

## LIFE AND DEATH ON YOUR TERMS: THE ADVANCE DIRECTIVES DILEMMA AND WHAT SHOULD BE DONE IN THE WAKE OF THE SCHIAVO CASE

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*In early 2005 the story of Terry Schiavo dominated newscasts around the world. The Schiavo story sparked debate and discussion about end-of-life treatment, including the religious and moral implications of advance directives. Advance directives are legal documents that allow a patient to convey their end-of-life wishes before the critical point when such decisions must be made. While the United States has taken steps to adopt both federal and state legislation to promote advance directives, a lack of uniformity of procedure and documentation between the states is hindering widespread documentation of end-of-life wishes. Advance directives are often not utilized despite increased awareness of the need for end-of-life protection. In this Note, Mr. Gruber supports the passage of pending federal legislation with the additional call for greater uniformity in state advance directive forms.*

### I. Introduction

On March 18, 2005, doctors at a Florida hospice carried out an order issued by the U.S. Supreme Court and removed

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the feeding tube from forty-one year-old Terri Schiavo.<sup>1</sup> She died nearly two weeks later.<sup>2</sup> The news story grabbed the hearts and minds of people across the nation and the world, sparking numerous debates regarding the moral, ethical, and legal arguments that saturated the event. In addition, the Schiavo case sparked new thoughts and conversations about living wills and, more encompassing, advance directives.

This Note examines the events leading to federal and state legislation regarding advance directives and addresses the pros and cons of the enactments. The newly proposed Advance Directives Improvement and Education Act of 2005 is also examined, as well as the resulting circumstances if the Act is passed. Additionally, this Note analyzes many of the reasons why a majority of the U.S. population does not execute advance directives and express their wishes regarding end-of-life care and describes a number of forms and programs offered by private entities that have enjoyed good results. Furthermore, the use of advance directives in other countries is compared to that of the United States. Finally, this Note recommends the passage of the Advance Directives Improvement and Education Act of 2005 and adoption of a standard advance directive form by the entire nation.

## II. Background

Federal regulations define advance directives as “written instructions, such as a living will or durable power of attorney for health care, recognized under State law, relating to the provision of health care when the individual is incapacitated.”<sup>3</sup> There are two forms of advance directives: instruction and proxy.<sup>4</sup> An instruction directive, most commonly a living will, is an advance directive in

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1. *A History of the Terri Schiavo Case*, 3 WASH. WATCH (SPECIAL ISSUE) 3 (2005), available at <http://www.ucp.org/uploads/WashingtonWatchVol3Iss3.doc>. On February 25, 1990, Terri Schiavo's heart temporarily stopped beating and oxygen was cut off to her brain, causing severe brain damage. *Id.* at 1. Among several possible explanations for why her heart stopped were an undiagnosed illness, a potassium imbalance possibly brought on by bulimia, and physical abuse from her husband. *Id.* The Supreme Court's order came after several years of court battles between Terri Schiavo's husband and her family. *Id.* at 1-3.

2. *Id.* at 3.

3. 42 C.F.R. § 489.100 (2006).

4. 1 JOAN M. KRAUSKOPF ET AL., *Incompetent Individuals: Who Speaks—Advance Directives*, in ELDERLAW ADVOCACY FOR THE AGING § 13:16 (2d ed. 2006).

which a person establishes a list of guidelines for his or her future care, but does not appoint someone to carry out those instructions.<sup>5</sup> A proxy directive, most often called a durable power of attorney, is an advance directive in which, in addition to care guidelines, a person is appointed to carry out the desired instructions or make decisions regarding the health care of the person executing the document.<sup>6</sup>

There are approximately two million deaths annually in the United States, and advance directives are executed in less than half.<sup>7</sup> Although the relatively young age of Schiavo at the time of her death suggests people of all ages should execute advance directives, the issue is most relevant to our nation's growing elderly population. Seventy-seven million people "born between 1946 and 1964, currently live in the United States."<sup>8</sup> These baby boomers represent 27.5% of the U.S. population.<sup>9</sup> A baby boomer turns sixty years-old every seven seconds,<sup>10</sup> and the U.S. Census Bureau predicts this large baby boomer population means approximately eighty million, or one in five, Americans will be sixty-five or older by the year 2050.<sup>11</sup> The constant improvement of medical technology is both partially responsible for increased life expectancy and another reason for the greater utilization of advance directives.<sup>12</sup> More and more situations where medical care is the only thing keeping a person alive are on the horizon, making the use of advance directives increasingly important.<sup>13</sup>

Despite these staggering statistics and the nation's heightened awareness of the need for advance directives, a 2005 CBS News Poll

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5. *Id.*

6. *Id.*

7. David Y. Nakashima, *Your Body, Your Choice: How Mandatory Advance Health-Care Directives Are Necessary to Protect Your Fundamental Right to Accept or Refuse Medical Treatment*, 27 U. HAW. L. REV. 201, 203 (2004).

