availability of Consumer Prices From US Hospitals for a Common Surgical Procedure*, 173 JAMA INTERNAL MED. 427, 431 (2013) (“The passage and pending implementation of the Patient Protection and Affordable Care Act is nearly certain to reduce the number of uninsured and boost demand for primary care, but it is also nearly certain that there will continue to be significant numbers of uninsured and underinsured Americans for whom the prices of healthcare services matter.”); *The Coverage Gap: Uninsured Poor Adults in States that Do Not Expand Medicaid*, THE HENRY J. KAISER FAMILY FOUND. 4 (Oct. 2013), <http://kaiserfamilyfoundation.files.wordpress.com/2013/10/8505-the-coverage-gap-uninsured-poor-adults8.pdf> (describing “coverage gaps” in which 4.8 million uninsured, nonelderly adults who fall below the poverty line will not be able to obtain Medicaid coverage in states that have not adopted the Medicaid expansion under the ACA). This problem is compounded by the Medicaid coverage gap created by some states’ decision not to expand Medicaid. See KAISER COMM’N ON MEDICAID & THE UNINSURED, CHARACTERISTICS OF POOR UNINSURED ADULTS WHO FALL INTO THE COVERAGE GAP 5 (Dec. 2013), available at <http://kff.org/health-reform/issue-brief/characteristics-of-poor-uninsured-adults-who-fall-into-the-coverage-gap/>. Nondisabled adults without children who fall below the federal poverty line were set to receive Medicaid under the ACA, but some states decided not to accept the federal money to expand the program. *Id.* Because the ACA anticipated these individuals would receive Medicaid, the people that fall into this gap receive none of the supports intended to help low-income people pay for coverage. *Id.* at 1. This means that

face the possibility of devastating financial burden should they experience an expensive acute or chronic illness.⁶⁹

III. HOW “SKIN IN THE GAME” OUGHT TO WORK

Many policy-makers continue to advocate for higher out-of-pocket costs for consumers or patients in order to increase their “skin in the game.” There are two primary goals policymakers have in mind in increasing out-of-pocket costs to consumers or patients. One goal is simply to relieve other parties of these costs, in essence to shift costs from payers (be they employers, insurance companies, or government) to patients.⁷⁰ The second goal is to bring more market discipline to healthcare to incentivize patients into becoming savvier consumers of healthcare services.⁷¹ With more “skin in the game,” theory holds that patients should be less willing to undergo unnecessary tests, to receive unproven procedures, or to consume overly expensive medications.⁷²

To meet the first goal of shifting costs, patients and physicians do not need to change any of their behavior in response to these financial incentives. Patients facing increased out-of-pocket costs could simply ask for the same services they have asked for before, and their doctors could recommend whatever tests or treatments they would have otherwise recommended at the same everyday prices. Even in this situation, healthcare costs will have successfully shifted, in part, from payers to patients. Raising deductibles, co-pays, or co-

many low-income people will continue to go without coverage, even when the ACA is fully implemented. *Id.* at 5.

69. See, e.g., POLLITZ ET AL., *supra* note 59, at 3 (describing the cost of three different chronic illnesses: breast cancer, heart disease leading to a heart attack, and diabetes); John D. Piette et al., *supra* note 58, at 1782 (finding that many chronically ill adults in a national study took less medicine than their doctor prescribed in order to reduce their costs). See generally COHEN ET AL., *supra* note 55 (analyzing the financial difficulties many Americans have in paying medical care as determined by a nationwide CDC study).

70. See Uwe E. Reinhardt, *The Many Different Prices Paid to Providers and the Flawed Theory of Cost Shifting: Is it Time for a More Rational All-Payer System?*, 30 HEALTH AFF. 2125, 2125 (2011) (describing cost shifting in the United States as the phenomenon created by “an opaque system in which payers with market power force weaker payers to cover disproportionate shares of providers’ fixed costs”).

71. See, e.g., Rosenthal et al., *supra* note 68, at 430 (“The desire for pricing transparency is based in fundamental principles of economics; the assumption that if patients know the prices of medical services, they will make rational decisions by avoiding high-cost health care providers *ceteris paribus*.”).

72. See GOLDHILL, *supra* note 37, at 33 (“We patients have bought into this model, demanding useless antibiotics for viral infections, tests to rule out improbable diagnoses, surgical procedures to lifestyle issues. . . . All this is . . . a result of our use of insurance to pay for everything.”).

insurance rates will, by definition, lead patients to pay a higher proportion of their healthcare expenses. But if giving patients more “skin in the game” does not influence medical decisions, and only succeeds in shifting costs from payers to patients, then the overall burden that healthcare costs place upon society at large will remain unchanged. We would spend the same amount of money as we currently do, but the money would be coming out of different pockets.

But of course, when patients have more “skin in the game,” they make different medical decisions.⁷³ Patients with higher out-of-pocket costs consume fewer medical services than their peers.⁷⁴ They are less likely to go to emergency rooms for acute illnesses for example,⁷⁵ or to receive preventive services like colonoscopies or mammograms.⁷⁶ But does that mean that they are savvier consumers of healthcare services? Unfortunately, it does not. The RAND health insurance study found that people with co-pays consumed fewer healthcare services than those randomized by the researchers to receive first dollar coverage.⁷⁷ But the people facing out-of-pocket costs for services were unselective in their parsimony—they were just as likely to forego necessary services as unnecessary ones.⁷⁸

For “skin in the game” to work properly, patients need to be more involved in their healthcare decisions. Shared decision making is a way to reduce financial distress and improve clinical choices.

73. See, e.g., J. Frank Wharam et al., *Low-Socioeconomic-Status Enrollees In High-Deductible Plans Reduced High-Severity Emergency Care*, 32 HEALTH AFF. 1398, 1403 (2013) (finding that enrollees of high deductible plans reduced their lower-severity emergency department care, regardless of their socioeconomic status, which suggests an attempt to minimize out-of-pocket expenses).

74. See JOSEPH P. NEWHOUSE & THE INS. EXPERIMENT GRP., *FREE FOR ALL? LESSONS FROM THE RAND HEALTH INSURANCE EXPERIMENT 338* (1993) (finding that the more a family had to pay out of pocket for medical expenses, the fewer medical services of any kind they used).

75. See, e.g., Wharam et al., *supra* note 73, at 1403 (finding that when using a high-deductible health insurance plan, enrollees of higher socioeconomic status reduced their lower-severity Emergency Department visits and hospital care, while those of lower socioeconomic status reduced both lower and higher-severity visits).

76. See NEWHOUSE, *supra* note 74, at 178 tbl.5.19, 179 tbl.5.20 (showing that cost-sharing does reduce the use of preventive care measures among adult men and women of various age groups).

77. See *id.* at 136 (“For 25 percent plans with a \$500 [Maximum Dollar Expenditure], total per capita expenditures fell 19 to 22 percent, depending on the size of the deductible, when compared with a plan with no initial deductible (that is, coinsurance started with the first dollar of spending). For larger MDEs the drop was 14–19%. Thus, the smaller the MDE, the greater the percentage drop for any given initial deductible.”).

78. See *id.* at 180 (stating that cost-sharing reduces the amount of appropriate and inappropriate services in the same proportion).

