
TALKING ABOUT THE TABOO TOPIC OF DEATH: STATE AND FEDERAL INITIATIVES TO REACH INFORMED CONSENT AT THE END OF LIFE THROUGH ADVANCE CARE PLANNING

ABSTRACT

Advance care planning is the process of determining what kind of care you do and do not want to receive at the end of life. The goal of this service is to reach informed consent for end-of-life decisions. The federal government tried to enact legislation to ensure advance care planning would be an integral part of health care reform, but notwithstanding the many benefits of the service, the legislation failed because of political mischaracterizations. This led a few states to enact statutes that give their patients the right to end-of-life information. After the political outcry subsided, the federal government enacted a regulation to reimburse physicians for advance care planning services.

These state and federal initiatives are good first steps on the road to informed consent at the end of life, but there can be improvements. First, the federal regulation allowing for reimbursement is not a national policy yet, which means coverage of this service can vary from one state to another. Next, medical schools do not include hospice and palliative care instruction in the curriculum, so physicians are not adequately educated to talk about all end-of-life options. Lastly, the federal regulation only reimburses physicians, physician assistants, and nurse practitioners for advance care planning services. There are many other qualified professionals, such as nurses and social workers, who are able to offer these services and should be able to be reimbursed for them.

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I. INTRODUCTION

Imagine a scenario where your mother, nearing the end of life, becomes unable to speak for herself. She never had conversations about the end of life, so you and your family are stuck guessing what kind of care she would want to receive or not want to receive. Would she want to sustain life, relieve the pain, or both? In this situation, research suggests that your mother would see a decrease in the quality of remaining life,¹ increase in

1. Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient*

medical costs,² and you and your family may regret the decisions you made for her.³

Now, imagine a different scenario where your mother had multiple conversations about the end of her life with her physician. When she is nearing the end of life and becomes unable to speak for herself, you and your family are not stuck guessing. Your mother has documented what treatments she would and would not want to receive in an advance directive. In this situation, research suggests your mother would see an increase in the quality of remaining life,⁴ decrease in medical costs,⁵ and you and your family would feel at peace with your mother's decision.⁶

These hypothetical situations illustrate why everyone should be talking about death. However, physicians fail to initiate these conversations, which leaves patients uninformed about their end-of-life care options.⁷ Four states tried to cure this problem by creating statutes that give patients a right to end-of-life information.⁸ The federal government created an incentive for physicians to have these conversations by creating a billing code that allows physicians to be reimbursed for them.⁹ These initiatives are good first steps to ensuring informed consent at the end of life, but they should not be the end of the road.

This Note highlights the importance of obtaining informed consent at the end of life through advance care planning. Part II briefly covers the doctrine of informed consent and how advance care planning ensures informed consent at the end of life. Part III explains how many Americans are uninformed about their options at the end of life and the many benefits

Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment, 300 JAMA 1665, 1670 (2008); see Baohui Zhang et al., *Health Care Costs in the Last Week of Life*, 169 ARCHIVES INTERNAL MED. 480, 480 (2009).

2. See Zhang et al., *supra* note 1, at 482.

3. Wright et al., *supra* note 1.

4. See Zhang et al., *supra* note 1, at 482.

5. *Id.*

6. See Wright et al., *supra* note 1.

7. See Kathryn L. Tucker, *When Dying Takes Too Long: Activism for Social Change to Protect and Expand Choice at the End of Life*, 33 WHITTIER L. REV. 109, 131 (2011).

8. CAL. HEALTH & SAFETY CODE § 442.5(a) (West 2017); MICH. COMP. LAWS ANN. § 333.5654(1) (West 2017); N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2017); VT. STAT. ANN. tit. 18, § 1871(a), (b) (West 2017).

9. See 42 C.F.R. § 410.15 (2016).

advance care planning creates. Part IV depicts the federal government's failed attempts to enact advance care planning legislation. Part V compares and contrasts four state statutes that give patients a right to end-of-life information. Part VI outlines and critiques the new federal regulation that reimburses physicians for advance care planning services. In Part VII, the Author gives three recommendations for the new regulation to make sure advance care planning truly ensures informed consent at the end of life.

II. INFORMED CONSENT AT THE END OF LIFE

One of the goals of advance care planning is to attain informed consent before the end of life.¹⁰ With informed consent, the patient will receive the end-of-life care she wants and avoid the care she does not want.¹¹

A. *The Doctrine of Informed Consent*

The first notion of informed consent was introduced by then-Judge Benjamin N. Cardozo when he stated, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."¹² At the beginning, informed consent was founded in the action of battery¹³ and was concerned with whether touching occurred without consent.¹⁴ Therefore, the physician was only required to disclose that they intended to perform a particular procedure on the patient.¹⁵ Many times it was used as a tool of persuasion and deception to get the patient to agree to a procedure the physician thought was best.¹⁶ These early notions of informed consent were driven by the ideas of medical paternalism and patient ignorance.¹⁷

10. See *Advance Care Planning*, NAT'L HOSPICE & PALLIATIVE CARE ORG., <http://www.nhpco.org/advance-care-planning> (last updated Sept. 12, 2016).

11. See *id.*

12. *Schloendorff v. Soc'y of N.Y. Hosp.*, 105 N.E. 92, 93 (N.Y. 1914), *abrogated by* *Bing v. Thunig*, 143 N.E. 3 (N.Y. 1957).

13. Sonia M. Suter, *The Politics of Information: Informed Consent in Abortion and End-of-Life Decision Making*, 39 AM. J.L. & MED. 7, 12 (2013) (explaining that, in the beginning, informed consent was concerned with protecting bodily integrity in the medical context).

14. *Id.*; see Jaime Staples King & Benjamin W. Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J.L. & MED. 429, 437 (2006).

15. Suter, *supra* note 13.

16. *Id.*

17. See *id.* at 12–13 (citations omitted) (explaining that until the 1960s, patients'

In the 1970s the more modern concept of informed consent was introduced, focusing on the patient being informed about the procedure and the associated risks and benefits.¹⁸ Now based in negligence,¹⁹ informed consent is concerned with “whether the physician disclosed adequate information for the consent to be a true exercise of self-determination.”²⁰ The focus is on the patient being adequately involved in her own decision-making.²¹ Therefore, consent alone is not sufficient. Truly informed consent requires a dialogue between the patient and physician, not just the physician disclosing information.²²

Patient autonomy, rather than medical paternalism, now drives the doctrine of informed consent.²³ Several developments in the medical field contributed to this shift, including specialization in medical fields and the isolation of physicians from the rest of society.²⁴ These developments led doctors to be seen as strangers and not to be trusted with life-or-death decisions.²⁵ Also, nonmedical professionals such as lawyers, legislators, and philosophers helped urge the importance of patient autonomy.²⁶

B. *What Is Advance Care Planning?*

Advance care planning focuses on obtaining informed consent for the end of life.²⁷ The goal is to ensure the patient gets the care she wants and avoids the care she does not want when she becomes unable to speak for

trust in physicians was so strong because physicians were so deeply integrated into the lives and communities of their patients).

18. See *Canterbury v. Spence*, 464 F.2d 772, 780 (D.C. Cir. 1972).

19. Suter, *supra* note 13.

20. *Id.*

21. See *Canterbury*, 464 F.2d at 781.

22. 2 TRIALS OF WAR CRIMINALS BEFORE THE NUERNBERG MILITARY TRIBUNALS UNDER CONTROL COUNCIL LAW NO. 10, at 181–82 (1949), http://www.loc.gov/rr/frd/Military_Law/pdf/NT_war-criminals_Vol-II.pdf; Suter, *supra* note 13, at 17.

23. See Benjamin Moulton & Jaime S. King, *Aligning Ethics with Medical Decision-Making: The Quest for Informed Patient Choice*, 38 J.L. MED. & ETHICS 85, 85 (2010).

24. Suter, *supra* note 13, at 13.

25. See *id.*

26. *Id.*

27. See *Advance Care Planning*, *supra* note 10. Some may refer to advance care planning as end-of-life counseling; the terms share the same definition. *Medicare to Cover End-of-Life Counseling*, CBS NEWS (July 8, 2015), <http://www.cbsnews.com/news/medicare-to-cover-end-of-life-counseling/>. This Note will refer to the idea of informed consent at the end of life solely as advance care planning because the Center for Medicare and Medicare Services refers to it as such. See 42 C.F.R. § 410.15 (2016).

herself.²⁸ There is a four-step process to advance care planning: (1) discussing, (2) deciding, (3) communicating, and (4) documenting end-of-life wishes.²⁹

1. *Discussing End-of-Life Decisions*

The first step is to learn about the types of decisions that might need to be made at the end of life and discuss them with a medical professional.³⁰ These decisions include life-sustaining treatments, comfort care, and organ and tissue donation.³¹ In states where it has been legalized, death with dignity should be discussed as well.³² Life-sustaining treatments include: cardiopulmonary resuscitation (CPR), ventilators, feeding tubes, and intravenous (IV) liquids.³³ The goal of these treatments is to sustain life.³⁴ Comfort care includes hospice and palliative care.³⁵ Here, the goal is focused

28. See Thaddeus Mason Pope, *Advance Care Planning*, MINN. HEALTH CARE NEWS, Nov. 2015, at 26, 26; *Advance Care Planning*, *supra* note 10.

