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DEATH PANELS AND THE RHETORIC OF RATIONING

Elizabeth Weeks Leonard*

I. INTRODUCTION

During the federal health care reform debates, we heard impassioned arguments over compelled purchases of broccoli, cell phones, burial insurance, gym membership, and General Motors vehicles.¹ A national media personality called a law student a “slut” and asserted a public right to videotapes of her sexual activities because she wanted her university’s health plan to cover prescription oral contraceptives.² State laws requiring women to view ultrasounds and listen to fetal heartbeats before they are allowed to terminate pregnancies introduced the phrases “state-mandated rape” and “transvaginal probe” into the public lexicon.³

* Associate Professor, University of Georgia School of Law. This Essay is based on a conversation that I was honored to share with esteemed bioethicists, philosophers, and health policy experts, including Daniel Callahan, Mark Sheehan, Allan Brett, and Jacqueline Fox, at a University of South Carolina Symposium on *Health Care Rationing and Public Debate: Are American Citizens Capable of Making Hard Healthcare Resource Decisions and Should They Be Entrusted with This Weighty Task?* on March 18, 2011, almost one year after the ACA’s enactment, available at http://law.sc.edu/health_care_rationing/. I thank Associate Dean Stacey Tovino and the *Nevada Law Journal* for inviting me to contribute to this Symposium and Katie McCabe for excellent research assistance.

¹ Einer Elhauge, *It’s Not About Broccoli: The False Case Against Health Care*, ATLANTIC (Apr. 16, 2012, 11:00 AM), <http://www.theatlantic.com/national/archive/2012/04/its-not-about-broccoli-the-false-case-against-health-care/255939/>; Mark A. Hall, *The Oral Arguments*, BLOGS: AM. HEALTH LAW. ASS’N (Mar. 27, 2012), <http://www.healthlawyers.org/HCR/HCRBlogs/Lists/Posts/Post.aspx?List=278744cf-f229-4c83-8b6f-4099ad9eaa83&ID=26>; Margot Sanger-Katz, *Justice Kennedy Tough on the Insurance Mandate*, NAT’L J. (Mar. 27, 2012, 12:03 PM), <http://mobile.nationaljournal.com/healthcare/justice-kennedy-tough-on-the-insurance-mandate-20120327>.

² See Limbaugh: *Student Denied Spot at Contraception Hearing Says “She Must Be Paid to Have Sex,” So She’s a “Slut” and “Prostitute”*, MEDIA MATTERS (Feb. 29, 2012, 2:46 PM), <http://mediamatters.org/video/2012/02/29/limbaugh-student-denied-spot-at-contraception-h>186411>; see also Rush Limbaugh Attacks Sandra Fluke Again, HUFFINGTON POST (Apr. 25, 2012, 12:25 AM), http://www.huffingtonpost.com/2012/04/24/rush-limbaugh-sandra-fluke-again_n_1449935.html.

³ See, e.g., Neil Aquino, *Here Is How State Senator Dan Patrick Defends the State-Mandated Rape of the Forced Sonogram Law*, TEX. LIBERAL (Mar. 14, 2012), <http://blog.chron.com/texasliberal/2012/03/here-is-how-state-senator-dan-patrick-defends-the-state-mandated-rape-of-the-forced-sonogram-law/>; see also Anita Kumar, *Virginia Senate OKs Abortion Ultrasound Bill*, SEATTLE TIMES (Feb. 28, 2012, 7:54 PM), http://seattletimes.com/html/nationworld/2017620351_abortion29.html; Dahlia Lithwick, *Virginia’s Proposed Ultrasound Law Is an Abomination*, SLATE (Feb. 16, 2012, 6:57 PM), http://www.slate.com/articles/double_x/doublex/2012/02/virginia-ultrasound-law_women_who_want_an_abortion_will_be_forcibly_penetrated_for_no_medical_reason.html.

In August 2010, well before those more recent examples of health care political rhetoric, during the congressional wrangling that culminated in the Patient Protection and Affordable Care Act (ACA) of 2010,⁴ then Republican presidential candidate and Alaska Governor Sarah Palin posted a diatribe on her Facebook page against the proposed federal health reforms. In pertinent part, the post, entitled “Statement on the Current Health Care Debate,” included this vitriol:

And who will suffer the most when they ration care? The sick, the elderly, and the disabled, of course. The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s “death panel” so his bureaucrats can decide, based on a subjective judgment of their “level of productivity in society,” whether they are worthy of health care. Such a system is downright evil.⁵

The apparent basis for Palin’s alarmist suggestion stemmed from an innocuous House proposal to cover end-of-life counseling under the Medicare program.⁶ Until the ACA, Medicare historically did not cover annual check-ups, much less doctors’ time spent discussing end-of-life options with patients. The House bill simply would have reimbursed physicians for having those important conversations with patients.⁷ But popular protest grossly misperceived the proposal as authorizing government panels of experts to make terminal decisions for patients. The outcry resulted in Congress striking the provision from the bill.⁸ Several months after the ACA was enacted, the provision reappeared, not in the statute itself, but sneaked into a voluminous regulatory rulemaking.⁹ But the regulation was again short lived. After the media brought it to light,¹⁰ the federal agency responsible for Medicare regulation, the Center for Medicare and Medicaid Services (CMS), quickly excised the offending provision.¹¹

This anecdote reveals something about current campaign politics in the era of the twenty-four-hour news cycle and social networking. But it reveals even more about the public’s deep discomfort with the notion of rationing essential medical care and, especially, the government’s involvement in that process. This Essay briefly considers the rhetoric and the reality around the “death

⁴ Patient Protection and Affordable Care Act (ACA), Pub. L. No. 111-148, 124 Stat. 119 (2010), *amended by* Health Care and Education Reconciliation Act of 2010, Pub. L. No. 111-152, 124 Stat. 1029.

⁵ Sarah Palin, *Statement on the Current Health Care Debate*, FACEBOOK (Aug. 7, 2009, 1:26 PM), https://www.facebook.com/note.php?note_id=113851103434.