8. USA Freedom Corps, For Baby Boomers—Get Involved!, [http://www.usafreedomcorps.gov/for\\_volunteers/boomers](http://www.usafreedomcorps.gov/for_volunteers/boomers) (last visited Oct. 18, 2007).

9. *Id.*

10. *Id.*

11. U.S. CENSUS BUREAU, STATISTICAL BRIEF: SIXTY-FIVE PLUS IN THE UNITED STATES 1 (1995), [http://www.census.gov/apscd/www/statbrief/sb95\\_8.pdf](http://www.census.gov/apscd/www/statbrief/sb95_8.pdf).

12. See Nakashima, *supra* note 7, at 205–06. Additionally, the increase in medical technology and the lack of advance directive use have unnecessarily increased the already exorbitant amount of money spent on health care in the United States. *Id.* at 204. The majority of the many thousands of people who may be receiving artificial life support against their wishes are likely receiving government financial support for their treatment through Medicare. *Id.* As a result, millions of dollars in taxpayer money is needlessly spent on possibly unwanted, end-of-life care because advance directives are not being used. *Id.*

13. *Id.* at 205–06.

found only one in three Americans executed advance directives.<sup>14</sup> Additional studies have found similar results, with the percentage of Americans having advance directives ranging from twenty to thirty percent.<sup>15</sup> Prior to the Schiavo controversy, a Florida nonprofit organization received approximately fifty requests per day for information on the documentation of end-of-life care wishes.<sup>16</sup> During the coverage of the Schiavo case, the number of requests increased to approximately six thousand per day, but then fell to about one hundred per day when Schiavo passed away and the public lost interest.<sup>17</sup> These astounding numbers suggest the general public is willing to take the necessary steps to document their end-of-life care wishes, but only when such matters are at the forefront of their minds. The heightened awareness and increasing elderly population over the past few past years still has not greatly increased the use of advance directive instruments.<sup>18</sup>

In early 2005, before the Schiavo case, Florida Senator Bill Nelson and Michigan Representative Sander Levin introduced the Advance Directives Improvement and Education Act (ADIEA).<sup>19</sup> The ADIEA requires a study by the Comptroller General of the United States on “the effectiveness of advance directives in making patients’ wishes known and honored by health care providers” and “the feasibility of a national registry for advance directives.”<sup>20</sup> The bill has not yet been passed but has been referred to committee.<sup>21</sup>

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14. Marlene Franklin et al., *Perspectives on Advance Directives*, MONOGRAPH, Aug. 2006, at 1, available at <http://www.ashrm.org/ashrm/resources/files/Monograph.AdvDirective.pdf>.

15. Susan E. Hickman et al., *Hope for the Future: Achieving the Original Intent of Advance Directives*, in IMPROVING END OF LIFE CARE: WHY HAS IT BEEN SO DIFFICULT? HASTINGS CENTER SPECIAL REPORT S26 (2005).

16. *Death & Dying Real Life Story—Private Discussion in Public: Panel Bares Personal Experiences to Continue End-of-Life Debate Begun with Schiavo*, SOCIAL WORKERS HELP STARTS HERE, Aug. 10, 2005, <http://www.helpstartshere.org/Default.aspx?PageID=456>.

17. *Id.*

18. Franklin et al., *supra* note 14, at 1; see also U.S. CENSUS BUREAU, *supra* note 11.

19. S. 347, 109th Cong. (2005).

20. *Id.*

21. Compassion and Choices, *Improving Laws: In Congress*, <http://www.compassionandchoices.org/improvinglaws/thecapitol.php> (last visited Oct. 18, 2007) [hereinafter Compassion and Choices].

### A. Court Cases Leading to Legislation

The legal authority for advance directives stems from the constitutional right to refuse unwanted medical treatment.<sup>22</sup> Prior to any federal legislation, the right to refuse medical treatment was discussed in a number of court cases.<sup>23</sup> In *In re Quinlan*,<sup>24</sup> twenty-one-year-old Karen Quinlan was in a persistent vegetative state and on a respirator after experiencing a lack of oxygen to her brain.<sup>25</sup> Her father sought to be appointed guardian of her person and property in order to authorize the discontinuance of all extraordinary procedures for sustaining her vital processes.<sup>26</sup> The Supreme Court of New Jersey held Karen's decision to allow the termination of a noncognitive, vegetative existence by natural forces was included in her right to privacy, which could be asserted by her guardian.<sup>27</sup> Although Karen did not have an advance directive, the court concluded it was her right to have a natural death, and her father, being the next of kin, was entitled to guardianship and the associated right to make the decision.<sup>28</sup> Before this case, a patient's right to limit life-sustaining medical treatment was not recognized by any state.<sup>29</sup> However, after *Quinlan*, some states enacted statutes to address advance directives.<sup>30</sup>

The U.S. Supreme Court first addressed the issue of refusing medical care in 1990 in the case *Cruzan v. Director, Missouri Department of Health*.<sup>31</sup> As in *Quinlan*, the patient did not have an advance direc-

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22. Nakashima, *supra* note 7, at 207–08.

23. *Id.* at 208.

24. 355 A.2d 647 (N.J. 1976).

