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From Schiavo to Death Panels: How Media Coverage of End-of-Life Issues Affects Public Opinion

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I. INTRODUCTION

Even before the most recent debate about the national health care reform legislation, commonly referred to as “Obamacare,” health care and politics have intersected for years. However, few issues in the wider health care sphere have the emotional impact, and therefore, the potential political importance, that end-of-life matters have.

News reporting shapes public opinion and has the ability to influence voters and political outcomes. It informs the public of facts and figures, but can also serve to enlighten—to broaden perspectives and add depth to politics and policy. What the media reports, and how it reports it, matters. At the 2012 presentation to the Association of Health Care Journalists, Dr. Otis Brawley, the chief medical and scientific officer for the American Cancer Society, recognized the important role that health care journalists play in providing public education, and how that education transforms the health care system.¹ Speaking on a variety of health care topics, including disease prevention and cost trends,² Dr. Brawley acknowledged how emotionally difficult end-of-life issues and decisions often are.³ He said, “People cannot accept that death is a part of life; death is an imminent part of life.”⁴ The media influences public debates on many issues that are highly emotional; as a result, it has a responsibility to use the correct language and offer a balanced perspective when reporting on these issues.

This article explores three discrete examples of aggregate media coverage of end-of-life issues. In Part II, the individual case of Terry Schiavo is examined; in Part III, the statewide Massachusetts Death with Dignity vote is discussed; and in Part IV, the federal health care reform legislation that sparked the “death panel” debate is addressed. Each of these controversial situations garnered national public attention. These examples do not represent, and do not attempt to analyze or critique, individual news outlets or an individual journalist’s coverage of the news. Instead, they are used to look at trends or patterns that may occur when reporting on end-of-life topics, as well as lessons that the media and the public can learn from them.

II. TERRY SCHIAVO AND THE MEDIA

Words and language are a reporter’s tools. They are used to clarify, but can sometimes confuse complex medical and scientific facts. In the early 2000s, the landmark Terry Schiavo case created a national controversy that continues to this day. In 1990, Schiavo, a twenty-seven-year-old Florida woman had a cardiac arrest

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1. See Dr. Otis Brawley, Chief Med. Officer, Am. Cancer Soc’y, Address at the Association of Health Care Journalists Annual Conference (Apr. 21, 2012), *available at* http://youtu.be/3ho_LMBiHVg.
 2. *See id.*
 3. *See id.*
 4. *Id.*

and was later diagnosed as being in a persistent vegetative state.⁵ By 1998, her husband, Michael Schiavo, requested that her feeding tube be removed because she would not want to live under her existing circumstances.⁶ However, her parents insisted that she had the potential for rehabilitation, and a nationally publicized battle ensued.⁷

In April 2001, Florida's Second District Court of Appeal upheld an order by Circuit Judge George Greer to have Schiavo's feeding tube removed.⁸ But two days later, it was reinserted after a ruling by Circuit Judge Frank Quesada.⁹ In September 2003, for the second time, Judge Greer ruled for the feeding to be removed on October 15, 2003.¹⁰ In order to intervene and continue the use of the feeding tube, a bill known as "Terri's Law"¹¹ was introduced and passed by the Florida House of Representatives and Senate, and signed by then-Governor Jeb Bush.¹² An ambulance rushed Schiavo to a hospital where the tube was reinserted and she began to receive nutrition again.¹³ Schiavo's husband appealed the decision and almost a year later, in 2004, the Florida Supreme Court ruled that Terri's Law was unconstitutional.¹⁴ Consequently, based upon a ruling from Judge Greer, Schiavo's feeding tube was removed for the final time on March 18, 2005.¹⁵ Additional attempts at judicial intercession failed,¹⁶ and Schiavo died on March 31, 2005.¹⁷

Beyond the moral or religious considerations related to the termination of artificial life support, Schiavo was diagnosed as being in a persistent vegetative state. Such a diagnosis is difficult for many people with no medical training to understand, and is even difficult for some people *with* medical training to comprehend. A critical retrospective analysis published in 2008 in *Neurology* evaluated the national media coverage of Schiavo's case.¹⁸ The study looked at the coverage by four major U.S.

5. See *Terri Schiavo Timeline*, ABC NEWS (Jan. 6, 2006), <http://abcnews.go.com/Health/Schiavo/story?id=531632&page=1>.

6. See *id.*

7. See *id.*

8. See *id.*

9. See *id.*

10. See *id.*

11. See Steve Bousquet, *How Terri's Law Came to Pass*, ST. PETERSBURG TIMES, Nov. 2, 2003, at 1B, available at http://www.sptimes.com/2003/11/02/State/How_Terri_s_Law_came_.shtml.

