

**PAYING DOCS FOR END-OF-LIFE DISCUSSIONS: CAN  
MONETARY INCENTIVES CHANGE THE FAILURES INHERENT  
WITH PHYSICIAN-PATIENT COMMUNICATION?**

I. INTRODUCTION

Unfortunately, [my father] had another stroke—this one even more debilitating. Once again, we were steered toward treatment as the only logical and responsible option. We were skeptical, so at every turn we gave doctors my father’s DNR and reminded them that he wanted no extraordinary measures or aggressive treatment of any kind. The next thing we knew, Dad had a feeding tube. He would never walk, talk or eat by mouth again. He was moved to the first of three nursing homes, where he died over a year later. I wish that doctors and nurses had been honest from the start and had given us a realistic prognosis, taking into consideration what his quality of life would almost certainly be after the surgeries. *I also wish that they had honored his wishes, which he had explicitly stated in official documents prepared years earlier with his attorney.*<sup>1</sup>

The physician-patient relationship is one centered on trust and collaboration, yet one major aspect of these relationships is consistently underappreciated—communication. The conversations between a patient and his or her physician are vital to ensuring that care plans are understood and mutual goals are honored. Although this may seem intuitive to fostering a strong relationship, effective communication is a component that is continuously neglected during the medical experience. Moreover, such communication is often non-existent when set in the context of end-of-life planning. In fact, over the last twenty years there have been various findings illustrating a systemic failure amongst physicians to have conversations about end-of-life care options, and further, a failure to honor patients’ previously designated wishes.<sup>2</sup>

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1. Pippa Hamman Comfort, *Tell Everyone You’re Good to Go*, COMPASSION & CHOICES, <https://www.compassionandchoices.org/voices-of-compassion/stories/tell-everyone-youre-good-to-go/> (last visited Oct. 8, 2015).

2. Alfred F. Connors et al., *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients: The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT)*, 274 [J]AMA 1591, 1595 (1995); *see also* Vyjeyanthi S. Periyakoil et al., *Do Unto Others: Doctors’ Personal End-of-Life Resuscitation Preferences and Their Attitudes Towards Advance Directives* PLOS ONE, May 2014, 1, 8, <http://www.plosone.org/article/fetchObject.action?uri=info:doi/10.1371/journal.pone.0098246&representation=PDF>; *cf.* Christopher Burkle et al., *Physician Perspectives and Compliance With Patient Advance*

The concerns surrounding planning for end-of-life care, although centered on subjective decisions, rise to more than just an individual issue. Because of the aggregate negative effects, the Centers for Disease Control and Prevention (CDC) classified the lack of advance care planning as a public health issue in 2012.<sup>3</sup> Not only do such decisions have the ability to prevent unnecessary suffering and improve quality of care, but planning can also lead to cost-effective care for the millions of individuals who die each year.<sup>4</sup> Furthermore, end-of-life planning completed before dire circumstances exist will both reinforce patient autonomy and dignity, and aid surrogates and family members in making valuable decisions. The current state of advance care planning is one that has remained somewhat stagnant over the past couple of decades, but recent shifts in cultural views have begun to influence further discussion on the subject.<sup>5</sup>

End-of-life planning in the United States is a topic plagued with great controversy and copious limitations.<sup>6</sup> Between drastic variance in state law, medical culture, and education, and personal preferences of both doctors and patients, this intersection of law and medicine is fraught with countervailing interests and beliefs. Many policymakers, such as the American Medical Association (AMA) and Congress, believe that incentivizing physicians through compensation reform will help to improve the quality of advance care planning by increasing the frequency of these physician-fostered conversations.<sup>7</sup> This paper dissects a recent proposal from the AMA<sup>8</sup> and a Final Rule from the Centers for Medicare and Medicaid Services (CMS) to reimburse physicians for these discussions by analyzing the factors impacting the likelihood and degree of success.

Part II of this paper examines the controversial history of this policy, as well as the most recent movements toward improvement, including the proposal from the AMA and final rule from CMS to deliver a one-sided solution to enhance this area of care. Part III discusses the best practices within

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*Directives: The Role External Factors Play on Physician Decision Making*, BMC MED. ETHICS, 2012, 1, 5, <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3528447/pdf/1472-6939-13-31.pdf>.

3. DEP'T HEALTH & HUMAN SERVS., CTRS. FOR DISEASE CONTROL & PREVENTION, ADVANCE CARE PLANNING: ENSURING YOUR WISHES ARE KNOWN AND HONORED IF YOU ARE UNABLE TO SPEAK FOR YOURSELF 5-6 (2012), <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf> [hereinafter CDC].

4. *Id.*

5. Pam Belluck, *Coverage for End-of-Life Talks Gaining Ground*, N.Y. TIMES (Aug. 30, 2014), <http://www.nytimes.com/2014/08/31/health/end-of-life-talks-may-finally-overcome-politics.html>.

6. *Id.*

7. *Id.*

8. *The Medicare Physician Payment Schedule*, AM. MED. ASS'N, <http://www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/medicare/the-medicare-physician-payment-schedule.page?> (last visited Oct. 8, 2015).

the medical field to both advance effective communication and to promote quality end-of-life care. Part IV examines how the proposed transformations fail to ultimately change physician and patient behavior sufficiently to sustain a considerable difference in end-of-life care. Finally, it concludes by suggesting other means for improving advance care planning in a comprehensive and meaningful way, such as the inclusion of other clinicians and professionals within the reimbursement scheme; the creation of a more centralized national structure for advance care planning; and improved medical education.

## II. HISTORY OF END-OF-LIFE DISCUSSIONS: THEN AND NOW

### A. *Prior Efforts Denied*

The ongoing movement towards improving end-of-life decision-making has been continuously attacked and stigmatized as morbid or distressing.<sup>9</sup> This is easily illustrated by the attitude surrounding the House of Representatives' version of the Affordable Care Act (ACA), America's Affordable Health Choices Act of 2009.<sup>10</sup> This bill included a dedicated provision, section 1233, which would have required physicians to conduct advance care planning consultations with Medicare beneficiaries.<sup>11</sup> Consultation in this context refers to a discussion encompassing various end-of-life topics, including an explanation of the patient's legal options, a list of state-provided resources, information on palliative care and hospice, and an explanation of life-sustaining treatment.<sup>12</sup> This section of the bill was quickly targeted as one of the pivotal downfalls of the proposed health reform and negatively touted for supporting "death panels."<sup>13</sup> In fact, then-House Minority Leader John Boehner criticized the section as being "a treacherous path toward government-encouraged euthanasia if enacted into law."<sup>14</sup> As a result of the controversy, the section on advance care planning was removed from the bill entirely and, therefore, absent from the ACA.<sup>15</sup>

As a second effort, the Obama Administration intended to enact the substantive changes proposed in section 1233 through the rulemaking process, where a proposed rule sought to reimburse physician discussions about end-of-

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9. See generally Angie Drobnic Holan, *Politifact's Lie of the Year: 'Death Panels'*, TAMPA BAY TIMES (Dec. 18, 2009), <http://www.politifact.com/truth-o-meter/article/2009/dec/18/politifact-lie-year-death-panels/>.

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

11. *Id.*

12. *Id.*

13. Holan, *supra* note 9.

14. Emily P. Walker, *Medicare to Cover End-of-Life Planning*, MEDPAGE TODAY (Dec. 27, 2010), <http://www.medpagetoday.com/PublicHealthPolicy/Medicare/24078>.

15. *Id.*

life treatment options.<sup>16</sup> Medicare patients who opted to receive such services would take part in counseling during their annual wellness visits.<sup>17</sup> Providers would then record these visits as “voluntary advance care planning” sessions.<sup>18</sup> Eventually, however, the administration forced CMS to withdraw the voluntary planning session from the finalized rule due to political pressure.<sup>19</sup> The concept of government-funded advance care planning still carried with it a societal stigma that prohibited any form of federal intervention.

### B. A Recent Push Towards Change

Since then, however, the idea of incentivizing physicians to advise patients on end-of-life matters has gained significant political support.<sup>20</sup> An increase in studies on the value of communication, palliative care, and the use of advance directives has influenced a shift towards better health care planning. One recent study, conducted by the American College of Physicians, reviewed evidence about advance care planning—focusing on the communications between patients with serious and life-threatening illnesses and their internal medicine and primary care doctors.<sup>21</sup> The study compared methods, barriers, and risks of communication to develop best practices for engaging physicians in advance care planning.<sup>22</sup> The study stated that “absent, delayed, or inadequate communication about end-of-life preferences is associated with poor quality of life and anxiety, family distress, prolongation of the dying process, undesired hospitalizations, patient mistrust of the health care system, physician burnout, and high costs.”<sup>23</sup> The survey emphasizes the difficulty in measuring cost-savings related to these communications, but relied upon other reports in supporting the practices offered.<sup>24</sup> One such report compared health care expenses across various settings and found that costs were approximately thirty-six percent less for those patients who had engaged in end-of-life

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16. Belluck, *supra* note 5.

17. *Id.*

18. 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) [hereinafter Medicare Program]; see also Walker, *supra* note 14.

19. Medicare Program, *supra* note 18, at 1366.

20. Walker, *supra* note 14.

21. Rachelle E. Bernacki et al., *Communication about Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174 [J]AMA INTERN. MED. 1994, 1994 (2014).