25. *Id.* at 654.

26. *Id.* at 651.

27. *Id.* at 664.

28. *Id.*

The only practical way to prevent destruction of the right [of privacy] is to permit the guardian and family of Karen to render their best judgment, subject to the qualifications hereinafter stated, as to whether she would exercise it in these circumstances. If their conclusion is in the affirmative this decision should be accepted by a society the overwhelming majority of whose members would, we think, in similar circumstances, exercise such a choice in the same way for themselves or for those closest to them. It is for this reason that we determine that Karen's right of privacy may be asserted in her behalf, in this respect, by her guardian and family under the particular circumstances presented by this record.

*Id.*

29. Nakashima, *supra* note 7, at 208.

30. *Id.* All states currently have statutes that recognize and contain requirements regarding advance directives. *Id.* at 207.

31. 497 U.S. 261 (1990).

tive and, after five years of being in a vegetative state and on a feeding tube, her guardians wished to terminate artificial hydration and nutrition.<sup>32</sup> The Court emphasized the constitutional right to refuse unwanted medical treatment and noted, “no right is held more sacred, or is more carefully guarded, by the common law, than the right of every individual to the possession and control of his own person, free from all restraint or interference from others, unless by clear and unquestionable authority of law.”<sup>33</sup> Again, even without an advance directive, the Court found the right to die of natural causes is important and family members can exercise that right on behalf of an incapacitated patient.<sup>34</sup>

The right to die of natural causes must be differentiated from the right to commit suicide or assist in suicide. The U.S. Supreme Court in *Washington v. Glucksberg*<sup>35</sup> addressed this issue when the plaintiffs argued that the decision in *Cruzan* supported an interest in self-sovereignty protected by the Due Process Clause.<sup>36</sup> This interest was said to include a right to commit suicide with another’s assistance.<sup>37</sup> The Court did not agree, noting that Anglo-American common law has punished or otherwise disapproved of assisting suicide for over seven hundred years.<sup>38</sup> Such actions were distinguished from the different, long-established legal tradition protecting the decision to refuse unwanted medical treatment and a person’s right to die of natu-

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32. *Id.* at 267.

33. *Id.* at 343 (quoting *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891)). Additionally, the Court noted, “[i]t is permissible for Missouri, in its proceedings, to apply a clear and convincing evidence standard, which is an appropriate standard when the individual interests at stake are both particularly important and more substantial than mere loss of money.” *Id.* at 261 (citing *Santosky v. Kramer*, 455 U.S. 745, 756 (1982)). The Court affirmed the Supreme Court of Missouri’s holding that “because there was no clear and convincing evidence of Nancy’s desire to have life-sustaining treatment withdrawn under such circumstances, her parents lacked authority to effectuate such a request.” *Id.* at 265.

34. *Id.*; see also *In re Quinlan*, 355 A.2d 647, 664 (N.J. 1976).

35. 521 U.S. 702, 707–08 (1997). Three terminally ill patients, four physicians, and a nonprofit organization brought a declaratory judgment action against the state of Washington seeking a finding that a statute banning assisted suicide violated the Due Process Clause. *Id.* The Court held the asserted right to assisted suicide was not a fundamental liberty interest protected by the Due Process Clause and Washington’s ban on assisted suicide was rationally related to legitimate government interests. *Id.* at 735.

36. *Id.* at 725.

37. *Id.* at 724.

38. *Id.* at 702.

ral causes.<sup>39</sup> While *Quinlan* and *Cruzan* laid the framework for establishing judicial acceptance of the constitutional right to refuse unwanted medical treatment, *Washington* drew a clear line regarding the limits of that right.

## B. Federal Legislation

### 1. THE PATIENT SELF-DETERMINATION ACT

Just as the New Jersey Supreme Court's decision in *Quinlan* generated state legislation regarding advance directives, the U.S. Supreme Court's decision in *Cruzan* put the wheels in motion for federal legislation.<sup>40</sup> Effective December 1, 1991, the Patient Self-Determination Act (Act)<sup>41</sup> followed state legislation and judicial recognition of the constitutional right to refuse unwanted medical treatment with an effort to ensure patients are given information about the extent to which the right exists under state law.<sup>42</sup> The goal of the Act was "to ensure that a patient's right to self-determination in health care decisions be communicated and protected."<sup>43</sup>

The Act contains four key provisions. First, it requires hospitals, skilled nursing facilities, home health agencies, hospice programs, and Health Management Organizations (HMOs) to have written policies and procedures guaranteeing written information concerning patient involvement in medical treatment decisions is given to every adult receiving medical care.<sup>44</sup> More specifically,

an individual's rights under state law to make medical treatment decisions, an individual's rights under state law to formulate advance medical directives, such as a living will or a durable power of attorney, should the individual become incapacitated, and policies and procedures that the institution has developed to honor these rights.<sup>45</sup>

Under the Act, the "written information must be provided" when the individual is admitted as a patient in a hospital, when the individual

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39. *Id.* at 703; see *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 277-78 (1990); *In re Quinlan*, 355 A.2d 647, 669 (N.J. 1976).