Shared decision making occurs when patients and providers partner to determine which medical interventions maximize a given patient's best interests, based in part on that patient's values or preferences.⁷⁹ As long as patients face high out-of-pocket costs, we face the risk that patients will mistakenly forego necessary treatments or mistakenly undergo unnecessarily expensive treatments. Ideally, the cost of care should be wrapped into broader discussions between patients and providers about the overall harms and benefits of treatment alternatives. Patient out-of-pocket costs should be treated like a treatment side effect and discussed as part of a more general process of shared decision making.⁸⁰ Patients need to know about the pros and cons of available healthcare alternatives, including the costs of receiving those services, and then they need to factor those pros and cons into their decisions. A forty-year-old woman considering whether to receive a mammogram not only needs to know the medical risks and benefits of this screening test, but also the cost, in a co-pay or co-insurance, of receiving this test. Similarly, a patient with acute bronchitis needs to be informed of the cost of her antibiotics, as well as the cost of alternative antibiotics. Ideally, she would even know the likelihood that the expensive versus the inexpensive antibiotic would cure her infection.

Unfortunately, there is little evidence that healthcare decisions in the United States regularly approach this type of rational, consumerist ideal.⁸¹ Instead, many barriers stand in the way of turning patients into rational and informed healthcare consumers.

IV. LACK OF PRICE TRANSPARENCY

Prices are normally a powerful tool for bringing consumer pressure to bear upon markets.⁸² A gas station that charges five cents more per gallon than the station across the street will not sell much gasoline. In that instance, consumers realize that the two competitors sell essentially identical products, and given the high visibility of each station's prices, the market will approach maximum efficiency—match your competitors' prices or go out of business.

79. See PETER A. UBEL, *CRITICAL DECISIONS* 213–14 (2012).

80. See Ubel et al., *supra* note 5, at 1484.

81. See UBEL, *supra* note 79, at 137, 154, 156 (arguing that rational decision making in the medical context is difficult to attain, even for those who are well-informed, because of the emotions involved).

82. See, e.g., Rosenthal et al., *supra* note 68, at 430 (stating that one of the fundamental principles of economics is that consumers will rationally avoid purchasing high-cost goods).

Even when consumers realize that competitors' products are not interchangeable like gasoline, prices still play a crucial role in making markets efficient. For example, a consumer who perceives that an Apple iPhone is superior to a Samsung smart phone will not necessarily purchase an iPhone if she can purchase a Samsung model at a significantly lower price. Consumers make cost and/or quality trade-offs with virtually every purchase, and prices play a powerful role in their purchasing decisions.⁸³

But in the United States, patients rarely make such cost and/or quality trade-offs when making healthcare decisions because most of the time patients are not aware of the cost of the healthcare services they receive.⁸⁴ Patients receiving hip replacement procedures, for example, almost never learn the costs of the procedure prior to their operations.⁸⁵ Even though making this decision ignorant of the cost would be irrational in economic terms, patients are not necessarily foolish to receive hip replacements without gathering cost information. For many people, after all, the vast majority of the expense of such a procedure will be picked up by insurance companies or government payers like Medicare.⁸⁶ There is little reason for patients to search out information on prices they do not have to pay.

For similar reasons, most patients have little or no incentive to comparison shop to find lower-priced surgeons to perform operations. Typically, patients pay a flat co-pay for such a procedure, meaning their costs will not vary based on their chosen hospital or doctor. Frequently, however, insurance companies distinguish between in-network and out-of-network providers, meaning patients will pay much more (perhaps even the full cost) of the procedure if they receive it from a provider outside the network.⁸⁷ In this case, most patients are likely to be extremely responsive to these costs, because the out-of-network provider will cost significantly more than in-network providers.⁸⁸ As this example reveals, healthcare markets in the United States are not completely price insensitive. However, this case hardly demonstrates consumer savviness as the primary force influencing purchasing behavior. Instead, it reveals the

83. See Valarie A. Zeithaml, *Consumer Perceptions of Price, Quality, and Value: A Means-End Model of Synthesis of Evidence*, J. MARKETING, July 1988, at 2, 4 figs.1, 12.

84. See Brill, *supra* note 66, at 23, 34.

85. See Rosenthal et al., *supra* note 68, at 429 tbl.1.

86. See Brill, *supra* note 66, at 43.

87. See Robinson, *supra* note 65, at 1883.

88. See *id.*

important role that third-party payers play in negotiating healthcare fees.

Back to the consumer: imagine a patient with degenerative hip disease who has either no insurance or a bare-bones insurance plan with a very high co-insurance rate and/or a high deductible. This patient has good reason to compare prices for surgeons in her vicinity who perform hip replacement procedures because such prices vary considerably. According to one study, prices for hip replacement in the United States range from approximately \$10,000 to over \$125,000.⁸⁹ Unfortunately for this consumer, such prices are not easy to discover. In fact, a research team collected price information on hip replacement procedures and discovered that more than half of the hospitals they called could not provide complete information about the cost of this operation.⁹⁰ Many of the remaining hospitals did not have such price information readily available, and the researchers had to make multiple calls to these institutions before receiving price estimates.⁹¹ This is not the behavior of a consumer-driven market. Indeed, the wide disparity of price itself is a strong signal that the market for hip replacements is not under pressure to price its services competitively, at least when providing such services to people who lack insurance.

As noted above, in considering prices of healthcare services in the United States, we must always remain aware of the difference between patients with and without access to third-party payers. Most U.S. hospitals do not charge a uniform price for a hip replacement procedure.⁹² Instead, a given hospital will negotiate fees with local health insurance companies, careful not to reveal the outcomes of, say, its Blue Cross negotiation with other insurance companies, and also hiding the results of these negotiations from competitor hospitals.⁹³ Perhaps it is not surprising that hospitals have such a difficult time providing cost information when asked for it.

89. See Rosenthal et al., *supra* note 68, at 429 tbl.3.

90. *Id.* at 430.

91. *Id.* at 429.

92. *Id.* at 429 tbls.1 & 3.

93. See, e.g., Brill, *supra* note 66, at 22 (explaining how a hospital and insurance company negotiate to include the hospital in the insurer's network of providers that its customers can use).

V. THE CHALLENGE OF GETTING PRICE INFORMATION IN TIME TO INFLUENCE HEALTHCARE DECISIONS

To briefly recap the previous section: patients often have little incentive to ascertain health care prices, but when they do have such incentive, the price information is frequently hard to come by. But the situation is even more dire than that because even if such cost information were readily available, and even if patients were incentivized to seek out such information, medical care often creates situations in which shopping for prices is not feasible. First, there is not always sufficient time to comparison shop. Moreover, one-time healthcare decisions often lead to complex trajectories of care that have important implications for patient out-of-pocket costs. Finally, determining patient-specific costs is often beyond the capabilities of both patients and clinical entities.

A. *Not Enough Time to Decide*

A patient with degenerative hip disease may have time to shop around for a good and affordable hip surgeon.⁹⁴ The same cannot be said for patients suffering from a wide range of acute and often very expensive illnesses. Heart attacks often occur suddenly, for example, leaving patients no time to do anything but get to a medical facility as soon as possible. These patients often face a range of treatment alternatives, alternatives with both medical and financial trade-offs. For example, consider a patient experiencing a heart attack who requires a procedure to prop open one of his coronary arteries.⁹⁵ Typically this would be done with something called a stent, a wire device inserted into the lumen of the artery to keep it open after it has been expanded by a balloon.⁹⁶ Assuming for the purposes of illustration that this stenting procedure is uncontroversially indicated—in other words, it is what medical experts agree ought to be done—the patient and doctor still face a choice of what kind of stent the patient should receive. Until roughly a decade ago,

94. See Rosenthal et al., *supra* note 68, at 431 (concluding, however, that it is often very difficult to obtain price information, even for a common elective procedure such as total hip arthroplasty).

95. Coronary arteries are the vessels that provide blood to the heart. *Anatomy and Function of the Coronary Arteries*, STANFORD HOSP. & CLINICS, <http://stanfordhospital.org/healthLib/greystone/heartCenter/heartIllustrations/anatomyandFunctionoftheCoronaryArteries.html> (last visited Mar. 1, 2014).