29. See NAT'L INST. ON AGING, U.S. DEP'T OF HEALTH & HUMAN SERVS., ADVANCE CARE PLANNING: TIPS FROM THE NATIONAL INSTITUTE ON AGING *passim* (2014), <https://www.nia.nih.gov/health/publication/advance-care-planning> [hereinafter ADVANCE CARE PLANNING TIPS] (click on the PDF link to download); *Advance Care Planning*, *supra* note 10.

30. See ADVANCE CARE PLANNING TIPS, *supra* note 29, at 3.

31. See *id.* at 3–4, 5.

32. See *Advance Directive*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/advance-directive/> (last visited Mar. 13, 2017). Six states and the District of Columbia permit death with dignity. CAL. HEALTH & SAFETY CODE §§ 443–443.22 (West 2017); COLO. REV. STAT. ANN. §§ 25-48-101 to 25-48-123 (West 2017); OR. REV. STAT. ANN. §§ 127.800–127.897 (West 2017); VT. STAT. ANN. tit. 18, §§ 5281–5293 (West 2017); WASH. REV. CODE ANN. §§ 70.245.010–70.245.903 (West 2017); Death with Dignity Act of 2016, D.C. Act No. 21-577, 63 D.C. Reg. 15697 (Dec. 23, 2016) (enacted December 19, 2016; effective February 18, 2017); *Baxter v. State*, 224 P.3d 1211, 1222 (Mont. 2009).

33. ADVANCE CARE PLANNING TIPS, *supra* note 29, at 2 (explaining CPR is an attempt to restore the patient's heartbeat after the heart stops, a ventilator is a machine that helps a patient who cannot breathe on her own, and feeding tubes and IV liquids help provide nutrition to a patient who cannot eat or drink).

34. See *id.*

35. *Id.* at 2–3. “Palliative care . . . is ‘health care treatment, including interdisciplinary end-of-life care, and consultation with patients and family members, to prevent or relieve pain and suffering and to enhance the patient’s quality of life, including hospice care.’” *Questions and Answers About Palliative Care, Hospice, and the Palliative Care Information Act*, N.Y. ST. DEP'T HEALTH, http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/practitioners/questions_and_answers.htm (last revised Apr. 2013) (citation omitted). The difference between palliative

on making the patient comfortable for the remainder of her life, rather than sustaining life.³⁶ Death with dignity “allow[s] mentally competent, terminally-ill adult[s] . . . to voluntarily request and receive a prescription medication so they can die in a peaceful, humane manner in a place and time of their choosing.”³⁷ While other end-of-life decisions, such as removing a ventilator, could be carried out by a health care proxy if the patient were to become incapacitated, death with dignity laws require that the person be mentally competent and capable of making and communicating health care decisions.³⁸

During this first step, the physician must discuss the benefits and risks of each end-of-life decision.³⁹ CPR might start a heart again but “is less likely to work for an older person who is ill, can’t be successfully treated, and is already close to death.”⁴⁰ Ventilators can help you breathe, but “the tube is uncomfortable, [and] medicines are used to keep you sedated.”⁴¹ Feeding tubes and IV liquids can provide nutrition, but “if you are near death, these could actually make you more uncomfortable.”⁴²

2. Making End-of-Life Wishes

After being informed of the options offered at the end of life and their risks and benefits, the patient should decide which end-of-life options she would or would not want to receive ahead of time.⁴³ This requires the patient to determine her health care values and goals from conversations with her family, friends, and medical professionals.⁴⁴ Then, the patient can align her decisions with those values and goals.⁴⁵

care and hospice is palliative care can be offered along with medical treatments and hospice is offered only after medical treatment has stopped. *See* ADVANCE CARE PLANNING TIPS, *supra* note 29, at 3.

36. *See* ADVANCE CARE PLANNING TIPS, *supra* note 29, at 2–3.

37. *Learn*, DEATH WITH DIGNITY, <https://www.deathwithdignity.org/learn/> (last visited Mar. 13, 2017).

38. *See id.*

39. *Cf.* *Canterbury v. Spence*, 464 F.2d 772, 781 (D.C. Cir. 1972) (requiring physicians to provide patients with adequate information “to enable the patient to chart his course”).

40. ADVANCE CARE PLANNING TIPS, *supra* note 29, at 2.

41. *Id.*

42. *Id.*

43. *See Advance Care Planning*, *supra* note 10.

44. Pope, *supra* note 28.

45. *See id.*

3. Documenting End-of-Life Wishes

After a patient decides what her end-of-life wishes are, those wishes should be transferred into a legal document—an advance directive.⁴⁶ An advance directive has two components: “a living will and a durable power of attorney for health care.”⁴⁷ “A living will is a [legal] document that helps you tell doctors how you want to be treated if you are dying or permanently unconscious”⁴⁸ It specifically lists “which of the procedures . . . you would want, which ones you wouldn’t want, and under which conditions each of your choices applies.”⁴⁹ A durable power of attorney for health care names a health care proxy to carry out the patient’s end-of-life wishes.⁵⁰ A health care proxy is “someone to make medical decisions for you at times when you might not be able to do so.”⁵¹ An advance directive will only go into effect if the patient becomes incapacitated and unable to speak for herself.⁵²

A study found that people with advance directives are “more likely to get the care they prefer at the end of life than people who do not [have an advance directive].”⁵³ If a patient becomes incapacitated and does not have an advance directive, it is likely that her spouse, parents, or adult children will make her medical decisions.⁵⁴

In addition to advance directives, other documents exist that allow people to express their end-of-life wishes. A do not resuscitate (DNR) order can be executed to tell medical professionals that a patient does not want her heart to be restarted if it stops.⁵⁵ Physician Orders for Life-Sustaining Treatment (POLSTs) can be executed in addition to an advance directive.⁵⁶ This document is tailored for detailed wishes in the final stages of life, “[s]o, it is appropriate only when death within the next year would not be

46. See *Advance Care Planning*, *supra* note 10.

47. ADVANCE CARE PLANNING TIPS, *supra* note 29, at 4.

48. *Id.*

49. *Id.*

50. *Id.*

51. *Id.*

52. *Id.* at 1.

53. *Id.*

54. *Id.* at 7.

55. *Id.* at 5.

56. *Id.* at 6. POLST may also stand for *Provider Orders for Life-Sustaining Treatment*. Pope, *supra* note 28, at 27.

unexpected.”⁵⁷ “Emergency workers like . . . paramedics are legally required to prolong the lives of dying patients unless they have a specific order from a physician.”⁵⁸ A POLST qualifies as such an order, while an advance directive does not.⁵⁹

4. *Communicating End-of-Life Wishes*

Patients should share their health care goals and treatment preferences with others to reduce confusion at the end of life.⁶⁰ The health care proxy, who will act on the patient’s behalf, should keep these goals and values in mind when making decisions for the patient.⁶¹ Doctors and hospital staff should also use these values and goals as a guideline when the patient is nearing the end of life.⁶² Family members and close friends will feel more comfortable with a loved one’s end-of-life decisions if those decisions are communicated to them beforehand.⁶³

5. *Reviewing End-of-Life Wishes*

Advance care planning is intended to be an ongoing process.⁶⁴ People should review their end-of-life documents—at a minimum—every 10 years.⁶⁵ Certain life events have proven to be valuable times to review end-of-life documents, such as “the death of a loved one, divorce, [a] new diagnosis, or [a] significant decline in [health].”⁶⁶

III. WHY THE UNITED STATES NEEDS ADVANCE CARE PLANNING

Advance care planning aims to inform patients of their end-of-life options.⁶⁷ The United States would not necessarily need advance care planning if physicians were already having these conversations with their patients, but they are not.⁶⁸ The argument for advance care planning is even

57. Pope, *supra* note 28, at 27.

58. *Id.*

59. *Id.*

60. *See id.* at 26; accord ADVANCE CARE PLANNING TIPS, *supra* note 29, at 7.

61. *See* ADVANCE CARE PLANNING TIPS, *supra* note 29, at 4, 5.

62. *See id.* at 6.

63. *See id.* at 7; *Advance Care Planning*, *supra* note 10.