40. Nakashima, *supra* note 7, at 211.

41. S. 1766, 101st Cong. (1990).

42. Fred H. Cate & Barbara A. Gill, *The Patient Self-Determination Act: Implementation Issues and Opportunities*, 6 HEALTH L. 1, 1 (1992).

43. S. 1766, 101st Cong. (1990).

44. Cate & Gill, *supra* note 42, at 1, 3.

45. KRAUSKOPF ET AL., *Federal Patient Self-Determination Act*, in ELDERLAW ADVOCACY FOR THE AGING, *supra* note 4, § 13:37.

is admitted as a resident in a nursing facility, before the individual comes under the care of a home health agency, at the time of the initial receipt of hospice care in hospices, and at the time of enrollment of the individual in an HMO.<sup>46</sup> Additionally, the health care provider must document whether an advance directive has been executed in each patient's medical records.<sup>47</sup>

Second, the Act requires health care providers to educate staff and the community regarding advance directive issues.<sup>48</sup> Third, states are required to develop a written description of the state laws pertaining to advance directives, and whether the laws are statutory or result from court decisions.<sup>49</sup> The last significant provision of the Act focuses on education and requires the Secretary of Health and Human Services to create and put into action a national campaign to inform people of the option to execute advance directives and of their right to participate in and direct health care decisions.<sup>50</sup> Additionally, the Secretary is required to create or approve materials for nationwide distribution by providers, "to inform the public and the medical and legal profession of each person's right to make decisions concerning medical care, including the right to accept or refuse medical or surgical treatment, and the existence of advance directives."<sup>51</sup>

Broadly speaking, the Act attempts to make people more aware of advance directives and their other related rights. On its face, it may seem the Act provides a uniform system useful to both health care providers and patients throughout the nation. However, it is not enough to simply require health care providers to uphold their own policies and procedures and provide information about advance directives. The United States still lacks a uniform system for advance directives. It is still mostly the responsibility of individual states and health care providers themselves to ensure people obtain adequate knowledge on advance directives.<sup>52</sup> It would be much more effective to choose one national advance directive form that would be portable from state to state thereby eliminating discrepancies in law between the states.

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46. Cate & Gill, *supra* note 42, at 3.

47. *Id.*

48. *Id.*

49. *Id.*

50. *Id.*

51. *Id.*

52. *See id.* at 4-5.



## 2. THE UNIFORM HEALTH-CARE DECISIONS ACT

The next attempt at uniformity regarding the use of advance directives was introduced by the Uniform Law Commissioners in August 1993.<sup>53</sup> In response to the sporadic implementation of rules set by the states regarding advance directives, the Uniform Health-Care Decisions Act (UHDA) was promulgated in an attempt to bring uniformity among the states.<sup>54</sup> The purposes of the UHDA were “(1) to recognize the right of a competent individual to decide all aspects of his health care in all circumstances, including the right to refuse life-sustaining medical treatment; (2) replace existing legislation on advance directives with a single statute; (3) simplify and facilitate the execution of advance directives; (4) ensure that decisions regarding an individual’s health care be governed by the individual’s own desires; (5) ensure compliance by health care providers; and (6) provide a procedure for the resolution of disputes.”<sup>55</sup>

The UHDA, to aid simplification, states that an individual instruction may be written or documented orally, and, while a power of attorney for health care must be in writing and signed by the patient, no witness or acknowledgment is necessary.<sup>56</sup> Additionally, recognizing that people generally do not plan ahead for incapacitating situations, the UHDA includes two back-up provisions.<sup>57</sup> First, it specifies when individuals other than a patient’s agent or guardian may act as a surrogate,<sup>58</sup> and second, it addresses the guardian’s role in health care decision making.<sup>59</sup>

Although the UHDA sought to create uniformity, only Hawaii, Delaware, Maine, Mississippi, California, and New Mexico have adopted it.<sup>60</sup> This may be due to the fact it still requires patients to do most of the work involved in executing advance directives themselves.<sup>61</sup> Therefore, federal legislation that will shift the burden to health care providers and demand a more uniform system is still necessary.

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53. Nakashima, *supra* note 7, at 212–13.

54. *Id.* at 214.

55. *Id.* at 213.

56. *Id.*

57. *Id.*

58. *Id.*

59. *Id.*

60. *Id.* at 214.

