

2010

A Missed Opportunity: Health Care Reform, Rhetoric, Ethics and Economics at the End of Life

Joshua E. Perry

Follow this and additional works at: <https://dc.law.mc.edu/lawreview>



Part of the [Law Commons](#)

Custom Citation

29 Miss. C. L. Rev. 409 (2010)

This Article is brought to you for free and open access by MC Law Digital Commons. It has been accepted for inclusion in Mississippi College Law Review by an authorized editor of MC Law Digital Commons. For more information, please contact walter@mc.edu.

A MISSED OPPORTUNITY: HEALTH CARE REFORM, RHETORIC, ETHICS AND ECONOMICS AT THE END OF LIFE

Joshua E. Perry*

[T]he chronically ill and those toward the end of their lives are accounting for potentially 80 percent of the total health care bill [T]here 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. And that's part of why you have to have some independent group that can give you guidance. It's not determinative, but I think [it] has to be able to give you some guidance. – Barack Obama, President of the United States¹

I. INTRODUCTION

On January 24, 2010, my grandmother, June Fuqua Walker, did something that we will all one day do. She passed away. At over eighty-two years old, she had lived a long and full life. And, with the exception of a few minor strokes in her late seventies, a mild heart condition, and diabetes-related vision impairment, her life had been mostly healthy. Mostly healthy, that is, for the first eighty-two years and three months of her life. During the last six months of her life, however, my grandmother's health deteriorated relatively rapidly and her visits to hospital emergency departments and intensive care units increased. Unsure about the precise cause of the internal bleeding in her colon, bladder, and urinary tract, my grandmother's medical team examined her on three different occasions—for a total of twenty days—during her final six months of life.

During these three visits, the diagnostic wizardry on display was incredibly impressive; the array of tests and scans and minimally invasive procedures was awesome. Blood was transfused, medications were administered, and a half-dozen specialists were consulted. Yet, at the end of this six month period of time, during which her health care costs—to be paid by Medicare—totaled in excess of \$100,000, she elected not to undergo the recommended course of even more invasive and risky surgeries, which her

* Assistant Professor of Business Law and Ethics and Life Science Research Fellow, Kelley School of Business, Indiana University. I am grateful to the members of the Mississippi College Law Review for the invitation to contribute to their timely symposium exploring the intersection of economics and bioethics in American health care. Thanks also to Matthew Laydon for research assistance.

1. David Leonhardt, *After the Great Recession*, N.Y. TIMES SUNDAY MAG., May 3, 2009, at 36, available at http://www.nytimes.com/2009/05/03/magazine/03Obama-t.html?pagewanted=1&_r=1.

physicians predicted would almost certainly result in the wearing of one, maybe two, ostomy pouches for the rest of her life. Although never confirmed, the medical team suspected cancerous tumors were causing the internal bleeding and disruptions throughout her gastrointestinal tract.

My grandmother's decision to decline further treatments followed an approximately ten minute conversation with her primary care physician, during which it was clarified that refusing additional diagnostic procedures and life-sustaining surgeries would shorten her life-span to a matter of days. The decision was, the physician underscored, "your grandmother's choice," and in the end she opted for transfer to a hospice facility where she would be made comfortable during a death process that would occur in a relatively peaceful and controlled environment. Fifteen days later and far away from the cold and costly confines of a critical care unit, my grandmother calmly and quietly passed away, surrounded by family in an environment and manner that she had chosen of her own free will. The total hospice cost—again, to be paid by Medicare—was just under \$5,000.

As documented recently by the television newsmagazine *60 Minutes*, Medicare pays approximately \$50 billion for physician and hospital services during the last two months of patients' lives, with an estimated "20 to 30 percent of these medical expenditures" having "no meaningful impact."² Thus, in some ways, my grandmother's story is neither unique nor unusual. Before entering hospice, over \$100,000 in health care resources were expended in an effort that, my grandmother would finally conclude before she finally passed, did not add meaningfully to the quantity or quality of her last months of life.

My grandmother, however, was fortunate. She was, at least, counseled briefly by her physician and provided enough information to make an informed decision about treatment options, recovery prognosis, and end-of-life scenarios. Concluding that the additional cost—physically, psychologically, and financially—was no longer justified, my grandmother made the brave decision to accept the conclusion to a life well-lived. Importantly, she was provided guidance that empowered her to make an autonomous decision, supported by her family and health care team, that was consistent with the strong-willed and feisty zest that had animated decision making throughout her life.

Driven by the ethics and economics of these end-of-life realities, preliminary drafts of America's Affordable Health Choice's Act³ that surfaced during the early summer of 2009 included an "Advance Care Planning Consultation" provision that would have incentivized physicians to spend longer than ten minutes with patients wrestling with final decisions regarding whether to keep fighting for prolonged life or to accept the death that ultimately awaits us all. The financial incentive would have taken the form

2. *60 Minutes* (CBS television broadcast Nov. 22, 2009) ("Most of the bills are paid for by the federal government with few or no questions asked."), available at <http://www.cbsnews.com/stories/2009/11/19/60minutes/main5711689.shtml?tag=contentMain;contentBody>.

3. H.R. 3200, 111th Cong. § 1233 (2009).

of a Medicare reimbursement code, intended to reimburse physicians for end-of-life consultations, not merely for end-of-life medical procedures. Yet, when the historic health care reform legislation was finally passed by Congress and signed by the President in the early spring of 2010,⁴ the bill did not contain this provision because it had become politically toxic and widely misunderstood as creating bureaucratically-administered government “death panels.”⁵ This article argues that Congress’s failure to include a provision for Medicare reimbursement that would have incentivized physicians to consult with patients regarding end-of-life issues was a missed opportunity to address both rising costs for unwanted or unwarranted intensive and technological medical interventions at the end of life and enduring concerns about patient dignity and autonomy during their final days, as well as to begin a more reasonable national discussion of these interwoven policy, legal, economic, and ethical issues.

II. DEATH PANELS: RHETORIC, FACTS, GRANDMA AND NAZIS

A. *The Rhetoric*

On August 7, 2009, approximately six months prior to my grandmother’s death, former Alaska Governor and 2008 Republican nominee for Vice President of the United States, Sarah Palin made political headlines when she posted this on her Facebook page:

As more Americans delve into the disturbing details of the nationalized health care plan that the current administration is rushing through Congress, our collective jaw is dropping, and we’re saying not just no, but hell no!