96. See *How Are Stents Used?*, NAT'L HEART, LUNG, & BLOOD INST. (Dec. 17, 2013), <http://www.nhlbi.nih.gov/health/health-topics/topics/stents/used.html>; *What Is a Stent?*, NAT'L HEART, LUNG, & BLOOD INST. (Dec. 17, 2013), <http://www.nhlbi.nih.gov/health/health-topics/topics/stents/>.

cardiologists propped open coronary arteries with bare metal stents.⁹⁷ Think of them as tubular springs, pushing out on artery walls to keep them open. The stents did a great job of opening up arteries in the short term, but had a nasty habit of clogging up over the longer term.⁹⁸ In 2002, a randomized trial showed that drug eluting stents—which slowly release clot-dissolving chemicals—are less likely to clog in the long run.⁹⁹ However, to keep arteries open, patients receiving such stents need to continue taking other clot-dissolving medicines for long periods of time.¹⁰⁰ Strangely enough, those bare metal stents do not require prolonged doses of anticlotting medicines because if they stay open long enough, they get covered by a surface that is resistant to clot.¹⁰¹ Confused yet? Well that's the problem. In choosing between these two types of stents, patients face a trade-off: between a newer stent that forces them to take an expensive pill (the cost of which will be partly borne by the patient), and a standard stent which may not work as well in the short run but has a longer track record and also does not obligate the patient to take any additional medications.

This is a challenging decision to make for a host of reasons. The facts are uncertain, the financial costs to the patient are not easily obtained, and, most importantly, the decision needs to be made immediately. Is it any wonder that this decision is made largely by cardiologists, with patient involvement limited to passive acceptance of physician recommendations?

97. See Patrick W. Serruys, Michael J.B. Kutryk & Andrew T.L. Ong, *Coronary Artery Stents*, 354 *NEW ENG. J. MED.* 483, 483–86 (2006) (noting that prior to FDA approval of drug eluting stents in 2003, more than 84% of coronary interventions were conducted using bare-metal stents).

98. See Stéphane Cook & Stephan Windecker, *Early Stent Thrombosis: Past, Present, and Future*, 119 *CIRCULATION* 657, 657 (2009) (noting a high rate of stent thrombosis with the use of bare metal stents); see also Stefan K. James et al., *Long-Term Safety and Efficacy of Drug-Eluting Versus Bare-Metal Stents in Sweden*, 360 *NEW ENG. J. MED.* 1933, 1940 (2009) (finding that restenosis occurred less frequently with drug-eluting stents than with bare metal stents).

99. Marie-Claude Morice et al., *A Randomized Comparison of a Sirolimus-Eluting Stent with a Standard Stent For Coronary Revascularization*, 346 *NEW ENG. J. MED.* 1773, 1773 (2002).

100. See *id.* at 1774; see also Anthony A. Bavry et al., *Late Thrombosis of Drug-Eluting Stents: A Meta-Analysis of Randomized Clinical Trials*, 119 *AM. J. MED.* 1056, 1058, 1060 (2006); Laura Mauri et al., *Stent Thrombosis in Randomized Clinical Trials of Drug-Eluting Stents*, 356 *NEW ENG. J. MED.* 1020, 1022 (2007); Jeffrey W. Moses et al., *Sirolimus-Eluting Stents Versus Standard Stents in Patients with Stenosis in a Native Coronary Artery*, 349 *NEW ENG. J. MED.* 1315, 1316 (2003).

101. See Bavry, *supra* note 100, at 1060.

Many medical decisions are made by physicians under time pressure. Say, for example, a patient hospitalized with pneumonia decompensates¹⁰² and, just to be safe, the physician transfers the patient to the intensive care unit (“ICU”) for closer monitoring. ICUs are significantly more expensive places to stay than regular hospital beds.¹⁰³ Yet when patients are sick enough to require transfer to the ICU, it is very difficult—sometimes impossible—to make time to talk with them about the cost of such care. Moreover, most clinicians likely would not deem it appropriate to hold such a conversation at that time, when medical necessity looms so large. Even non-urgent out-patient decisions frequently happen under significant time pressure.¹⁰⁴ In my experience, primary care physicians do not have time during fifteen minute encounters to query patients about whether to order a blood test to check for kidney disease, liver failure, thyroid function and the like. So I expect that most physicians decide whether such tests are “indicated” without discussing it with their patients, leaving patients to pay their portion of the bill.

In determining how best to use patient “skin in the game” to improve the functioning of medical markets, we need to do a better job of determining which kinds of medical decisions are most amenable to the kind of reflection and investigation that will allow empowered patients to decide how they want to spend their healthcare dollars. Meanwhile, we are largely left with a system that uses patient out-of-pocket costs as a blunt instrument—a \$45 co-pay for all physician visits, whether or not those visits are discretionary, or a 10% co-insurance rate for hospital expenses, regardless of whether those expenses are avoidable. In such a system, we cannot expect patient financial incentives to bring the marvels of market discipline to bear upon medical practice.

B. Unpredictable Trajectories of Care

Making medical decisions is complicated for another important reason: a choice at one point in time can create a trajectory of care

102. “Decompensation” is the inability of the heart to maintain adequate circulation. MERRIAM-WEBSTER’S COLLEGIATE DICTIONARY 323 (11th ed. 2003).

103. See Adrian G. Barnett et al., *The Increased Risks of Death and Extra Lengths of Hospital and ICU Stay from Hospital-acquired Bloodstream Infections: A Case-Control Study*, 3 *BMJ OPEN* 1, 5 (2013), available at <http://bmjopen.bmj.com/content/3/10/e003587.full.pdf+html>.

104. Pauline W. Chen, *For New Doctors, 8 Minutes Per Patient*, N.Y. TIMES WELL BLOG (May 30, 2013, 12:01 AM), <http://well.blogs.nytimes.com/2013/05/30/for-new-doctors-8-minutes-per-patient/> (noting that increased time restraints limit new doctors to an average of eight minutes with each patient).

that has unknowable medical and financial consequences for patients. Consider a patient with early stage breast cancer deciding between mastectomy (surgical removal of her entire breast) or lumpectomy (removal of the tumor and surrounding tissue, with preservation of the remainder of the breast).¹⁰⁵ This is the kind of important decision that is generally handled with lengthy appointments, in which women learn about the pros and cons of their treatment alternatives. Early stage breast cancer involves a choice in which the financial implications of treatment alternatives may not be obvious to patients. The main choice—between mastectomy and lumpectomy—may appear to be cost neutral to most patients, who will pay a standard co-pay for a surgical procedure, making the two choices appear equivalent. But the mastectomy choice may be accompanied by a decision to receive reconstructive surgery, which may entail additional procedures and corresponding co-pays.¹⁰⁶ And the choice of lumpectomy typically commits a woman to a six-week course of radiation treatment with its attendant costs, and it also requires more frequent post-operative imaging, given the higher risk of local recurrence.¹⁰⁷ Most women facing this choice will not be able to estimate the costs of all these different procedures and tests. Indeed, most physicians would have a hard time estimating these costs. To date, no experts have determined the typical out-of-pocket costs for patients choosing between mastectomy and lumpectomy. Patients making this decision do so in a financial void.

C. *The Challenge of Determining Patient-Specific Costs*

Making market-based medical decisions is also challenging because different patients receiving the same set of interventions will often bear very different costs. This is because the U.S. healthcare system consists of so many different third-party payers. When physicians are asked whether they commonly discuss costs of care with patients, many state that determining such costs is too difficult, rendering such conversations moot.¹⁰⁸ Once again, the medical market functions quite differently than standard markets. People usually

105. See Bernard Fisher et al., *Twenty-Year Follow-Up of a Randomized Trial Comparing Total Mastectomy, Lumpectomy, and Lumpectomy Plus Irradiation for the Treatment of Invasive Breast Cancer*, 347 *NEW ENG. J. MED.* 1233, 1233–34 (2002).