22. *Id.* at 1995.

23. *Id.* at 1998.

24. *Id.* at 1999.

discussions, realizing a cost savings of approximately \$1,041 per patient in his or her final week of life.<sup>25</sup>

Another report, focusing instead on the value of palliative care<sup>26</sup> consultations, highlights the benefits of utilizing this approach for delivery of end-of-life care. This particular study analyzed administrative data from eight different hospitals over two years.<sup>27</sup> It compared the quality and costs of delivering care to both patients receiving some form of palliative care and to those who did not.<sup>28</sup> The study ultimately found that the patients who received palliative care realized a higher cost-savings than those who did not.<sup>29</sup> The patients who opted to receive palliative care attained an adjusted net savings of about \$2,642 in direct costs per admission and \$279 in direct costs per day.<sup>30</sup> The savings were even greater for terminally ill individuals who died before the study concluded, showing a total savings of approximately \$4,908 in direct costs per admission and \$374 in direct costs per day.<sup>31</sup> Perhaps as a result of these studies, which emphasize the importance of early and ongoing communication about end-of-life options and palliative care, private insurers have begun reimbursing physicians for such conversations.<sup>32</sup>

Third party insurers ordinarily follow Medicare's reimbursement policies, but in this instance, they have been willing to create their own payment methodologies for advance care planning services because they see a financial benefit in having such discussions.<sup>33</sup> Some commercial insurers are going so far as to hire external social workers to cold-call specific enrollees who have chronic or terminal conditions to begin the early phases of these conversations.<sup>34</sup> Although it is extremely unorthodox, the goal is for the counselors to build a personal relationship with enrollees and have discussions that most physicians are currently failing to have with their patients.<sup>35</sup> The fact that insurers are willing to commit resources and create separate

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25. *Id.* (citing Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations With End-of-Life Conversations*, 169 ARCH INTERN. MED. 480, 482 (2009), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2862687/pdf/nihms191650.pdf>).

26. See CDC, *supra* note 3, at 7. Palliative care is used to "provide[] pain relief and comfort care to anyone who is seriously ill regardless of prognosis." *Id.*

27. R. Sean Morrison et al., *Cost Savings Associated With US Hospital Palliative Care Consultation Programs*, 168 ARCH INTERN. MED., 1783, 1783 (2008) (published in [J]AMA).

28. *Id.* at 1783-85.

29. *Id.* at 1785.

30. *Id.*

31. *Id.*

32. Belluck, *supra* note 5.

33. *Id.*

34. Elana Gordon, *A Hotline for End-of-Life Care*, THE ATLANTIC (Aug. 27, 2014, 1:45 PM), <http://www.theatlantic.com/health/archive/2014/08/a-hotline-for-end-of-life-care/379212/>.

35. *Id.*

reimbursement codes illustrates the value insurers place on having these conversations with patients.

Health care payors are not the only stakeholders looking to improve this area of health care, as momentum builds among the general public and even Congress. One poll conducted in 2011 illustrated that seventy-one percent of Americans “believe it is more important to enhance the quality of life for seriously ill patients, even if it means a shorter life, than to extend the life of seriously ill patients through every medical intervention possible.”<sup>36</sup> This same study uncovered that a strong majority of Americans believe there should be more public policies addressing this issue, with most believing Medicare should cover the discussions surrounding end-of-life options.<sup>37</sup> Moreover, statistics gathered by an active right to die organization, Compassion & Choices, show that a majority of Americans fifty years and older would support withholding payment to providers for failure to conduct these counseling sessions.<sup>38</sup> Finally, twenty-five percent of individuals surveyed admitted they had personally received some form of unwanted medical care.<sup>39</sup>

As public views begin to change, legislators and policymakers are prompted to adapt to satisfy their constituents. There is currently great diversity amongst the states on end-of-life care and decision-making tools.<sup>40</sup> Some states, such as California, have implemented statewide requirements for the use of Physician Orders for Life Sustaining Treatment (POLST),<sup>41</sup> while other states have done little to aid in the planning process.<sup>42</sup> The most recent push towards bettering end-of-life care comes from Massachusetts, where the state health department is now requiring providers to offer end-of-life counseling to terminally ill patients.<sup>43</sup> This rule differs from the AMA

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36. See CDC, *supra* note 3, at 5 (referencing a 2011 Regence Poll).

37. *Id.*

38. Thaddeus Pope, *Stop Unwanted Medical Treatment*, MEDICAL FUTILITY BLOG (Nov. 24, 2014, 7:18 AM), <http://medicalfutility.blogspot.com>.

39. *Id.*

40. *Programs in Your State*, POLST, <http://www.polst.org/programs-in-your-state/> (last visited Feb. 17, 2015) (select state of interest to obtain link to state website information.).

41. Takehior Sugiyama et al., *Implementing Physician Orders for Life-Sustaining Treatment in California Hospitals: Factors Associated with Adoption*, 61 J. AM. GERIATRICS SOC. 1337, 1337-38 (2013).

42. *About the National POLST Paradigm*, POLST, <http://www.polst.org/about-the-national-polst-paradigm/> (last visited Feb. 17, 2015). Physician Orders for Life Sustaining Treatment (POLST) forms are used to turn patients' wishes on future treatment and care into actionable medical orders to eliminate medical errors. *Id.* These forms are designed to be transferred across care settings from hospital providers to emergency care providers. *Id.* They are historically used for patients who are expected to have a life expectancy of one year or less. *Id.*

43. *Doctors In Massachusetts Now Required to Offer End-of-Life-Counseling*, NAT'L PUB. RADIO (Dec. 19, 2014), <http://wnpr.org/post/doctors-massachusetts-now-required-offer-end-life->

proposal, as it mandates various providers, including physicians, hospitals, and nursing homes to initiate and conduct these conversations, so long as the patient has no objection.<sup>44</sup> The agency, although not currently focused on enforcement efforts, will eventually consider compliance with this regulation during licensure review.<sup>45</sup> Advocates believe that these efforts will help to standardize the end-of-life planning process to better equip patients for future decisions.<sup>46</sup>

These efforts can also be found through three separate federal bills, two in the Senate and one in the House, which have been introduced in the prior two years to help provide a statutory authority for health care reimbursement and increase funding to foster advance planning discussions.<sup>47</sup> Senate Bill 1439, entitled the “Care Planning Act of 2013,” is similar to recent proposals, centering the issue of reimbursement on physicians and their role in the process.<sup>48</sup> The other Senate proposal, Senate Bill 2240, shifts the focus to Medicare beneficiaries.<sup>49</sup> The bill aims to encourage the use of advance directives through the coordination of certified organizations, the voluntary registration of advance directives within a national clearinghouse, and through delivery of a one-time incentive payment for beneficiaries to create and register their advance directives.<sup>50</sup> The final action initiated in Congress is the House Resolution entitled “Personalize Your Care Act of 2013,” which would direct the Secretary of Health and Human Services (HHS) to make grants available to entities to establish statewide programs for POLST and to adopt standards for electronic health records to adequately incorporate all levels of a patient’s wishes into practice.<sup>51</sup> Although the three bills did not pass before the end of the 2014 legislative session, they may serve as a future foundation for improved practices.<sup>52</sup> The enhanced support from private payors and

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counseling. Terminally ill patients are ones who are considered to be in the last six months of their lives. *Id.*

44. *Id.*

45. *Id.*

46. *Id.*

47. *See generally* S. 1439, 113th Cong. (2013); S. 2240, 113th Cong. (2013); H.R. 1173, 113th Cong. (2013).

48. *See generally* S. 1439, 113th Cong. (2013).

49. *See generally* S. 2240, 113th Cong. (2013).

50. Tim Mullaney, *Government Would Pay Seniors to Create Advanced Directives Under Senate Bill*, MCKNIGHT’S (April 16, 2014), <http://www.mcknights.com/government-would-pay-seniors-to-create-advanced-directives-undersenate-bill/article/342803/>.

51. *See generally* H.R. 1173, 113th Cong. (2013).

52. The proposed legislations mentioned are not the first attempts at federalizing advance care planning, but are recent efforts from Congress since the 2009 movement lost momentum in the post-death panel fiasco. *See* Peter Ubel, *Why It Is So Difficult to Kill the Death Panel Myth*, FORBES (Jan. 9, 2013), <http://www.forbes.com/sites/peterubel/2013/01/09/why-it-is-so-difficult-to-kill-the-death-panel-myth/#6f42fa2f7062>.

government officials has fostered further conversation, leading to the most hopeful policy proposal to-date.