The Democrats promise that a government health care system will reduce the cost of health care, but . . . government health care will not reduce the cost; it will simply refuse to pay the cost. 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.

4. Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. (2010) (enacted); Health Care and Education Affordability Reconciliation Act of 2010, H.R. 4872, 111th Cong. (2010) (enacted).

5. See *infra* Part II.

Health care by definition involves life and death decisions. Human rights and human dignity must be at the center of any health care discussion.⁶

According to journalists at *The St. Petersburg Times* who maintain the website PolitiFact, Ms. Palin's comment was the "Lie of the Year."⁷

Although the proposed health care reform legislation never included anything even remotely close to the "evil system" described by Palin, her Facebook comments contributed rhetorical kerosene to a wild fire of political opposition against the health care reform legislation that was being debated throughout the summer of 2009. While Palin was the first to coin the phrase "death panel," she was certainly not the first critic of Democratic efforts to reform the health care system that made reference to euthanasia. Again, as PolitiFact has chronicled, it was several weeks before Ms. Palin's Facebook posting that conservative commentators and members of congress were already suggesting that the proposed reform legislation included governmental mandates requiring end-of-life counseling sessions intended to hasten the death of senior citizens.

In fact, it was on former presidential candidate Fred Thompson's July 16, 2009, radio show that Betsy McCaughey, New York's former lieutenant governor and a "conservative health care commentator," erroneously stated that proposed legislation "would make it mandatory—absolutely require—that every five years people in Medicare [would be required to have a] counseling session that will tell them how to end their life sooner."⁸ A week later on July 23 it was the House Republican Leader John Boehner who warned that the proposed legislation "may start us down a treacherous path toward government-encouraged euthanasia if enacted into law."⁹ Five days later, on July 28, U.S. Representative Virginia Foxx argued on the floor of the House that an alternative Republican reform bill was "pro-life because it will not put seniors in a position of being put to death by their government."¹⁰ Palin's infamous Facebook post would follow about a week later, and two polls conducted in mid-August revealed that about thirty percent of the United States population believed that death panels were included in health reform legislation then under consideration.¹¹ By mid-October, the end-of-life advance care planning consultation provisions that had been mischaracterized as bureaucratic "death panels" were no longer in the legislation pending before Congress.

6. Posting of Sarah Palin to Facebook, *Statement on the Current Health Care Debate*, http://www.facebook.com/note.php?note_id=113851103434 (Aug. 7, 2009, 13:26).

7. Angie Drobnic Holan, *PolitiFact's Lie of the Year: 'Death Panels'*, PolitiFact.com, Dec. 18, 2009, <http://www.politifact.com/truth-o-meter/article/2009/dec/18/politifact-lie-year-death-panels/>.

8. *Id.*

9. *Id.*

10. *Id.*

11. *Id.*

B. *The Facts*

So if the term “death panels” was merely a rhetorical distraction animated by political opposition, what exactly was the truth about the end-of-life consultation provision originally proposed in the health care reform legislation?

The idea to reimburse physicians for end-of-life consultations, i.e., “reward end-of-life planning,”¹² with Medicare patients was born out of the lived reality of the clinical setting. Having established itself as a national leader in the development and utilization of advance care directives and end-of-life consultations, physicians and ethicists at Gundersen Lutheran hospital in La Crosse, Wisconsin noted that “[t]hose conversations take a lot of time—a good hour, plus follow-up talks to alter directives as medical situations evolve. And Medicare does not reimburse doctors for the time spent on such discussions.”¹³ Having refined their end-of-life protocols over several decades, Bud Hammes, the medical ethics director at Gundersen Lutheran, emphasized to inquiring journalists that end-of-life discussions were not intended to promote less aggressive treatment, although he noted that many patients do opt for fewer end-of-life treatments.¹⁴ As reported in *The Washington Post*, Hammes explained, “We’re not trying to talk them into anything. We’re trying to understand their values and goals, and tell them what medical science can and can’t do. In our community, people don’t want to die hooked up to machines.”¹⁵

Ironically, the idea to amend the Social Security Act to provide Medicare coverage for consultations regarding orders for life sustaining treatment was one that enjoyed bipartisan support in the spring of 2009. Three Republicans and three Democrats co-sponsored the Life Sustaining Treatment Preferences Act of 2009 when it was introduced to the House of Representatives on April 2, 2009 as House Bill 1898.¹⁶

By July 14, the primary provisions of House Bill 1898 had been incorporated into Section 1233 of House Bill 3200.¹⁷ The proposed reform

12. Alec MacGillis, *The Unwitting Birthplace of the ‘Death Panel’ Myth*, WASH. POST, Sept. 4, 2009, at A01, available at <http://www.washingtonpost.com/wp-dyn/content/article/2009/09/03/AR2009090303833.html?sid=ST2009090303848>.

13. *Id.*

14. *Id.*

15. *Id.*

16. H.R. 1898, 111th Cong. (2009). The House Republicans were Charles Boustany (LA), Geoff Davis (KY), and Patrick Tiberi (OH). The House Democrats were Ron Kind (WI), John Yarmuth (KY), and Earl Blumenauer (OR).

17. H.R. 3200, 111th Cong. § 1233 (2009). The final version of the Affordable Health Care for America Act was House Bill 3962. It passed the House of Representatives on November 7, 2009. The companion legislation, House Bill 3590, titled Patient Protection and Affordable Care Act, passed the Senate on December 24, 2009. This bill passed the House on March 21, 2010 and was signed by President Obama on March 23, 2010. The Fixes bill was House Bill 4872, Health Care and Education Affordability Reconciliation Act of 2010. Neither House Bill 3590 nor House Bill 4872 contained any Medicare-reimbursable end-of-life consultation provisions similar to those originally introduced in Section 1233 of House Bill 3200.

would amend Section 1861 of the Social Security Act creating a new subsection entitled, Advance Care Planning Consultation.¹⁸ Similarly to the bipartisan bill introduced in April, the proposed language in House Bill 3200 would have made voluntary conversations about end-of-life concerns between certain health care providers—physicians, nurse practitioners, and any assistant with authority to sign orders for life sustaining treatments—and patients eligible for Medicare reimbursement.¹⁹ The *mandatory content* – the “guidance” suggested by this article’s epigraph²⁰ – to be included in these “advance care” or end-of-life *voluntary consultations* was set forth in detail:

(A) An explanation by the practitioner of advance care planning, including key questions and considerations, important steps, and suggested people to talk to.