106. See Eric Muñoz et al., *Lumpectomy vs Mastectomy: The Costs of Breast Preservation for Cancer*, 121 *JAMA SURGERY* 1297, 1301 (1986).

107. See *id.* at 1298–99.

108. See Alexander et al., *supra* note 6, at 859 (discussing the difficulty that physicians have in determining patient costs and encouraging patients to bring up cost-related conversations rather than having the physician initiate these conversations).

know how much they are going to pay for a pair of basketball shoes, and the clerks at Famous Footwear do not need to check on their customers' shoe insurance coverage to know how much to bill them.

Here we see a tension in how best to bring market discipline to bear upon the healthcare system. If we standardize patient costs, doctors and patients could more easily determine the out-of-pocket consequences of given healthcare interventions, and therefore the market could work more efficiently. In such a system, where more patients are aware of the cost of their care, costs could more readily be factored into a larger number of decisions. However, such a system would also interfere with the healthcare marketplace, because it would reduce consumers' ability to choose insurance plans that differ in terms of their out-of-pocket costs, and it would reduce insurance companies' abilities to compete based upon such factors.

VI. THE CHALLENGE OF DISCUSSING PATIENT OUT-OF-POCKET COSTS DURING CLINICAL ENCOUNTERS

The preceding Part laid out a number of factors that make it difficult for doctors and patients to discuss patient out-of-pocket costs in time for such considerations to influence clinical decisions. Such costs are often difficult to ascertain, and there is not always time to factor costs into clinical decisions. But let us assume that a patient faces an important decision, and her out-of-pocket costs are readily available in time to influence that decision. Another set of barriers stands in the way—patients and physicians are often unwilling to discuss such costs, and even when they do hold such conversations, they do not necessarily converse in ways that promote optimal decision making. The following subsections explore some of the reasons doctors hesitate to discuss the costs of healthcare they are providing with their patients.

A. *Reluctance to Discuss Costs of Care*

Studies have consistently shown that physicians and patients often have difficulty discussing patient out-of-pocket costs during clinical encounters.¹⁰⁹ Patients report being worried that bringing up such costs will threaten their relationship with their physician.¹¹⁰

109. *See id.* at 858 (finding that at least 10% of patients and 20% of physicians studied did not bring up costs when they wanted to on at least one occasion).

110. Roseanna Sommers et al., *Focus Groups Highlight That Many Patients Object to Clinicians' Focusing on Costs*, 32 HEALTH AFF. 338, 341 (2012) (reporting that low-income patients are especially worried about the relationship between costs and the level of care).

Physicians from several specialties—including general internal medicine, cardiology, and oncology—report that they, too, are uncomfortable holding such conversations with patients and worry that such conversations will take up valuable time.¹¹¹

The absence of such conversations causes avoidable harm. First, it leads patients to receive unnecessarily expensive treatments. To illustrate, consider a study of the financial burden of breast cancer treatment that I conducted with Jessica Harris, Yousuf Zafar, and Amy Alderman. In the study, we interviewed twenty-two participants selected from a prospective, nationwide survey that the Duke Cancer Care Research Program completed in 2011.¹¹² We selected female breast cancer survivors between sixty-five and seventy-five years old and eligible for Medicare at the time of completion of the baseline survey. Eligible participants had all received anti-cancer therapy for breast cancer (chemotherapy or hormonal treatment) within the past year.¹¹³ One of the women we interviewed reported telling her clinician: “I’m not taking this if it’s going to be \$500 a month,” only to learn from her clinician that, “[w]e can put you on something [less expensive that is] just as effective.”¹¹⁴

Second, cost discussions would potentially benefit patients who are willing to trade some chance of medical benefit for less financial distress. This trade-off makes clinical sense if we think of financial costs as treatment side effects.¹¹⁵ And yet, the majority of the twenty-two women we interviewed either reported never holding such conversations or did so, but only when faced with financial distress.¹¹⁶ Most of these women did not discuss out-of-pocket costs at the time they were making important treatment decisions.¹¹⁷

111. See G. Caleb Alexander, Lawrence P. Casalino & David O. Meltzer, *Physician Strategies to Reduce Patients’ Out-of-Pocket Prescription Costs*, 165 ARCHIVES INTERNAL MED. 633, 634 tbl.2 (2005) (identifying barriers preventing greater patient-physician communication about out-of-pocket costs).

112. Zafar et al., *supra* note 57, at 385 (finding that treatment costs are not adequately addressed with patients, especially those that will face financial hardships because of the treatment).

113. To be eligible, participants were required to speak English, read, and be able to interview independently.

114. Jessica R. Harris, *Communicating About Costs: A Qualitative Analysis to Understand the Out-of-Pocket Financial Burden Associated with Cancer Care* 12 (May 1, 2012) (unpublished Master’s thesis, Duke University).

115. See, e.g., Ubel et al., *supra* note 5, at 1484–85 (describing sacrifices made by patients dealing with high-cost health care).

116. Harris, *supra* note 114, at 10 (“Many survivors discussed the cost of their care only when the burden became unmanageable.”).

117. *Id.* at 10–11, 22.

Third, discussing out-of-pocket costs could benefit patients by enabling them to seek financial assistance early enough in their care to avoid financial distress. One of the patients in our interview study explained:

My husband died, and we were in debt, I was sick, he was sick, I lost my house . . . and I told [my doctor], that I could not afford to take the Femara,¹¹⁸ and she said, well, you can apply for help . . . and I got help.¹¹⁹

One has to wonder whether an earlier discussion of out-of-pocket costs might have saved the patient the loss of her home.

Clinical interactions are not cold, calculating market negotiations. Instead, they often involve very delicate and personal relationships. Patients want to trust their doctors and rely upon them for guidance and comfort. They do not necessarily want to interact with doctors the way they interact with used car salesmen, kicking the proverbial tires and haggling over prices.¹²⁰ Similarly, many physicians I have spoken with have expressed their interest in keeping financial discussions out of the doctor-patient relationship, so that the relationship can focus on healing and other purer considerations. While to date this evidence is largely anecdotal, the strength of physicians' opinions has been impressive. For example, when I approached oncologists to see if they would allow me to record them discussing the cost of care with their patients, the first few oncologists I spoke with told me, flat out, that it would be unethical to discuss the costs of care, even a patient's out-of-pocket costs, in the setting of a serious illness.¹²¹

Another aspect of the doctor/patient relationship stands as a barrier to more market-like interactions—doctors and patients typically encounter each other in the setting of a major knowledge and power gap. Physicians usually know much more about their patients' healthcare alternatives than patients could plausibly learn.

118. Femara is a type of hormone therapy that reduces the amount of estrogen produced in postmenopausal women and can be used to treat women with hormone receptor-positive or advanced breast cancer. FEMARA, <http://www.femara.com/index.jsp> (last visited Feb. 24, 2014).

119. Harris, *supra* note 114, at 12.

120. See, e.g., John D. Piette et al., *The Role of Patient-Physician Trust in Moderating Medication Nonadherence Due to Cost Pressures*, 165 ARCHIVE INTERNAL MED. 1749, 1750 (2005) (“[P]atients who trust their clinicians may place a higher value on their prescription drugs and be more likely to maintain adherence, at least when costs are within a financially feasible range.”).