⁶ America’s Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233(a)(1)(E).

⁷ *Id.* § 1233(a).

⁸ See Joshua E. Perry, *A Missed Opportunity: Health Care Reform, Rhetoric, Ethics and Economics at the End of Life*, 29 *MISS. C. L. REV.* 409, 411–12 (2010) (citing Sarah Palin’s Facebook post and describing controversy surrounding proposed § 1233).

⁹ Payment Policies Under the Physician Fee Schedule, 75 *FED. REG.* 73,170, 73,406 (Nov. 29, 2010) (to be codified at 42 C.F.R. pts. 405, 409–11, 413–15, 424).

¹⁰ See, e.g., Robert Pear, *Obama Returns to End-of-Life Plan That Caused Stir*, N.Y. TIMES (Dec. 25, 2010), www.nytimes.com/2010/12/26/us/politics/26death.html (stating that the Obama administration used the regulation writing process to achieve its policy objective).

¹¹ Amendment to Payment Policies Under the Physician Fee Schedule, 76 *FED. REG.* 1366, 1366 (Jan. 10, 2011) (to be codified at 42 C.F.R. pt. 410).

panel” controversy and its adverse impact on at least two provisions of the ACA.

II. TWO TABOOS: SUBSIDIZATION AND RATIONING

Health care is a highly personal, fundamental, and often life-or-death matter for individual patients and their doctors. Thus, it is perhaps not surprising that health care policy conversations are framed in highly charged rhetoric and that emotions run high when the government becomes involved in those intimate encounters and decisions. But how a patient-favoring, personal-choice-protecting, physician-patient-relationship-preserving proposal like Medicare coverage for end-of-life counseling becomes synonymous in the public’s mind with Orwellian government control over whether individuals may continue to live, or be sentenced to death, is telling.

I should note at the outset that I approach the death panels issue not as a philosopher or bioethicist, but as someone who mostly thinks and writes about more mundane issues of health care financing, regulation, and delivery systems. Without regard to my particular expertise, when I explain to non-health lawyers that I “do” health law, the inevitable questions are, “Why don’t we have universal health care? A single-payer system? If Great Britain and Canada can do it, why can’t we? Isn’t that the easy fix to our health care system woes?” In the interest of returning the conversation to a lighter, cocktail-party level of discourse, I usually resist extoling how I believe that there are efficiency- and quality-producing benefits of markets and competition, even in health care. Instead, my standard answer is two-fold: First, we cannot tolerate the level of taxation that is required to support a universal health care system. Second, we cannot tolerate the inevitable rationing of care that is necessary for a single-payer system to function.

I soon may be able to amend my stock response because the United States is making progress on both of those fronts. One of the most beneficial effects of the otherwise rancorous national health care reform debate over the last few years is that we have become more informed as a nation about the realities of our health care system and all of its complexities. Lawmakers and the electorate better appreciate the interdependencies and policy choices that underlie our particular blend of public and private health care delivery. Perhaps building on that understanding, we can begin to confront the taboos of taxation and rationing.

We are making progress on the taxation issue. I now hear regular people, Joe the Plumbers, not to mention Supreme Court Justices¹² (that is to say, not

¹² See, e.g., *Nat’l Fed’n of Indep. Bus. v. Sebelius*, 132 S. Ct. 2566, 2585 (2012) (evaluating government’s argument that “the health care market is characterized by a significant cost-shifting problem” and explaining how the individual health insurance mandate aims to address cost-shifting); *id.* at 2588 (noting cost-shifting dynamic with medical costs of obesity-related illnesses); *id.* at 2611 (Ginsburg, J., concurring in part, concurring in the judgment in part, and dissenting in part) (noting that health care providers shift the cost of uncompensated care onto the government and private health insurance companies and citing congressional findings about cost-shifting); *id.* at 2650 (Justices Scalia, Kennedy, Thomas, and Alito, dissenting) (questioning the cost-shifting argument in the context of the “broccoli mandate”).

just health economists and regulatory wonks), discuss “cost shifting”: a form of private cross-subsidization for health care. Cost-shifting refers to the common practice of health care providers making up losses from unprofitable services by charging more to patients who have insurance.¹³ Over the years that I have been “doing” health law, I repeatedly have tried to explain cost-shifting to my parents and other incensed health care consumers when they complained that health insurers charge thousands of dollars for an MRI procedure or one-night hospital stay, or hundreds of dollars for an Ace bandage and Band-Aids in the emergency room. The simplest explanation for those seemingly outrageous charges is cost-shifting. The insured pay more for health care because providers are offsetting revenue losses for treating uninsured and under-insured patients.

The public is beginning to understand that. People now realize that those of us who are fortunate enough to have health insurance are, in effect, already being “taxed” to fund health care for those who do not. But it is a very messy, uncoordinated, loosely regulated way of subsidizing health care. As the public begins to appreciate the reality of private cost-shifting, we may well get to the point of recognizing, and perhaps even preferring, an overt, systematized, and rationalized tax program to subsidize health care for the uninsured. Even so, taxation only gets us part way toward a single-payer system because health care costs continue to rise. Unless we find a way to contain costs, perhaps by limiting care, we will have to continue increasing taxes to support our current level of health care consumption.¹⁴

Which leads us to the second hurdle: the debate around the ACA also facilitated our national conversation about rationing. Just as the public is more attuned to the reality of cost-shifting, the public is more attuned to the fact of rationing. We know that we cannot get every drug, test, procedure, and service that we want. We chafe at the notion yet tolerate the reality of non-physician gatekeepers for insurance companies deciding whether certain treatment is medically necessary or not and, therefore, covered or not. A recent *New Yorker* cartoon illustrated the point: A doctor is on the phone with a patient and says, “Before we try assisted suicide, Mrs. Rose, let’s give the aspirin a chance.”¹⁵ The cartoon is absurdist gallows humor because it suggests that a terminal condition might be as readily managed with the cheapest, most pedestrian, over-the-counter pill. We recognize and even laugh about the reality of private rationing in the health care system.