### C. *The Proposals Become Rule*

The proposal garnering the greatest support and attention came from neither the government nor private insurers, but rather from the AMA's publication of reimbursement codes for advance care planning in 2014.<sup>53</sup> The AMA proposes new physician-billing codes to CMS in the Medicare Physician Fee Schedule (MPFS).<sup>54</sup> The MPFS is made up of various codes from the Healthcare Common Procedure Coding System (HCPCS), including Level I codes known as Current Procedural Technology (CPT) codes.<sup>55</sup> These code sets are maintained and published on an annual basis by the AMA.<sup>56</sup> During the comment period for the 2015 MPFS rulemaking, the AMA submitted proposed codes for advance care planning.<sup>57</sup> The proposal included two codes: one encompassing thirty minutes of physician face-to-face time with patients, family members, and/or surrogate decision-makers to explain advance directives; and a second thirty-minute "add on" code for any additional time needed for the consultation.<sup>58</sup>

These codes are centered on encouraging primary care and internal medicine physicians to take a more active role during the annual wellness visit. In fact, Congressman Earl Blumenauer, along with thirty-three other members of Congress, wrote to CMS encouraging them to incorporate the proposed codes into the Medicare reimbursement scheme.<sup>59</sup> The letter specifically stated that the signatories "find it troubling that Medicare reimburses almost every medical procedure, yet places no value on the time doctors take to provide thoughtful counsel to prepare patients and families for the delicate, complex and emotionally demanding decisions surrounding the end-of-life."<sup>60</sup>

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53. Lara C. Pullen, *New End-of-Life Discussions Codes A Step Towards Reimbursement?* MEDSCAPE MED. NEWS (Sept. 19, 2014), <http://www.medscape.com/viewarticle/832017>.

54. *The Medicare Physician Payment Schedule*, *supra* note 8.

55. *HCPCS Coding Questions*, CMS.GOV, [http://www.cms.gov/Medicare/Coding/MedHCP\\_CSGenInfo/HCPCS\\_Coding\\_Questions.html](http://www.cms.gov/Medicare/Coding/MedHCP_CSGenInfo/HCPCS_Coding_Questions.html) (last updated June 22, 2013).

56. *HCPCS – General Information*, CMS.GOV, [http://www.cms.gov/Medicare/Coding/MedHCP\\_CSGenInfo/index.html?redirect=/MEDHCP\\_CSGenInfo/](http://www.cms.gov/Medicare/Coding/MedHCP_CSGenInfo/index.html?redirect=/MEDHCP_CSGenInfo/) (last updated June 26, 2015).

57. *See* Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule, Clinical Laboratory Fee Schedule, Access to Identifiable Data for the Center for Medicare and Medicaid Innovation Models & Other Revisions to Part B for CY 2015, 79 Fed. Reg. 67,547, 67,671-72 (Nov. 13, 2014) (to be codified at 42 C.F.R. pts. 403, 405, 410, 411, 412, 413, 414, 425, 489, 495, 498) [hereinafter CMS MPFS].

58. Pullen, *supra* note 53.

59. *See generally* Letter from Earl Blumenauer et al. to Marilyn Tavenner (Sept. 24, 2014), <http://www.blumenauer.house.gov/images/pdf/Blumenauer-Letter-to-CMS.pdf>.

60. *Id.* at 1.

On October 30, 2015, after a full year of review and debate, CMS issued the final physician payment rule for 2016, including the proposed codes created by the AMA in the reimbursement scheme.<sup>61</sup> The publication of this final rule illustrates a common intersection amongst multiple stakeholders who agree that having these conversations is vital to managing health care costs and improving quality of life. Nevertheless, the central issue surrounding this conclusion is whether or not incentivizing physicians alone will have the intended effect of fostering advance care planning, or whether it will fail to create substantial positive change.

### III. BEST PRACTICES FOR EFFECTIVE COMMUNICATION AT THE END-OF-LIFE

In order to assess whether the recommendation to reimburse physicians to improve end-of-life planning will be successful, it is crucial to understand what constitutes an exemplary advance care planning program. Promoting end-of-life counseling is a complex process that requires a positive preexisting relationship between a physician and a patient, as individuals often view this subject as personal and anxiety-ridden.<sup>62</sup> The Institute of Medicine (IOM) highlights specific elements of communication needed to cultivate a strong physician-patient relationship.<sup>63</sup> These elements cover diverse features of trust, including “discussing prognosis, handling emotional encounters, nurturing patients’ hopes, and addressing spirituality and religion.”<sup>64</sup> The IOM extends from these basic elements their ideal aspects of a successful end-of-life plan. The fundamental facet of the model plan revolves around patient-centered care and decision-making, allowing the patient to feel as though he or she has shared autonomy in driving the health care process.<sup>65</sup> This focus is illustrated in the IOM’s recommendations to the health care team, including actions such as: actively listening to the patient, speaking in terms that are meaningful to the patients’ daily lives, fully explaining the outcomes of treatment, and dedicating substantial time to an advance care planning counseling session.<sup>66</sup>

To promote a standardized process for advance care planning, the IOM has also issued best practices for physicians to incorporate into their end-of-life

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61. Press Release, Ctrs. for Medicare & Medicaid Servs., Proposed policy, payment, and quality provisions changes to the Medicare Physician Fee Schedule for Calendar Year 2016 (Oct. 30, 2015), <https://www.cms.gov/Newsroom/MediaReleaseDatabase/Fact-sheets/2015-Fact-sheets-items/2015-10-30-2.html>; CMS MPFS, *supra* note 57, at 67,671-72.

62. *See generally* INST. OF MED, DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE (2015) [hereinafter IOM].

63. *See id.* at 117.

64. *Id.* at 160.

65. *Id.* at 83, 166.

66. *Id.* at 158-59.

counseling.<sup>67</sup> These best practices recommend early initiation in the physician-patient relationship, focusing specifically on the continuity of communications.<sup>68</sup> When conducting the initial conversation about future wishes, it is vital that the physician document the content of the discussion including agents involved in the process, goals of care, treatment options, and setting of care.<sup>69</sup> This documentation should then be translated and incorporated into actionable medical orders that can be transferred across various settings.<sup>70</sup> Alongside the physician's documentation from the counseling session should be documentation of the legal tools utilized for advance care planning, such as any existing advance directives or surrogacy decisions.<sup>71</sup> To be fully effective, these actions require that physicians and other health care providers have access to meaningful use electronic health records (EHR) or other Health Insurance Portability and Accountability Act (HIPAA) certified databases to integrate documentation into the course of care.<sup>72</sup> In addition to improving the individual relationship with the patient, the IOM advises physicians to develop health care and community health collaborations to promote the use and completion of advance care planning tools.<sup>73</sup> The final recommendation asks physicians to actively educate themselves on effective strategies for end-of-life planning through ethics training or participation on ethics committees.<sup>74</sup> If physicians utilize the aforementioned methods, it is hoped that advance care planning will become a staple in the health care continuum, aiming to address these topics during wellness visits and thereafter at the point of diagnosis.<sup>75</sup>

The Agency for Healthcare Research and Quality (AHRQ) issues a more simplistic framework for fostering effective advance care planning that relies on five basic steps: initiation, information, preparation, review and update, and finally application.<sup>76</sup> When initiating these conversations, the agency believes physicians should translate their medical knowledge into hypothetical situations to illustrate the types of scenarios a patient may face in order to

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67. See IOM, *supra* note 62, at 172, 185-91 (discussing best practices and suggesting conclusions and recommendations compiled from research).

68. *Id.* at 191.

69. *Id.* at 172.

70. *Id.*

71. *Id.*

72. See IOM, *supra* note 62, at 172.

73. *Id.* at 172-73.

74. *Id.* at 173.

75. See generally *id.* at 49-52.

76. Barbara L. Kass-Bartelmes & Ronda Hughes, Agency for Healthcare Research & Quality, *Advance Care Planning, Preferences for Care at the End of Life*, RESEARCH ACTION, Mar. 2003, at 1, 4-5, <http://archive.ahrq.gov/research/findings/factsheets/aging/endliferia/endria.pdf>.

familiarize the patient with his or her own preferences.<sup>77</sup> Once these preferences have been declared, the agency encourages physicians to offer information on advance directives and other legally binding instruments to develop the patient's intended plan of care, and to then help those patients fill out documents with specificity to mitigate confusion.<sup>78</sup> Once completed, the physician should remind their patients that these documents represent static preferences that can be changed at any time, and should periodically prompt the patient to reevaluate their plans.<sup>79</sup> Finally, the agency persuades physicians to uphold their end of the process by applying the instruments and incorporating patient preferences into practice.<sup>80</sup> This proposed method of advance care planning relies solely upon the physician to initiate appropriate documentation and to assure patients understand the value of such instruments.<sup>81</sup>

One final consideration that has been recommended by a handful of scholars is for physicians to disclose the full costs of end-of-life options to their patients during advance care planning.<sup>82</sup> In doing so, the physician must incorporate health care costs into the medical conversation in a meaningful and comprehensive manner to aid patients in understanding.<sup>83</sup> Furthermore, physicians must strike a balance that allows them to divulge this information in a non-threatening manner to assist in patient education and engagement.<sup>84</sup> This method, however, may raise ethical issues, as it might unduly persuade patients to withhold necessary treatment and limit their overall access to health care.

It is important to recognize that these proposals to improve end-of-life care are not the first of their kind and have been reintroduced on various occasions throughout the past thirty years. For example, one major push from the federal government to better manage advance care planning was through the enactment of the Patient Self Determination Act of 1990.<sup>85</sup> This federal statute mandated Medicare and Medicaid providers to offer information about advance health care directives to individuals upon their admission into a facility or hospital.<sup>86</sup> The law, however, created certain gaps in the universal

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77. *Id.* at 4.

78. *Id.*

79. *Id.*

80. *Id.* at 5.

81. See Kass-Bartelmes & Hughes, *supra* note 76.

82. See Zhang, *supra* note 25, at 480-88; see also Greer Donley & Marion Danis, *Making the Case for Talking to Patients about the Costs of End-of- Life Care*, 39 J. L. MED. & ETHICS, 183, 183-193 (2011).