121. Interview with oncologists, Duke University Hospital, in Durham, N.C. (2013).

Patients often come to their doctors looking for advice. They ask surgeons whether they should have surgery and oncologists whether they should receive chemotherapy. These are hardly the kinds of questions consumers would ask in many other market settings. No one would expect a Toyota salesperson to give objective advice about whether the best car for that consumer is a Toyota. People's reliance upon physicians for clinical advice makes it that much more difficult for patients to ask about the cost of their care.

B. Difficulties Sharing in Clinical Decisions

Even when doctors and patients seek to partner in decisions (rather than let the doctor decide on her own), they often have difficulty conversing with each other in ways that lead to optimal decisions.¹²² Nearly thirty years ago, medical practice in the United States experienced a patient empowerment revolution, with prominent legal cases establishing that patients have rights not only to information about their medical conditions but also to have a final say about their medical care.¹²³ The goal of the revolution was to make sure that healthcare decisions would be based not only in medical facts, but also on patients' individual preferences.¹²⁴ Unfortunately, the ideals of patient empowerment are frequently undermined by the norms of clinical conversations.

Consider the following exchange between a urologist and a man about to learn that he has prostate cancer.¹²⁵ In serious tones, the urologist broke the bad news: "Out of [twelve cores] there were three cores that had . . . a little bit of cancer in them."¹²⁶ In another minute or two, the urologist explained this patient's treatment choices: the patient could choose surgery, radiation, or active surveillance in which the urologist would watch the cancer closely with blood tests and biopsies.¹²⁷ The urologist also explained each of the choices in elaborate detail because he knew that the "right choice" would

122. See UBEL, *supra* note 79, at 83, 87 (noting that one barrier to effective communication between doctor and patient is language, both when physicians use medical jargon, and when they use lay terms to describe medical care).

123. See *id.* at 75.

124. TOM L. BEAUCHAMP & JAMES F. CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 126–27 (4th ed. 1994) (discussing the importance of a patient's autonomy and preferences in making health care decisions).

125. See UBEL, *supra* note 79, at 11. This conversation was recorded as part of a study on how doctors and patients make these decisions, under the leadership of Angie Fagerlin, at the University of Michigan.

126. See *id.* at 11.

127. See *id.*

crucially depend on what the patient—a seventy-year-old man—thought about the relative pros and cons of treatment versus surveillance.¹²⁸ But before explaining these treatment choices, the urologist wanted to make sure his patient understood the limited extent of his cancer:

“We also grade prostate cancer on how it looks under the microscope. We give it a score between 6 and 10.”

“Is that the Teason?” [the patient] asked.

“That’s the Gleason Score.”

“Oh, Gleason Score. Okay,” the patient replied.

“Yep, so 6 is what we consider the most low-grade, least aggressive-looking, but it’s the most . . . it’s just abnormal enough for us to call it cancer. If it were any less than that, if there were less atypical-looking cells, we couldn’t call it cancer. So it’s just enough to get a grade of cancer and then that goes all the way up to a score of 10, which is very abnormal looking and is more aggressive.”

“But 6 is the beginning number?”

“Yes, 6 is the least aggressive, 10 is the most aggressive.”

“I’m used to, like, 1,” [the patient] said, laughing.

“Yeah, well, the way we typically split it up is into thirds—low risk, intermediate risk, and high risk.”

“Right.”

“Low risk is Gleason 6, intermediate is usually 7s—either 3+4 or 4+3, depending on how it looks under the microscope—and then 8, 9, and 10 are all high risk. So yours was an intermediate risk. So it’s in the middle. It was 3+3 and 3+4, so just enough of the atypical cells of the grade 4 to make it 3+4, which means you’re intermediate risk.”¹²⁹

This conversation is remarkable not just for its inscrutability, but for the very fact that it took place. In the 1960s, surveys of American

128. *See id.*

129. *See id.* at 11–12.

physicians revealed that almost none of them informed patients of cancer diagnoses if they thought such information would cause patients to experience emotional distress.¹³⁰ By the late 1980s, it was “almost impossible” to find “a doctor in the United States who withheld cancer diagnoses from patients.”¹³¹

Unfortunately, as evidenced by this urologist’s earnest attempt to explain this patient’s Gleason score, physicians’ efforts to educate patients about their medical conditions can fail when physicians resort to jargon beyond a layperson’s grasp. Imagine yourself sitting half-naked on an exam table with the word “cancer” rattling around your brain. Do you think you would be ready to comprehend this conversation? Studies have established that jargon is ubiquitous in physician/patient encounters, with doctors frequently using undefined technical terms and patients rarely having the confidence or assertiveness to ask for clarification.¹³² All too often, the result is precious time wasted on ineffective communication despite the many important decisions doctors and patients need to make together. Medical terminology becomes so second nature to physicians that they seemingly forget that their words sound like a foreign tongue to many of their patients.

To make matters worse, physicians often fail to account for the negative emotions arising during medical encounters. In one study of senior oncologists, researchers discovered that when patients expressed negative emotions (“I’m scared,” for example, or “I can’t sleep because of pain”), the oncologists acknowledged and responded to these emotions only one in five times.¹³³ The remainder of the times they either continued talking, as if the patients had never uttered these cries for help, or changed the topic to something less difficult to talk about, often shifting to lecture mode, doing their best to make sure their patients were adequately informed about their illness.¹³⁴

In my view, the patient empowerment revolution has stalled in mid-course in large part because doctors do not know how to partner

130. Donald Oken, *What to Tell Cancer Patients: A Study of Medical Attitudes*, 175 JAMA 1120, 1122 (1961).

131. See UBEL, *supra* note 79, at 74.

132. See Cesar M. Castro et al., *Babel Babble: Physicians’ Use of Unclarified Medical Jargon with Patients*, 31 AM. J. HEALTH BEHAV. S85, S92 (2007); See Sharon E. Barrett & Jennifer Sheen Puryear, *Health Literacy: Improving Quality of Care in Primary Care Settings*, 17 J. HEALTH CARE FOR POOR & UNDERSERVED 690, 693 (2006).

133. Kathryn I. Pollak et al., *Oncologist Communication About Emotion During Visits with Patients with Advanced Cancer*, 25 J. CLINICAL ONCOLOGY 5748, 5751 (2007).

134. *Id.* at 5748.

with patients to make preference-sensitive decisions. In the old days, in the more than two millennia lying between the time of Hippocrates and the patient empowerment revolution of the 1970s, physicians were the deciders—deciding what patients should and should not know and determining what treatments patients should or should not receive.¹³⁵ Indeed, the Hippocratic Oath compelled physicians to remain silent if such silence would reduce patient suffering: “Give necessary orders with cheerfulness and serenity, turning his attention away from what is being done to him; sometimes reprove sharply and emphatically, and sometimes comfort with solicitude and attention, revealing nothing of the patient’s future or present condition.”¹³⁶

With the new paradigm, physicians have been knocked off their “doctor knows all” pedestals, without being told where to stand. Too often, physicians see their role as that of an information provider. Sometimes patients ask their doctors for advice, and the doctors refuse to help. Often, doctors respond to patients’ requests for treatment recommendations by saying: “It’s not for me to decide, it’s your decision,” not realizing perhaps that the patients have asked for advice because they were overwhelmed by the information they have just received.¹³⁷ Other times, physicians willingly provide treatment recommendations, but only rarely after learning enough about what patients care about to make recommendations that reflect patient preferences.¹³⁸

Our prostate cancer study demonstrated how difficult it is for doctors and patients to make decisions based on patient preferences even when financial considerations were not an issue. In the study, men faced a decision between three treatments, with the best choice for any patient dependent in large part on that patient’s preferences—on what that patient thought about the relative pros and cons of active treatments that cause impotence and incontinence versus surveillance-oriented approaches that would not cure them of their cancer but would avoid these side effects. In this particular study, neither doctors nor patients faced significant financial considerations. The urologists all worked in the Veteran’s Affairs (“VA”) medical system and received salaries that did not depend on the volume of procedures they performed. The patients in the study were largely protected from the cost of their care by their VA

135. See UBEL, *supra* note 79, at 2.

136. KATZ, *supra* note 10, at 4.

137. See UBEL, *supra* note 79, at 3, 74–75.

138. The author is in the process of compiling the information in this Section into a series of working papers.

benefits. And yet still, our study showed that both physicians and patients had a difficult time partnering with each other to make treatment choices that reflected patient preferences. To begin with, as mentioned above, urologists rarely assessed patient preferences before making treatment recommendations. In addition, urologists frequently took treatment alternatives off the table for what they purported to be medical reasons—"you are young and healthy, so watchful waiting is not an option for you"—even though those treatment approaches were still viable.