64. Pope, *supra* note 28, at 27.

65. ADVANCE CARE PLANNING TIPS, *supra* note 29, at 6; Pope, *supra* note 28, at 27.

66. Pope, *supra* note 28, at 27.

67. *See Advance Care Planning*, *supra* note 10.

68. Tucker, *supra* note 7.

stronger because of the many benefits it creates, such as higher quality of remaining life,⁶⁹ lower medical costs at the end of life,⁷⁰ and peace of mind to loved ones.⁷¹

A. Uninformed of End-of-Life Options

Decisions regarding end-of-life care are the most important decisions patients will have to make.⁷² “The breadth of choices available to patients at the end of life” does not make the decision process any easier.⁷³ Unfortunately, many patients are uninformed about these choices.⁷⁴ Studies have shown that patients are ignorant about or misunderstand their options at the end of life.⁷⁵ Patients are also unaware of their legal rights at the end of life.⁷⁶ This problem stretches across socioeconomic and educational classifications—providers have failed to fully inform the entire populace of end-of-life options.⁷⁷ Once patients become fully informed, studies have found patients usually opt for comfort care such as hospice or palliative care instead of aggressive medical treatments.⁷⁸

Public discussion about end-of-life options and filling out advance

69. Zhang et al., *supra* note 1, at 487–88.

70. *See id.* at 487.

71. MICH. COMP. LAWS ANN. § 333.5652(1)(d) (West 2017); *Advance Care Planning*, *supra* note 10.

72. Jane E. Brody, *Frank Talk About Care at Life’s End*, N.Y. TIMES (Aug. 23, 2010), <http://www.nytimes.com/2010/08/24/health/24brod.html> [hereinafter Brody, *Frank Talk About Care at Life’s End*] (quoting Compassion and Choices of New York); Jane Gross, *The Right to Know, Then to Say ‘No.’*, N.Y. TIMES: THE NEW OLD AGE (Oct. 21, 2008, 6:04 AM) (quoting Barbara Coombs Lee, president of Compassion and Choices), <http://newoldage.blogs.nytimes.com/2008/10/21/the-right-to-know-then-to-say-no/>.

73. *See* Tucker, *supra* note 7.

74. *Id.*; *see* Brody, *Frank Talk About Care at Life’s End*, *supra* note 72 (quoting Compassion and Choices of New York); Gross, *supra* note 72 (quoting Barbara Coombs Lee, president of Compassion and Choices).

75. *E.g.*, Maria J. Silveira et al., *Patients’ Knowledge of Options at the End of Life: Ignorance in the Face of Death*, 284 JAMA 2483, 2487–88 (2000).

76. Brody, *Frank Talk About Care at Life’s End*, *supra* note 72 (quoting Compassion and Choices of New York); Gross, *supra* note 72 (quoting Barbara Coombs Lee, president of Compassion and Choices).

77. *See* Silveira et al., *supra* note 75, at 2488 (“[N]o group of patients knows enough about end-of-life care . . . , not even those with better socioeconomic situations or higher education levels.”).

78. Brody, *Frank Talk About Care at Life’s End*, *supra* note 72.

directives fails to fully inform patients of their own end-of-life options.⁷⁹ All patients, not just the terminally ill and elderly, need to have conversations about end-of-life options with their physician.⁸⁰ “Health-care experts near universally agree that [end-of-life] conversations are important.”⁸¹ However, these conversations do not regularly occur.⁸² This deprives patients of the significant benefits of end-of-life conversations, as discussed below.⁸³

Physicians resist and avoid end-of-life conversations with their patients, which leads patients to be uninformed about their end-of-life options.⁸⁴ These conversations are hard to have; thinking about the end of life is scary, and physicians rarely want to bring up death when it is not an impending concern.⁸⁵ Some physicians believe they will cause the patient psychological harm if they have these end-of-life conversations; however, a study found no correlation between end-of-life conversations and patient psychological harm whatsoever.⁸⁶ The study also found “end-of-life discussions were not associated with patients feeling ‘depressed,’ ‘sad,’ ‘terrified,’ or ‘worried.’”⁸⁷ Interestingly, when there were no end-of-life conversations, patients and caregivers showed more signs of psychological harm.⁸⁸ Some physicians feel that end-of-life conversations can be coercive and promote hospice and palliative care over aggressive medical treatment.⁸⁹

79. See Silveira et al., *supra* note 75.

80. See *id.* at 2488; *Medicare to Cover End-of-Life Counseling*, *supra* note 27 (explaining that end-of-life conversations should start as early as when patients receive their driver’s licenses).

81. Sarah Kliff, *Medicare Wants to Pay Doctors to Talk About Death. Expect Political Controversy.*, VOX (July 8, 2015), <http://www.vox.com/2015/7/8/8915841/medicare-end-of-life> [hereinafter Kliff, *Medicare Wants to Pay Doctors to Talk About Death*].

82. Tucker, *supra* note 7.

83. See *id.*

84. See Wright et al., *supra* note 1, at 1672; Brody, *Frank Talk About Care at Life’s End*, *supra* note 72; Jane E. Brody, *Law on End-of-Life Care Rankles Doctors*, N.Y. TIMES (June 6, 2011), <http://www.nytimes.com/2011/06/07/health/07brody.html> [hereinafter Brody, *Law on End-of-Life Care Rankles Doctors*].

85. See Brody, *Law on End-of-Life Care Rankles Doctors*, *supra* note 84.

86. Wright et al., *supra* note 1.

87. *Id.* at 1668.

88. *Id.* at 1670.

89. See, e.g., Gross, *supra* note 72 (noting the California law requiring doctors to inform patients about end-of-life options was supported by the California Medical Association only after the proposed legislation was modified to mitigate the risk of undue influence by doctors).

However, the intention of the conversation is not to promote one form of end-of-life care over another, it is simply to fully inform the patient of her options.⁹⁰ One study found end-of-life conversations were less daunting and more successful to discuss “by exploring [a patient’s] prior experiences with a loved one’s illness or death.”⁹¹

Another reason physicians avoid end-of-life conversations is they are “reluctant to take the necessary time” the conversations require.⁹² Initial conversations about end-of-life care options can take at least an hour and may require follow-up sessions as the patient’s health changes.⁹³ Physicians are paid for doing discrete tasks, such as diagnosing and treating injuries and illnesses.⁹⁴ Therefore, they are not motivated to spend time talking with patients.⁹⁵ Conversations about end-of-life planning are undervalued⁹⁶ and underfunded.⁹⁷

B. Benefits of Advance Care Planning

Advance care planning creates many benefits for patients. When physicians have end-of-life conversations with patients, the quality of remaining life increases,⁹⁸ medical costs at the end of life decrease,⁹⁹ and loved ones feel more peace of mind.¹⁰⁰

90. See Alec MacGillis, *Debate over End-of-Life Care Began in Small Midwestern Town*, WASH. POST (Sept. 4, 2009), <http://www.washingtonpost.com/wpdyn/content/article/2009/09/03/AR2009090303833.html?sid=ST2009090303848>.

91. Silveira et al., *supra* note 75, at 2488.

92. Pope, *supra* note 28, at 28.

93. MacGillis, *supra* note 90.

94. Pope, *supra* note 28, at 28; see also MacGillis, *supra* note 90 (noting doctors at Gunderson Lutheran Hospital in La Crosse, Wisconsin are salaried “instead of being paid for each procedure they perform”).

95. See Pope, *supra* note 28, at 28; MacGillis, *supra* note 90 (noting doctors do not always get paid for time spent having end-of-life discussions with patients).

96. 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, 327 (2009).

97. *Id.*; see MacGillis, *supra* note 90 (explaining that prior to January 1, 2016, Medicare did not reimburse physicians for end-of-life conversations).

98. Wright et al., *supra* note 1.

99. See Zhang et al., *supra* note 1, at 482.

100. MICH. COMP. LAWS ANN. § 333.5652(1)(d) (West 2017); *Advance Care Planning*, *supra* note 10.

1. Higher Quality of Remaining Life

Patients who have end-of-life conversations suffer less physical distress, which improves their quality of remaining life.¹⁰¹ Those end-of-life conversations include discussing aggressive medical treatment and comfort care.¹⁰² The patients who choose to have aggressive medical treatment have low quality of remaining life, while the patients that choose comfort care, such as hospice or palliative care, have a high quality of remaining life.¹⁰³

A patient whose goal is sustaining life will likely seek aggressive medical intervention such as a breathing machine, feeding tube, or powerful drugs.¹⁰⁴ The quality of remaining life is highly correlated with the level of medical intervention the patient seeks.¹⁰⁵ The more aggressive the care sought, the more painful and unpleasant the end of life will be for the patient, reducing the quality of remaining life.¹⁰⁶ Therefore, as medical interventions increase, the patient's quality of life decreases.¹⁰⁷ Also, medical intervention does not necessarily result in longer life, which can make the painful and aggressive treatments futile.¹⁰⁸ In fact, when patients are informed about the benefits and risks of medical intervention, they are less likely to opt for those life-sustaining treatments and receive fewer of them.¹⁰⁹ Some patients with reduced life expectancy fear that they will receive unwanted medical intervention at the end of life.¹¹⁰ Therefore, it has become reasonable and ethical to ask patients if they want "to spend their last, dying days 'connected to a machine.'"¹¹¹

101. See Zhang et al., *supra* note 1, at 482.

102. See, e.g., Brody, *Frank Talk About Care at Life's End*, *supra* note 72 (noting the New York Palliative Care Information Act requires physicians to inform their terminally ill patients about life-sustaining treatment, hospice, and similar options).