In addition to medical necessity review and gatekeepers, the managed care system, by design, erects other barriers to medical care. The system typically requires patients to contribute to the cost of care through co-payments and deductibles. Daniel Callahan characterizes those practices as “indirect ration-

¹³ See DAVID DRANOVE, *THE ECONOMIC EVOLUTION OF AMERICAN HEALTH CARE* 25–26 (2000).

¹⁴ See Daniel Callahan, *Must We Ration Health Care for the Elderly?*, 40 *J.L. MED. & ETHICS* 10, 12 (2012) (maintaining that rationing is the only option to avert Medicare financial crisis because of “perennial resistance” to tax increases and because “that would be a short-term solution only; there would be no end to it”).

¹⁵ See Marianne Matzo & David Miller, *Humor and Death: A Qualitative Study of The New Yorker Cartoons (1986–2006)*, 7 *PALLIATIVE & SUPPORTIVE CARE* 487, 491 (2009) (quoting cartoon).

ing.”¹⁶ I think of them as “self-rationing.” The aim is to shift the choice about whether to seek out or receive medical care onto patients by forcing them to internalize at least some of the costs. Co-payments and deductibles are supposed to make us think hard about the treatments we request.

But the seismic shift that the public would have to make to become comfortable with rationing, as with taxation, is around that “we.” Who is the “we” that is doing the rationing? In the above examples, it is private insurance companies, or individuals themselves, under the influence of managed care restrictions. Perhaps that makes it particularly offensive: money-grubbing, financially motivated, unfeeling insurance companies are deciding what care we do and do not receive. That is certainly the message of Michael Moore’s documentary feature film, *Sicko*:¹⁷ private insurance companies are the problem with our health care system. But would we be any more comfortable with government officials making those choices?

III. APPROACHES TO RATIONING

The starting point for accepting the necessity of rationing is accepting the reality that resources are limited.¹⁸ We cannot provide everything to every patient. Accordingly, “someone must decide who gets what.”¹⁹ If we dislike profit-motivated insurance companies deciding, one alternative is to have the government decide.

To some, government rationing will be even more offensive than private insurance rationing. Certainly, that is the suggestion of Sarah Palin’s Facebook post. The government’s role is to protect certain values in society and promote the common good. Justice and fairness require that people be treated equally unless they are sufficiently different. Accordingly, to have our government, our *parens patriae*, making decisions about who is in and who is out of medical treatment requires admitting, first, that we are making a choice and, second, that the government is the one brushing aside those core societal values.

A. *Tragic Choices*

Guido Calabresi’s and Philip Bobbitt’s 1978 book, *Tragic Choices*,²⁰ wrestles with societal rationing choices, engaging political, economic, and moral imperatives. Accepting that resources in society are necessarily limited, at least inasmuch as we have already made a choice not to devote all available resources to one particular end (what Calabresi and Bobbitt call “first-order” rationing),²¹ then the question is how to divide up the remainder of the pie

¹⁶ Callahan, *supra* note 14, at 12 (“By indirect rationing I mean to encompass a class of financial tactics aiming to influence patient behavior, such as copayments and deductibles.”).

¹⁷ *SICKO* (The Weinstein Company 2007).

¹⁸ Howard Brody, *From an Ethics of Rationing to an Ethics of Waste Avoidance*, 366 *NEW ENG. J. MED.* 1949, 1949 (2012).

¹⁹ *Id.*

²⁰ GUIDO CALABRESI & PHILIP BOBBITT, *TRAGIC CHOICES* (1978).

²¹ *Id.* at 19.

(“second-order” rationing).²² Sometimes society’s discomfort with second-order rationing decisions leads to changes in first-order rationing policy.

For example, in the 1960s, when kidney dialysis became available, there were not enough machines to treat all of the patients.²³ Attempts to define relevant criteria, such as medical condition, age, educational background, economic status, and occupation, generated considerable controversy.²⁴ To resolve the situation, in 1972, Congress authorized Medicare coverage for all end-stage renal disease (ESRD) patients.²⁵ Medicare coverage ameliorated the first-order supply limit, making dialysis available to every patient meeting the Medicare eligibility requirements. By increasing the supply of dialysis, the policy largely avoided the difficult second-order rationing decisions.²⁶ To this day, ESRD is the only diagnosis-specific Medicare coverage category.²⁷

Calabresi and Bobbitt offer a rather eloquent description of societal rationing as “composed of the succession of decision, rationalization, and violence as quiet replaces anxiety and is replaced by it when society evades, confronts, and remakes the tragic choice.”²⁸ They suggest various ways that society might avoid, or at least obscure, the tragic choice to deny life-saving care.

By sticking with our current approach of allowing commercial insurers to do most of the choosing, we largely avoid the anxiety and discomfort. Moreover, allowing the private market to accomplish the rationing comports with individual autonomy and free market principles, other core United States values. Consumers, so it appears, are making their own decisions about how much care they want to receive based on their available resources. The fallacy of that suggestion, of course, is that we do not all have the same resources to begin with. Therefore, our willingness—and, more importantly, our ability—to purchase health care does not necessarily reflect our true preferences.²⁹

Another way to avoid the anxiety of rationing is to use some type of random process: drawing lots, first-come-first-serve, or queuing up. We could say that the first five hundred people in any given year who need hip replacements or kidney transplants get the procedures. Otherwise, they must wait and try again the next year. The advantage of that approach is that we entirely avoid the discomfort of making the choice and drawing distinctions between similarly

²² *Id.*

²³ David Orentlicher, *Controlling Health Care Costs Through Public, Transparent Processes: The Conflict Between the Morally Right and the Socially Feasible*, 36 J. CORP. L. 807, 813 (2011).

²⁴ *Id.*; Norman G. Levinsky, *The Organization of Medical Care: Lessons from the Medicare End Stage Renal Disease Program*, 329 NEW ENG. J. MED. 1395, 1397 (1993) (describing the “ethical muddle,” before Medicare coverage, of selecting which patients should receive dialysis).