61. *Id.*

### 3. THE ADVANCE DIRECTIVES IMPROVEMENT AND EDUCATION ACT

Asking for a uniform system and more responsibility to be given to health care providers for advance directive execution, Senator Nelson and Representative Levin introduced the ADIEA in 2005.<sup>62</sup> Senator Nelson stated the purpose of the ADIEA is “to encourage all adults in America, especially those [sixty-five] and older, to think about, talk about and write down their wishes for medical care near the end of life should they become unable to make decisions for themselves.”<sup>63</sup> Reaching that goal, according to Senator Nelson, requires public education on the overall importance of advance directives, opportunities for discussion of the issues be embraced, and a reinforcement of the requirement that health care providers honor patients’ wishes.<sup>64</sup>

The ADIEA is designed to:

improve access to information about individuals’ health care options and legal rights for care near the end of life, to promote advance care planning and decisionmaking so that individuals’ wishes are known should they become unable to speak for themselves, to engage health care providers in disseminating information about and assisting in the preparation of advance directives, which include living wills and durable powers of attorney for health care, and for other purposes.<sup>65</sup>

The ADIEA does several things to achieve this purpose. First, it authorizes Medicare coverage for patients to consult with their physicians about the importance of executing an advance directive and the necessity of periodic updates.<sup>66</sup> Physicians are instructed to assist patients in identifying state-specific information for preparing advance directives, and to inform the patient whether the physician will follow his or her choices.<sup>67</sup> Next, it waives certain deductible and coinsurance payments for consultation with physicians.<sup>68</sup> Medicare providers are also required to include advance directives in a “prominent” part of the patient’s medical record and to honor advance directives executed in another state, thus making advance directives portable from state to state.<sup>69</sup> The ADIEA also requests the Department of Health

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62. S. 347, 109th Cong. (2005).

63. 151 CONG. REC. S1275 (daily ed. Feb. 10, 2005) (statement of Sen. Nelson).

64. *Id.*

65. S. 347.

66. Compassion and Choices, *supra* note 21.

67. *Id.*

68. *Id.*

69. *Id.*

and Human Services to commence an education campaign to increase awareness and provide state-specific information on advance directives.<sup>70</sup> The ADIEA also asks the General Accounting Office (GAO) to conduct studies on the effectiveness of advance directives and whether they are being honored.<sup>71</sup>

The ADIEA has not yet been passed, but advance directives have recently been a topic of discussion in both the Senate and the House of Representatives. On February 10, 2005, Senator Nelson noted the importance for all Americans, especially the elderly, to document their health care preferences.<sup>72</sup> Senator Nelson believes passage of the ADIEA will help facilitate additional documentation by expanding public education on advance directives, offering opportunities for discussion of the issues, and stressing the requirement that health care providers follow their patients' wishes.<sup>73</sup> Senator Nelson also points to a potentially tangible benefit of passing the ADIEA in regard to Medicare, noting that 83% of the 2.5 million people who die each year are Medicare beneficiaries and 27% of Medicare expenditures cover health care in the last year of the patient's life.<sup>74</sup> Another major benefit of the ADIEA is the provision of a free physician office visit for a patient to discuss end-of-life care choices and other issues involving medical decision making in case the patient ultimately becomes incapacitated.<sup>75</sup> Additionally, physicians will be reimbursed for this time spent with the patient.<sup>76</sup>

After Schiavo's death, Oregon Senator Ron Wyden addressed three important factors regarding advance directives on April 4, 2005.<sup>77</sup> First, he emphasized that the Senate should empower Americans to make their own end-of-life choices and make sure those choices are carried out.<sup>78</sup> Second, suggesting the nation was focused on the facts surrounding the Schiavo case, such as respirators and feeding tubes, he urged the Senate to look at more fundamental aspects surrounding advance directives such as "conquering pain, expanding hospice care, and capping the great potential of comfort

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70. *Id.*

71. *Id.*

72. 151 CONG. REC. S1275 (daily ed. Feb. 10, 2005) (statement of Sen. Nelson).

73. *Id.*

74. *Id.*

75. *Id.*

76. *Id.*

77. 151 CONG. REC. S3120 (daily ed. Apr. 4, 2005) (statement of Sen. Wyden).

78. *Id.*

care.”<sup>79</sup> Finally, Wyden encouraged the Senate to address end-of-life issues with respect to constitutional boundaries, which he believed had been ignored in the past.<sup>80</sup>

On April 14, 2005, the House of Representatives passed three key resolutions.<sup>81</sup> First, the House “reaffirm[ed] the rights of individuals to make medical decisions as guaranteed under the Fourteenth Amendment to the Constitution.”<sup>82</sup> The House also “recogniz[ed] the importance and benefits to all Americans, regardless of age, of having living wills that designate health care surrogates or of using advance directives to express their wishes and values regarding their medical care.”<sup>83</sup> Finally, the House “encourage[ed] all Americans to set forth their health care wishes in living wills that designate health care surrogates or in other advance directives” before it is too late.<sup>84</sup>

Numerous organizations throughout the country support the ADIEA, including the National Hospice and Palliative Care Organization, the American Bar Association, the Hospice Foundation of America, and the National Association of Social Workers (NASW).<sup>85</sup> Social workers are often involved in the decision-making process of patients and loved ones in regard to end-of-life care, and the NASW sees the education and funding the ADIEA provides as a way to make that difficult task easier.<sup>86</sup>

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79. *Id.*

80. *Id.*

81. H.R. Res. 217, 109th Cong. (2005).

82. *Id.*

83. *Id.*

84. *Id.*

85. Press Release, Nat'l Ass'n of Soc. Workers, NASW Supports Advance Directives Improvement and Education Act of 2005 (Apr. 8, 2005), <http://www.socialworkers.org/pressroom/2005/040805.asp>. Additional organizations that support the Advance Directives Improvement and Education Act include the American Academy of Family Physicians, the American Geriatric Society, the American Health Care Association, the American Hospital Association, and American Academy of Hospice and Palliative Medicine. *Congressman Snyder Co-sponsors Bill to Improve Living Wills*, NEWS FROM CONGRESSMAN VIC SNYDER (Office of Congressman Vic Snyder, Little Rock, Ark.), Apr. 8, 2005, available at [http://www.house.gov/snyder/news\\_views/eneletters/ene04\\_08\\_05.html](http://www.house.gov/snyder/news_views/eneletters/ene04_08_05.html).