103. Wright et al., *supra* note 1, at 1670.

104. See Brody, *Law on End-of-Life Rankles Doctors*, *supra* note 84 ("[S]ome patients are likely to choose to take advantage of anything and everything in the medical armamentarium that could conceivably grant them extra days, weeks or months of life."); cf. *Medicare to Cover End-of-Life Counseling*, *supra* note 27.

105. Wright et al., *supra* note 1, at 1668.

106. *Id.*

107. *Id.* at 1668, 1670.

108. See Brody, *Law on End-of-Life Care Rankles Doctors*, *supra* note 84.

109. Wright et al., *supra* note 1, at 1668, 1670; Zhang et al., *supra* note 1, at 482.

110. See MICH. COMP. LAWS ANN. § 333.5652(1)(b) (West 2017).

111. Joshua E. Perry, *A Missed Opportunity: Health Care Reform, Rhetoric, Ethics and Economics at the End of Life*, 29 MISS. C. L. REV. 409, 422 (2010) (quoting *60 Minutes: The Cost of Dying* (CBS television broadcast Nov. 19, 2009),

Another option for patients at the end of life is hospice or palliative care, which is focused on comfort rather than treatment.¹¹² Studies show that the longer a patient is in hospice or receiving palliative care, the higher quality of life she experiences.¹¹³ The sooner the referral to hospice is made, the higher the quality of life.¹¹⁴ For example, if a patient is in hospice for less than a week, then the quality of life is the same as if no referral was made.¹¹⁵ Patients that have end-of-life conversations usually prefer treatment based on relieving pain and discomfort such as hospice and palliative care.¹¹⁶ Not surprisingly, patients that have end-of-life conversations are more likely to receive hospice for more than one week, which increases the quality of remaining life.¹¹⁷

2. Lower Medical Costs

Talking about saving medical costs near death “sounds like a discussion about rationing” and seems “callous and inappropriate.”¹¹⁸ However, the reality is that “[d]ying in America is expensive.”¹¹⁹ “[N]early 30 percent of Medicare’s \$600 billion annual budget is spent on treatment in the last six months of life”¹²⁰ In 2014, Medicare spent an average of \$34,529 per beneficiary that died that year.¹²¹ Public spending on health care is only going to increase as aging baby boomers increase the number of people eligible for Medicare and Medicaid.¹²²

www.cbsnews.com/news/the-cost-of-dying).

112. See *Hospice Care*, NAT’L HOSPICE & PALLIATIVE CARE ORG., <http://www.nhpco.org/about/hospice-care> (last updated Dec. 16, 2016).

113. Wright et al., *supra* note 1, at 1668.

114. See *id.* at 1670.

115. *Id.*

116. See *id.*

117. *Id.*; Zhang et al., *supra* note 1, at 482.

118. Sarah Kliff, *2015 Is the Year America Started Having a Sane Conversation About Death*, VOX (Dec. 16, 2015), <http://www.vox.com/2015/12/16/10117442/advance-care-planning-debate-2015> [hereinafter Kliff, *2015 Is the Year*].

119. *Id.*

120. Michael Ollove, *In 40 States, a New Focus on End-of-Life Care and Counseling*, PEW CHARITABLE TR. (Aug. 5, 2015), <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/08/05/in-40-states-a-new-focus-on-end-of-life-care-and-counseling>.

121. *10 FAQs: Medicare’s Role in End-of-Life Care*, HENRY J. KAISER FAM. FOUND. (Sept. 26, 2016), <http://kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/>.

122. See Ollove, *supra* note 120.

Studies reveal medical costs at the end of life decrease when a patient starts having end-of-life conversations.¹²³ Aggressive medical intervention is costly and, when patients have end-of-life conversations, they opt for fewer medical interventions.¹²⁴ Therefore, medical costs decrease.¹²⁵ In fact, patients that have end-of-life conversations have 35 percent lower medical costs than patients that do not.¹²⁶

3. *Peace of Mind for Loved Ones*

End-of-life decisions are not purely medical.¹²⁷ Many patients have their loved ones, family, and close friends in mind when making end-of-life decisions.¹²⁸ If patients do not have end-of-life conversations or make their end-of-life wishes known, such as through an advance directive, then it leaves loved ones to guess what they would have wanted.¹²⁹ Having end-of-life conversations provides loved ones with many benefits, such as relieving the need to guess, providing a sense of control, easing stress, and providing guidance.¹³⁰ A study found that loved ones who acted as caregivers experienced depression and felt unprepared for the death if the patient received aggressive medical intervention.¹³¹ It also found that caregivers felt more prepared for the death and experienced less regret if the patient had a high quality of life at the end of life.¹³²

IV. FAILED FEDERAL EFFORTS

Because the medical profession had not yet addressed the problem of repeated physician failure to discuss end-of-life options, the federal and state legislatures had to take action.¹³³

123. See Zhang et al., *supra* note 1, at 482.

124. Wright et al., *supra* note 1, at 1668; Zhang et al., *supra* note 1, at 482.

125. See Zhang et al., *supra* note 1, at 482.

126. *Id.*

127. Suter, *supra* note 13, at 18–19.

128. See *id.*

129. See Kliff, *Medicare Wants to Pay Doctors to Talk About Death*, *supra* note 81.

130. MICH. COMP. LAWS ANN. § 333.5652(1)(d) (West 2017); *Advance Care Planning*, *supra* note 10.

131. Wright et al., *supra* note 1, at 1668.

132. *Id.* at 1670.

133. See Brody, *Law on End-of-Life Care Rankles Doctors*, *supra* note 84.

A. Failed Legislation

In 2008, Representative Earl Blumenauer led the way in making advance care planning an important part of health care reform. He introduced the Life Sustaining Treatment Preferences Act of 2008 “to provide for coverage under the Medicare Program for consultations regarding orders for life sustaining treatment.”¹³⁴ The bill was reintroduced in 2009, co-sponsored by three Democrats and three Republicans,¹³⁵ and was eventually incorporated into the Affordable Health Care for America Act.¹³⁶

The Affordable Health Care for America Act would have amended the Social Security Act, creating a new subsection titled Advance Care Planning Consultation.¹³⁷ The new subsection would have allowed for qualified health care providers to be reimbursed for voluntary conversations about end-of-life concerns with their patients.¹³⁸ Reimbursement for each patient would have been available only once every five years,¹³⁹ but more frequent conversations could have been reimbursed if the patient experienced a significant change in health condition or was admitted to “a skilled nursing facility, a long-term care facility . . . , or a hospice program.”¹⁴⁰ The final bill, the Patient Protection and Affordable Care Act, deleted this subsection,¹⁴¹ and therefore it was not enacted into law.

B. Initial Support

The deletion of the advance care planning provision came as a surprise to many. Initially, it appeared that both Republicans and Democrats agreed advance care planning would be an integral part of health care reform.¹⁴²

134. Life Sustaining Treatment Preferences Act of 2008, H.R. 7181, 110th Cong. (2008).

135. See Life Sustaining Treatment Preferences Act of 2009, H.R. 1898, 111th Cong. (2009).

136. See Affordable Health Care for America Act, H.R. 3962, 111th Cong. § 240 (as passed by House of Representatives, Nov. 7, 2009).

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

138. See *id.* § 1233(a)(1)(B).

139. See *id.* § 1233(a)(3)(A).

140. *Id.* § 1233(a)(3)(B).

141. See Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. (enrolled bill, Mar. 22, 2010).

142. See Life Sustaining Treatment Preferences Act of 2009, H.R. 1898, 111th Cong. (2009) (showing that Republican Representatives Charles Boustany, Geoff Davis, and Patrick Tiberi were co-sponsors of the failed House of Representatives bill in 2009).