(B) An explanation by the practitioner of advance directives, including living wills and durable powers of attorney, and their uses.

(C) An explanation by the practitioner of the role and responsibilities of a health care proxy.

(D) The provision by the practitioner of a list of national and State-specific resources to assist consumers and their families with advance care planning, including the national toll-free hotline, the advance care planning clearinghouses, and State legal service organizations (including those funded through the Older Americans Act of 1965).

(E) An explanation by the practitioner of the continuum of end-of-life services and supports available, including palliative care and hospice, and benefits for such services and supports that are available under this title.

(F)(i) Subject to clause (ii), an explanation of orders regarding life sustaining treatment or similar orders, which shall include—

(I) the reasons why the development of such an order is beneficial to the individual and the individual’s family and the reasons why such an order should be updated periodically as the health of the individual changes;

18. America’s Affordable Health Choices Act of 2009, H.R. 3200, § 1233(a)(1) (2009).

19. H.R. 3200, § 1233(a)(2), (a)(5)(B)(2).

20. See Leonhardt, *supra* note 1.

(II) the information needed for an individual or legal surrogate to make informed decisions regarding the completion of such an order; and

(III) the identification of resources that an individual may use to determine the requirements of the State in which such individual resides so that the treatment wishes of that individual will be carried out if the individual is unable to communicate those wishes, including requirements regarding the designation of a surrogate decisionmaker (also known as a health care proxy).

(ii) The Secretary shall limit the requirement for explanations under clause (i) to consultations furnished in a State—

(I) in which all legal barriers have been addressed for enabling orders for life sustaining treatment to constitute a set of medical orders respected across all care settings; and

(II) that has in effect a program for orders for life sustaining treatment described in clause (iii).

(iii) A program for orders for life sustaining treatment for a State described in this clause is a program that—

(I) ensures such orders are standardized and uniquely identifiable throughout the State;

(II) distributes or makes accessible such orders to physicians and other health professionals that (acting within the scope of the professional's authority under State law) may sign orders for life sustaining treatment;

(III) provides training for health care professionals across the continuum of care about the goals and use of orders for life sustaining treatment; and

(IV) is guided by a coalition of stakeholders includes representatives from emergency medical services, emergency department physicians or nurses, state long-term care association, state medical association, state surveyors, agency responsible for senior services, state department of health, state

hospital association, home health association, state bar association, and state hospice association.²¹

Reimbursement for these advance care consultations would be available only once every five years, unless the patient experienced a “significant change” in health condition, “including diagnosis of chronic, progressive, life-limiting disease, a life-threatening or terminal diagnosis or life-threatening injury,” or was admitted to a “skilled nursing facility, a long-term care facility (as defined by the Secretary), or a hospice program,” in which case payment for more frequent conversations would be possible.²²

As clarified by Dr. J. James Rohack, the President of the American Medical Association, a physician organization that supported House Bill 3200, “[T]he bill would create a new Medicare benefit to pay physicians for time spent on advance-care planning consultations with seniors. It would be completely voluntary, and [would] allow patients, if they wish, to discuss a broad range of issues, including hospice, living wills, advance directives and appropriate pain care.”²³ Dr. Rohack also noted that such discussions are important to the task of fully informing patients and ensuring that their wishes are known.²⁴ “That’s not controversial,” he said, “it’s plain, old-fashioned patient-centered care.”²⁵

C. *Pulling the Plug on Grandma and Nazi Comparisons*

On August 11, at a town hall meeting in Portsmouth, New Hampshire, President Obama attempted to debunk some of the “wild misrepresentations that bear no resemblance to what’s in the bill.”²⁶

[L]et me just be specific about some things that I’ve been hearing lately that we just need to dispose of here. The rumor that’s been circulating a lot lately is this idea that somehow the House of Representatives voted for “death panels” that will basically pull the plug on grandma because we’ve

21. H.R. 3200, § 1233(a)(1).

22. H.R. 3200, § 1233(a)(3)(B).

23. Kevin B. O’Reilly, *End-of-Life Care Provision Stirs Angst in Health Reform Debate*, AMERICAN MEDICAL NEWS, Aug. 24, 2009, <http://www.ama-assn.org/amednews/2009/08/24/prsa0824.htm>. Moreover, these end-of-life discussions would have been private conversations between the patient and the health care provider. The government was nowhere to be found and there was certainly no bureaucratic decision-making panel in the offering. Furthermore, as with any other medical intervention, competent adult patients enjoy fundamental rights of refusal and participation in these advance care conversations was to be completely voluntary. See *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir. 1972) (“[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body. . . .” (quoting *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914))).

24. *Id.*

25. *Id.*

26. See Posting of Jake Tapper and Sunlen Miller to Political Punch, <http://blogs.abcnews.com/politicalpunch/2009/08/president-obama-addresses-sarah-palin-death-panels-wild-representations.html> (Aug. 11, 2009, 14:04 EST).

decided that we don't—it's too expensive to let her live any more It turns out that I guess this arose out of a provision in one of the House bills that allowed Medicare to reimburse people for consultations about end-of-life care, setting up living wills, the availability of hospice, et cetera. So the intention of the members of Congress was to give people more information so that they could handle issues of end-of-life care when they're ready, on their own terms. It wasn't forcing anybody to do anything.²⁷

Yet even after the president addressed the issue directly, “pulling the plug on Grandma” continued to be the language trumpeted by political opponents.²⁸ Perhaps most notable were the comments of Senator Charles Grassley, the Iowa Republican and ranking member on the Finance Committee, who addressed a town hall meeting in Winterset, Iowa a day after the president had spoken in New Hampshire. Senator Grassley told his audience that they “had every right to fear” a government program “to pull the plug on Grandma.”²⁹

By mid-autumn, the rhetoric had grown even more hyperbolic. Most notably, Richard Land, the president of the Southern Baptist Ethics & Religious Liberty Commission, educated at Princeton and Oxford, and labeled by *Time* magazine as one of the “twenty-five most influential evangelicals” in 2005,³⁰ told the Christian Coalition of Florida at a September banquet that what the president and Democrats “are attempting to do in healthcare, particularly in treating the elderly, is not something *like* what the Nazis did. It is precisely what the Nazis did.”³¹ While he later apologized for what he termed “hyperbole for effect,”³² the rhetorical Nazi genie was out of the bottle and given legitimacy by an influential leader of the religious right.³³ Hope for the “very difficult democratic conversation”

27. President Barack Obama, Remarks by the President in Health Insurance Reform Town Hall (Aug. 11, 2009) (transcript available at http://www.whitehouse.gov/the_press_office/Remarks-by-the-President-at-Town-Hall-on-Health-Insurance-Reform-in-Portsmouth-New-Hampshire/).