86. Press Release, Nat'l Ass'n of Soc. Workers, *supra* note 85. The NASW has developed policy and practice standards for palliative and end-of-life care which guide social workers in the field. *Id.*

### C. Choices Within the U.S. System

Because advance directive processes are generally governed by state law,<sup>87</sup> there are many different forms and systems governing advance directives throughout the country. Some of these programs are Respecting Choices, Physician Orders for Life-Sustaining Treatment, New York State's IPRO, and the Five Wishes form.

#### 1. THE RESPECTING CHOICES PROGRAM

Respecting Choices began in La Crosse, Wisconsin, in 1991 as part of a community-wide health care planning system designed to ensure that written advance directives were available in every individual's medical record where necessary.<sup>88</sup> Key aspects of the program include

staff education about the program and advance care planning, clearly defined roles and expectations of physicians, training for advanced care planning facilitators, routine public and patient engagement in advance care planning, clinically relevant advance directives incorporated into clinical care, and written protocols telling emergency personnel to follow physician orders that reflect patient preferences.<sup>89</sup>

Over an eleven-month period, 85% of all decedents had a written advance directive in some form by the time of their death, and 96% of those written advance directives were found at the place of their death.<sup>90</sup> In 98% of the deaths in which advance directives were executed, treatment decisions made near the end of life were consistent with those written instructions.<sup>91</sup> Australia is implementing the Respecting Choices program nationwide, and throughout the United States and Canada more than fifty-five communities and organizations have begun to put the program into practice.<sup>92</sup>

#### 2. PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT

Advocated by the Respecting Choices program, the Physician Orders for Life-Sustaining Treatment (POLST) form was developed in Oregon and is designed for seriously ill or frail patients.<sup>93</sup> The POLST

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87. Nakashima, *supra* note 7, at 207–08.

88. Hickman et al., *supra* note 15, at S27.

89. *Id.*

90. *Id.* at S27–S28.

91. *Id.*

92. *Id.* at S28.

93. *Id.*

document is a form that takes patient treatment preferences discovered from conversations about treatment goals among health care professionals, the patient, and/or their surrogates, and converts them into written medical records.<sup>94</sup> In addition, the POLST form transfers with the patient across health care settings to guarantee the patient's preferences are honored throughout all levels of health care.<sup>95</sup>

In a study conducted at eight nursing homes, residents whose POLST forms included a "Do Not Resuscitate" order with an order for comfort measures were followed for one year.<sup>96</sup> The POLST form seemed to promote the desired care, as no patients received unwanted intensive care, ventilator support, or cardiopulmonary resuscitation.<sup>97</sup> Most nursing homes and hospices in Oregon use the POLST program and at least thirteen states have some version of the POLST program, with minor changes to accommodate state-specific regulations and statutes.<sup>98</sup>

### 3. ADVANCE DIRECTIVES QUALITY IMPROVEMENT INTERVENTION MANUAL

A variety of interventions were implemented by IPRO, various partnering organizations, and several hospitals in New York State "to improve the quality and quantity of patient education provided about advance directives and to increase the utilization of advance directives."<sup>99</sup> As a result of this collaboration, the Advance Directives Quality Improvement Intervention Manual was created as well as including educational materials for patients and staff, intervention suggestions, communication and public relation information, and tools and protocols for best practice.<sup>100</sup> According to one study, quality indicators reflecting patient involvement in advance directive decision making, patient information provided about advance directives on admission and before discharge and death, and the opportunity for

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94. *Id.*

95. *Id.*

96. *Id.*

97. *Id.*

98. *Id.*

99. Theodore O. Will, Chief Executive Officer, IPRO, The Impact of an Advance Directive Quality Improvement Project in New York State (Sept. 22, 1999), [http://providers.ipro.org/index/admin\\_memos/id.37](http://providers.ipro.org/index/admin_memos/id.37).