Representative Blumenauer stated that he specifically included advance care planning in the House bill because it was “a rare common denominator of health care politics.”¹⁴³ On July 16, 2009, at the House Ways and Means Committee markup session, not one word was spoken in opposition to the advance care planning provision.¹⁴⁴

C. Political Outcry

Not but a week after the silent markup session, opposition to advance care planning came from the House Republican Party leader, John Boehner, and the Republican Policy Committee Chairman, Thaddeus McCotter.¹⁴⁵ They were concerned end-of-life conversations would persuade patients to sign end-of-life directives they would not otherwise sign and “create a slippery slope for a more permissive environment for euthanasia, mercy-killing and physician-assisted suicide.”¹⁴⁶ The most notable opposition was from former Governor Sarah Palin who dubbed advance care planning as Obama’s “death panels.”¹⁴⁷ New York’s former Lieutenant Governor, Betsy McCaughey, stated that advance care planning “would make it mandatory, absolutely require, that every five years, people in Medicare have a required counseling session that will tell them how to end their life sooner,” despite no such language existing in the new subsection.¹⁴⁸ Representative Virginia Foxx said the bill would “put seniors in a position of being put to death by their government.”¹⁴⁹ Only a week after Palin’s “death panel” comment, a

Republican Senators Susan Collins, Richard Lugar, and John Isakson were co-sponsors of a similar bill in the Senate. Medicare End-of-Life Care Planning Act, S. 466, 110th Cong. (2007).

143. Earl Blumenauer, Opinion, *My Near Death Panel Experience*, N.Y. TIMES (Nov. 14, 2009), http://www.nytimes.com/2009/11/15/opinion/15blumenauer.html?_r=0.

144. *Id.*

145. *Id.*

146. Melinda Warner, *Rep. Boehner Comes Out Against Providing Seniors with Choices*, POL. CORRECTION: BLOG (July 24, 2009, 4:01 PM), <http://politicalcorrection.org/blog/200907240005> (quoting Press Release, Minority Leader John Boehner, U.S. House of Representatives (July 23, 2009)).

147. Don Gonyea, *From the Start, Obama Struggled with Fallout from a Kind of Fake News*, NPR (Jan. 10, 2017), <http://www.npr.org/2017/01/10/509164679/from-the-start-obama-struggled-with-fallout-from-a-kind-of-fake-news>.

148. Jim Dwyer, *Distortions on Health Bill, Homegrown*, N.Y. TIMES (Aug. 25, 2009), <http://www.nytimes.com/2009/08/26/nyregion/26about.html>.

149. C-SPAN, *Rep. Foxx Says Health Care Reform Will Cause Seniors to Be “Put to Death by Their Government.”* YOUTUBE (July 28, 2009), <https://www.youtube.com/watch?v=hea-4VJZXRE>.

poll indicated about 30 percent of the population believed death panels were a part of the health reform legislation.¹⁵⁰ These comments politicized the previously neutral issue of advance care planning.

Advocates of advance care planning tried to debunk the mischaracterizations. At a town hall meeting in Portsmouth, New Hampshire, President Barack Obama tried to convince the public that the proposed bill was not forcing anybody to do anything, and “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.”¹⁵¹ Despite his efforts, the President’s remarks were largely ignored; even after his town hall meeting, mischaracterizations were still made. Senator Charles Grassley told an audience they “[had] every right to fear” a government program “to pull the plug on grandma.”¹⁵² Richard Land, president of the Southern Baptist Ethics & Religious Liberty Commission, said what President Obama and Democrats “are attempting to do . . . is precisely what the Nazis did.”¹⁵³

This led more supporters of advance care planning to speak out and again to try to correct the mischaracterizations. Jim Dau, national spokesperson for AARP, clarified that the only mandatory provision in the proposed bill was reimbursement for the end-of-life counseling session, not the counseling session itself.¹⁵⁴ He stated the purpose was “to make sure people are making the right decision. If some one wants to take every life-saving measure, that’s their call. Others will decide it’s not worth going

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

151. President Barack Obama, Remarks by the President in Health Insurance Reform Town Hall (Aug. 11, 2009), <https://obamawhitehouse.archives.gov/the-press-office/remarks-president-town-hall-health-insurance-reform-portsmouth-new-hampshire> [hereinafter Obama, Remarks in Health Insurance Reform Town Hall].

152. Sam Stein, *Grassley Endorses “Death Panel” Rumor: “You Have Every Right to Fear,”* HUFFINGTON POST (Sept. 12, 2009), http://www.huffingtonpost.com/2009/08/12/grassley-endorses-death-p_n_257677.html.

153. James A. Smith Sr., *More “Nazi” Health Care Lies from the Christian Coalition,* CONSTANTINE REP. (Oct. 8, 2009), <http://www.constantinereport.com/more-nazi-health-care-lies-from-the-christian-coalition/>.

154. Catharine Richert, *McCaughey Claims End-of-Life Counseling Will Be Required for Medicare Patients,* POLITIFACT (July 23, 2009), <http://www.politifact.com/truth-o-meter/statements/2009/jul/23/betsy-mccaughey/mccaughey-claims-end-life-counseling-will-be-requi/>.

through this trauma just for themselves and their families, and that's their decision, too."¹⁵⁵ Republican Senator John Isakson was unsure how the proposed legislation became so mischaracterized because "[y]ou're putting the authority in the individual rather than the government."¹⁵⁶

D. *Advance Care Planning Dropped*

The efforts to correct the mischaracterizations were drowned out by the political outcry, ultimately leading to the demise of the proposed bill. Senator Grassley said, "We dropped end-of-life provisions from consideration entirely because of the way they could be misinterpreted and implemented incorrectly."¹⁵⁷ President Obama opined the real reason behind the mischaracterizations was "to kill [health care] reform at any cost."¹⁵⁸ The *Seattle Times* staff thought it was "a shame for those who may not have access to information that would aid them in making excruciatingly painful decisions."¹⁵⁹ Senator Jay Rockefeller pled to keep advance care planning in the bill: "I am extremely concerned that the Committee mark does nothing to inform consumers of their treatment options at the end of life or help them document their individual wishes for care."¹⁶⁰ But because the proposed bill was dropped, hope for the "very difficult democratic conversation"¹⁶¹ about the ethics and economics of dying had been lost.

155. *Id.*

156. Ezra Klein, *Is the Government Going to Euthanize Your Grandmother? An Interview with Sen. Johnny Isakson.*, WASH. POST: VOICES BLOG (Aug. 10, 2009 5:51 PM), http://voices.washingtonpost.com/ezra-klein/2009/08/is_the_government_going_to_eut.html.

157. *Grassley: End-of-Life Care Concerns, Other Concerns in House Health Care Legislation*, CHUCK GRASSLEY: U.S. SENATOR FOR IOWA (Aug. 13, 2009), <http://www.grassley.senate.gov/news/news-releases/grassley-end-life-care-concerns-other-concerns-house-health-care-legislation>.

158. President Barack Obama, Remarks by the President to a Joint Session of Congress on Health Care (Sept. 9 2009), <https://obamawhitehouse.archives.gov/the-press-office/remarks-president-a-joint-session-congress-health-care>.

159. Opinion, *Health-Care Reform: Distortions Doom End-of-Life Counseling*, SEATTLE TIMES (Aug. 16, 2009), <http://www.seattletimes.com/opinion/health-care-reform-distortions-doom-end-of-life-counseling/>.

160. COMM. ON FIN., U.S. SENATE, AMERICA'S HEALTHY FUTURE ACT OF 2009, S. REP. NO. 111-89, at 439 (2009).

161. David Leonhardt, *After the Great Recession*, N.Y. TIMES MAG. (Apr. 28, 2009), http://www.nytimes.com/2009/05/03/magazine/03Obama-t.html?pagewanted=6&_r=0.

V. STATE EFFORTS

While the federal government was inactive, a few states enacted informed consent laws for the end of life because of patients being inadequately informed of end-of-life options, the lack of communication between physician and patient, and the exorbitant medical costs associated with end-of-life care.¹⁶² The goals for the state laws were very similar to those of the failed federal legislation, including increasing participation in hospice and palliative care, which both result in better quality of life and reduced medical costs at the end-of-life.¹⁶³ It was also hoped that the legislation would move patients into those programs earlier with the goal of increasing the quality of remaining life.¹⁶⁴

A. Current State Laws

Four states have informed consent laws for end-of-life decisions: California, Michigan, New York, and Vermont.¹⁶⁵ Arizona and Maryland have tried to pass similar legislation but have not been successful.¹⁶⁶ All of the statutes share the same goal: informed decision-making regarding medical care at the end of life.¹⁶⁷ This gives patients a chance to be informed on treatment options such as hospice, palliative care, life-sustaining treatments, and refusing food and hydration.¹⁶⁸

1. California Terminal Patients' Right to Know End-of-Life Options Act

In 2008, California became the first state to provide terminally ill patients with “a legal right to information from their doctors, . . . about end-of-life options.”¹⁶⁹ In California, a patient must request to have a

162. See MICH. COMP. LAWS ANN. § 333.5652(1)(c), (d) (West 2017); THOMAS K. DUANE, SPONSOR MEMO, S. 4498, 2009–2010 Legis. Sess. (N.Y. 2009), reprinted in *Senate Bill S4498*, N.Y. ST. SENATE, <https://www.nysenate.gov/legislation/bills/2009/s4498> (last visited Mar. 21, 2017); Suter, *supra* note 13, at 29, 30, 31–32.