28. Nick Coleman, *At Least Some are Angry for the Right Reasons*, STAR TRIBUNE, Sept. 20, 2009, at 30P, available at <http://www.startribune.com/opinion/59780992.html> (“Don't worry about pulling the plug on Grandma. That lie has been repeated so many times by Obama haters and political opportunists that it doesn't matter that it is untrue.”).

29. Roger Simon, *Obama Must Tell us What He Stands for*, CHICAGO SUN-TIMES, Sept. 9, 2009 at 21; Holan, *supra* note 7.

30. David Van Biema et al., *25 Most Influential Evangelicals in America*, TIME, Feb. 7, 2005, at 34, available at <http://www.time.com/time/covers/1101050207/photoessay/16.html>.

31. James A. Smith, *Healthcare Reform Rationing 'Precisely what the Nazis did,' Land says*, FLORIDA BAPTIST WITNESS, Sept. 30, 2009 (emphasis added), available at <http://www.gofbw.com/News.asp?ID=10836>. For a background discussion of Richard Land, see Joshua E. Perry, *Biblical BioPolitics: Judicial Process, Religious Rhetoric, Terri Schiavo and Beyond*, 16 HEALTH MATRIX 553, 613 (2006).

32. Dwayne Hastings, *Land Clarifies Remarks, Apologies to Anti-Defamation League*, BAPTIST PRESS, Oct. 21, 2009, available at <http://www.bpnews.net/bpnews.asp?id=31506>. Land noted that he had previously used “imprecise language,” and “should have said some of the philosophies that are being espoused ‘bear a lethal similarity in their attitudes toward the elderly and the terminally ill and could ultimately lead to the kinds of things the Nazis did.’” *Id.*

33. Roger Lovette, *An Issue of Morality*, THE BIRMINGHAM NEWS (ALABAMA), Sept. 20, 2009, at 1F (“We need to tell the truth. We must not overinflate the figures in this debate. We know millions of people have no health coverage. Neither are we to fall victim to scare tactics such as death panels,

about the ethics and economics of dying that had been called for by the president³⁴ was lost—for the second time in the last five years.³⁵

III. REVISITING SCHIAVO AND THE USE OF RADICAL RHETORIC TO KILL REASONABLE DISCOURSE ABOUT END-OF-LIFE ISSUES

Observers of U.S. culture wars and biopolitics³⁶ will vividly recall that in 2005, the bioethical dilemma on the front page of newspapers around America and throughout the world concerned the fate of Theresa Marie Schiavo, known to many as “Terri.”³⁷ Terri Schiavo was the unfortunate Florida woman who, at the age of twenty-six, had a heart attack that resulted in a loss of blood-flow to her brain for several minutes.³⁸ The severe hypoxia left her unconscious, and she was eventually determined to be in a persistent vegetative state (PVS) without “hope of ever regaining consciousness.”³⁹ Ms. Schiavo’s husband fought for over five years to have his wife’s artificial nutrition and hydration discontinued, an act that he claimed she would have desired given the circumstances.⁴⁰ Her parents fought to keep their daughter alive.⁴¹ Ultimately it was this struggle that would transform Terri Schiavo into a religious and political cause célèbre, a poster child for those individuals and organizations concerned with the preservation of a “culture of life.”⁴²

Throughout the 1990s, Ms. Schiavo’s tragedy remained a mostly private, intra-family dispute.⁴³ And then between 2000 and 2005, the National

loaded words such as ‘Nazi,’ ‘fascist’ and ‘socialists.’); Garry Rayno and Trent Spinner, *Temperatures Hot at Forum*, THE UNION LEADER (MANCHESTER, NH), Aug. 30, 2009, at 1 (“Audience members heatedly questioned . . . whether Nazi principles of eugenics are behind the current push for health-care reform. ‘This isn’t about providing health care, it’s economic policy. . . . It’s about cutting costs. It’s about killing human beings.’”).

34. See Leonhardt, *supra* note 1.

35. See *infra* Part III.

36. See Joshua E. Perry, *Biopolitics at the Bedside: Proxy Wars and Feeding Tubes*, 28 J. LEGAL MED. 171, 174 (2007) (“Biopolitics, on the other hand, referred to the state’s regulatory control over the population as a whole: the ‘species body, the body imbued with the mechanics of life and serving as the basis of the biological processes,’ put differently, the ratio of births to deaths, the rate of reproduction, the fertility of the population, the level of health, and life expectancy and longevity.” (quoting 1 MICHEL FOUCAULT, THE HISTORY OF SEXUALITY: AN INTRODUCTION 139 (Robert Hurley trans., 1978))); Jeffrey P. Bishop & Fabrice Jotterand, *Bioethics as Biopolitics*, 31 J. MED. & PHIL. 205-12 (2006) (“Bioethics has always been a biopolitics and the political dimension is only now coming into relief for bioethicists.”).

37. See Joshua E. Perry, et al., *The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives*, 143 ANNALS INTERNAL MED. 744, 744-48 (2005); Danica Kirka, *Euthanasia Discussion Heats Up*, MIAMI HERALD, Apr. 12, 2005, A1.

38. See JAY WOLFSON, GUARDIAN AD LITEM FOR THERESA MARIE SCHIAVO, A REPORT TO GOVERNOR JEB BUSH AND THE 6TH JUDICIAL CIRCUIT IN THE MATTER OF THERESA MARIE SCHIAVO 7 (Dec. 1, 2003), <http://abstractappeal.com/schiavo/WolfsonReport.pdf>.

39. *In re* Guardianship of Schiavo, No. 90-2908GD-003, 2000 WL 34546715, at *4 (Fla. Cir. Ct. Feb. 11, 2000).

40. *In re* Guardianship of Schiavo, 780 So. 2d 176, 177-78 (Fla. Dist. Ct. App. 2001).

41. *Id.* at 178-79.

42. See George J. Annas, “Culture of Life” Politics at the Bedside – The Case of Terri Schiavo, 352 NEW ENG. J. MED. 1710, 1710-15 (2005).