100. *Id.*

patient discussion about advance directives, all increased after distribution of the manual.<sup>101</sup>

#### 4. THE FIVE WISHES FORM

Created by Aging with Dignity, Inc.,<sup>102</sup> the Five Wishes form is a twelve-page document that attempts to help the patient express how they would like to be treated if they become seriously ill and are unable to communicate their wishes in the future.<sup>103</sup> Five wishes are listed that the patient can leave as they are, cross out, or supplement to indicate specific wishes about end-of-life care.<sup>104</sup> The document lets family and health care professionals know who will make health care decisions for the patient when they are unable to make them, the kind of medical treatment they do or do not want, how comfortable they want to be, how they want people to treat them, and what they want their loved ones to know about their condition.<sup>105</sup>

Aging with Dignity advocates the use of their form because it speaks to people in language they can comprehend, rather than “doctor speak” or “lawyer talk,” it can be executed in the comfort of one’s own home, and it helps people talk with their physicians about a difficult subject.<sup>106</sup> Over nine million copies of the document have already been circulated and more than ten thousand organizations are currently distributing it, including churches, synagogues, hospices, hospitals, doctor and law offices, and social service agencies.<sup>107</sup> The Five Wishes form does not yet meet the legal requirements imposed by some states, typically due to the requirement that either a specific state form be used or that the person completing an advance directive be read a mandatory notice or warning.<sup>108</sup> However, residents of

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101. *Id.*

102. Aging with Dignity, Inc. is a nonprofit organization that attempts to provide people with practical information, advice, and legal tools to assist in end-of-life care decision making. Aging with Dignity, <http://www.agingwithdignity.org> (last visited Oct. 18, 2007).

103. Aging with Dignity, Five Wishes, <http://www.agingwithdignity.org/5wishes.html> (last visited Oct. 18, 2007) [hereinafter Five Wishes].

104. Charles P. Sabatino, *National Advance Directives: One Attempt to Scale the Barriers*, 1 NAT’L ACAD. ELDER L. ATT’YS 131, 135 (2005).

105. Five Wishes, *supra* note 103.

106. *Id.*

107. *Id.*

108. *Id.* Additionally, along with similar programs, the Five Wishes form faces barriers to national use due to a wide range of potentially conflicting legal requirements imposed by state laws. *Id.* These barriers include differing proxy or agent requirements, differing execution requirements, differing ranges of condi-

those states can still use the Five Wishes form as many health care professionals will honor a patient's wishes in whatever manner they are documented.<sup>109</sup>

### III. Analysis

#### A. Currently Used Advance Directives Do Not Work

Despite the attention given to advance directives by legislators both on the state and federal level, they remain greatly underused. But how can something that most people agree is important, especially in end-of-life circumstances, go so overlooked in actual practice?<sup>110</sup>

Several issues contribute to this quandary. First, the focus of an advance directive is often on a patient's legal right to refuse unwanted medical treatment. However, most people who create an advance directive do not receive assistance in understanding or discussing their actual goals and values in applicable circumstances.<sup>111</sup> Second, the instructions given with many currently used advance directive documents, and the scenarios used in their discussion, are often either too vague or too medically specific.<sup>112</sup> For example, wording such as, "If I am close to death" is too vague to determine the patient's true wishes, while phrasing such as, "If I am in a persistent vegetative state" refers to a specific medical situation and is often too complex for a patient to fully understand.<sup>113</sup>

Third, when an individual executes an advance directive, further discussion of the matter is rare, even if the individual's health or feelings about end-of-life care change.<sup>114</sup> For example, the Patient Self-Determination Act requires only that health care providers to ask the patient if he or she has an advance directive, not if he or she wishes to make alterations or execute a new one.<sup>115</sup> Fourth, advance directives

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tions that may be addressed or that may be preconditions for implementation of the directive, differing state procedural requirements, state-specific magic words, mandatory disclosures or notices, mandatory form requirements, and special institutional protocols for execution. Sabatino, *supra* note 104, at 136-37.

109. Five Wishes, *supra* note 103.

110. Hickman et al., *supra* note 15; see *supra* note 15 and accompanying text.

111. Hickman et al., *supra* note 15, at S26.

112. *Id.*

113. *Id.*

114. *Id.* at S27.

115. *Id.*



typically do not include directions for the surrogate or health care professional about treatment preferences unless special instructions are provided.<sup>116</sup> One-third of Americans say they have had to make decisions regarding end-of-life care for a loved one.<sup>117</sup> Therefore, many surrogates are often put in the extremely difficult situation of making decisions regarding the lives of loved ones without adequate assistance. There are six main factors to properly consider when addressing these issues.

### 1. PHYSICIAN-PATIENT INTERACTION

The minimal utilization of advance directives may arise from the relationship between, and the inherent human nature of, physicians and patients. Discussions of advance directives are likely to occur during a patient's first office visit, a periodic physical examination, an office visit prior to an elective procedure, or a routine office visit.<sup>118</sup> However, advance directives often address care that will take place in a surgicenter, hospital, or nursing home, rather than in an office setting.<sup>119</sup> Additionally, discussions about end-of-life care are simply an uncomfortable for both the physician and the patient. Some physicians may feel uneasy initiating a discussion about advance directives or may even be concerned about adequate reimbursement for the amount of time spent on the discussion.<sup>120</sup>

A recent survey found that conversations regarding advance directives averaged 5.6 minutes with physicians accounting for two-thirds of the conversation.<sup>121</sup> This survey indicates patients are listening more than they are asking important questions and expressing their wishes. The survey also showed physicians failed to provide enough substantive information to allow patients to make an informed decision by not exploring the reasoning behind a patient's particular preferences and often presenting worst-case scenarios rather than the possibility of uncertain outcomes or reversible conditions.<sup>122</sup> Another study found that after executing an advance direc-

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116. *Id.*

117. Public Agenda, Right to Die: Red Flags, [http://www.publicagenda.org/issues/red\\_flags.cfm?issue\\_type=right2die](http://www.publicagenda.org/issues/red_flags.cfm?issue_type=right2die) (last visited Oct. 18, 2007).