163. See Gross, *supra* note 72.

164. *Id.*

165. CAL. HEALTH & SAFETY CODE § 442.5 (West 2017); MICH. COMP. LAWS ANN. § 333.5654(1); N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2017); VT. STAT. ANN. tit. 18 § 1871 (West 2017); Suter, *supra* note 13, at 29.

166. Suter, *supra* note 13, at 29.

167. See *id.* at 31–32.

168. See Gross, *supra* note 72.

169. *Id.*

conversation about end-of-life options.¹⁷⁰ The physician is not required to talk about it unless asked.¹⁷¹ For this statute to apply, a patient must qualify as “terminally ill.”¹⁷² The statute sets out a specific, detailed list of end-of-life information the physician is to disclose to the patient.¹⁷³ The patient is also entitled to information that is not strictly medical, such as her legal rights at the end of life.¹⁷⁴ The physician may refer the patient to another provider for the services if the provider is uncomfortable complying with the patient’s wishes.¹⁷⁵ The legislation was backed by the California Medical Association after it was changed to make the disclosure required only upon request and to include an opt-out provision for providers.¹⁷⁶

2. *New York Palliative Care Information Act*

The New York statute requires the provider to disclose end-of-life information, whether or not the patient asks for it, but the patient can refuse the physician’s offer.¹⁷⁷ The statute covers a broader group of patients as it applies to any patient that expects “death within six months.”¹⁷⁸ This statute is the only one that includes criminal penalties for violations.¹⁷⁹ It provides a non-exclusive list of what end-of-life information the physician must give to the patient.¹⁸⁰ In addition to relevant medical information, the patient is entitled to be informed about legal rights at the end of life.¹⁸¹ The statute has an opt-out provision for the provider if she is unwilling or feels unqualified to provide these services, as long as she can refer the patient to another

170. CAL. HEALTH & SAFETY CODE § 442.5(a)(2).

171. *See* Gross, *supra* note 72.

172. CAL. HEALTH & SAFETY CODE § 442.5(a).

173. *Id.* § 442.5(b).

174. *See id.* § 442.5(a)(2).

175. *Id.* (authorizing referrals to professionals specializing in end-of-life care options).

176. Gross, *supra* note 72.

177. N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2017); Brody, *Law on End-of-Life Care Rankles Doctors*, *supra* note 84.

178. N.Y. PUB. HEALTH LAW § 2997-c(1)(d).

179. *See Questions and Answers for Providers*, N.Y. ST. DEP’T HEALTH, http://www.health.ny.gov/professionals/patients/patient_rights/palliative_care/2011-12-14_questions_and_answers.htm (last revised Dec. 2011) (showing the statute does not prescribe penalties, but because it is codified in the public health code, penalties apply, including fines up to \$10,000 or imprisonment for one year).

180. N.Y. PUB. HEALTH LAW § 2997-c(2).

181. *Id.* § 2997-c(2)(b).

provider who will provide them.¹⁸² The New York State Medical Society opposed this statute because it believed these laws would intrude on the physician–patient relationship and mandate a standard of care devised by the legislature.¹⁸³

3. *Michigan Dignified Death Act*

The Michigan statute requires the physician to disclose end-of-life options even if the patient does not ask.¹⁸⁴ The statute applies to a broad range of patients, including those that have an “advanced illness” or “terminal illness.”¹⁸⁵ The statute provides a list of end-of-life information that the physician must disclose.¹⁸⁶ The patient is also entitled to more than just medical information, including legal rights at the end of life.¹⁸⁷

4. *Vermont Patient’s Bill of Rights for Palliative Care and Pain Management*

Vermont’s statute is the most ambiguous. It gives all patients the “right to be informed of all evidence-based options for care and treatment.”¹⁸⁸ However, it specifically addresses patients with terminal illnesses and states they have the “right to be informed . . . of all available options related to terminal care.”¹⁸⁹

B. *State Comparisons*

Michigan’s statute has the strongest disclosure requirement: the physician must disclose end-of-life information whether or not the patient requests it, and the statute does not explicitly allow the patient to refuse getting the information.¹⁹⁰ New York’s statute also requires the physician to disclose end-of-life information, but the statute’s language, “shall offer to provide the patient,” suggests that the patient may refuse the disclosure.¹⁹¹ Physicians in California are only required to inform the patient of the *right*

182. *Id.* § 2997-c(3).

183. *See* Brody, *Frank Talk About Care at Life’s End*, *supra* note 72.

184. *See* MICH. COMP. LAWS ANN. § 333.5654(1) (West 2017).

185. *Id.* § 333.5653(1)(a).

186. *Id.* §§ 333.5654(1), 333.5655.

187. *Id.* at § 333.56502(1)(c).

188. VT. STAT. ANN. tit. 18, § 1871(a) (West 2017).

189. *Id.* § 1871(b).

190. *See* MICH. COMP. LAWS ANN. § 333.5655.

191. *See* N.Y. PUB. HEALTH LAW § 2997-c(2) (McKinney 2017).

to end-of-life information but are not required to talk about end-of-life information unless the patient requests it.¹⁹²

In California, the statute applies to the narrowest group of patients, those with a “terminal illness,” but it does not define what qualifies as a terminal illness.¹⁹³ One journalist highlighted the problem of this narrow definition when her 87-year-old mother who was “paralyzed, incontinent, unable to speak and losing the ability to swallow” did not qualify as having a terminal illness.¹⁹⁴ New York’s and Michigan’s statutes are more specific about what group of patients the statutes apply to. Michigan’s statute gives a detailed definition of what constitutes as a qualifying “advanced illness.”¹⁹⁵ New York’s statute is the only one that sets a timeline; the patient must expect “death within six months.”¹⁹⁶

California’s, Michigan’s, and New York’s statutes each provide a detailed list of what end-of-life information the physician must disclose.¹⁹⁷ All three states require disclosure of the patient’s right to continue to pursue treatment and to information about pain and symptom management.¹⁹⁸ California and Michigan require disclosure of the right to refuse or withdraw from treatment and the option to appoint a health care decision maker or patient advocate.¹⁹⁹ New York and Michigan require disclosure about palliative care.²⁰⁰ California specifically mentions disclosure about hospice and advance care directives.²⁰¹ New York’s list is the most expansive, requiring disclosure about end-of-life options appropriate to the patient and the associated risks and benefits of each.²⁰²

California’s and New York’s statutes both include an opt-out provision

192. CAL. HEALTH & SAFETY CODE § 442.5(a) (West 2017).

193. *See id.* §§ 442, 442.5(a).

194. Gross, *supra* note 72.

195. MICH. COMP. LAWS ANN. § 333.5653(1)(a).

196. N.Y. PUB. HEALTH LAW § 2997-c(1)(d).

197. CAL. HEALTH & SAFETY CODE § 442.5(b); MICH. COMP. LAWS ANN. §§ 333.5654(1), 333.5655; N.Y. PUB. HEALTH LAW § 2997-c(2).

198. CAL. HEALTH & SAFETY CODE § 442.5(b)(4), (5); MICH. COMP. LAWS ANN. §§ 333.5654(1), 333.5655(c), (d); N.Y. PUB. HEALTH LAW § 2997-c(2).

199. CAL. HEALTH & SAFETY CODE § 442.5(b)(3); MICH. COMP. LAWS ANN. §§ 333.5654(1), 333.5655.

200. MICH. COMP. LAWS ANN. § 333.5655(c); N.Y. PUB. HEALTH LAW § 2997-(2)(a).

201. CAL. HEALTH & SAFETY CODE § 442.5(b).

202. N.Y. PUB. HEALTH LAW § 2997-c(2)(a).

for providers that are not comfortable disclosing end-of-life information.²⁰³ Each requires the physician to refer the patient to another health care provider that is willing to give the information.²⁰⁴

VI. APPROVED FEDERAL LEGISLATION

Six years after political outcry forced it out of consideration, advance care planning is back.²⁰⁵ On July 8, 2015, the Centers for Medicare & Medicaid Services (CMS) announced it would start reimbursing physicians for voluntary end-of-life discussions between physicians and patients.²⁰⁶ The announcement was part of a massive overhaul of physician fee schedules²⁰⁷ that took effect January 1, 2016.²⁰⁸ The CMS received 725 public comments on the proposal—a majority expressing support²⁰⁹—before it issued the final regulation on October 30, 2015, with advance care planning intact.²¹⁰ The final regulation was viewed as “a great first step in recognizing that providing this service to patients and their families is better care.”²¹¹

203. CAL. HEALTH & SAFETY CODE § 442.7; N.Y. PUB. HEALTH LAW § 2997-c(3).

204. CAL. HEALTH & SAFETY CODE § 442.7; N.Y. PUB. HEALTH LAW § 2997-c(3).

205. *See Medicare to Cover End-of-Life Counseling*, *supra* note 27.