43. Perry, *supra* note 31, at 588.

Right to Life Committee, Focus on the Family, the Family Research Council, and many other politically and religiously conservative groups used the Internet, as well as their massive financial and broadcast media resources, to garner national attention and compel state and federal politicians to intervene.⁴⁴ In 2003, politicians in the state of Florida—both legislators and the governor—were motivated by grass-roots political and religious activists to pass “Terri’s Law,” over-ruling a judicial order to remove Ms. Schiavo’s feeding tube.⁴⁵ This legislative and executive action was eventually overturned by the Florida Supreme Court on the basis that it violated principles of separation of powers.⁴⁶ Not to be outdone, however, two years later, again in response to another judicial order to remove Ms. Schiavo’s feeding tube, the United States Congress passed legislation—dramatically signed by the president in the middle of the night—to once again “save Terri.”⁴⁷ This special legislation was also struck down upon judicial review.⁴⁸

Given the fact that tens of thousands of persons in the United States are living in a persistent vegetative state⁴⁹ and that decisions regarding removal of life-sustaining technologies are made every day, an obvious question is why did Terri Schiavo rise to such unprecedented national prominence and what motivated the Florida legislature, the Governor—and eventually the United States Congress and President George W. Bush—to pass statutes attempting to circumvent the repeated judicial determinations that Terri Schiavo’s artificial hydration and nutrition should be removed pursuant to the laws of the state of Florida?

At least one of the answers to this question boils down to the way in which emotionally charged rhetoric high-jacked what otherwise should have been a private decision between grieving family members.⁵⁰ Similar to the “death panel” mischaracterization of the proposed advance care planning consultation legislation, the language used to describe Ms. Schiavo that was reported by the media included repeated references to “murder,” “starvation” or “killing.”⁵¹ Consider these few examples:

44. See generally JON B. EISENBERG, USING TERRI: THE RELIGIOUS RIGHT’S CONSPIRACY TO TAKE AWAY OUR RIGHTS (2005).

45. Perry, *supra* note 31, at 593-603.

46. *Bush v. Schiavo*, 885 So. 2d 321, 324 (Fla. 2004).

47. Perry, *supra* note 31, at 604-09.

48. See *Schiavo ex rel. Schindler v. Schiavo*, 357 F. Supp. 2d 1378 (M.D. Fla. 2005); *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223 (11th Cir. 2005), *reh’g en banc denied*, 403 F.3d 1261 (11th Cir. 2005); *Schiavo ex rel. Schindler v. Schiavo*, 358 F. Supp. 2d 1161 (M.D. Fla. 2005); *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289 (11th Cir. 2005).

49. Joy Hirsch, Editorial, *Raising Consciousness*, 115 J. CLINICAL INVESTIGATION 1102, 1102 (2005), available at <http://www.jci.org/articles/view/25320/version/1/pdf>.

50. For additional development of this critique see Joshua E. Perry & Jeffrey P. Bishop, *Life, Death (Panels), and the Body Politic*, SYRACUSE L. REV. (forthcoming 2010).

51. Perry, *supra* note 31, at 589-91. The data in Notes 52-58 represent a small sample of the much larger collection of rhetoric that was originally presented by the author in the article cited in note 31.

“I consider [removing a feeding tube] murder in the first degree.”⁵²

“I just can’t understand why these judges are in such a hurry to starve my daughter to death . . . I just don’t understand. I think it’s cruel.”⁵³

“The real issue is not whether Terri Schiavo has a ‘right’ to die, but whether we as a society have the right to kill her.”⁵⁴

“To me, they’re going to murder this girl. I think she’s gotten railroaded by this kangaroo court.”⁵⁵

“I think people overlook that not even an animal would be allowed to starve to death.”⁵⁶

“I am disappointed that these judges are willing to starve Terri to death without giving her . . . a fair trial . . . There is nothing physically wrong with her.”⁵⁷

“Well, the liberal court system has done it again. Michael Schiavo can be very thankful . . . that Judge Greer thinks it’s okay to starve handicapped people to death . . . Judge Greer has opened the door to legalized murder. . . .”⁵⁸

Richard Land⁵⁹ also weighed-in on the Schiavo controversy noting that “we have devalued and de-sanctified human life to the point that now a court can casually sentence a human being to die by malnutrition and dehydration.”⁶⁰ Finally, allusions to Nazi Germany were also employed, this time by James Dobson, a child development specialist, founder of the influential Focus on the Family ministry, and the “religious right’s new

52. Anita Kumar, *Taking Care of Mick*, ST. PETERSBURG TIMES, Feb. 11, 2000, at 1B (comparing Terri Schiavo’s condition to Dianne “Mick” Menchion, another person in a PVS, and quoting Lillian Menchion, Mick’s mother, on their decision not to remove Mick’s feeding tube).

53. Anita Kumar, *Court: Appeal Can’t Stop Removal of Life Support*, ST. PETERSBURG TIMES, Apr. 12, 2001 at 1B (quoting Bob Schindler).

54. Jana Carpenter, Letter to the editor, “*Right to die*” is Really About Killing, ST. PETERSBURG TIMES, Feb. 9, 2001, at 19A (Ms. Carpenter is a member of PEHC.).

55. Craig Pittman, *Judge: Schiavo Can’t Recover*, ST. PETERSBURG TIMES, Nov. 23, 2002, at 1A (quoting Bob Schindler).

56. Judy DeStefano, *Rants and Raves*, THE TAMPA TRIBUNE, May 11, 2001, at P.5 (Ms. DeStefano’s remarks appeared in a collection of reader feedback).

57. Anita Kumar, *Terri Schiavo’s Life, Case Enter Final Chapter*, ST. PETERSBURG TIMES, Apr. 19, 2001, at 3B (quoting Bob Schindler); see also, David Sommer, *Justices Won’t Review Ruling in Schiavo Case*, THE TAMPA TRIBUNE, Apr. 19, 2001, at 1 (quoting Bob Schindler stating that “[t]hey are going to starve [Terri] and it’s going to take up to two weeks. There is nothing physically wrong with her.”).