²⁵ 42 U.S.C. § 426-1(a) (2012); *see also* Act of Oct. 30, 1972, Pub. L. No. 92-603, § 299I(e)(3), 86 Stat. 1463; Levinsky, *supra* note 24, at 1395.

²⁶ *See* Levinsky, *supra* note 24, at 1395 (noting that in the 1960s and 1970s, when health care costs were lower, “the pressure not to deny lifesaving treatment to Americans solely because of expense was irresistible.”).

²⁷ Gina Kolata, *When Ailments Pile Up, Asking Patients to Rethink Free Dialysis*, N.Y. TIMES (Mar. 31, 2011), <http://www.nytimes.com/2011/04/01/health/01dialysis.html>.

²⁸ CALABRESI & BOBBITT, *supra* note 20, at 19.

²⁹ *See id.* at 32.

situated people.³⁰ The disadvantage is that we cannot very well tolerate the arbitrariness of the outcomes.³¹

What happens if we let the government choose? Often we leave hard tasks that call for coordination and consideration of multiple, competing interests to our representative government. There are a couple of different ways to go about it.³² First, we could do it in a bottom-up, democratic sort of way, entrusting citizens themselves with the weighty task. A bottom-up system could operate as a legislature, comprised of elected, politically responsible representatives,³³ or a jury, selected to represent the diverse views of the populous, with no expectation of having to justify its decisions.³⁴ Alternatively, we might prefer some sort of top-down process, a carefully appointed panel of experts or administrative agency, largely insulated from political or social pressures.³⁵ Broad public objection to the top-down approach is what gave Palin's Facebook post such salience. But it is not a far stretch to suggest that President Obama might prefer it.

B. Panels of Experts

Several Obama Administration health reform policies suggest a preference for the top-down, expert-driven approach.³⁶ This Administration does not appear willing to trust the political process or the public with the weighty task of rationing health care. President Obama's comments in an August 2009, Portsmouth, New Hampshire, Town Hall Meeting are illustrative.³⁷ (Incidentally, that was the same town hall meeting in which the President awkwardly rebutted Palin's death panel accusation with his own wince-worthy assurance that he would not "pull the plug on Grandma."³⁸) More eloquently, the President said in the same appearance:

Right now, insurance companies are rationing care. They are basically telling you what's covered and what's not. They're telling you, "We'll cover this drug but we won't cover that drug. You can have this procedure or you can't have that procedure." So why is it that people would prefer having insurance companies make those

³⁰ *Id.* at 41 (characterizing this approach as "a choice not to choose," which approximate "egalitarianism, since allocation by lot treats everyone within the eligible group in the same way.").

³¹ *Id.* at 42.

³² For one example of a government rationing system, see Dr. Mark Sheehan, Oxford Biomedical Research Centre Ethics Fellow at the University of Oxford, Speech at the Nuffield Trust Workshop: Ethical Issues in Priority Setting (May 24, 2011), available at <http://www.nuffieldtrust.org.uk/talks/slideshows/mark-sheehan-ethical-issues-priority-setting>.

³³ See CALABRESI & BOBBITT, *supra* note 20, at 34–41.

³⁴ See *id.* at 57–64.

³⁵ See *id.* at 64–65.

³⁶ See Elizabeth Weeks Leonard, *Can You Really Keep Your Health Plan? The Limits of Grandfathering Under the Affordable Care Act*, 36 J. CORP. L. 753, 753–756 (2011) (describing examples of the Administration's populist rhetoric belied by top-down federal regulation).

³⁷ Laura Conaway, *Obama Says His Health Plan Won't "Pull the Plug on Grandma"*, PLANET MONEY (Aug. 11, 2009, 1:24 PM), http://www.npr.org/blogs/money/2009/08/Obama_defends_health_insurance.html (citing President Barack Obama's statement at town hall meeting in Portsmouth, N.H.).

³⁸ *Id.*

decisions rather than medical experts and doctors figuring out . . . what are good deals for care and providing that information to you as a consumer and your doctor so you can make good decisions?³⁹

The President clearly echoed the popular view—the *Sicko* message—that it is insidious for private insurance companies to ration. But the President further suggested an apparent preference for official, government “medical experts and doctors” performing the rationing calculus.

Also consider the President’s reference to “good deals” for health care: when we shop at Wal-Mart, we look for “good deals”; but we do not typically worry about “good deals” when it comes to health care.⁴⁰ If anything, it seems to be “the popular belief that cost should be no object at the bedside.”⁴¹ The President’s reference to “good deals,” however, contemplates trade-offs, cost-benefit analysis, and getting adequate bang for our health care buck. The amount that we spend on sickness avoidance should be justified by the amount of wellness gained. In short, “good” health care is about quality. But “good deals” for health care is about rationing.

But the President’s trust in experts is in tension with his rhetoric of self-determination and market-based health care—core American values. His statement also emphasizes “providing . . . information to you as a consumer,” so that you may, in consultation with your doctor, make health care choices.⁴² The vision of patients as cost-conscious, quality-savvy consumers and comparison shoppers comports with a competitive market for health care, not a single-payer system. The President’s ideal, it seems, starts with expert-driven research into cost-effective treatment, followed by dissemination of that data to patients and providers, who then make informed health care choices as rational consumers.

The President offered similar views months before Palin’s death panel Facebook post. In a lengthy *New York Times Magazine* interview, on April 28, 2009, the President squarely addressed the 800-pound gorilla of health care costs.⁴³ The interviewer asked how to deal with the fact that the vast majority of health care costs are expended on the chronically ill and people at the end of their lives. The President responded:

I think that there is going to have to be a conversation that is guided by doctors, scientists, ethicists. And then there is going to have to be a very difficult democratic conversation that takes place. It is very difficult to imagine the country making those decisions just through the normal political channels.⁴⁴

The context and statement gives credence to Palin’s sickening charge. The President’s suggestion of how to deal with the cost of end-of-life care affirms the necessity of rationing. Moreover, he again assigned a central role to “doctors, scientists, [and] ethicists” and contemplated a behind-the-scenes, apolitical

³⁹ *Id.*

⁴⁰ See generally Kenneth J. Arrow, *Uncertainty and the Welfare Economics of Medical Care*, 53 AM. ECON. REV. 941, 941–48 (1963) (discussing various market failures in health care).