206. *Proposed Rule Would Reimburse Physicians for ACP*, NAT'L HOSPICE & PALLIATIVE CARE ORG. (July 8, 2015), <http://www.nhpco.org/press-room/press-releases/proposed-rule-would-reimburse-physicians-acp-0>.

207. “A fee schedule is a complete listing of fees used by Medicare to pay doctors or other providers/suppliers. This comprehensive listing of fee maximums is used to reimburse a physician and/or other providers on a fee-for-service basis.” *Fee Schedules - General Information*, CMS.GOV, <https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/FeeScheduleGenInfo/index.html> (last modified May 19, 2015).

208. *See Medicare to Cover End-of-Life Counseling*, *supra* note 27.

209. Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 70,886, 70,956 (Nov. 16, 2015) [hereinafter Medicare Program; Revisions to Payment Policies].

210. *Proposed Policy, Payment, and Quality Provisions Changes to the Medicare Physician Fee Schedule for Calendar Year 2016*, CMS.GOV (Oct. 30, 2015), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html> [hereinafter *Proposed Policy, Payment, and Quality Provisions Changes*].

211. Mike Tighe, *Medicare to Pay for End-of-Life Counseling*, LA CROSSE TRIB. (July 9, 2015) (quoting Bud Hammes, Medical Humanities and Respecting Choices director at Gundersen Health System), http://lacrossetribune.com/news/local/medicare-to-pay-for-end-of-life-counseling/article_a6f78510-14f1-5482-bdb0-7f9cad8eaa15.html.

A. Overwhelming Support and Minimal Outcry

Because advance care planning is no longer considered politically toxic, the new regulation has been welcomed with open arms.²¹² Members of Congress, both Democrats and Republicans, now support advance care planning.²¹³ Chaplains and ethicists even sent comments to the CMS in support of the proposal.²¹⁴ Medicare received comments, and all but one of them were in favor of advance care planning.²¹⁵ Doctors almost universally agree that advance care planning is a common sense option and support it.²¹⁶ Representative Blumenauer, who advocated for the failed legislation in 2008,²¹⁷ is glad that the federal government has reached a consensus and is finally following “where the rest of America is going.”²¹⁸

While there has still been opposition to advance care planning, the outcry has been minimal.²¹⁹ This is because most politicians are realizing that empowering patients to take control of their end-of-life decisions is a good idea.²²⁰ The idea is nothing new, as it has always been the purpose behind advance care planning legislation, even in 2009.²²¹ The motivations to eliminate advance care planning in 2009 were “an attempt to derail the [Affordable Care Act] with scare tactics.”²²² Finally, the mischaracterizations have been silenced, and advance care planning is now

212. See *CMS Finalizes 2016 Medicare Payment Rules for Physicians, Hospitals & Other Providers*, CMS.GOV (Oct. 30, 2015), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Press-releases/2015-Press-releases-items/2015-10-30.html>.

213. *Rare Bipartisan Health Legislation Pushes Advance Care Planning*, LIFE MATTERS MEDIA (June 15, 2015), <http://www.lifemattersmedia.org/2015/06/rare-bipartisan-health-legislation-pushes-advanced-care-planning/>.

214. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,956.

215. Kliff, *Medicare Wants to Pay Doctors to Talk About Death*, *supra* note 81.

216. *Id.*; see *Medicare to Cover End-of-Life Counseling*, *supra* note 27.

217. See Life Sustaining Treatment Preferences Act of 2008, H.R. 7181, 110th Cong. (2008).

218. *Medicare to Cover End-of-Life Counseling*, *supra* note 27 (quoting Representative Earl Blumenauer).

219. See Robert I. Field, *Death Panels Are Back – Just Ask Sarah Palin*, PHILLY.COM: HEALTH CENTS BLOG (July 13, 2015, 6:00 AM), <http://www.philly.com/philly/blogs/fieldclinic/Death-panels-are-back--just-ask-Sarah-Palin.html> (quoting Sarah Palin: “Politicians just don’t get it. Their ‘Death Panels’ still won’t die. . . . Obamacare masterminds decided they’ll pay healthcare providers for vulnerable patients’ ‘end-of-life’ plans.”).

220. *Id.*

221. See Obama, Remarks in Health Insurance Reform Town Hall, *supra* note 151.

222. Field, *supra* note 219.

being considered more rationally.²²³

B. The New Regulation: Advance Care Planning

In 2015, the CMS started to consider reimbursement for advance care planning but did not authorize it for payment.²²⁴ Instead, it waited a year to go through notice and comment rulemaking.²²⁵ After the CMS received widespread support, as discussed above, they approved the proposed regulation to reimburse practitioners for advance care planning.²²⁶

The new regulation reflects that people should be getting expert advice and making their wishes known about end-of-life care “as early as when they get a driver’s license.”²²⁷ For now, physicians can only be reimbursed for advance care planning conversations with Medicare beneficiaries, but this will allow these patients to have “early conversations [with] their practitioners, both before an illness progresses and during the course of treatment, to decide on the type of care that is right for them.”²²⁸

Before this new regulation, advance care planning could have been covered on a Medicare patient’s first visit as a Medicare beneficiary.²²⁹ However, this may not be the most appropriate time for patients to have these conversations.²³⁰ The new regulation allows for practitioners to be reimbursed by Medicare outside this first visit, providing for “greater opportunity and flexibility to utilize these planning sessions.”²³¹

The most important part of the new regulation is the two billing

223. *Id.*

224. Joyce Frieden, *Medicare’s Pay Rules for Docs Open Door to \$\$ for Advance Planning*, MEDPAGE TODAY (Nov. 4, 2014), <http://www.medpagetoday.com/PublicHealthPolicy/Medicare/48407>.

225. *See* Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. 70,886, 70,955 (Nov. 16, 2015).

226. *See id.*

227. *Medicare to Cover End-of-Life Counseling*, *supra* note 27.

228. *Proposed Policy, Payment, and Quality Provisions Changes*, *supra* note 210.

229. *Id.*

230. *See id.*

231. *Id.*

codes²³² it establishes for two advance care planning services.²³³ Both codes, 99497 and 99498, reimburse for “[a]dvance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health care professional.”²³⁴ The difference is the first code reimburses about \$80²³⁵ for the “first 30 minutes, face-to-face with the patient, family member(s), and/or surrogate,”²³⁶ while the second code reimburses about \$75²³⁷ for “each additional 30 minutes” and has no face-to-face requirement.²³⁸ Of equal importance, the new regulation added a provision allowing for reimbursement for optional advance care planning at an annual wellness visit.²³⁹ This is important because billing codes 99497 and 99498 can be furnished “incident to” a health care service and cannot be utilized at an annual wellness visit.²⁴⁰

1. Criticisms of the New Regulation

Billing codes 99497 and 99498 set a limit on the time the practitioner is allowed to be reimbursed for furnishing the advanced care planning services: 30 minutes.²⁴¹ While the CMS states that the “time increments . . . are appropriate,”²⁴² others disagree. They believe a time limit is not conducive to fit various patients’ needs.²⁴³ Some patients may require much longer

232. Medicare assigns a Healthcare Common Procedure Coding System (HCPCS) code to every task and service a medical practitioner may provide to a patient. Trisha Torrey, *What Are Medicare’s HCPCS Codes? Billing Codes Used for Medicare Payment*, VERYWELL, <https://www.verywell.com/what-are-medicare-hcps-codes-2614952> (last updated Dec. 10, 2016). Those HCPCS codes are also assigned a fee amount that physicians can be reimbursed for through Medicare. *Id.* For example, after the physician renders a service that falls under a HCPCS code, they can “bill” that HCPCS code to Medicare and be reimbursed the fee amount. This Note will refer to HCPCS codes as “billing codes.”

233. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. 70,886, 70,955 (Nov. 16, 2015).

234. *Id.*

235. Kliff, *2015 Is the Year*, *supra* note 118.

236. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,955.

237. Kliff, *2015 Is the Year*, *supra* note 118.

238. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,955.