58. Sue Hill, Letter to the Editor, *Calling Judge Kevorkian*, ST. PETERSBURG TIMES, Nov. 30, 2002, at 15A.

59. Smith, *supra* note 31 and accompanying text.

60. Press Release, Ethics and Religious Liberty Commission, *Schiavo Case a “Wake-up Call” To Nation* (Oct. 23, 2003) (on file with author).

kingmaker,”⁶¹ who categorized the *Schiavo* case as a “cooperative effort between the judiciary and the media to kill an innocent woman.”⁶² Dobson pondered provocatively:

Is every mentally disabled human being now fair game . . . ? Apparently, all they have to do is assert that starvation is what the victim wanted, and then find a wicked judge like George Greer who will order them subjected to slow execution [I]t is eerily similar to what the Nazis did in the 1930s. They began by ‘euthanizing’ the mentally retarded, and from there, it was a small step to mass murder.⁶³

Like the “death panel” rhetoric of the summer of 2009, the reckless language used to discuss the Terri Schiavo tragedy arrested the attention of the media and spurred action from elected government officials. When the drama subsided, Ms. Schiavo had entered into the pantheon of America’s culture war celebrities and “pro-life” organizations had raised a lot of money, but the ethical and legal issues had either gotten completely lost or, at best, had become confused amidst political posturing and moral sloganeering.⁶⁴ The entire saga was very unfortunate, most obviously for Ms. Schiavo and her family, but also for those who care about end-of-life issues at the intersection of law, ethics, economics, and public policy, which, of course, should be all of us.

IV. ECONOMICS AND ETHICS AT THE END OF LIFE

Like with the rhetoric surrounding the Schiavo case, the conversation about proposed Medicare reimbursement for advance care planning consultations was overtly politicized and thoroughly demonized in the midst of a larger health care reform debate that was primarily focused on both (1) how to cut overall systematic health care costs, and (2) the appropriate role for government action in United States health policy. In the midst of a spirited political climate, these two concerns mixed with latent end-of-life anxieties to create a volatility that “made the nation’s nerves jump and its skin itch.”⁶⁵ Consequently and unfortunately, the nation missed an opportunity during the 2009–2010 health care reform debate to explore more

61. Michael Crowley, *James Dobson: The Religious Right’s New Kingmaker*, SLATE, Nov. 12, 2004, <http://slate.msn.com/id/2109621> (detailing Dobson’s role as advisor to Karl Rove during George W. Bush’s 2004 re-election campaign).

62. James Dobson, *Life, Death and Judicial Tyranny*, FOCUS ON THE FAMILY ACTION NEWSLETTER (Focus Action, Colorado Spring, CO.), Apr. 2005 (on file with author), available at <http://www.citizenlink.org/focusaction/fofafeatures/A000006869.cfm>.

63. *Id.*

64. See Perry, et al., *supra* note 37, at 744–48 (reasoning that even some media commentators who attempted to advance the conversation, e.g., New York Times columnist David Brooks, only served to keep the debate “at the superficial level of moral slogans.”).

65. Eugene Robinson, *Behind the Rage, a Cold Reality*, THE WASH. POST, Aug. 11, 2009, at A13 (“[R]eform is being sold not just as a moral obligation but also as a way to control rising health-care costs. That should have been a separate discussion. It is not illogical for skeptics to suspect that if millions of people are going to be newly covered by health insurance, either costs are going to skyrocket or services are going to be curtailed. The unvarnished truth is that services are ultimately going

fully an important and related question: What is the connection between ethics and economics at the end of life? Moving beyond the rhetoric about death panels and allusions to Nazi Germany, a recent study of end-stage cancer patients provides important insights on the potential connection.

A. *End-of-life Costs Can Be Lowered Through Conversations*⁶⁶

Studies have repeatedly demonstrated that the approximately five percent of Medicare patients who die each year account for approximately thirty percent of the program's cost.⁶⁷ Moreover, medical costs increase as one gets closer to death, with approximately seventy-eight percent of total health care costs in the final year of life being spent on the last thirty days of one's life, often resulting in breath-taking amounts of money being spent to keep patients alive in an intensive care environment during those final days or weeks of life.⁶⁸ A reasonable and ethical question to ask is whether a patient really wants to spend their last, dying days "connected to a machine."⁶⁹ The question is reasonable, given the financial costs associated

to have to be curtailed regardless of what happens with reform. We perform more expensive tests, questionable surgeries and high-tech diagnostic scans than we can afford. We spend unsustainable amounts of money on patients during the final year of life. . . . That's the reason people are so frightened and enraged about the proposed measure that would allow Medicare to pay for end-of-life counseling. If the government says it has to control health-care costs and then offers to pay doctors to give advice about hospice care, citizens are not delusional to conclude that the goal is to reduce end-of-life spending. It's irresponsible for politicians, such as Sarah Palin, to claim – outlandishly and falsely – that there's going to be some kind of 'death panel' to decide when to pull the plug on Aunt Sylvia. But it's understandable why people might associate the phrase 'health-care reform' with limiting their choices during Aunt Sylvia's final days.”)

66. *But see* Ezekiel J. Emanuel & Linda L. Emanuel, *The Economics of Dying: The Illusion of Cost Savings at the End of Life*, 330 *NEW ENG. J. MED.* 540, 540 (1994) (“[C]ost savings due to changes in practice at the end of life [e.g., advance directives, hospice care, or the elimination of futile care] are not likely to be substantial.”)[hereinafter Emanuel, *The Economics of Dying*]; Michael Ash & Stephen Arons, *Economic Parameters of End-of-Life Care: Some Policy Implications in an Era of Health Care Reform*, 31 *W. NEW ENG. L. REV.* 305, 317 (2009) (“Despite the common sense of the assumption that replacing futile, high-intensity curative care for dying patients with palliative care would reduce health care costs, a consensus has developed that such cost reductions are illusory.”).

67. Amber E. Barnato et al., *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 *HEALTH SERV. RES.* 363, 364 (2004). *See also* Ezekiel J. Emanuel, *Cost Savings at the End of Life: What do the Data Show?*, 275 *JAMA* 1907, 1907 (1996) [hereinafter Emanuel, *Cost Savings at the end of life*].

68. Baohui Zhang, et al. *Health Care Costs in the Last Week of Life*, 169 *ARCH. INTERN. MED.* 480, 480 (2009) (“Previous investigations have found that most [end-of-life] costs result from life-sustaining care (e.g., mechanical ventilator use and resuscitation), with acute care in the final 30 days of life accounting for 78% of costs incurred in the final year of life.” (citing W. Yu, *End of Life Care: Medical Treatments and Costs by Age, Race, and Region*, HEALTH SERVICES RESEARCH AND DEVELOPMENT STUDY IIR 02-189, http://www.hsr.d.research.va.gov/research/abstracts/IIR_02-189.htm)).