83. Donley & Danis, *supra* note 82, at 188.

84. *Id.* at 192.

85. Milos D. MilijkoVIC et al., *From Euthanasia Society to Physician Orders for Life Sustaining Treatment*, 19 CANCER 438, 439 (2013).

86. *Id.*

adoption of advance directives. First, the statute left the legality of advance directives up to the states to define and allowed providers to refuse to implement provisions of an advance directive based on conscientious objections.<sup>87</sup> Furthermore, the statute did not extend obligations to individual physicians, excluding arguably the most vital actor in the health care continuum.<sup>88</sup> As a result of the flawed legislation, only minor advances have been made toward universal adoption of advance directives. In fact, multiple studies show that a third or less of the adult population has completed an advance directive.<sup>89</sup>

It is clear that exemplary end-of-life planning is not simply described, organized, or implemented. Rather, the ideal method to having successful conversations on this topic centers on patients and their right to be engaged in the decision-making process. The question is: will the policy change incentivize physicians in a manner that promotes the best practices outlined above, or will it fall short of revolutionizing end-of-life care?

#### IV. WHY THE POLICY FALLS SHORT

Numerous stakeholders support the same fundamental approach to promoting end-of-life planning: incentivizing physicians to have conversations through increased reimbursement.<sup>90</sup> Nevertheless, it is worth asking whether the physician should be the primary and sole provider to engage in advance care planning conversations with patients. Physicians, of course, are the obvious solution as they are the drivers and experts in care and, presumably, have existing relationships with patients; but, it is unlikely that they will relinquish the appropriate amount of professional autonomy to actively employ the patient in the shared decision-making process. Shared decision-making is

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87. *Id.* The specified criteria for issuing a conscientious objection to an advance directive include: a clear and precise statement of limitations of not following; whether there are institution-wide conscience objections or individual-based objections; identify the state legal authority permitting the objection; and describe the range of medical conditions or procedures that may be affected by the objection. *Id.*

88. Nancy Aldrich, CTRS. FOR DISEASE CONTROL & PREVENTION, ADVANCE CARE PLANNING: ENSURING YOUR WISHES ARE KNOWN AND HONORED IF YOU ARE UNABLE TO SPEAK FOR YOURSELF 13 (2011), <http://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>.

89. See Jaya K. Rao et al., *Completion of Advance Directives Among U.S. Consumers*, 46 AM. J. PREVENTATIVE MED. 65, 65-70 (2014) (current and ongoing survey of adults in the U.S., showing just above twenty-six percent had an advance directive); see also Dan K. Morhaim & Keshia M. Pollack, *End-of-Life Care Issues: A Personal, Economic, Public Policy and Public Health Crisis*, 103 AM. J. PUB. HEALTH, e8 (2013), [http://www.medscape.com/viewarticle/805452\\_2](http://www.medscape.com/viewarticle/805452_2) (Maryland study showing that approximately one-third of the population had completed advance directive; applied to national demographics).

90. See Belluck, *supra* note 5; Gordon, *supra* note 34; CDC, *supra* note 3; see also S. 1439, 113th Cong. (2013); S. 2240, 113th Cong. (2013); H.R. 1173, 113th Cong. (2013).

an element of medical care that has received increased attention and garnered advocacy for improvement, especially in recent health reform initiatives.<sup>91</sup> Shared decision-making requires both the patient and the provider to be equally involved in the conversation where “[p]roviders help patients understand medical evidence . . . and patients help providers understand their needs, values, and preferences concerning these decisions.”<sup>92</sup>

By and large, the goal of shared decision-making is to ensure that the plan of care is specifically customized to fit each individual patient.<sup>93</sup> Unfortunately, complete collaborative involvement has not been entirely realized in the United States, where physicians often fail to seek guidance on patients’ preferences when deciding a course of medical action.<sup>94</sup> Ordinarily, alluring individuals with financial incentives would undoubtedly increase targeted behavior.<sup>95</sup> Nevertheless, solely incentivizing physicians presents distinct complications because of their professional status and expertise, and leaves out a multitude of other clinicians who may be well equipped to facilitate these discussions.<sup>96</sup> Furthermore, the culture of medicine, as a whole, acts as a primary factor inhibiting behavioral change in physicians specifically.<sup>97</sup> As will be demonstrated, there are numerous studies and pieces of literature that highlight the issues inherent in medical culture, limiting the likelihood of improved communication and shared decision-making between patient and physician.

#### A. *Communication Failures*

Meaningful communication is crucial to the design of the proposals aimed at improving quality end-of-life care and saving overall costs resulting from improper planning. Various studies show that communication with patients

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91. Dominick L. Frosch et al., *Authoritarian Physicians And Patients’ Fear of Being Labeled ‘Difficult’ Among Key Obstacles To Shared Decision Making*, 31 HEALTH AFF. 1030, 1030 (2012); see also NAT’L PRIORITIES P’SHIP, NATIONAL PRIORITIES AND GOALS: ALIGNING OUR EFFORTS TO TRANSFORM AMERICA’S HEALTHCARE 16 (2008). The National Quality Forum, along with other stakeholders, listed patient and family engagement as a top priority in 2009 for improving health quality, illustrating its failures in the U.S. health system. *Id.* at 8.

92. Mark W. Friedberg et al., *A Demonstration of Shared Decision Making in Primary Care Highlights Barriers to Adoption and Potential Remedies*, 32 HEALTH AFF. 268, 268 (2013).

93. *Id.*

94. See Brian J. Zikmund-Fisher et al., *Deficits and Variations in Patients’ Experience with Making 9 Common Medical Decisions: The Decisions Survey*, 30 MED. DECISION MAKING 85s (2010). This national survey examined patients’ preferences regarding their experience with medical decision-making, and found that providers solicited patient preferences during care consultations at inconsistent rates—the low scores ranking below forty percent of the time for colon cancer screenings. *Id.* at 89s.

95. See Belluck, *supra* note 5.

96. See *infra* part V (A).

97. See *infra* part IV (B).

may seem like a simplistic process in the field of medicine, but it is often fraught with many hindrances.<sup>98</sup> One study illustrates these barriers by evaluating in-person interviews between physicians and patients who were diagnosed with terminal cancer or end-stage congestive heart failure.<sup>99</sup> The study utilized a matched approach, where individuals (both patients and physicians) submitted responses to questions concerning previous conversations on end-of-life care.<sup>100</sup> Once answers were provided, they were compared to measure the overall concordance between patients' and physicians' answers regarding the discussion.<sup>101</sup> The study ultimately found a drastic variance between the reports of physicians versus those of their patients.<sup>102</sup> While there was a ninety-two percent agreement regarding patient diagnosis, other issues were not communicated as clearly.<sup>103</sup> For example, there was a mere fourteen percent concordance score for physicians' knowledge of patients' stated preferences on both pain management and on place of death.<sup>104</sup>

In short, although physicians and patients usually are of the same understanding about diagnosis, physicians rarely (only fourteen percent of the time) know their patients' preferences and wishes regarding more important treatment concerns such as pain management and place of death.<sup>105</sup> Furthermore, these findings did not vary greatly by the differences in physician characteristics, including gender, specialty, location, or even the duration of the physician-patient relationship.<sup>106</sup> The report supports the unfortunate reality that physician-patient communication surrounding end-of-life care is nearly universally poor or nonexistent, even with terminal patients.<sup>107</sup> This study illustrates that although conversations may be occurring within the physician-patient relationship, the discussions are not generating the meaningful exchange necessary to promote mutual understanding of the care process.

Similar findings of failed methods of communication exist between physicians and chronically ill patients who have not yet approached terminal status. One popular report studied the communication practices between physicians and patients with Chronic Obstructive Pulmonary Disease (COPD),

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98. See Susan Desharnais et al., *Lack of Concordance Between Physician and Patient: Reports on End-of-Life Care Discussions*, 10 J. PALLIATIVE MED. 728, 730 (2007).

99. *Id.* at 730.

100. *Id.* at 730-32.

101. *Id.* at 733.

102. *Id.* at 735-36.

103. Desharnais, *supra* note 98, at 736.

104. *Id.*

105. *Id.* at 736-38.

106. *Id.* at 738.

107. *Id.* at 737.

a chronic yet treatable ailment affecting the ability of patients to breathe.<sup>108</sup> The survey measured approximately 376 patients who completed a questionnaire aimed to review the content of communications about the end-of-life care from the patient perspectives.<sup>109</sup> Targeted topic areas addressing the content of communication included: a discussion of patient longevity, shared ideas about dying, the ability for patients to facilitate future communications, and patient clinical and religious preferences.<sup>110</sup> The questionnaires revealed that all measured end-of-life topics were under-addressed by physicians a majority of the time.<sup>111</sup> In fact, the survey found that clinicians discussed the four specific topics with less than a quarter of their patients.<sup>112</sup> Like the previous study, these findings exemplify the consistent shortcomings inherent in physician-patient discussions surrounding end-of-life care, whether for terminal patients approaching time of death or those planning at a distance.