12. See *Terri Schiavo Timeline*, *supra* note 5.

13. See *Terri Schiavo's Husband Allows Her Family to Visit*, CNN (Oct. 23, 2003, 11:40 AM), <http://www.cnn.com/2003/LAW/10/22/coma.woman/>.

14. See *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004).

15. See *Terri Schiavo Timeline*, *supra* note 5.

16. See *id.*

17. See *id.*

18. See E. Racine et al., *Media Coverage of the Persistent Vegetative State and End-of-Life Decision-Making*, 71 NEUROLOGY 961, 1027–32 (2008).

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newspapers and found that “media coverage included refutations of the persistent vegetative state diagnosis, attributed behaviors inconsistent with PVS, and used charged language to describe end-of-life decision making.”¹⁹

In the print media, 10% of those reports on the case affirmed that Schiavo’s behavior included the ability to “respond,” while 1% said that she could not.²⁰ In addition, 9% of stories reported that her behavior was such that she could “react,” while 1% refuted that assertion.²¹ The words “responds” and “reacts” create mental imagery of purposeful behavior.²² These words suggest that the person has potential for cognitive recovery and, as such, are essentially inconsistent with the diagnosis of a persistent vegetative state in the absence of a more clinical explanation of the person’s potential for recovery.²³

Commenting on Schiavo’s case, Dr. Steven Sparr, a neurologist at the Albert Einstein College of Medicine in New York City, explained that between the states of brain death and full consciousness, there are various “nebulous” neurological states, including that of a persistent vegetative state.²⁴ In covering this type of story, news reporters should educate themselves regarding the various neurological states in order to better inform the public.²⁵ From Dr. Sparr’s perspective, reporters should present the statistical arguments about the percentage of cases in which there is any real chance for recovery or prognosis for improvement, because “it is the media’s responsibility not to throw gasoline on the fire—not to create a story where there is none.”²⁶ He continued, “The problem was the politicization of the whole thing The issue at the center of the case was the legal question of who has the right to make the decision when a person cannot decide for him or herself.”²⁷ Dr. Sparr noted that it is up to the media to help readers distinguish the legal issues in a case from the medical considerations.²⁸ In essence, the media “can help by not having a political agenda.”²⁹

After the ruling, opponents maintained that the removal of Schiavo’s feeding tube was tantamount to “starving her to death,”³⁰ which is an example of language

19. *Id.* at 1027.

20. *Id.* at 1030.

21. *Id.*

22. *See id.* at 1029–30.

23. *See id.*

24. Interview with Dr. Steven Sparr, Albert Einstein Coll. of Med., in N.Y.C. (Nov. 7, 2012).

25. *Id.*

26. *Id.*

27. *Id.*

28. *Id.*

29. *Id.*

30. A LexisNexis Academic Search for the terms “Terri Schiavo” and “starvation” for the period 2000–12 returned 928 results. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. newspapers and wire services, search for “Terri Schiavo” and “starvation”; then narrow the timeline to 2000–12).

often used by those opposed to stopping artificial feedings.³¹ However, according to Rev. Dr. Martha Jacobs, providing people with any nutrition when their bodies are failing, at times, can actually make them more uncomfortable.³² Dr. Jacobs, an adjunct professor at the New York Theological Seminary and author of *A Clergy Guide to End-of-Life Issues*,³³ regularly blogs about end-of-life issues for the *Huffington Post*. Dr. Jacobs stated, “We, as a society, are so hung up on eating that we cannot fathom how it might be more comfortable for someone to be without feeding.”³⁴ Furthermore, Dr. Jacobs explained that the public often confuses artificial nutrition with food.³⁵ The distinction that artificial nutrition is “not the same as steak and mashed potatoes” is not always made clear in media coverage on the topic of withdrawing tube feedings.³⁶

III. MASSACHUSETTS DEATH WITH DIGNITY VOTE

A more recent example of the end-of-life political battleground can be found in Massachusetts. On November 6, 2012, voters rejected an initiative known as Dignity 2012 by a narrow margin of 51% to 49%.³⁷ The hotly contested ballot measure was modeled after the 1994 Oregon Death with Dignity law.³⁸ The Massachusetts law would have allowed physicians to prescribe life-ending medication to terminally ill patients who requested it, were able to take the medication without assistance from anyone else, and met other specific medical and legal criteria.³⁹ At the time of the vote, only three states—Oregon, Washington, and Montana—allowed physicians to legally prescribe medications for such an intended purpose. Had the vote passed, Massachusetts would have become the only East Coast state to legalize physician-assisted dying.⁴⁰

The Massachusetts campaign had gathered grass roots support throughout the state, but also drew highly publicized opposition, especially from religious organizations,

31. See Lisa M. Krieger, *The Cost of Dying: Simple Act of Feeding Poses Painful Choices*, SAN JOSE MERCURY NEWS (Nov. 2, 2012), http://www.mercurynews.com/cost-of-dying/ci_21905632/cost-dying-simple-act-feeding-poses-painful-choices.