⁴¹ M. Gregg Bloche, *Beyond the “R Word”? Medicine’s New Frugality*, 366 NEW ENG. J. MED. 1951, 1951 (2012).

⁴² Conaway, *supra* note 37.

⁴³ David Leonhardt, *After the Great Recession*, N.Y. TIMES MAG. (April 28, 2009), <http://www.nytimes.com/2009/05/03/magazine/03Obama-t.html?pagewanted=all>.

⁴⁴ *Id.*

process. The President nodded to the “difficult democratic conversation” but concluded that the decisions likely cannot be made through “normal political channels.” He seemed to doubt the possibility of a bottom-up, representative legislature or jury approach to these hard questions.

During the same interview, Obama personalized the question, referring to his terminally ill grandmother who needed hip replacement. He readily admitted that from his perspective as a grandson, of course, he would want her to have hip replacement.⁴⁵ But he also acknowledged that the answers to these questions, for society in the aggregate, may be far different. We (at this point, he is careful to avoid identifying the “we”) have to decide whether “making those decisions to give my grandmother, or everybody else’s aging grandparents or parents, a hip replacement when they’re terminally ill is a sustainable model.”⁴⁶ The difficulty of those decisions, the President suggested, is “why you have to have some independent group that can give you guidance.”⁴⁷ To the public’s rationing-wary mind, the President’s express reference to an “independent group” deciding whether to authorize treatment for terminally ill patients was not a far leap to Palin’s government death panel.

Further, the President’s concern for a “sustainable model” recognizes resource limits and the necessity of rationing. Indeed, for Callahan, the essential justification for rationing is “in the name of preserving the economic sustainability” of the health care system.⁴⁸ But the general public is loath to embrace an economic calculus when it comes to health care. That aversion is manifested in the ACA as a fear of any suggestions to either limit end-of-life care or consider cost in evaluating treatment alternatives.

IV. LEGISLATIVE CASUALTIES OF THE DEATH PANEL CONTROVERSY

Despite the President’s measured suggestions that the inevitable, tragic choices might be guided by experts, the political rhetoric around health care reform continues to evidence deep distrust of government rationing. The death panel imagery penetrated the public conscious, rendering one provision of the ACA impassable and another impotent. Even after the ACA was signed into law, more than half of seniors either affirmatively believed or were unsure whether the new federal statute permitted government panels to make decisions about their end-of-life care.⁴⁹

Two separate provisions of the ACA, each of which could have improved health care decision making and helped bend the health care cost curve, were stunted by the death panel controversy. The innocuous, patient-empowering proposal to allow Medicare patients to have a conversation with their doctors about choices at the end of life was killed, first, in Congress, and, later, in

⁴⁵ *Id.*; see also Callahan, *supra* note 14, at 14 (noting similarly, “Again and again over the years I have heard a common refrain: ‘Yes, we need to control costs, but not if that will harm my wife, or child, or elderly parent.’ ”).

⁴⁶ Leonhardt, *supra* note 43.

⁴⁷ *Id.*

⁴⁸ Callahan, *supra* note 14, at 12.

⁴⁹ See Kaiser Health Tracking Poll: *Public Opinion on Health Care Issues*, KAISER FAM. FOUND., 7 (Sept. 2010), <http://www.kff.org/kaiserpolls/upload/8104-F.pdf>.

administrative rulemaking.⁵⁰ In addition, potentially transformative evidence-based, patient-centered research⁵¹ was cut off at the knees, with sharp restrictions on its use in comparing cost-effectiveness of various treatment alternatives. The following discussion describes the ACA provisions curtailed by the death panel rhetoric.

A. *Voluntary Advanced Care Planning*

House Bill 3200 § 1233 was a bipartisan proposal, sponsored by three Republicans and three Democrats, that would have amended the Social Security Act to add a new subsection called *Advance Care Planning Consultation*.⁵² Section 1233 would have provided Medicare reimbursement to certain health care providers for voluntary conversations with their patients about end-of-life concerns.⁵³ Specifically, the conversation would occur every five years, or upon a significant change in health condition, including admission to skilled nursing, long-term care, or hospice.⁵⁴ Many providers were having those conversations anyway, recognizing that it was good clinical practice to allow patients control over their medical care, especially before they faced a terminal or debilitating condition. But providers were not getting paid for that time because government programs, like most private health insurance plans, typically do not pay for talk-time, but instead for writing prescriptions and performing procedures. It seemed a fairly innocuous suggestion to reimburse physicians for the time they spend counseling patients about these crucial issues. Moreover, the proposal was really not that new or radical.

Since 1990, Medicare has (under a Bush I-era law, the Patient Self Determination Act) required participating health care institutions to provide written information to every patient describing the patient's right to complete a living will or a durable power of attorney for health care under applicable state laws.⁵⁵ Since 2003, the Medicare Prescription Drug, Improvement, and Modernization Act⁵⁶ (a Bush II piece of legislation), which most notoriously added Medicare Part D Prescription Drug Coverage,⁵⁷ also added reimbursement for

⁵⁰ See *supra* text accompanying notes 6–11 (describing § 1233 and regulatory analogue).

⁵¹ See Richard S. Saver, *The New Era of Comparative Effectiveness: Will Public Health End Up Left Behind?*, 39 J.L. MED. & ETHICS 437, 437 (2011) (citing M. N. Akhter & R. A. Levinson, *Comparative Effectiveness Research and the Future Practice of Medicine*, 101 J. NAT'L MED. ASS'N 1301, 1301–02 (2009)).

⁵² Perry, *supra* note 8, at 413–14 & n.16 (listing bill sponsors); see also America's Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233.

⁵³ See America's Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233(a).