239. 42 C.F.R. § 410.15 (2016).

240. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,958.

241. *Id.* at 70,955.

242. *Id.* at 70,956.

243. *Id.*; Pam Belluck, *Medicare Plans to Pay Doctors for Counseling on End of Life*,

conversations if they have never thought about their end-of-life wishes.²⁴⁴

The second billing code, 99498, which allows for reimbursement for “each additional 30 minute” counseling session, does not limit the number of conversations that practitioners can be reimbursed for.²⁴⁵ Some were afraid that not setting limits on the service would lead to overutilization and practitioners harassing patients.²⁴⁶ This can be prevented because the services are voluntary and patients can decline to receive them.²⁴⁷ The CMS also “plan[s] to monitor utilization of the new [services] over time to ensure that they are used appropriately.”²⁴⁸

Another concern was “the potential for bias against choosing treatment options . . . requiring physicians to discuss questionable treatment options (such as physician assisted suicide or other patient choices that might violate individual physician ethics).”²⁴⁹ But again, the CMS reassures that this can be prevented because the services are voluntary and the patient can decline to receive them.²⁵⁰ It also notes patients can seek “independent counseling from other individuals outside the Medicare program.”²⁵¹

Physicians and “other qualified health professionals” are allowed to be reimbursed for advance care planning services.²⁵² While some argued other qualified health professionals should include social workers, clinical psychologists, registered nurses, and chaplains, the CMS has interpreted it to only include non-physician practitioners²⁵³ such as nurse practitioners and physician assistants.²⁵⁴

A few critics argued the advance care planning services should be

N.Y. TIMES (July 8, 2015), http://www.nytimes.com/2015/07/09/health/medicare-proposes-paying-doctors-for-end-of-life-counseling.html?partner=rss&emc=rss&_r=2.

244. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,955; Belluck, *supra* note 243.

245. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,955; *see* Belluck, *supra* note 243.

246. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,956.

247. *Id.*

248. *Id.*

249. *Id.* at 70,959.

250. *Id.*

251. *Id.*

252. *Id.* at 70,955.

253. *Id.* at 70,957.

254. Belluck, *supra* note 243.

limited to certain specialists.²⁵⁵ The CMS did not agree and stated that services “are not limited to particular physician specialties.”²⁵⁶ They also disagreed that standards and special training should be required before practitioners could be reimbursed for such services.²⁵⁷ The CMS does not believe it would be appropriate at this time because they do not require additional payment standards for similar services such as chronic care management.²⁵⁸

Some argued the advance care planning services should be limited as to the settings of care such as ambulatory and inpatient settings.²⁵⁹ The CMS believes the “services are appropriately furnished in a variety of settings” and even available in non-facility settings.²⁶⁰

One of the biggest criticisms of the new regulation is that the CMS declined to issue a national coverage decision, which may result in variation of local coverage.²⁶¹ However, the CMS wants to “allow time for implementation and experience with [advance care planning] services . . . prior to considering a controlling national coverage policy.”²⁶² It reassures patients can still receive these services as an optional element of their annual wellness visit.²⁶³

VII. PROPOSALS

Lastly, this Note addresses what the Author considers to be the biggest criticisms of the new regulation and what changes can be made to make advance care planning better.

A. National Coverage

As stated above, the CMS has declined to issue a national coverage

255. See Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,957.

256. *Id.* at 70,958.

257. *Id.*

258. See *id.*

259. *Id.* at 70,957.

260. *Id.* at 70,958.

261. See *id.* at 70,956. “In the absence of a national coverage policy, an item or service may be covered at the discretion of the Medicare contractors based on a local coverage determination” *Medicare Coverage Determination Process*, CMS.GOV, <https://www.cms.gov/Medicare/Coverage/DeterminationProcess/index.html> (last modified Apr. 8, 2015).

262. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,956.

263. *Id.*

determination.²⁶⁴ This means that each Medicare contractor will decide whether or not to reimburse for advance care planning services.²⁶⁵ After the CMS has evidence that the new billing codes are working effectively, it should issue a national coverage determination. Without this, patients will be forced to forum-shop. This will lead to a flood of patients in areas that are reimbursing for the service, and the patients will become a burden on those hospitals and medical staff.

B. Education and Training

As the comments to the CMS's new regulation point out, many are skeptical about whether physicians are equipped to have end-of-life conversations with patients.²⁶⁶ People are skeptical because physicians lack knowledge in hospice and palliative care. While the medical field has seen knowledge gains in these areas, the gains do not seem to translate to those physicians who care for patients at the end of life.²⁶⁷ There are specialists in hospice and palliative care, but the number is small.²⁶⁸ This leads primary care and other specialty physicians to fill the gap even though they are not proficient in hospice and palliative care.²⁶⁹

The cause of these deficiencies is educational obstructs.²⁷⁰ The main obstruct is that hospice and palliative care are not a part of the required curriculum in medical school.²⁷¹ Another obstruct is the way physicians are

264. *Id.*

265. *Medicare Coverage Determination Process*, *supra* note 261. This is done by a local coverage determination, which is “a determination by a fiscal intermediary or a carrier under part A or part B, as applicable, respecting whether or not a particular item or service is covered on an intermediary- or carrier-wide basis.” *Local Coverage Determinations*, CMS.GOV, <https://www.cms.gov/Medicare/Coverage/DeterminationProcess/LCDs.html> (last modified Nov. 2, 2015).

266. Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. at 70,958; Kliff, *2015 Is the Year*, *supra* note 118.

267. See COMM. ON APPROACHING DEATH, INST. OF MED., NAT'L ACADS. OF SCI., *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* 13 (2015) [hereinafter *DYING IN AMERICA*], <https://www.nap.edu/catalog/18748/dying-in-america-improving-quality-and-honoring-individual-preferences-near> (click “Download Free PDF” icon; log in, create a free account, or select “Download as Guest” icon; follow “Download PDF (Full Book)” hyperlink).

268. *Id.*

269. See *id.* at 13, 20.

270. See *id.* at 13.

271. *Id.*

taught, in “education silos.”²⁷² Medical schools tend to educate their students in isolation from—or even in competition with—each other, which is contrary to the team-based approach of hospice and palliative care.²⁷³ Lastly, there is not enough emphasis on learning good communication skills with patients at the end of life. While studies show that physicians can be taught these skills, “few medical educators teach [them].”²⁷⁴

To curtail these deficiencies, all physicians caring for people at the end of life should be competent in hospice and palliative care.²⁷⁵ This would require medical schools to provide training in hospice and palliative care.²⁷⁶ Also, accrediting organizations and certifying bodies should require education and experience in hospice and palliative care.²⁷⁷

C. Expand Scope for Reimbursement

Under the new regulation, “other qualified health professionals” who are also eligible for reimbursement for advance care planning discussions are strictly defined as physician assistants and nurse practitioners.²⁷⁸ The CMS should expand this definition of “other qualified health professionals” to include nurses, social workers, chaplains, pharmacists, and rehabilitative therapists.²⁷⁹ “[T]he fields of nursing, social work, and chaplaincy all have established specialty certifications programs in hospice and palliative care”²⁸⁰ This could help fill the gap of physicians who lack proficiency in those areas. Pharmacists and rehabilitative therapists do not have comparable certification programs, but both play important roles in palliative care.²⁸¹

VIII. CONCLUSION

State and federal governments are realizing the importance of advance

272. *Id.*

273. *See id.*

274. *Id.*

275. *Id.* at 14.

276. *See id.*

277. *Id.*

278. *See* Medicare Program; Revisions to Payment Policies, 80 Fed. Reg. 70,886, 70,957 (Nov. 16, 2015).

279. DYING IN AMERICA, *supra* note 267, at 14.

280. *Id.*

281. *See id.*

care planning and the many benefits the service creates.²⁸² A few states were proactive in creating statutes that give the patient a right to be informed of end-of-life options.²⁸³ Eventually, the federal government realized that end-of-life conversations were not going to happen unless doctors were reimbursed for their time, so the CMS created billing codes to reimburse physicians for this service.²⁸⁴

These state and federal initiatives are good first steps on the road to informed consent at the end of life, but there can be improvements. First, the CMS should issue a national coverage determination so there is no variation in coverage of this service from one state to another.²⁸⁵ Next, medical schools need to include hospice and palliative care instruction in the curriculum.²⁸⁶ Lastly, the CMS should expand the scope of qualified health professionals who are able to be reimbursed for these services to include nurses, social workers, chaplains, pharmacists, and rehabilitative therapists.²⁸⁷

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282. *See supra* Parts V, VI.

283. *See supra* Part V.

284. *See supra* Part VI.

285. *See supra* Part VII.A.

286. *See supra* Part VII.B.

287. *See supra* Part VII.C.

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