69. *60 Minutes*, *supra* note 2 (“This is the way so many Americans die. Something like 18 to 20 percent of Americans spend their last days in an ICU . . . [A]nd, you know, it's extremely expensive [“it costs up to \$10,000 a day to maintain someone in the intensive care unit”] . . . [I]t's uncomfortable. Many times they have to be sedated so that they don't reflexively pull out a tube, or sometimes their hands are restrained. This is not the way most people would want to spend their last days of life. And yet this has become almost the medical last rites for people as they die . . . [F]amilies cannot imagine there could be anything worse than their loved one dying. But in fact, there are things worse. Most generally, it's having someone you love die badly. . . . [D]ie Badly means [D]ying suffering. Dying connected to machines. I mean, denial of death at some point becomes a delusion, and we start acting in ways that make no sense whatsoever. And I think that's collectively what we're doing.”) (quoting

with many end-of-life interventions and the finite scope of health care resources, and ethical, given the legal and medical professions' commitment to respecting patients' wishes and shared social values that privilege compassionate and dignified care at the end of one's life.

While some literature questions the net systemic health care savings possible with end-of-life reforms,⁷⁰ other experts suggest that perhaps some association does exist between end-of-life consultations and end-of-life health care costs.⁷¹ One recent study explored the differences in health care use in the final week of life for patients with advanced cancer who did and did not have an advance care consultation with their physician.⁷² The researchers found that patients who have end-of-life conversations with their physicians are less likely to opt for life-sustaining medical interventions, e.g., mechanical ventilators or resuscitation, or to be admitted to or die in an intensive care unit in the final week of life.⁷³ Rather, these patients were more likely to receive outpatient hospice care.⁷⁴ Furthermore, with fewer technological interventions, medical costs for those patients who had an end-of-life consultation with their physician were over thirty-five percent lower than those who did not.

B. *End-of-life Quality Can Be Improved Through Conversations*

Moving beyond economics to ethics, the study referenced above also concluded that increasing communication between end-stage cancer patients and their physicians resulted in less "physical distress" and a better "quality of death" during the last week of their life.⁷⁵ The study's principle investigator noted, "The more aggressive care you get, the worse your quality of life. The longer you're in hospice and receive palliative care, the better your quality of life in that last week."⁷⁶

Dr. Ira Byock). It is beyond the scope of this article to explore fully the public policy, legal, and ethical issues raised by the suggestion that Medicare expenditures be "rationed" or "futile care" be reduced or even that the current fee-for-service model that arguably creates disincentives for physicians to have lengthy conversations about transfer to hospice or termination of aggressive medical interventions be overhauled. Suffice to say, as noted by commentator Eugene Robinson, *supra* note 65, many Americans do have understandable levels of angst and anxiety about any proposal that suggests the government might intervene in life-or-death medical decisions that should be left ultimately to the patient, in consultation with loved ones and trusted health care providers. These fears over the politicization of death are not without justification, even while the "death panel" rhetoric was outlandishly misleading. See generally Perry & Bishop, *supra* note 50.

70. See Emanuel, *Cost Savings at the End of Life*, *supra* note 67, at 1907; Emanuel, *The Economics of Dying*, *supra* note 66, at 540.

71. Baohui Zhang, et al., *supra* note 68, at 480.

72. *Id.*

73. *Id.* at 482.

74. *Id.*

75. *Id.* at 480.

76. Andrew Stern, *Discussing End-of-Life Care Lowers Cost – U.S. Study*, REUTERS, Mar. 9, 2009, <http://www.reuters.com/article/idUSN06415881>. Not only were these more intensive and expensive treatments associated with a worse quality of death, they were not found to result in longer life. Baohui Zhang, et al., *supra* note 68, at 482. See also Robert Pear, *Researchers Find Huge Variations in End-of-Life Treatment*, N.Y. TIMES, Apr. 7, 2008, at A17 (reporting on research at Dartmouth Medical School and quoting from Elliott S. Fisher, a co-author author of the study: "[And there is] no evidence

As Michael Ash and Stephen Arons have written, “excellent end-of-life care requires providers to communicate with patients and their families.”⁷⁷ Such communication needs to “begin early, with the negotiation of desires, needs, and intentions” and it needs to be memorialized in the form of an advance directive.⁷⁸ “Excellent end-of-life care,” they note, “can benefit from communication in the advance directive process,⁷⁹ through the difficult decisions around the discontinuation of curative efforts and the adoption of exclusively palliative care, through counseling and comfort for the dying person, and through solace and processing for the bereaved.”⁸⁰ Yet, as Ash and Arons note, “[c]ommunication is chronically undervalued and underfunded by the public and private health care finance systems.”⁸¹

V. CONCLUSION

It is unfortunate that the provision to reimburse physicians for talking with their Medicare patients about end-of-life options and advance care planning was dropped from both the health care reform effort as well as the national conversation that was suggested by President Obama.⁸² Having recently experienced the death of my grandmother, I am as leery as anyone about the intervention of government, or any group or individual, in private patient decision-making. I shudder to think about the government “pulling the plug on my grandma,” and so I too had an initial knee-jerk reaction against what Sarah Palin and Senator Charles Grassley were describing.⁸³ But, as this article illustrates, what health care reform opponents described was not what was being proposed in section 1233 of the early draft reform legislation.

that a higher-intensity pattern of care leads to better survival. Some patients benefit, but just as many or more may be harmed.”).

77. Ash & Arons, *supra* note 66, at 327. Michael Ash is an Associate Professor of Economics and a member of the faculty of the Center for Public Policy Administration at the University of Massachusetts, Amherst. Stephen Arons is a Professor of Legal Studies at the University of Massachusetts, Amherst, and a member of the faculty at the Smith College School for Social Work’s End-of-Life Care Certificate Program.

78. *Id.*

79. For many Americans, end-of-life consultations will result in an advance directive. Interestingly, lost amidst all the “death panel” rhetoric was the historical fact that twenty years ago Congress, in the Patient Self-Determination Act, mandated that Medicare-certified health care institutions provide written information to every patient detailing their right to complete a living will and/or a durable power of attorney for health care. See Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4206, 104 Stat. 1388, 1395 (1990). Distinctions between mandating the provision of end-of-life planning information and merely incentivizing voluntary advance care planning consultations were never seriously addressed during the “death panel” discussions of 2009.