⁵⁴ *Id.* §§ 1233(a)(1)(B), (a)(3)(B).

⁵⁵ Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4206, 104 Stat. 1388 (codified as amended at 42 U.S.C. § 1395cc(a)(2)(A)(i) (2012)).

⁵⁶ Medicare Prescription Drug, Improvement, and Modernization Act of 2003, Pub. L. No. 108-173, § 101, 117 Stat. 2066, 2071.

⁵⁷ See Elizabeth A. Weeks, *Cooperative Federalism and Healthcare Reform: The Medicare Part D "Clawback" Example*, 1 ST. LOUIS U. J. HEALTH L. & POL'Y 79, 81–82 (2007) (describing Part D implementation).

check-ups.⁵⁸ For the first time since the Medicare program was enacted in 1965, beneficiaries could receive at least one initial “Welcome to Medicare” appointment with their primary care physicians.⁵⁹ In 2008, the Welcome to Medicare visit coverage was amended to include end-of-life counseling.⁶⁰ The only change that proposed § 1233 would have made would have been to allow that conversation to happen more than just once in the beneficiary’s lifetime. Under § 1233, physicians would be reimbursed for discussing patients’ advance care plans every five years, or upon significant change in health status or condition, rather than in singular, frozen-in-time, conversations.⁶¹ It was that modest proposal that spawned Sarah Palin’s death panel rhetoric that eventually made § 1233 politically radioactive on Congress.⁶²

But eight months later, a federal agency, CMS, sought to achieve the same end that the political process could not. The approach was consistent with President Obama’s preference for expert-driven policy making. Each year, CMS updates Medicare program fee schedules for various participating providers, including physicians. The annual rulemaking comprises hundreds of pages in the Federal Register.⁶³ On November 29, 2010, three hundred pages deep in the 2011 Physician Fee Schedule update, under a section on “Requirements of Subsequent Annual Wellness Visits Providing Personalized Prevention Plan Services,”⁶⁴ CMS added a definition of “voluntary advance care planning”⁶⁵ and included it as an element of not only the Welcome to Medicare visit but also subsequent annual wellness visits.⁶⁶ Accordingly, under the regulation, end-of-life counseling could happen every year.

In support of the provision, CMS cited comments from physicians and other healthcare providers and research reports in British and American medical journals demonstrating the positive health benefits from, and patients’ desire to have, those conversations.⁶⁷ The fee schedule was to take effect (as it always does each year) on January 1, 2011. That is, until it caught the media’s attention. A Christmas Day story in the *New York Times* revealed the new policy.⁶⁸ The story also reported on communications from Representative Earl

⁵⁸ See *MMA—Initial Preventive Physical Examination*, MEDICARE LEARNING NETWORK, at 2 (Dec. 22, 2004), <http://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNMattersArticles/downloads/mm3638.pdf>.

⁵⁹ *Id.* at 1.

⁶⁰ See Medicare Improvements for Patients and Providers Act of 2008, Pub. L. No. 110-275, 122 Stat. 2494 (codified as amended at 42 U.S.C. § 1395x(w) (2012)); Julie Rovner, *The Many Lives of the “Death Panel”*, NPR (Jan. 5, 2011), <http://m.npr.org/news/front/132680683?page=3>.

⁶¹ See America’s Affordable Health Choices Act of 2009, H.R. 3200, 111th Cong. § 1233(a)(3)(B).

⁶² See Perry, *supra* note 8, at 411–12.

⁶³ See, e.g., Payment Policies Under the Physician Fee Schedule, 75 Fed. Reg. 73,170 (Nov. 29, 2010) (to be codified at 42 C.F.R. pts. 405, 409–11, 413–15, 424).

⁶⁴ *Id.* at 73,405.

⁶⁵ *Id.* at 73,406.

⁶⁶ *Id.* (“We agree that voluntary advance care planning should be added as an element of the definitions of both the ‘first annual wellness visit’ and the ‘subsequent annual wellness visit’”).

⁶⁷ *Id.*

⁶⁸ See Pear, *supra* note 10.

Blumenauer of Oregon who sponsored § 1233 and called the November regulations “ ‘a quiet victory,’ but urged supporters not to crow about it.”⁶⁹ Blumenauer said, “[t]hus far, it seems that no press or blogs have discovered it The longer this goes unnoticed, the better our chances of keeping it.”⁷⁰ The *Wall Street Journal* picked up the story a couple of days later, reporting, with more charged language, that “[t]he regulatory process [is not] supposed to be a black-ops exercise, but expect many more such nontransparent improvisations under the vast powers ObamaCare handed the executive branch.”⁷¹

The national media coverage and CMS’ response reveal deep public mistrust of the Administration’s preference for expert-driven policy making, especially when it is perceived to implicate health care rationing. Less than two weeks later, on January 10, 2011, CMS issued a line-item amendment to the 2011 Physician Fee Schedule, removing the definition of voluntary advanced care planning as an element of both the first and subsequent annual wellness visits.⁷² The agency asserted:

While we believe that we acted within our authority in including voluntary advance care planning as an additional specified element of the new annual wellness visit in the final rule, it has become apparent that we did not have an opportunity to consider prior to the issuance of the final rule the wide range of views on this subject held by a broad range of stakeholders (including members of Congress and those who were involved with this provision during the debate on the Affordable Care Act).⁷³

The reference to the “wide range of views” by a “broad range of stakeholders” surely included those who read and sympathized with Sarah Palin’s Facebook post. As far as the political process is concerned, the move demonstrates that the agency’s attempted end-run around the legislative process through expert-driven rulemaking was rebuffed.

The fate of the advance care planning provision suggests that, despite the hopes I expressed above, the rationing conversation may be stymied. If the simple suggestion to compensate doctors for facilitating patients’ autonomous decision making about the most critical juncture of their care reads as a government death panel, then we may not be ready for that conversation. The public’s aversion to any suggestion that limits on end-of-life care would be tolerable, even in a patient’s own assessment, rendered § 1233 and its regulatory analogue impassable and intolerable.