Despite a widespread understanding that patient-physician communication is necessary for end-of-life planning, especially for chronic or terminally ill patients, many doctors are continuously failing to have these conversations.<sup>113</sup> Furthermore, even if a physician shares information with a patient about treatment options and possible plans of care, it does not necessarily assure that the patient understands the information given.<sup>114</sup> Overall, there is a multitude

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108. *Understanding COPD*, AM. LUNG ASS'N, <http://www.lung.org/lung-disease/copd/about-copd/understanding-copd.html> (last visited Oct. 9, 2015).

109. Lynne F. Reinke et al., *Patient-Clinician Communication about End-of-Life Care Topics: Is Anyone Talking to Patients with Chronic Obstructive Pulmonary Disease?* 14 J. PALLIATIVE MED. 923, 923 (2011).

110. *Id.* at 925-26.

111. *Id.*

112. *Id.* at 926.

113. *See Doctors reluctant to discuss end-of-life care with heart failure patients: American Heart Association Meeting Report Abstract 352*, AM. HEART ASS'N (June 4, 2014), <http://newsroom.heart.org/news/doctors-reluctant-to-discuss-end-of-life-care-with-heart-failure-patients?pre-view=e794>. This study surveyed fifty physicians and forty-five nurse practitioners or physician assistants at three Mayo Clinic locations and found that only twelve percent of the providers reported having routine yearly discussions about end of life care, despite a care recommendation to do so. *Id.* Furthermore, the study found four common barriers to initiating end-of-life discussions including: (1) a perception that patients were not ready to discuss the issue; (2) providers expressing discomfort with the topic; (3) worry for destroying a sense of hope; and (4) lack of time. *Id.*; *see also*, Jennifer Mack et al., *Associations Between End-of-Life Discussion Characteristics and Care Received Near Death: A Prospective Cohort Study*, 30 J. CLINICAL ONCOLOGY 4387, 4387 (2012). In a survey of 2,155 patients with metastatic lung or colorectal cancer, the study found that physicians initiated end-of-life conversations a median of thirty-three days before the patient's death. *Id.*

114. Katherine B. Ledden, Comment, *A Nudge in the Right Direction with a Stick the Size of CMS: Physician-Patient Communication at the End of Life*, 6 ST. LOUIS U. J. HEALTH L. & POL'Y 389, 402 (2013).

of complexities that inhibit meaningful communications in medicine, therefore contributing to shortfalls in advance care planning. The issues with physician communication do not indicate that physicians should be excluded from the process, but rather, should not be viewed as the single solution to improvement.

### B. *Cultural Inhibitions*

The inability of physicians to effectively communicate with their patients about end-of-life wishes is exacerbated by the lack of professional acceptance for advance care planning instruments.<sup>115</sup> A PlosOne study analyzed the attitudes of physicians in following advance directives and what personal characteristics led to their overall acceptance or denial of the forms.<sup>116</sup> The study compared a group of doctors before the enactment of the Patient Self Determination Act of 1990<sup>117</sup> and a group of doctors in 2013 to examine whether attitudes had changed.<sup>118</sup> Surprisingly, the study found that physicians, even those in the 2013 group, did not have widespread acceptance of advance directives.<sup>119</sup> As a result of this lack of acceptance, costly life-saving treatments were continually delivered despite the listed preferences of the patients.<sup>120</sup> Furthermore, approximately eighty-eight percent of physicians who participated in the study would choose to have “do-not-resuscitate” (DNR) status for themselves and would not want the same treatment that they often deliver.<sup>121</sup> This study illustrates a clear disconnect between physicians’ expectations of their roles and patients’ expectations of their rights. Many physicians, both primary care doctors and specialists, do not accept the functionality of advance directives and other end-of-life tools, and instead feel their role is to push forward and find a cure.<sup>122</sup>

The shortcomings associated with widespread acceptance of advance care planning techniques are not the fault of the physicians, but are attributed to the cultural reliance on healing, even in the most dire of circumstances.<sup>123</sup> Medicine in the United States has been centered on “sustaining life with medical discoveries and new technology, [rather] than on practicing realistic and just evaluation of a dying patient’s quality of life and working toward a

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115. Periyakoil, *supra* note 2, at 2.

116. *Id.*

117. *See* Milijkovic, *supra* note 85, at 439.

118. Periyakoil, *supra* note 2, at 2.

119. *Id.* at 5.

120. *Id.* at 7.

121. *Id.* at 5.

122. *Id.* at 7.

123. Periyakoil, *supra* note 2, at 7-8.

dignified death with the least possible suffering.”<sup>124</sup> Giving hope to terminally ill patients is commendable and appropriate because it eases anxieties that develop in a patient near the end of life.<sup>125</sup> That being said, it is common practice within the medical field to encourage terminal patients to continue to fight and move forward with treatment, sparking a deeper hope that turns ultimately into belief.<sup>126</sup>

The general failure for patients to distinguish between research and treatment has been labeled as “therapeutic misconception,”<sup>127</sup> presenting distinctive issues with proper informed consent in clinical trials. One study measured the beliefs of cancer patients who were enrolled in early phase trials, and found that between fifty and eighty percent of individuals expected some sort of therapeutic benefit.<sup>128</sup> Participants of the study often reported that physicians or nurses told them to be hopeful, and believed that the purpose of the trial was to benefit them individually rather than test the treatment for broader use.<sup>129</sup> Although providing patients with hope is comforting and helps to ease patient fears, it may also lead to extreme cases of optimism where no positive outcome exists. This practice is reinforced by the entire culture of medicine, because there is a notion that a clinician must do everything within his or her power to heal. In sum, the common practice is as follows: “[the patient] agree[s] to become a patient . . . the clinician[] agree[s] to try to fix [the patient], whatever the improbability, the misery, the damage, or the cost.”<sup>130</sup> Anything less is to give up on a patient.

Moreover, although physicians are permitted to have conscientious objections to certain requests by patients, they are required as a term of their profession to “work within the professional consensus on the boundaries of medicine and the appropriate use of resources within medicine.”<sup>131</sup> That being said, there are unique limitations inherent in the physician-patient relationship,

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124. Susan Clabots, *Strategies to Help Initiate and Maintain the End-of-Life Discussion With Patients and Family Members*, 21 MEDSURG NURSING 197, 199 (2012) (citing D.K. Boyle et al., *Communication and End-of-Life Care in the Intensive Care Unit: Patient, Family, and Clinical Outcomes* 28 CRITICAL CARE NURSING Q. 302 (2005)).

125. *Id.* at 201.

126. *Id.* at 198.

127. Gail E. Henderson et al., *Clinical Trials and Medical Care: Defining the Therapeutic Misconception*, 4 PLOS MED. 1735, 1736 (2007), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2082641/pdf/pmed.0040324.pdf>.

128. Daniel P. Sulmasy et al., *The Culture of Faith and Hope: Patients' Justifications for Their High Estimations of Expected Therapeutic Benefit When Enrolling in Early Phase Oncology Trials*, 116 CANCER 3702, 3704-05 (2010).

129. *Id.* at 3705.

130. ATUL GAWANDE, *BEING MORTAL: ILLNESS, MEDICINE, AND WHAT MATTERS IN THE END* 224 (Metropolitan Books 2014).

131. Mary Ann Baily, *Futility, Autonomy, and Cost in End-of-Life Care*, 39 J. L., MED. & ETHICS 172, 174 (2011).

which ultimately encourage futile care practices. Futility within the medical field refers specifically to particular interventions that are unlikely to produce any significant benefit for the patient.<sup>132</sup> The increased value placed on patient preferences causes physicians to feel reluctant to discuss the practicality of medical care.<sup>133</sup> As a result, physicians often hesitate in their recommendation to limit futile services, as the patient may view such recommendations as an effort to ration care.<sup>134</sup> Therefore, providers have a perverse incentive to deliver excessive and inappropriate care to ensure they are protecting themselves from the negative consequences of a diminished patient relationship.<sup>135</sup> In fact, there is evidence from a 2013 survey that critical care clinicians believed approximately twenty percent of their patients received care that was either definitely or likely futile.<sup>136</sup> The issues concerning medical futility do not necessarily fall solely on physician behavior, but on the perspective and culture of Western medicine and society as a whole.

### C. Physicians' Locus of Control & Patient Obedience

There is also evidence that even when the physician involves the patient in the decision-making process, extensive barriers, such as perception of acceptable roles, inhibit comprehensive patient participation.<sup>137</sup> Evidence suggests that physicians will often direct their discussions to ensure the patient agrees with the proposed course of action.<sup>138</sup> For example, one study analyzed the dynamics of a real-time physician-patient encounter to understand how various factors including attitudes, preferences, and needs are balanced in the decision-making process.<sup>139</sup> The study ultimately found that most of the time spent during the encounters was dedicated to the treatment options rather than the diagnostic and prognostic information.<sup>140</sup> The study also broke down encounters by method of approach, finding eight different approaches used by

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132. Nancy S. Jecker, *Medical Futility*, ETHICS MED. U. WASH. SCH. MED., <https://depts.washington.edu/bioethx/topics/futil.html> (last visited Oct. 10, 2015).

133. See Baily, *supra* note 131.

134. Cf. Jecker, *supra* note 132.

135. See generally Baily, *supra* note 131.

136. Thanh N. Huynh et al., *The Frequency and Cost of Treatment Perceived to be Futile in Critical Care*, 173 [J]AMA INTERN. MED. 1887, 1889 (2013); see also Peter Whoriskey, 'Warehouse for the Dying': Are We Prolonging Life or Prolonging Death?, WASH. POST (Dec. 12, 2014), <http://www.washingtonpost.com/news/storyline/wp/2014/12/12/warehouses-for-the-dying-are-we-prolonging-life-or-prolonging-death/>.