Partnering between physicians and patients to make medical decisions is made more difficult when finances enter into the discussion—when the cost of care further complicates already complex decisions. What happens when doctors and patients discuss the cost of care in the context of important medical decisions?

C. *What We Talk About When We Talk About Money*

Even in a system where financial considerations are often discussed by doctor and patient, doctors struggle with how to present the financial considerations in a manner that can inform the patient's decision making. To date, there is almost no research exploring how physicians and patients discuss the cost of care during clinical encounters. The literature relies almost exclusively on survey data, involving recollections of past conversations, with no detailed observations of how such conversations are actually handled. In hopes of addressing this deficiency, I discovered a pilot study conducted in Singapore that recorded encounters between twenty patients with advanced cancer and their oncologists.¹³⁹ These conversations showed that patient out-of-pocket costs were discussed in eighteen of the twenty encounters, a stark contrast to practice in the United States.¹⁴⁰ These financial discussions may be common in Singapore, because of the prominent role that out-of-pocket costs play in the Singaporean healthcare system.¹⁴¹ In Singapore, all workers are required to contribute 6% to 8% of their salary to a Medisave account, a tax-free medical savings account they can use for a specified range of healthcare services for themselves or their

139. See Peter A. Ubel et al., *Money Talk: Discussion of Patient Out-of-Pocket Costs in Singapore Oncology Clinics* (forthcoming 2014).

140. See *id.*

141. See Michael D. Barr, *Medical Savings Accounts in Singapore: A Critical Inquiry*, 26 J. HEALTH POL., POL'Y & L. 709, 710 (2001); Rob Taylor & Simon Blair, *Financing Health Care: Singapore's Innovative Approach*, VIEWPOINT, May 2003, at 1, 1–2.

family.¹⁴² This money rolls over year-to-year and can be passed down to loved ones upon death.¹⁴³

In an analysis of the Singapore data, several findings stand out. First, cost discussions were initiated by a wide range of parties, with patients sometimes asking about costs, families other times asking about the costs patients will incur, and even oncologists initiating such conversations.¹⁴⁴ Second, discussion of costs occurred almost uniformly *after* the oncologist had made a definitive treatment recommendation.¹⁴⁵ Typically, the oncologist explained the patient's cancer status, for example by telling her that she has Stage 4 cancer, and described the role that chemotherapy would play in reducing cancer recurrence or prolonging her survival.¹⁴⁶ The oncologist continued to describe treatment side effects and explained what the medical team would do to reduce the impact of side effects on the patient's quality of life.¹⁴⁷ Then, and only then, the oncologist described how expensive the treatment was.¹⁴⁸ Importantly, the cost of treatment and the side effects of treatment were not presented as reasons to consider avoiding the chemotherapy or turning towards other treatments with better side effect profiles or with lower costs.¹⁴⁹ Instead, the oncologist arrived at a treatment recommendation early in the visit, generally based on the standard of care for maximizing patient survival, and discussed the cost of care as just another treatment side effect.¹⁵⁰ This paternalistic approach to clinical decision-making may be more common in Singapore than the United States. But our Singapore analyses suggest one way that discussion of patient out-of-pocket costs may fail to influence medical decision making—by only occurring after patients and their doctors make treatment choices.

Consider one encounter in which two relatives interacted with an oncologist-in-training and a supervising oncologist to figure out how to treat their mother, who recently received surgery for recto-sigmoid cancer, a cancer near the end of the colon.¹⁵¹ The patient was elderly with a psychological illness that began when she was thirteen years

142. Barr, *supra* note 141, at 712; Taylor & Blair, *supra* note 141, at 2.

143. See Barr, *supra* note 141, at 712.

144. See Ubel, *supra* note 139.

145. *Id.*

146. *Id.*

147. *Id.*

148. *Id.*

149. *Id.*

150. *Id.*

151. The information concerning this encounter is original data and analysis.

old, which caused her to be “easily agitated,” and on occasion, “depending on her mood,” also interfered with her ability to understand. The patient’s husband had died recently, after which she began experiencing abdominal pain, pain that the doctors discovered was caused by cancer. She had the cancer removed by a surgeon, who found that the cancer had invaded three of twenty-two local lymph nodes. The cancer in those lymph nodes had been removed, but the patient still needed additional treatment, according to the oncologists:

Oncology Trainee: Based on her report, she does need chemotherapy.

Daughter: Oh she does need. Is it because of?

Oncology Trainee: Basically, she has what we call nodal disease
...

Daughter: So it has spread, has it?

Oncology Trainee: There is tumor in these lymph nodes, yes.

Daughter: That’s why you are trying to kill these cells?

Oncology Trainee: Correct.

After the young oncologist examined the patient, the daughter asked about the cost of treatment:

Daughter: I would also like to know, if we plan for chemotherapy, how is the financial, because it is a real difficulty in payment. How can we get help?

Oncology Trainee: Who in her family is supporting her financially?

Daughter: She is under my care.

Oncology Trainee: So are you working, right? And you are the sole income in your family?

Daughter: No, my husband and myself.

Oncology Trainee: This one is not to worry too much about costs and all that as it can be deducted by Medisave [the Singaporean National Insurance System]. But if there really is a

problem, the social worker can come in and help with the finances.

The oncologist tried to minimize the daughter's concerns about the financial impact of treatment, but the daughter was still worried.

Daughter: Our Medisave account also has very little and we use it to pay for children's insurance and all that . . . so if that deducts, then no insurance for kids also.

The oncologist promised to refer her to a social worker, who could help them find financial assistance:

Oncology Trainee: There is this thing called the Medifund. It's a fund where patients come if they need help, can get treatment, which will either be free or heavily subsidized . . . so don't worry too much about the cost and all that. We will sort it out.

The daughter's forthrightness did not cause the oncologist to swerve from the belief that the patient needed chemotherapy, nor to go into specifics about the actual cost of the treatment, but did increase the chance that the family would not bear the brunt of related treatment costs. Discussion of cost is crucial if for no other reason than to help people find financial assistance before they undergo courses of treatment.

The oncologist continued the visit by describing the likely side effects of the chemotherapy. At that point, the senior oncologist entered the room, and the junior oncologist explained what two drugs the patient would receive.

Senior Oncologist: So what are we giving?

Oncology Trainee: Xeloda and Oxali.

Senior Oncologist: You have to take into consideration her condition. Who is looking after her?

Daughter: I myself.

The senior oncologist went on to explain what the treatment would entail. The daughter explained that her mother might not allow them to give treatment—she might get agitated and pull out the IV, for example, or refuse to swallow the pill. The patient remained silent throughout the vast majority of this encounter, in part because the

discussion happened in English which, while she understood the language, was not her primary tongue.