32. Telephone Interview with Rev. Dr. Martha Jacobs, Adjunct Professor, N.Y. Theological Seminary (Nov. 12, 2012).

33. MARTHA R. JACOBS, *CLERGY GUIDE TO END-OF-LIFE ISSUES* (The Pilgrim Press 1st ed. 2010).

34. Telephone Interview with Rev. Dr. Martha Jacobs, *supra* note 32.

35. *Id.*

36. *Id.*

37. See Carolyn Johnson, *Assisted Suicide Measure Narrowly Defeated; Supporters Concede Defeat*, BOS. GLOBE (Nov. 7, 2012), <http://www.boston.com/2012/11/07/dying/gBqan95E7zK3elChciPBOP/story.html>.

38. See Jaime Joyce, *The Evolving State of Physician-Assisted Suicide*, THE ATLANTIC (July 15, 2012), <http://www.theatlantic.com/health/archive/2012/07/the-evolving-state-of-physician-assisted-suicide/259862/>.

39. *See id.*

40. After the Massachusetts vote failed to pass, Vermont became the fourth state to legalize aid in dying. See Wilson Ring, *Aid in Dying Now the Law of Vt.*, RUTLAND HERALD (May 21, 2013), <http://rutlandherald.com/article/20130521/NEWS03/705219779/1004>.

including the Roman Catholic Church.⁴¹ As the time for the vote grew closer, the publicity reflected strong opinions from both proponents and opponents. Both sides used emotionally charged words and language to frame the issue. Proponents referred to the act with gentler and more compassionate language, such as “assisted dying” and “death with dignity.” In contrast, opponents often used the emotionally laden phrase “assisted suicide,” which was also frequently repeated by the media.

Most people recoil from the term “suicide.” It is a word associated with a stigma and heaves a heavy emotional impact. While “suicide” is routinely used to refer to someone taking his or her own life, proponents explain that allowing a terminally ill person to choose when and how to die—and then calling it “suicide”—is misleading.⁴² In an op-ed piece in the Canadian media, *Globe and Mail* health reporter André Picard made a case for the power of language to influence perceptions. Picard wrote, “Calling medically assisted dying suicide is a lot like calling surgery a knife attack.”⁴³ The news coverage of the Massachusetts law typically included explanations about the medical and legal considerations, as well as the psychosocial “pro and con” perspectives from both sides, but nevertheless latched onto the word “suicide” with disproportionate frequency. A LexisNexis Academic search of content from major U.S. newspapers and wire service reports for the ninety-day period preceding the November 6 vote yielded results showing a propensity toward use of the term “assisted suicide,” with 244 citations for that term as opposed to eighty-six citations for “death with dignity” and fifteen for “assisted dying.”⁴⁴

Reporters are obliged to use the language of the sources they are covering, especially in direct quotations. Therefore, the frequency with which the term “assisted suicide” is used in news coverage may reflect the popular language of those being interviewed. However, choices about headlines and leads are within the reporter’s or editor’s discretion. A LexisNexis Academic search shows that in the ninety days prior to the vote, “assisted suicide” was used in headlines and leads at almost one-and-a-half times the rate of the other two terms—“death with dignity” and “assisted dying”—combined.⁴⁵ “Assisted suicide” had fifty-four citations, compared to thirty citations for “death with dignity” and four citations for “assisted dying.”⁴⁶ Furthermore,

41. See Joan F. Desmond, *Euthanasia Opponents in Boston Gird for Ballot Battle*, NAT’L CATHOLIC REGISTER (Sept. 21, 2012), <http://www.ncregister.com/daily-news/euthanasia-opponents-in-boston-gird-for-ballot-battle/#ixzz2BwoLy4d7>.

42. See André Picard, *The Importance of Picking a Vocabulary for Dying*, GLOBE & MAIL (Toronto) (June 18, 2012), <http://www.theglobeandmail.com/news/politics/the-importance-of-picking-a-vocabulary-for-dying/article4338418/>.

43. *Id.*

44. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. newspapers and wire services with duplicate options turned off and set content to “everywhere”; then search specified term; then narrow the timeline to 8/06/2012–11/06/2012).

45. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. newspapers and wire services with duplicate options turned off and content set to “headline and lead”; then search specified term; then narrow the timeline to 8/06/2012–11/06/2012).

46. *Id.*

a LexisNexis Academic search of television and radio news transcripts for the same time period reveals a similar pattern, with two citations for “assisted dying,” four for “death with dignity,” and twenty-one for “assisted suicide.”⁴⁷

Opinion poll results illustrate how strongly this language matters.⁴⁸ In 2007, a Gallup poll asked, “When a person has a disease that cannot be cured, do you think doctors should be allowed by law to end the patient’s life by some painless means if the patient and his family request it?”⁴⁹ In response, 69% of people said yes and 27% said no.⁵⁰ In contrast, a 2006 CBS News/*New York Times* poll used wording that is more reflective of suicide: “If a person has a disease that will ultimately destroy their mind or body and they want to take their own life, should a doctor be allowed to assist the person in taking their own life, or not?”⁵¹ In this poll, 56% responded yes and 37% answered no.⁵² These results reflect an 11% difference in the actions people said they supported depending on how the question was worded. In the second case, the phrase “taking their own life,” a nuanced reference to suicide, was mentioned twice and the response to the question was 11% less positive than when people were asked about ending a person’s life by painless means.

IV. HEALTH CARE REFORM LEGISLATION AND “DEATH PANELS”

The U.S. health care system does not readily support or assist physicians who want to have conversations with non-terminally ill patients about considering end-of-life decisions, especially before a health crisis. Instead, many people are left to make difficult end-of-life decisions, for themselves or their loved ones, after being told about a terminal illness or following a traumatic accident—a time of emotional turmoil. Schiavo’s case is a prime example of the importance of having discussions in advance about one’s wishes, and sharing those wishes with a designated health care decisionmaker and, preferably, one’s entire family.

As part of a 2011 compromise in the health care reform legislation,⁵³ the Obama administration withdrew a provision of the Medicare regulation that would have paid doctors for taking the time to have end-of-life planning discussions with

47. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. television and radio transcripts with duplicate options turned off; then search specified term; then narrow the timeline to 8/06/2012–11/06/2012).

48. See *Euthanasia Gallup and CBS News/New York Times Polls*, PROCON.ORG, <http://euthanasia.procon.org/view.resource.php?resourceID=000134#3> (last updated Aug. 17, 2011).

49. *Id.*

50. *Id.*

51. *Id.*

52. *Id.*

53. See Paul Kane et al., *Government Shutdown Averted: Congress Agrees to Budget Deal, Stopgap Funding*, WASH. POST (Apr. 8, 2011), http://www.washingtonpost.com/politics/reid-says-impasse-based-on-abortion-funding-boehner-denies-it/2011/04/08/AFO40U1C_story.html.

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Medicare beneficiaries during patients' annual wellness visits.⁵⁴ Opponents claimed that paying doctors to have such discussions was akin to creating "death panels." Many within the media used the "death panel" terminology, but sought to focus on and clarify what the legislation actually stated.⁵⁵ However, the phrase took on a figurative life of its own where less catchy references did not.⁵⁶

In another LexisNexis Academic search of news coverage during the ninety-day period before the health care legislation was amended to remove that provision, 426 references to "death panels" appeared in newspapers.⁵⁷ This was drastically more than the combined number of references to "advance care planning" (fifty-one), "end of life planning" (sixty-six), and "end of life discussions" (sixteen).⁵⁸ The results from television and radio transcripts were even more dramatic, with 215 citations for "death panels" and a total of thirty-three citations for the other phrases combined.⁵⁹

The sound bites, and their associated fears, became entrenched in the public's mind. In a November 2011 Kaiser Family Foundation poll, 35% of those surveyed responded that they believed that the health care reform law, which was then under debate, had a provision that "allows a government panel to make decisions about end-of-life care for people on Medicare," and another 12% said they did not know whether the proposed legislation included such a provision.⁶⁰ Although this public perception was based on incorrect information, the specter of death panels had permeated the American consciousness.

In contrast, after listening to a detailed, well-informed debate about the similarly taboo topic of rationing end-of-life care, audience poll results changed. In October 2012, National Public Radio aired a broadcast hosted by the live online public debate forum *Intelligence Squared*, during which a four-person expert panel argued for almost fifty minutes about whether end-of-life care should be rationed.⁶¹ Audience polls showed that 22% were opposed to rationing end-of-life care before the program.

54. See Medicare Program; Amendment to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2011, 76 Fed. Reg. 1366 (Jan. 10, 2011) (codified at 42 C.F.R. pt. 410).