137. Orit Karnieli-Miller & Zvi Eisikovits, *Physicians as Partner or Salesman? Shared Decision-Making in Real-Time Encounters*, 69 SOC. SCI. & MED. 1, 7 (2009).

138. *Id.*

139. *Id.* at 2.

140. *Id.* at 3.

physicians to *persuade* patients to agree with their treatment options.<sup>141</sup> Overall, the findings uncovered that although physicians involved their patients in the conversation, most decisions were made unilaterally with little participation from patients.<sup>142</sup> The ability of physicians to maintain overall control over the goals of care without actively seeking guidance on a patient's preferences hinders valuable care planning.<sup>143</sup>

Aside from the prominent role physicians play in steering health care decisions is the perception of patients about their roles in the health care continuum. Patients believe that part of their responsibility in the process is to "conform to socially sanctioned roles," where their ability to partake in decision-making relies solely on the doctor's indication that such participation is acceptable.<sup>144</sup> In fact, many patients are reluctant to be overly assertive or question a physician's plan of action because they fear they will be deemed a "difficult" patient.<sup>145</sup> Patients believe that such categorization may ultimately lead to resentment from the physician, which could negatively alter the relationship and the physician's willingness to continue the relationship.<sup>146</sup> The mere perception of patient roles, without more, may seem unfounded; however, there is evidence illustrating that some physicians and other health care clinicians consider a "good patient" to be someone who does what the physician advises with a "minimum of interference."<sup>147</sup> This mentality is extremely troublesome when placed in the context of end-of-life care, where mutual understanding of goals and preferences is absolutely essential. These perceptions illustrate a reluctance to overstep predefined boundaries of patient roles in the care process, and highlight the significance of physicians' acceptance of patient involvement.

Current medical culture continues to thrive as a paternalistic field, despite efforts towards a more collaborative direction.<sup>148</sup> This professional paternalism is demonstrated by physicians' repeated insistence that decision-making be driven by medical discretion, and is easily evidenced through a continuous

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141. *Id.* at 3-6. The eight listed approaches include: (1) dramatizing the evil; (2) deterring versus encouraging; (3) presenting treatment as an authorized "we" decision; (4) presenting an illusory power to decide; (5) avoidance of offering other treatment; (6) emphasizing benefits of treatment and consequences of noncompliance; (7) emphasizing ability to control side effects of treatment; and (8) presenting a gradual decision. *Id.*

142. Karnieli-Miller & Eisikovits, *supra* note 137, at 6.

143. *Id.*

144. See Frosch et al., *supra* note 91, at 1032.

145. *Id.*

146. *Id.*

147. Harvey Tettlebaum, *Quality Measurements, Payment and the Law: Disincentives to Physician-Patient Discussions of End-of-Life Care*, 6 J. HEALTH & LIFE SCI. L. 63, 68-69 (2013) (citing Dr. Summers).

148. Arthur L. Caplan & Barron H. Lerner, *Is There Still a Place for 'Paternalistic' Doctors?*, MEDSCAPE (Jul. 8, 2014), <http://www.medscape.com/viewarticle/827006>.

failure to appropriately involve the patient in the care planning process. Traditionally, physicians were taught that, because of their expertise and role as health care agents, certain decisions should be left entirely to them without the patient's knowledge.<sup>149</sup> This dynamic did not produce entirely negative results, as physicians often had a better understanding of what their patients wanted through the formation of stronger and more consistent relationships.<sup>150</sup>

Traditional paternalism has since dissipated with a rise in patient autonomy;<sup>151</sup> however, the existence of paternalistic practices is far from abandoned in the health care sector. Rather than making unilateral decisions for all medical situations, the practice of medicine has shifted towards a pattern of "selective paternalism" in instances where shared decision-making becomes burdensome or cannot be reached.<sup>152</sup> In fact, patients have cited "authoritarian physicians" as a limitation to increased involvement in the care planning process; finding that many physicians perpetuate the ideal that since they are of expert knowledge, they ultimately know what is best for the patient.<sup>153</sup>

The consequences of paternalism are also evident in end-of-life care, where the physician assumes he or she understands the optimum care path for the patient, even when directly conflicting with the patient's will.<sup>154</sup> One particular study found that almost sixty percent of physicians surveyed admitted they would likely ignore a listed preference to "pass away in peace" when patients were in an emergency situation and likely to be treated successfully.<sup>155</sup> Furthermore, more than half of the physicians surveyed believed that "physicians should be allowed to provide care independent of the advance directive as patients do not have the knowledge to best appreciate the idiosyncrasies involved with the practice of medicine."<sup>156</sup> The efforts of physicians to maintain overall control over the goals of care without actively seeking guidance on a patient's preferences limit the ability to facilitate effective planning and may ultimately lead to unwanted care. This problem illustrates a necessity to incorporate other clinicians in the planning scheme to help mitigate the negative implications of patients' and physicians' preconceived roles.

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149. *Id.*

150. *Id.*

151. *Id.*

152. See Brian C. Drolet & Candace L. White, *Selective Paternalism*, 14 AM. MED. ASS'N J. ETHICS 582, 583 (2012) (publication formerly known as Virtual Mentor).

153. See Frosch et al., *supra* note 91, at 1033.

154. Brian McKinstry, *Paternalism and the Doctor-Patient Relationship In General Practice*, 42 BRIT. J. GEN. PRAC. 340, 341 (1992).

155. See Burkle et al., *supra* note 2, at 3.

156. See Burkle et al., *supra* note 2, at 7.

*D. Payment Persuasion—Technology & Professional Expectation*

Aside from ineffective communication and the cultural lack of acceptance for advance care planning, physicians in modern medicine are persuaded by professional expectations and payments resulting from technological advances. There is currently substantial weight placed on technology in the field of medicine as being the principal and preferred method of care.<sup>157</sup> This shift in care has depreciated other important aspects of care including communication and counseling.<sup>158</sup> Collectively, “scientific advances have turned the processes of aging and dying into medical experiences, matters to be managed by health care professionals . . . . And [providers] in the medical world have proved alarmingly unprepared for it.”<sup>159</sup> Enhanced technology and expensive care has not only become an indicator of physician expertise and prestige, but has also been the key to realizing increased reimbursement rates.<sup>160</sup> Medicare and commercial payors currently pay more for higher technology and intensive services, while paying minimally for chronic disease management and in-home care.<sup>161</sup>

Even if some doctors choose to counsel their patients, they may still influence patients to act in specific ways as a result of higher payment for these intensive services.<sup>162</sup> In 2013, the National Commission on Physician Payment Reform published a report that highlighted the host of issues inherent in the physician fee schedule.<sup>163</sup> One recommendation the Commission offered to counterbalance the perverse incentive to deliver costly, high-intensive services is to increase the average reimbursement rate for evaluation and management (E&M) codes.<sup>164</sup> These codes are used predominantly by primary care physicians to bill for wellness visits, including preventive care and disease management consultations.<sup>165</sup> The final rule utilizes E&M codes to initiate payment; therefore, it is likely that the monetary value placed on this service will be minimal when compared with the costs of life-saving care.

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157. Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 ELDER L. J. 1, 3-4 (2013).

158. *Id.* at 4.

159. See GAWANDE, *supra* note 130, at 16.

160. NAT'L COMM'N ON PAYMENT REFORM, REPORT OF THE NATIONAL COMMISSION ON PHYSICIAN PAYMENT REFORM 7 (2013).

161. Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMEDICAL L. 27, 54 (2012).

162. *Id.* at 46 (explaining monetary incentives associated with providing chemotherapy treatment up to the final days of life, though the practice is an indicator of poor quality of care); see generally NAT'L COMM'N OF PHYSICIAN PAYMENT REFORM, *supra* note 160.

163. See generally NAT'L COMM'N OF PHYSICIAN PAYMENT REFORM, *supra* note 160.

164. *Id.* at 4.

165. *Id.* at 15.

Professional prestige and peer acceptance has always driven physician practices within the medical world. Although this practice has generated many progressive health care advances such as prescription drug research and life-saving technology, it can also be pointed to as a cause of excessive costs and even futility.<sup>166</sup> In the case of end-of-life care, life-saving technologies that were once applied to only a small pilot group are now the default for everyone, despite the certainty of targeted outcomes.<sup>167</sup> This practice is illustrated through the default of using cardiopulmonary resuscitation (CPR) to resuscitate individuals, regardless of their likelihood for survival and longevity or the effects of the treatment. In truth, only between five and ten percent of individuals over the age of seventy who receive CPR leave the hospital alive.<sup>168</sup>

Widespread acceptance of medical advances occurs frequently in the end-of-life context, creating a professional reliance on new life-sustaining treatment with few limitations on its practice. The medical field greets an advancement of this kind with great eagerness as it provides physicians with a method to prolong life. Even when clinicians begin to see a drop in the benefits realized from the new treatment or procedure, many struggle in their approach to limit its uses.<sup>169</sup> When combining the expectations of physicians to use novel practices that save lives with the higher rates of compensation for life-saving treatment and technology, it undermines the options for end-of-life planning.<sup>170</sup> On the contrary, “what people need most on this journey is not the promise of the next new technology but rather a guide to help navigate this dark forest in which they will undoubtedly find themselves.”<sup>171</sup>

#### E. *Reliance on Flawed Legal Instruments*

Neither the skill sets of physicians nor the overall culture of medicine are the only inhibiting factors to having meaningful conversations. Currently, advance directives provide clinicians, who accept their functionality, with a legal safe harbor for delivering specific end-of-life services that would otherwise be illegal without directives.<sup>172</sup> Many physicians are turning to these legal forms as the sole method to conducting advance planning for patients, yet

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166. J. Andrew Billings & Eric L. Krakauer, *On Patient Autonomy and Physician Responsibility in End-of-Life Care*, 171 ARCH. INTERN. MED. (SPECIAL ARTICLE) 848, 852 (2011) (explaining how harms from certain medical interventions can greatly outweigh possible benefits).