The senior oncologist became concerned at that point that the patient would not comply with treatment, and explained the magnitude of benefit from chemotherapy.

Senior Oncologist: Surgery alone—70% of patients like her, stage 3, are cured already. But if we give surgery and chemotherapy, then another 10% of patients like her are cured. You understand? So there is 100 patients right. 70 will be cured by surgery and if we give chemotherapy, we save another 10.

Prior to this point in the conversation, there had been no discussion of the patient's chance of cure, nor of how chemotherapy would change that chance. When discussing how much the treatment cost, and whether treatment would put the family under financial duress, these cure rates were not deemed relevant. But now, the oncologists feared that the patient might not be able to psychologically tolerate chemotherapy. And hence, they reframed the choice of chemotherapy as being optional. After deciding the patient might not cooperate with treatment, the senior oncologist recommended that "we will just monitor her." After beginning to make follow-up arrangements, another relative chimed in:

Family 2: So we don't want chemo?

Daughter: No.

Family 2: Don't want to try the tablet?

Daughter: No.

Family 2: Why don't we try it and then if don't work out, we throw it away?

Daughter: The tablet is very expensive.

The daughter then turned to the junior oncologist.

Daughter: So, what do you think about the decision I took?

Oncology Trainee: Like the senior oncologist said, there is no right or wrong decision because this case is a bit different. Because let's say the patient can make decisions for themselves, they can follow instructions, comply with their medications

regarding the chemotherapy. We would do it because there is an added 10% benefit of cure.

The junior oncologist then stated that the side effects of treatment were outweighed by a 10% increase in survival expectancy, and that if diagnosed with the same cancer, he would choose the treatment.

Oncology Trainee: But in your mom's case, it is a bit different.

In this patient's case, chemotherapy would increase cure rates by 10%, a benefit that both oncologists believed outweighed the side effects and financial costs of chemotherapy. Only when the oncologists discovered that the patient's psychological condition might preclude treatment did they mention the 10% figure, in the context of describing the likely 70% cure rate achieved by surgery alone.

Were these oncologists correct to assume that any reasonable patient would opt for chemotherapy in this situation? The oncologists could have avoided this assumption by simply describing the benefits and harms of chemotherapy and asking the patient (or her family) whether they desired chemotherapy. Such a conversation would respect patient autonomy and better inform patients than their more paternalistic approach. Along these same lines, the oncologist could have asked the patient or family whether they were willing to take on the financial burdens of treatment in order to achieve the higher cure rate. This family, in fact, was concerned that paying for such care could compromise their ability to provide health insurance for their children. At a minimum, the oncologist should have waited to make a treatment decision until the full financial consequences of the treatments were better understood. But even in a culture where discussion of medical costs appears to be quite common, the physicians and patients had a difficult time factoring the financial cost of care into the clinical decision.

VII. IMPROVING THE HEALTHCARE MARKET PLACE

The days of first dollar coverage are gone for the foreseeable future. We can expect Americans to bear an increasing portion of the cost of their healthcare services at the point of care, regardless of whether they receive private health insurance or Medicare.¹⁵² And as discussed above, at a minimum this "skin in the game" will both shift

152. See, e.g., Julie Appleby, *Expect to Pay More for Your Employer-Sponsored Health Care Next Year*, KAISER HEALTH NEWS (Dec. 20, 2013), <http://www.kaiserhealthnews.org/stories/2013/december/20/expect-to-pay-more-for-employer-health-care.aspx>.

some costs from payers to patients, and also reduce overall costs by dissuading patients from seeking certain types of care.¹⁵³ Ideally, however, patients would only be dissuaded from seeking discretionary care, and incentivized to make explicit cost and quality trade-offs that balance their medical and financial interests. As we have seen, this ideal is a long way from being realized.

Nevertheless, there are several steps we can take to come closer to that ideal. Specifically, this Part describes several measures necessary to improve patients' abilities to make informed decisions as healthcare consumers. These measures are all largely unproven. Therefore, we need more research on how each of these measures influence medical decision making.

A. *Price Transparency*

Out-of-pocket costs cannot influence medical decision making if these costs are unknown. Clinicians cannot discuss out-of-pocket costs with patients if it is difficult to determine what those costs are. For medical decision making to begin to work like a normal consumer market, healthcare prices need to be more transparent.

Fortunately, both governments and private companies are working to increase healthcare price transparency. For example, Massachusetts¹⁵⁴ and New Hampshire¹⁵⁵ have passed legislation requiring healthcare providers to publish information on their prices, legislation that has received high praise from consumer advocacy groups.¹⁵⁶ A multitude of other states have passed price transparency bills of their own.¹⁵⁷ It is too soon to know how well these laws will work, specifically, whether price information will be easy to discover in time to influence clinical decisions, and whether the information will be specific enough to help patients determine their out-of-pocket costs.

153. See *supra* notes 70–81 and accompanying text.

154. See An Act to Promote Cost Containment, Transparency and Efficiency in the Delivery of Quality Health Care, ch. 305, 2008 Mass. Acts 1322 (codified as amended in scattered sections of MASS. GEN. LAWS (2008)).

155. See N.H. REV. STAT. ANN. § 420-G:11-a (LexisNexis 2009) (“Development of a Comprehensive Health Care Information System”); N.H. CHIS, <https://nhchis.com/NH/> (last visited Oct. 31, 2013).

156. See, e.g., *Price Transparency*, CATALYST FOR PAYMENT REFORM http://www.catalyzepaymentreform.org/images/documents/CPR_Action_Brief_Price_Transparency.pdf (last visited Feb. 24, 2014).

157. See *Transparency and Disclosure of Health Costs and Provider Payments: State Actions*, NAT'L CONF. ST. LEGISLATURES, <http://www.ncsl.org/research/health/transparency-and-disclosure-health-costs.aspx> (last updated Apr. 2014).

One force which may make these state laws more effective is the emergence of companies providing cost information to healthcare consumers. I have spoken with a number of start-up companies in recent months, all of which are trying to develop applications and other software systems to give consumers accurate estimates of how much they will need to pay out of pocket for specific healthcare services.¹⁵⁸ In the world these companies envision, empowered patients will pull out cell phones in their doctors' offices and question their clinicians when the costs of recommended services appear to be too high. Or, these patients will go home with a recommendation to obtain, say, a knee MRI, and then compare prices at nearby imaging centers. One company CEO I spoke with envisions physicians using a tablet device, loaded with company software, to show patients the costs of such imaging tests linked to a Google map of the area.¹⁵⁹

Price transparency is a necessary step towards helping patients factor their out-of-pocket costs into medical decisions, but it is far from sufficient. Price information alone will not improve medical decision making unless the information is better incorporated into clinical conversations about the relative pros and cons of available healthcare interventions.

B. Improving Communication About Out-of-Pocket Costs During Clinical Encounters

For out-of-pocket costs to influence patients' healthcare choices, patients not only need to know these costs before receiving healthcare interventions, but also need to know the medical and financial costs and benefits of *alternative* interventions. An application may inform a patient that a medication for her rheumatoid arthritis will cost \$300 per month, but this information will not help the patient make a good decision unless she also gets information about alternative rheumatoid arthritis treatments. In some cases, information about treatment alternatives will be available outside of a clinical encounter. Patients can find information on websites.¹⁶⁰ Sometimes they can find high quality decision aids specific

158. See, e.g., CASTLIGHT HEALTH, <http://www.castlighthealth.com/> (last visited April 29, 2014); HEALTHCARE BLUEBOOK, <https://www.healthcarebluebook.com/> (last visited April 29, 2014).

159. Interview with startup CEO (2013). Identifying information has been withheld because this information is not available for public consumption.