B. Patient-Centered Comparative Effectiveness Research

Another ACA provision with the potential to inform health care resource allocation was also stunted by the death panel rhetoric. The President’s particular vision of expert guidance on good quality health care is, to a limited extent,

⁶⁹ *Id.*

⁷⁰ *Id.*

⁷¹ *Death Panels Revisited: The Left Won’t Admit that Sarah Palin Had a Point About Rationed Care*, WALL ST. J. (Dec. 29, 2010), <http://online.wsj.com/article/SB10001424052970203731004576045702803914780.html>.

⁷² See Amendment to Payment Policies Under the Physician Fee Schedule, 76 Fed. Reg. 1366, 1366 (Jan. 10, 2011) (to be codified at 42 C.F.R. pt. 410).

⁷³ *Id.*

codified in the ACA provisions on comparative effectiveness research (CER).⁷⁴ There will, in fact, be “medical experts and doctors” providing information to patients and providers about health care. There will be an “independent group” giving us guidance on difficult decisions. But they will not tell us what constitutes “good deals” for health care, and they will not develop a “sustainable model” from an economic perspective.⁷⁵

The usefulness of CER under the ACA as a rationing tool is expressly restricted. The ACA authorizes research comparing the *clinical* effectiveness of various treatment alternatives but prohibits those data from being used to determine which treatments are most *cost* effective.⁷⁶ In the face of the death panel image, the cost-effectiveness approach would skirt intolerably close to a dollars-for-lives rationing calculus.

The ACA establishes a panel of experts housed in the Patient-Centered Outcomes Research Institute (PCORI).⁷⁷ PCORI replaces the Federal CER Council, which was established with \$1.1 billion of federal funding as part of President Obama’s 2009 stimulus package.⁷⁸ PCORI, unlike its predecessor entity, is not a public agency or commission, but an independent, trust-endowed, non-profit corporation operating under specific statutory parameters, with significant government funding.⁷⁹ The ACA also establishes a Patient-Centered Outcomes Research Trust Fund (PCORTF) supported initially by general appropriations and later by fees imposed on health insurance and self-insured health plans.⁸⁰ Three government agency representatives sit on the PCORI Board of Governors, while the remaining eighteen seats are held by private stakeholders representing patients, providers, insurers, manufacturers, and researchers.⁸¹

PCORI is charged with conducting CER of competing medical interventions in order to determine which are most effective in treating particular conditions or illnesses.⁸² Specifically, PCORI’s purpose is to

assist patients, clinicians, purchasers, and policy-makers in making informed health decisions by advancing the quality and relevance of evidence concerning the manner in which diseases, disorders, and other health conditions can effectively and appro-

⁷⁴ See Saver, *supra* note 51, at 438 (defining CER).

⁷⁵ See *id.*

⁷⁶ See *id.*

⁷⁷ Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 6301, 124 Stat. 119, 728 (2010); see also 42 U.S.C. §§ 1320e(b), (c), (d)(4)(A) (2012).

⁷⁸ See Callahan, *supra* note 14, at 14; Saver, *supra* note 51, at 438.

⁷⁹ See 42 U.S.C. § 1320e(b)(1) (describing PCORI as “neither an agency nor establishment of the United States Government”); see also Saver, *supra* note 51, at 438–39; John Donnelly, *Health Policy Brief: Comparative Effectiveness Research*, HEALTH AFF., Oct. 8, 2010, at 2, available at http://www.healthaffairs.org/healthpolicybriefs/brief_pdfs/healthpolicy_brief_28.pdf [hereinafter Donnelly, *Health Policy Brief*].

⁸⁰ 42 U.S.C. § 1320e-2(a); 26 U.S.C. § 9511(a)–(b) (2012) (regarding funding).

⁸¹ 42 U.S.C. § 1320e(f); Saver, *supra* note 51, at 438–39; Donnelly, *Health Policy Brief*, *supra* note 79, at 4; Sarah Kliff, *PCORI: Funny Acronym, Serious Work*, WASH. POST (Jan. 18, 2012, 2:47 PM), http://www.washingtonpost.com/blogs/ezra-klein/post/pcori-funny-acronym-serious-work/2012/01/18/gIQAhSxk8P_blog.html.

⁸² Kliff, *supra* note 81.

priately be prevented, diagnosed, treated, monitored, and managed through research and evidence synthesis that considers variations in patient subpopulations⁸³

Initially, PCORI's charge is to develop a research policy agenda, the results of which can be used to improve individual patient health and inform the national health care policy agenda.⁸⁴

Precisely as the President described in media statements, PCORI involves "medical experts and doctors" providing "information to you as a consumer and your doctor" to make "good" quality health care decisions.⁸⁵ PCORI does not, however, encompass the President's notion of "good deals for care." Moreover, it is likely no accident that PCORI operates in the private sector, rather than as a government agency or commission. These are not "his bureaucrats," as Palin charged, but a carefully selected, representative cross-section of health care constituents. The ACA's CER provisions also expressly foreclose the President's suggestions regarding "good deals" for care and the need for a "very difficult democratic conversation" about limiting expensive end-of-life care through a number of specific provisions.

As a baseline, PCORI "shall not develop or employ a dollars-per-quality adjusted life year (or similar measure that discounts the value of a life because of an individual's disability) as a threshold to establish what type of health care is cost effective or recommended."⁸⁶ Quality-adjusted life-years (QALYs), a common metric in single-payer systems, such as the British National Institute for Clinical Excellence (NICE),⁸⁷ seem unthinkable in the United States.⁸⁸ In the roughest sense, health care policymaking based on QALYs might suggest that "[a] regulation that saves thirteen children while jeopardizing fifteen elderly people may well be worthwhile, at least if the thirteen children are likely to have decent life prospects."⁸⁹ To the general public not yet ready to embrace the necessity of health care rationing, QALYs sound much too similar to Sarah Palin's suggestion that President Obama's death panel would decide the fate of her Down Syndrome-affected son based on his level of productivity in society.⁹⁰ Accordingly, PCORI is prohibited from generating QALY data, which commercial insurers, providers, and patients might use to compare cost effectiveness of treatment alternatives just as the President envisioned.