167. *Id.* at 850.

168. See Whoriskey, *supra* note 136 (citing to Dr. Paul Marik).

169. See Billings & Krakauer, *supra* note 166, at 850.

170. See Whoriskey, *supra* note 136.

171. ANGELO VOLANDES, *THE CONVERSATION: A REVOLUTIONARY PLAN FOR END-OF-LIFE CARE* 5-6 (2015).

172. Lois Shepherd, *The End of End-of-Life Law*, 92 N. C. L. REV. 1693, 1696 (2014).

these documents are often anything but comprehensive.<sup>173</sup> In fact, because advance directives often have default options, the forms themselves may have the effect of altering patients' decisions.<sup>174</sup> One study assessed patient choices by presenting them with three distinct default options; it found that patients are more likely to be influenced by default decisions but have less satisfaction in their care planning.<sup>175</sup>

Moreover, the AHRQ references the consistent failures of advance directives to appropriately account for patient wishes and be accurately applied when needed.<sup>176</sup> Less than fifty percent of the severely or terminally ill patients studied had an advance directive in their medical record, and for those that did, documentation was not found in the medical chart regarding patient wishes.<sup>177</sup> This is due, in part, to difficulty in promoting transferability of advance directives across various provider settings.<sup>178</sup> Furthermore, language in advance directives was found to be too nonspecific and failed to provide clinicians with clear direction on how to move forward.<sup>179</sup> Even in cases where language may be written with specificity, nearly half of clinicians will misunderstand instruments and may misinterpret the advance directive in a manner that is inconsistent with a patient's wishes.<sup>180</sup> These findings illustrate the flaws inherent in relying upon advance directives as the primary tool for end-of-life planning, as it may prohibit patients from making thoughtful decisions about their care and leaves out much of the information necessary for clear directions.

The laws surrounding end-of-life care add to the concern of using advance directives and other advance care planning tools. There are a multitude of policy decisions addressing end-of-life care, ranging from state and federal statutes to judicial decisions; yet none seem to actively require the use of legal forms or tools.<sup>181</sup> Further adding to this inconsistency is the fact that almost

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173. See *id.* at 1696-97 (explaining different laws across states define these directives differently).

174. Scott D. Halpern et al., *Default Options in Advance Directives Influence How Patients Set Goals for End-of-Life Care*, 32 HEALTH AFF. 408, 409 (2013).

175. *Id.* at 412-13.

176. Kass-Bartelmes & Hughes, *supra* note 76, at 2.

177. *Id.*

178. IOM, *supra* note 62, at 134. Researchers tracking portability of documents found that, "the likelihood that advance care planning documentation would be available and/or in concordance 'was no greater than chance.'" *Id.*, quoting V.Y. Yung et al., *Documentation of Advance Care Planning for Community-Dwelling Elders*, 13 J. PALLIATIVE MED. 861, 865 (2010).

179. Thaddeus Pope, *Clinicians May Not Administer Life-Sustaining Treatment Without Consent: Civil, Criminal, and Disciplinary Sanctions*, 9 J. HEALTH & BIOMED. L. 213, 233 (2013).

180. *Id.* at 231.

181. Noah, *supra* note 157, at 8.

every state has its own statute regarding advance directives, none of which necessarily carry legal authority across state lines.<sup>182</sup> In 1993, there was a push towards universal acceptance of these tools through the Uniform Health Care Decisions Act, which promoted the use of a more comprehensive and standardized method of making advance care decisions.<sup>183</sup> Despite its creation, however, there was little traction amongst the states in adopting this uniform statute, as only six states had fully adopted the statute by 2001.<sup>184</sup> In addition to the nation-wide inconsistency concerning end-of-life care are the various judicial decisions addressing the legal and human rights of patients; most of which turn on the question of whether there is enough substantive evidence supporting a patient's wishes for taking specific actions in the end phases of life.<sup>185</sup> It is clear that the legal landscape for this area of patient autonomy is afflicted with contradiction and a general lack of resources to promote best practices in end-of-life care.

There are a myriad of concerns afflicting the current practice for advance care planning, ranging from cultural issues to professional norms and patient expectations. Problems become somewhat exacerbated when, as here, policy changes rely solely on the actions of physicians to revolutionize an entire sector of medical planning. These complications, however, should not be viewed as a complete impediment to improving this essential area of health care. Instead, policymakers should expand their potential solutions to more than just physicians, as they are only a single element of a vast health care continuum.

#### V. RECOMMENDATIONS FOR IMPROVED ADVANCE CARE PLANNING

As illustrated throughout this article, the final rule issued by CMS to reimburse physicians for discussions on advance care planning carries with it a host of limitations. Nevertheless, the most current push towards improving end-of-life care should not be ignored. It is crucial that the United States' health care system shift towards creating better options for patients within the final years of their lives and foster a seamless transition into the end of life. Despite the fact that the policy changes seem to fall short of reaching this ultimate goal, it is still possible to promote better practices of advance care planning to reinforce patient autonomy and choice in the decision-making process. Specifically, improvements in end-of-life planning can be managed

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182. *Id.* at 9.

183. *Id.* at 10.

184. David English, *The Uniform Health-Care Decisions Act and its Progress in the States*, PROB. & PROP., May/June 2001, at 1, 19, 20, [http://www.americanbar.org/publications/probate\\_property\\_magazine\\_home/rppt\\_publications\\_magazine\\_2001\\_01mj\\_01mjenglish.html](http://www.americanbar.org/publications/probate_property_magazine_home/rppt_publications_magazine_2001_01mj_01mjenglish.html).

185. Joshua E. Perry et al., *The Terri Schiavo Case: Legal, Ethical, and Medical Perspectives* 15 ANN. INTERN. MED. 744, 746 (2005).

effectively through the inclusion of non-physician clinicians, the creation of a centralized adoption of POLST, and a system-wide overhaul of medical education.

A. *Inclusion of Non-physician Clinicians in the Advance Planning Scheme*

The largest issue associated with the final rule is the sole reliance on physicians' ability to appropriately respond to financial incentives to improve an entire area of medicine. Although there is evidence that many physicians react positively towards a carrot and stick approach, it is also clear that, collectively, physicians often fumble in their ability to meaningfully communicate with patients concerning this topic.<sup>186</sup> As a whole, this policy overlooks the value of utilizing non-physician clinicians, such as nurses and social workers, in conjunction with physicians to effectively facilitate patient involvement in advance care planning.

In the clinical setting, nurses regularly interact with both patients and families, providing a range of supportive services and interventions directly impacting comfort and quality of life.<sup>187</sup> In caring for patients in the end of their lives, comfort care is thought to relieve approximately ninety percent of symptoms.<sup>188</sup> As a result of supplying this care, many nurses are able to develop a rapport with their patients and families, which, as discussed throughout, is fundamental for effective communication. The dynamic of physician-patient relationships differ greatly from nurse-patient relationships, specifically in the time spent with patients throughout their stays and visits.<sup>189</sup> It is true that many individuals may have a long-standing relationship with their physicians, but it is likely that even in a trusted relationship, those physicians spend minimal amounts of face-time with their patients. The quantity of time spent allows nurses to better understand those patients as

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186. Mieke Visser et al., *Physician-Related Barriers to Communication and Patient and Family-Centered Decision-Making Towards the End of Life in Intensive Care: A Systematic Review* CRITICAL CARE 1, 2 (2014).

187. Kellie Lewis, *How Nurses Can Help Ease Patient Transitions to End of Life Care*, 25 NURSING OLDER PEOPLE 22, 23 (2013). (including fundamental services such as: "bathing, hair care, mouth care, pressure area care, spiritual care, and the administration of analgesics, sedatives, and antimucolytics").

188. Sharon Valente & Judith Saunders, *Psychiatric Nurses' Expertise, Interest in End-of-Life Care, and Requests for Continuing Education on End of Life*, 27 AM. J. HOSPICE & PALLIATIVE MED. 24, 24 (2010).