160. See, e.g., *Medicare Provider Charge Data*, CENTERS FOR MEDICARE & MEDICAID SERVICES, <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Medicare-Provider-Charge-Data/index.html> (last updated Jan. 8, 2014) (providing a database of different costs for common inpatient and outpatient services); see

to their situations that help them understand the pros and cons of their alternatives.¹⁶¹ But often, information about alternative treatments will not be readily available to patients, or the information that is available will be hard for patients to interpret. In such cases, patients will often rely on clinicians to help them sort through their healthcare alternatives.

For shared decisions regarding medical treatment between clinicians and patients to go well, clinicians need to do a better job of partnering with their patients. To improve shared decision making, clinicians need to: explain patients' alternatives in simple language; assess patients' understanding of the information through "teach back" techniques;¹⁶² assess patient preferences relative to the decision at hand;¹⁶³ and help patients understand the role their preferences play in determining the "best" choice.¹⁶⁴ Our ongoing prostate cancer research has made it clear that many clinicians fall far short of these ideal practices. Other investigators have found similar shortcomings.¹⁶⁵

Medical training needs to give more emphasis to communication techniques. In addition, medical licensing boards and specialty societies ought to do more to reduce the chance that clinicians develop bad communication habits.

also *Medicines for Rheumatoid Arthritis: A Review of the Research for Adults*, AGENCY FOR HEALTHCARE RES. & QUALITY (Nov. 20, 2012), <http://www.effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1314> (providing a table comparing costs of different rheumatoid arthritis treatments).

161. Annette M. O'Connor et al., *Do Patient Decision Aids Meet Effectiveness Criteria of the International Patient Decision Aid Standards Collaboration? A Systematic Review and Meta-Analysis*, 27 *MED. DECISION MAKING* 554, 554 (2007) ("Patients decision aids (PtDAs) are adjuncts to counseling that explain options, clarify personal values for the benefits versus harms, and guide patients in deliberation and communication.").

162. Andrew J. Jager & Matthew K. Wynia, *Who Gets a Teach-Back? Patient-Reported Incidence of Experiencing a Teach-Back*, 17 *J. HEALTH COMM.: INT'L PERSP.* (Special Issue) 294, 295 (2012) (explaining that a "teach-back" is a method where "clinicians explicitly request that patients repeat instructions using their own words").

163. See Richard Wexler, *Six Steps of Shared Decision Making for Health Care Providers*, INFORMED MED. DECISIONS FOUNDATION (Feb. 9, 2012), available at http://www.informedmedicaldecisions.org/imdf_provider_tool/six-steps-of-shared-decision-making-for-health-care-providers/.

164. See *id.*

165. See Clarence H. Braddock III et al., *Informed Decision Making in Outpatient Practice: Time to Get Back to Basics*, 282 *JAMA* 2313, 2313 (1999) (finding that among fifty-nine primary care physicians and sixty-five general and orthopedic surgeons, informed decision making was often incomplete, signaling the need to encourage informed decision making in clinical practice).

C. *Designing Smarter Incentives*

Good communication about healthcare prices will help patients factor out-of-pocket costs into their healthcare alternatives. But in an ideal world, patients' exposures to out-of-pocket costs will be designed in ways that promote good medical decision making. When patients face choices between healthcare alternatives that differ dramatically in price, for example, but differ only slightly in effectiveness, it makes sense to require patients to pay a substantial out-of-pocket fee for choosing the more expensive (and barely more effective) therapy. By contrast, when the best alternative is significantly better than the next one, and only moderately more expensive, patients should not necessarily have to pay a great deal out-of-pocket to receive that better alternative.

This general approach has been labeled value-based insurance design ("VBID") by some experts.¹⁶⁶ Early evidence is mixed on how much VBID influences patients' and doctors' medical decisions.¹⁶⁷ It is likely that VBID will not reach its potential unless patients' healthcare prices are made more transparent and their clinicians do a better job of informing them about their healthcare alternatives.

Another approach to better aligning medical decision making and patient financial incentives is a practice known as reference pricing.¹⁶⁸ Take, for example, a 2011 decision by the California public employees' retirement system ("CalPERS") which decided to give employees an incentive to shop around for affordable orthopedic services.¹⁶⁹ California public employees were told that if they needed

166. See A. Mark Fendrick & Michael E. Chernew, *Value-Based Insurance Design: Aligning Incentives to Bridge the Divide Between Quality Improvement and Cost Containment*, 12 AM. J. MANAGED CARE (Special Issue) SP5, SP5 (2006).

167. See Niteesh K. Choudhry, Meredith B. Rosenthal & Arnold Milstein, *Assessing the Evidence for Value-Based Insurance Design*, 29 HEALTH AFF. 1988, 1992 (2010) (discussing the "lack of evidence of impact on health costs").

168. See, e.g., Karen M. Wieghaus, Note, *The Medicare Prescription Drug, Improvement, and Modernization Act of 2003: The Wrong Prescription for Our Nation's Senior Citizens?*, 11 CONN. INS. L.J. 401, 413-15 (2005) (explaining what "reference-pricing" is and its benefits); Uwe E. Reinhardt, *The Sleeper in Health Care Payment Reform*, N.Y. TIMES (Aug. 2, 2013, 12:01 AM), http://economix.blogs.nytimes.com/2013/08/02/the-sleeper-in-health-care-payment-reform/?_php=true&_type=blogs&_r=0 (providing a comparison between a "reference-pricing" scheme and a tiered-insurance scheme); David Williams, *Assessing the Role of Reference Pricing in Healthcare*, HEALTH CARE FIN. NEWS (Nov. 11, 2013), <http://www.healthcarefinancenews.com/blog/assessing-role-reference-pricing-healthcare> (discussing "reference-pricing" in relation to CalPERS).

169. See James C. Robinson & Timothy T. Brown, *Increases in Consumer Cost Sharing Redirect Patient Volumes and Reduce Hospital Prices For Orthopedic Surgery*, 32 HEALTH AFF. 1392, 1393 (2013).

services such as hip or knee replacements, they could use any hospital or surgeon they chose. But their insurance would cover only \$30,000 of hospital expenses.¹⁷⁰ That means that if a patient chose to go to a hospital that charged \$40,000 for a hip replacement, that patient was responsible for the extra \$10,000.¹⁷¹ The results of this program were dramatic. For starters, patients quickly began selecting different hospitals for their procedures, increasing the business to hospitals that charged \$30,000 or less for these procedures by 21.2%.¹⁷² In addition, a number of hospitals that previously charged more than \$30,000 for hip replacements reduced their prices by an average of more than 25%.¹⁷³

The thinking of the public employees' union was probably that the quality of orthopedic procedures did not vary dramatically as a function of their prices. By giving people an incentive to check on prices before receiving hip replacements, CalPERS dramatically altered the marketplace for such services in California. If this program's success is any indication, practices such as reference pricing will become more common in the near future.

CONCLUSION

My main goal in this Article has been to reveal the clinical barriers to making healthcare decision making more closely resemble the kind of consumer decision making common in other sectors of the economy. We need to be cautious about assuming that exposing patients to greater out-of-pocket costs will necessarily bring market efficiency to the healthcare system. With physicians often still the primary medical decision makers, and with patients often unaware of the costs and benefits of their healthcare alternatives, we cannot expect patient exposure to healthcare costs to lead them to make wise trade-offs between cost and quality. Without better price transparency, better physician-patient communication, and a smarter alignment of incentives with clinical benefits, exposing patients to more out-of-pocket costs will simply end up costing patients more money, without improving their healthcare decisions.

170. *Id.*

171. *Id.*

172. *Id.* at 1394.

173. *Id.* at 1395.