Furthermore, the Secretary of Health and Human Services is prohibited from using QALYs or similar measures in determining Medicare "coverage, reimbursement, or incentive programs."⁹¹ Specifically, the Secretary may not use CER evidence or findings "in a manner that treats extending the life of an

⁸³ 42 U.S.C. § 1320e(c).

⁸⁴ 42 U.S.C. § 1320e(d).

⁸⁵ Conaway, *supra* note 37.

⁸⁶ 42 U.S.C. § 1320e-1(e) (2012).

⁸⁷ See Callahan, *supra* note 14, at 13; Donnelly, *Health Policy Brief, supra* note 79, at 3; see generally Marilyn Dix Smith et al., *Moving the QALY Forward: Rationale for Change*, 12 VALUE IN HEALTH S1, S1 (2009), <http://www.ispor.org/meetings/invitational/QALY/Paper1.pdf>.

⁸⁸ See Donnelly, *Health Policy Brief, supra* note 79, at 3.

⁸⁹ Cass R. Sunstein, *Health-Health Tradeoffs*, 63 U. CHI. L. REV. 1533, 1552 (1996).

⁹⁰ See Donnelly, *Health Policy Brief, supra* note 79, at 3 (suggesting that QALYs became "a political minefield" associated with "rationing"); Saver, *supra* note 51, at 439.

⁹¹ 42 U.S.C. § 1320e-1(e).

elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill.”⁹² The Secretary also cannot use CER findings to preclude or discourage Medicare patients from choosing health care treatments based on the trade-offs between extending life versus risking disability.⁹³

In addition to the prohibition on development of QALY data and cost-effectiveness considerations in Medicare policy, the ACA’s provisions on CER require PCORI to ensure that its research findings are not construed as “practice guidelines, coverage recommendations, payment, or policy recommendations.”⁹⁴ Accordingly, even the President’s modest suggestion that a panel of experts, like PCORI, might provide “information to you as a consumer and your doctor” to guide your health care decisions seems foreclosed. The CER findings are to be made available to providers, patients, and the public,⁹⁵ but their usefulness is blunted.

The ACA limitations on CER defy established health care policy, especially when the reality of subsidization is coupled with the inevitability of rationing. When I mentioned the topic of this Essay to my former colleague, Donald Marquis, a philosopher and bioethicist,⁹⁶ his characteristically terse response was:

We already ration health care. So the question is: *how* should we ration health care? And there are some fairly obvious answers. Here’s one: abandon the public financing of expensive treatments for which there is no good evidence that they are superior to cheaper treatments. Ask any taxpayer whether she wishes to finance such treatments. Where’s the problem?⁹⁷

My response was: *there*, precisely, is the problem: the death panel furor barred even Professor Marquis’s seemingly obvious solution. Although we acknowledge the reality of subsidizing other citizens’ health care, we still are not prepared to ration care. We are not willing to make those tragic choices through either a bottom-up political process or a top-down, expert-driven process. As a result, for now, we continue to obscure the choice, relying on private insurers to perform the rationing calculus through coverage decisions and cost-sharing requirements.

V. CONCLUSION

This Essay began as an attempt to answer some of the questions posed at a public forum on health care rationing.⁹⁸ So what does this Essay suggest about

⁹² *Id.* § 1230e-1(c)(1).

⁹³ *Id.* § 1320e-1(d)(1).

⁹⁴ *Id.* § 1320e(d)(8)(A)(iv).

⁹⁵ *Id.* § 1320e(d)(8)(A) (“The Institute shall, not later than 90 days after the conduct or receipt of research findings under this part, make such research findings available to clinicians, patients, and the general public.”).

⁹⁶ Professor Donald Marquis, University of Kansas, Department of Philosophy. Biography available at *People*, KU DEP’T OF PHIL., <http://www.philosophy.ku.edu/people/marquis.shtml> (last visited Apr. 28, 2013).

⁹⁷ E-mail from Donald Marquis to Elizabeth Weeks Leonard, Assoc. Professor, Univ. of Ga. Sch. of Law (Mar. 2011) (on file with author).

⁹⁸ See *supra* note * (citing conference and listing participants).

the rationing conversation? Are we prepared to have President Obama's "very difficult democratic conversation"? Is the public capable of making the hard health care resources decisions? If not, whom should we entrust with that weighty task?

The public does, now, seem to recognize that resources are scarce and that, as much as we might like, especially when it is our grandmother who needs hip replacement, we simply cannot do everything for everyone. We complain about insurance companies' rationing decisions but accept them as a necessary evil of our preferred market-based, consumer-directed health care system. We also have come to accept the reality of cost-shifting and the fact that, informally—if not formally through a rational tax system—the "haves" fund some part of the medical care of the "have-nots."

Perhaps Professor Marquis's simple suggestion is correct: if you ask taxpayers squarely what sort of health care they are willing to fund, they will come around to the idea of rationing. To do so, the public must couple the two taboos: tax aversion and rationing aversion. We have made progress on recognizing that health care is expensive, more expensive than many people can afford. If we agree that it nevertheless is important for everyone to have health care, then we must find a way to pay for it. Moreover, if we decide that it is preferable to redistribute resources formally, through the tax system rather than informally through private insurance companies, then maybe we can get past the first taboo.

The next step will be to accept the need to limit how much we spend on health care (first-order rationing) and to decide how best to use those limited resources (second-order rationing). Health care is not getting any cheaper; therefore, even if we tax more to pay for more, that process will never cease and will never solve the rationing problem. We must find a way to limit how much health care we consume. Despite the President's apparent preference for expert-driven health care policy-making, the public continues to resist that approach. As long as "they," the government, appear to be deciding what health care "we," the public, receive, there likely will be pushback. But if we can start to connect the fact that "we" are the ones truly paying for health care, "we" may be less willing to spend our own money on expensive treatments of limited efficacy.