189. Kathy Hebert et al., *The Nurse Advocate in End-of-Life Care*, 11 OCHSNER J. 325, 326 (2011).

individuals, which aids in understanding the patients' cultures,<sup>190</sup> preferences,<sup>191</sup> and goals.<sup>192</sup>

Nurses, like physicians, are trained to understand a patient's conditions and outcomes; however, they may be better equipped to provide information to the patient about care options because they are likely more knowledgeable about a patient's wishes.<sup>193</sup> In one study that measured nurses' perspectives on end-of-life care challenges, nurses reported that one of the most difficult barriers was interprofessional conflict between physicians, families, and nurses.<sup>194</sup> Physicians and families often want curative and aggressive treatment, but nurses aim to advocate for patients' wishes and move toward palliative care.<sup>195</sup> Nurses also reported that, in their perspective, they aid in the collaboration between the health care team, family, and patient because they can effectively communicate a patient's wishes to both parties and provide support in steering care coordination.<sup>196</sup> Overall, nurses help to provide a holistic approach to end-of-life planning where patient decision-making takes precedent over all else.

Inclusion of specialty nurses, such as psychiatric nurses, in advance care planning may prove to be beneficial for patients, families, and even care teams. These nurses are specially trained in facilitating discussions about difficult topics, evaluating patients' mental statuses, and assessing and managing mood variations.<sup>197</sup> Furthermore, psychiatric nurses have expertise in enhancing communication and conflict management, often necessary to cultivate meaningful cooperation amongst physicians, patients, and families.<sup>198</sup> In addition to their collaborative skills is their experience in managing stress and anxiety, two common issues associated with advance care planning plaguing both patients and caregivers.<sup>199</sup> These areas of expertise differ greatly from that of physicians, who admittedly are not well-equipped in dealing with end-of-life decision-making and discussing palliative care.<sup>200</sup>

In addition to increased utilization of nurses in the advance care planning process, it is recommended that care teams seek help from clinical social workers. Although clinical social workers do not have extensive training in medical practice, they have other unique skills that enable them to add great

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190. Sharon Valente, *Nurses' Perspectives of Challenges in End of Life Care*, 55 JOCEPS 28, 30 (2011).

191. Lewis, *supra* note 187, at 22, 24.

192. *Id.* at 25.

193. Valente, *supra* note 190, at 30.

194. *Id.* at 28.

195. *Id.* at 30.

196. *Id.*

197. Valente & Saunders, *supra* note 188, at 24.

198. *Id.* at 24-25.

199. *Id.* at 24.

200. *See also* GAWANDE, *supra* note 130, at 10.

value to end-of-life care.<sup>201</sup> Health care social workers are able to provide various assessments of the needs of patients and families, communicate psychosocial needs of patients and families to team members, facilitate effective family and team communication, and supply crisis intervention.<sup>202</sup> Furthermore, although clinical social workers may not initially be considered providers for policy purposes, they do have the ability to enroll as Medicare providers, eligible for valid reimbursement rates.

If the ultimate goal is to improve quality of care at the end of life, it is appropriate and necessary for policymakers to include nursing professionals and clinical social workers alongside physicians in the planning scheme. The two professions, although different in practice, both have expertise in providing quality patient-centered care that often gets overlooked by physicians. As illustrated throughout, meaningful communication is vital to promoting best practices in advance care planning and reinforcing patient autonomy in end-of-life decision-making. Incorporating non-physician clinicians into the advance care planning system will undoubtedly aid in fostering strong communication and patient involvement. Allowing patients to have a stronger role in the decision-making process will ultimately enable them to express their preferences and care planning goals, which once understood, can be translated into portable medical orders.<sup>203</sup> Inviting involvement from all actors in the medical chain of command will help to ensure the patient receives quality, integrated care that respects previously designated wishes concerning one's final moments.

#### B. *Centralized Structure of Advance Care Planning Instruments*

One significant downfall in the advance care planning process is that even where advance directives exist, there lacks a universal method of documentation that can translate patient preferences into actions. The foundation for creating a policy aimed at correcting this issue has already been laid through the proposed legislation in the "Personalize Your Care Act of 2013."<sup>204</sup> As noted previously, this legislation creates grants used to establish statewide POLST programs and to improve EHR functions to better maintain related documentation.<sup>205</sup> Making POLST programs more available to patients

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201. KARYN WALSH, NAT'L ASS'N OF SOC. WORKERS, SOCIAL WORKERS IN HOSPICE AND PALLIATIVE CARE 2 (2013), <http://www.socialworkers.org/practice/bereavement/updates/EndOfLifeCare-PU0204.pdf>.

202. *Id.* (referencing findings from a 2003 study of 400 clinical social workers placed in end-of-life settings).

203. John E. Jesus et al., *Physician Orders for Life-Sustaining Treatment and Emergency Medicine: Ethical Considerations, Legal Issues, and Emerging Trends*, 64 ANN. OF EMERGENCY MED. 140, 140 (2014).

204. *See* H.R. 1173, 113th Cong. (2013).

205. *Id.*

will promote patient autonomy through the ability to document wishes about end-of-life care in a medium understood by clinicians.<sup>206</sup> Having POLST documentation integrated into an individual's EHR will help to ensure that providers are aware of a patient's preferences in all settings, which ultimately leads to minimized confusion, delay, and burden.<sup>207</sup>

Utilization of POLST is not only valuable in providing the capability to understand and incorporate patient wishes into practice, but it also places accountability on the physician to act in accordance with the listed preferences.<sup>208</sup> States that have implemented POLST programs, such as California, have required providers to follow orders contained in patients' POLST unless revoked by the patient.<sup>209</sup> Although this legislation may raise objections from providers who do not want to be held responsible for actions taken pursuant to documented orders, any legislation should be drafted to ensure that following POLST orders in good faith creates immunity for providers.

One amendment to the proposed legislation on improved adoption of POLST is to allow for increased involvement of non-physician clinicians.<sup>210</sup> Although the orders themselves must come from a physician, nurses and clinical social workers can facilitate the initial discussions and aid the physician in understanding the patient's wishes. This system would be no different than the current roles in an outpatient doctor's office; the nurse or other clinician delivers general patient care and asks a series of questions pertaining to the patient's health to better prepare the physician for his visit. In the context of implementing POLST, it would be more cost-efficient and effective for a nurse or social worker to discuss, in depth, patient preferences, goals, and questions surrounding end-of-life planning.<sup>211</sup> This information could then be documented for the physician to evaluate and discuss with the patient during their visit. Utilizing the distinct skills of non-physician clinicians to foster increased adoption of written physician orders will help the care team to better understand a patient's personal wishes and the future plan of care. The widespread development of POLST programs not only reduces confusion and anxiety in end-of-life circumstances, but it both strengthens patient autonomy and helps to improve best practices of advance care planning across the entire care team.

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206. Jesus et al., *supra* note 203, at 141.

207. *Id.*

208. See Sugiyama et al., *supra* note 41, at 1338.

209. *Id.*

210. H.R. 1173, 113th Cong. § 1-2 (2013).

211. See Valente & Saunders, *supra* note 188, at 29.

### C. *Overhaul of Medical Education*

A consistent theme arising out of the end-of-life dilemma is the failure of physicians to appropriately and effectively communicate with their patients about advance care planning. As illustrated through various studies, it seems that physicians fall short in their ability to fully engage patients in planning, and it is questioned whether they currently have the skill set to successfully do so.<sup>212</sup> The IOM highlights education as a central solution to resolve this failure in communication and identifies improvements in professional education as a key initiative to improve end-of-life care.<sup>213</sup> Doing so would require the creation of a uniform curriculum that could be taught across universities, as well as the implementation of increased programming for continuing medical education.<sup>214</sup> Although this may be a solution geared towards ineffective communication and relationships, it is an effort that will take a substantial period of time to complete and is unlikely to change behavior in the near future. As such, policymakers should understand that this proposal should be promulgated in conjunction with more accelerated solutions.

A few major shortcomings currently exist in medical education as it pertains to end-of-life care; a lack of education about hospice and palliative care, a persistence of single-profession education silos, and a lack of development focused on effective communication about dying.<sup>215</sup> These academic deficiencies are a reflection of the current culture of medical care discussed in this article, which tends to shy away from seamless integration into palliative, hospice, and end-of-life care. Adjustments in education and training, however, will help to reinforce the importance of these areas of care from the ground up, and eventually lead to changes in attitude and culture. If medical professionals are taught appropriate skills initially, it will be easier to apply those skills to practice in an effective manner. Combining improved education on end-of-life planning with the ACA's shift in promoting primary care and prevention will ultimately improve the landscape for effective advance care planning.

### CONCLUSION

The three listed recommendations aim to reform advance care planning techniques to better serve patients in their final moments. It seems the AMA, CMS, and various other stakeholders seek to achieve the same goal in their policy changes; however, as argued throughout, simply reimbursing physicians to have discussions will not effectuate meaningful change in this area of care.

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212. See IOM, *supra* note 62, at 223-24.

213. *Id.* at 225.

214. *Id.* at 226, 229.

215. *Id.* at 251-52.

There exist multiple shortcomings in physicians' ability to communicate with patients and to respect their personal autonomy in the care planning process. These shortcomings are exacerbated by the Western culture of medicine, focusing on survival and improvement rather than comfort and quality of life. It must be emphasized that these findings do not suggest that physicians should be excluded from the advance care planning process. Rather, their expertise should be used in conjunction with other providers and better clinical tools to optimize patient experience and participation. In order to improve patient care at the end of life, it is crucial that patients not only be given a place in the decision-making process, but also have their values and goals respected by those directing care. The final moments of one's life should not be plagued with regret and discomfort, but rather integrity and self-reflection.

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