80. Ash & Arons, *supra* note 66, at 327.

81. *Id.* at 327.

82. See Leonhardt, *supra* note 1.

83. See Charles Lane, *Undue Influence: The House Bill Skews End-of-Life Counsel*, THE WASH. POST, Aug. 8, 2009, at A13 (“Ideally, the delicate decisions about how to manage life’s end would be made in a setting that is neutral in both appearance and fact. Yes, it’s good to have a doctor’s perspective. But Section 1233 goes beyond facilitating doctor input to preferring it. Indeed, the measure would have an interested party—the government—recruit doctors to sell the elderly on living wills, hospice care and their associated providers, professions, and organizations. You don’t have to be a right-wing wacko to question that approach.”).

Yet I understand that people get nervous—maybe even appalled—when money enters into our conversation about end-of-life matters. As Professors Ash and Arons observe, “[s]ome people find it unpleasant, even morally offensive, to contemplate how the economics of health care policy might affect end-of-life care, holding that money should not matter when life and death are on the line and that any form of health care ‘rationing’ may convey a disrespect for human life.”⁸⁴ The reality, however, is that the United States population is aging rapidly⁸⁵ and health care resources are finite. Consequently it is simply not possible to disentangle cost considerations and ethical considerations from our public policy deliberations about life and death. They are inextricably interwoven components of hard decisions our society will continue to encounter as we move further into the 21st century.

Moreover, when there are synergies that can be created between cost-savings strategies and ethical practices that uphold cherished values of dignity and informed self-determination, it is all the more critical that we move beyond demonizing slogans and fear-inducing, radical rhetoric. As that recent *60 Minutes* story about the cost of dying reminded us, “every medical study ever conducted has concluded that 100 percent of all Americans will eventually die.”⁸⁶ Thus, even while studies are in conflict over the extent to which the costs that might be saved at the end of life are significant or systematic, measures that will reduce any Medicare expenditures during the last months of life by even a few percentage points, while enhancing patient autonomy through systematized channels of communication between patient and providers, are non-trivial.

Ash and Arons state the matter bluntly when they ask “whether some Americans die in unnecessary pain and suffering, robbed of dignity and separated from the comfort of their families, because of economic incentives and disincentives built in particular government regulations of end-of-life care.”⁸⁷ Perhaps my grandmother was one of the relatively lucky ones, because her last days were spent surrounded by family, in a calm and

84. Ash & Arons, *supra* note 66, at 306.

85. Although current estimates put the number of Americans aged 65 or older at 13% of the population, in the next twenty years the percentage of Americans age 65 and older is predicted to reach 20%. See Administration on Aging, U.S. Dep’t of Health & Human Services, *Projected Future Growth of the Older Population*, (2009), http://www.aoa.gov/aoaroot/aging_statistics/future_growth/docs/State-Percent_65+yr-age-projections-2005-2030.xls. Similar predictions were made by the Congressional Budget Office in their July 3, 2002 report. Dave Koitz, Melissa D. Bobb, and Ben Page, CBO, *THE LOOMING BUDGETARY IMPACT OF SOCIETY’S AGING 3* (2002) (“[Ten] years out, the outlook starts to change. The population age 65 or older will be growing rapidly. Although that segment constitutes 12 percent of the population today, according to the Social Security and Medicare trustees it is expected to grow to 18 percent in 2025, 21 percent in 2050, and 23 percent in 2075 . . . [B]y 2035, the number of elderly will double, while the number of workers contributing to Social Security and Medicare will rise by only 17 percent. The ratio of the population ages 65 or older to the population in its prime working years (ages 20 to 64) will grow from 21 percent today to 32 percent in 2025 and 42 percent in 2075.”), <http://www.cbo.gov/ftpdocs/35xx/doc3581/July3.pdf>.

86. *60 Minutes*, *supra* note 2.

87. Ash & Arons, *supra* note 66, at 307.

peaceful environment she had selected following a brief and honest conversation with her primary care provider.⁸⁸ However, the conversation could have perhaps been longer and maybe occurred sooner. It is often difficult to know in real time what medical procedures and tests are necessary and which ones will turn out to be superfluous, but in the aggregate we know “[s]ome chronically ill and dying Americans are receiving too much care—more than they and their families actually want or benefit from.”⁸⁹ While some percentage of dying individuals will presumably always insist on receiving every possible medical intervention, not all terminal patients desire such an aggressive course of treatment, and advance care planning consultations are the most certain way to ensure that individual patients die with as much personal dignity and self-control over the process as possible.⁹⁰

Yet, due in large measure to the demonizing rhetoric of “death panels,” Nazis, and euthanasia, an opportunity to incentivize health providers, many of whom are working in systems where they are financially compensated on the basis of performing increasingly more time-consuming procedures, to have more thorough conversations was lost during this most recent reform effort. Perhaps most physicians, like my grandmother’s, will continue to find a little extra time, even at their own personal expense, to discuss with patients the range of medical options available and which ones will actually promote life, as opposed to those that might merely postpone death. But for now, there is not likely to be any organized and deliberate proliferation throughout the United States health care system of the type of robust culture of open and honest advance care consultations, such as the one that has been developed at Gundersen Lutheran hospital.⁹¹ And this is certainly unfortunate, because in the end, we know that these opportunities for doctors and patients to talk are absolutely critical to the task of treating patients in ways consistent with ethical norms and responsible economics, and that when contemplating these intertwined and complex end-of-life matters, the conversations people have and the rhetoric people hear will have tremendous influence on the ways in which all of us, ultimately, will die.

88. See Evan Thomas, *The Case for Killing Granny*, NEWSWEEK, Sept. 21, 2009 at 34 for a discussion documenting a similar experience of the death of the author’s mother, who insisted on transferring out of intensive care and into hospice.

89. Robert Pear, *Researchers Find Huge Variations in End-of-Life Treatment*, N.Y. TIMES, Apr. 7, 2008, at A17 (reporting on research at Dartmouth Medical School and quoting from Dr. John E. Wennberg, chief author of the study), available at http://www.nytimes.com/2008/04/07/health/policy/07_care.html.

90. It is beyond the scope of this article to consider the public policy, legal, and ethical issues surrounding the question of whether unlimited government or public resources should be made available on demand for those who insist that “everything” be done, even in the face of impending death.

91. MacGillis, *supra* note 12 and accompanying text.