55. See, e.g., Robert Pear, *U.S. Alters Rule on Paying for End-of-Life Planning*, N.Y. TIMES (Jan. 4, 2011), http://www.nytimes.com/2011/01/05/health/policy/05health.html?_r=1.

56. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. newspapers and wire services and U.S. television and radio transcripts with duplicate options turned off and content set to "everywhere" and "headline and lead"; then search specified term; then narrow the timeline to 9/10/2010–1/10/2011).

57. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. newspapers and wire services with duplicate options turned off and content set to "everywhere" and "headline and lead"; then search specified term; then narrow the timeline to 9/10/2010–1/10/2011).

58. *Id.*

59. LEXISNEXIS, <http://www.lexisnexis.com> (using advanced search of U.S. television and radio transcripts with duplicate options turned off and content set to "everywhere"; then search specified term; then narrow the timeline to 9/10/2010–1/10/2011).

60. *Kaiser Health Tracking Poll—November 2011*, HENRY J. KAISER FAMILY FOUND. (Nov. 2, 2011), <http://kff.org/health-reform/poll-finding/kaiser-health-tracking-poll-november-2011/>.

61. *See Should We Ration End-of-Life Care?*, NPR (Oct. 16, 2012), <http://n.pr/PsSpYF>.

However, after the robust debate, only 12% opposed it.⁶² This reflects a 10% change in favor of rationing end-of-life care based on an informed debate.

Reporting on stories to which emotionally laden phrases have been attached can be a legitimate dilemma for reporters. According to Thomas Edsall, a professor at the Columbia University Graduate School of Journalism and a well-known political journalist, “Once a debate has been provoked by a value-laden phrase, it is hard to figure out how to get around that phrase.”⁶³ Edsall said that reporters might not be able to avoid a phrase that has become central to a controversy, but they “should make every effort they can to make clear in simple language what the issue is.”⁶⁴

V. CONCLUSION

Members of the news media are frequently tasked with covering the unwieldy—and often emotional—aspects of death and dying. It must be remembered that the news media, to a great extent, report on what other people are saying. However, the examples addressed in this article illustrate the need to maximize the use of experts to help clarify, elaborate, and differentiate the complex medical, legal, and policy issues that end-of-life topics can pose. In being consulted or interviewed on those issues, medical professionals should be attuned to how language is easily open to various interpretations and, therefore, use precise language and examples that will help to make complex issues clearer.

These examples also illustrate for the media—and, more importantly, for the public—the power of emotionally charged language. Although perhaps an idealistic proposal, the public should be aware that any sole news source may simply reinforce whatever their existing perspective or political point of view may be. Therefore, the public should avoid relying solely on any one narrowcast media source and instead seek broad and diverse discussions to inform their opinions, especially on matters of such vital importance as death and dying.

Finally, what is the role and duty of the media in reporting on end-of-life issues, a topic that can generate so much public fear? Although not specific to end-of-life matters, Danah Boyd, senior researcher at Microsoft Research and research assistant professor in media, culture, and communication at New York University, addressed the balance the news media needs to strike between capturing attention and fear mongering.⁶⁵ Boyd wrote, “There’s a fine line between creating an informed citizenry and creating a fearful citizenry.”⁶⁶

62. *See id.*

63. Telephone Interview with Thomas Edsall, Professor, Columbia Univ. Graduate Sch. of Journalism (June 20, 2013).

64. *Id.*

65. *See* Danah Boyd, *The Ethics of Fear and How It Undermines an Informed Citizenry*, POYNTER (Oct. 23, 2012, 6:40 AM), <http://www.poynter.org/latest-news/top-stories/192509/fear-undermines-an-informed-citizenry-as-media-struggles-with-attention-economy/>.

66. *Id.*

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Journalists should also be aware of their own biases in reporting a story and use that bias to strengthen, not damage, their reporting.⁶⁷ Edsall opined, “It is perfectly legitimate to let your concerns and interests drive the subjects you report on,” but added the caution that “journalists should be aware of, and manage biases and make sure they are not blind to them.”⁶⁸ Consequently, reporters can use their interest in an issue to delve deeply into the subject with a clear mind and examine the strengths and weaknesses of the subject from both sides.⁶⁹ A reporter’s biases can, therefore, make for stronger reporting.⁷⁰

As Boyd wrote, “Democracy depends on an informed citizenry and, ideally, the role of the journalist is to inform the public.”⁷¹ Given that, perhaps, the best chance for a well-informed public about end-of-life issues is ensuring and investing in a well-informed news media.

67. Telephone Interview with Thomas Edsall, *supra* note 63.

68. *Id.*

69. *Id.*

70. *Id.*

71. Boyd, *supra* note 65.