118. Franklin et al., *supra* note 14, at 3.

119. *Id.*

120. *Id.*

121. *Id.* at 4.

122. *Id.*

tive, 77% of subjects changed their opinions when presented with a different end-of-life scenario with the same interventions, proving that some currently utilized forms and tools are confusing or misleading.<sup>123</sup>

## 2. HEALTH CARE PROVIDER'S PERSPECTIVE VERSUS PATIENT'S PERSPECTIVE

A study was conducted in Michigan to determine how health care providers viewed the effectiveness of advance directive arrangements in ensuring compliance with the patients' wishes, as well as the health care providers' overall satisfaction with the process.<sup>124</sup> Two-thirds of the responding hospitals reported that fewer than 26% of their patients completed advance directives, while two-thirds of the nursing homes reported that greater than 26% of their patients had completed them.<sup>125</sup> Overall, hospitals reported more difficulty than nursing home, assisted living, home care, and hospice groups in following up on advance directive information, obtaining advance directives from other facilities and agencies, and knowing when to implement an advance directive.<sup>126</sup> This is likely due to such factors as the shorter average length of stay and the crisis-oriented care found in hospitals.<sup>127</sup>

The study also compared the perceptions of health care providers with those of consumers as to why advance directives fail to be completed.<sup>128</sup> Overall, the top three reasons consumers believe patients fail to execute advance directives were: "not interested," "not ready," and "family knows wishes."<sup>129</sup> From the health care providers' perspective, the top three reasons were: "not ready," "in excellent

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123. *Id.*

124. Karen Neuman & Lois Wade, *Advance Directives: The Experience of Health Care Professionals Across the Continuum of Care*, 28 SOC. WORK IN HEALTH CARE 39, 44-45 (1999) ("[A] survey was administered to an interdisciplinary sample of health care providers practicing in a variety of settings. . . . Sixty-four percent . . . of the respondents indicated that they had direct responsibility in overseeing the facility's advance directives program or in discussing advance directives with patients' families.").

125. *Id.* at 45.

126. *Id.* at 45-46.

127. *Id.* at 46.

128. *Id.* at 39.

129. *Id.* at 47 tbl.3. The subsequent reasons, in order, were "being in excellent health," "needing to learn more," "waiting too long," "needing an attorney," and "it was too depressing." *Id.*

health,” and “need to learn more.”<sup>130</sup> More specifically, health care professionals from community-based programs, in home care, and assisted living were more likely to report the patients’ reasons were lack of interest or that they were in good enough health as to not need advance directives.<sup>131</sup> On the other hand, those in hospices, hospitals, and nursing homes reported that the reasons were the patients waited too long and no longer had the mental capacity to complete them.<sup>132</sup>

### 3. SURROGATE DECISION MAKING

Studies have shown that family members and physicians exhibit substantial inaccuracy when predicting patients’ life-sustaining treatment preferences without the use of an advance directive.<sup>133</sup> A 2001 study examined whether instructional directives are effective in improving the accuracy of surrogate decisions.<sup>134</sup> Elderly outpatients and their self-designated surrogate decision makers were either put into the control condition (in which surrogates predicted patients’ preferences for four life-sustaining medical treatments<sup>135</sup> in nine illness scenarios<sup>136</sup> without the benefit of a patient-completed advance directive) or into one of four intervention conditions (in which surro-

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130. *Id.* The last five reasons, in order, were “it was too depressing,” “the family knew the wishes,” “needing an attorney,” “not being interested,” and “having waited too long.” *Id.*

131. *Id.* at 46.

132. *Id.* at 47.

133. *Id.* at 50.

134. Peter H. Ditto et al., *Advance Directives as Acts of Communication: A Randomized Controlled Trial*, 161 *ARCHIVES INTERNAL MED.* 421, 422 (2001).

135. *Id.* at 422. The four life-sustaining medical treatments used were antibiotics for life-threatening pneumonia, cardiopulmonary resuscitation for cardiac arrest, emergency gallbladder surgery for life-threatening gallbladder infection, and artificial nutrition and hydration for inability to take food or water. *Id.* The four were chosen to represent different levels of invasiveness. *Id.*

136. *Id.* The nine different illness scenarios chosen were the patient’s current health; Alzheimer disease with moderately severe cognitive impairment; emphysema with severe physical limitations; coma persisting six weeks after a stroke with no obvious cognitive abilities and a physician opinion of no chance of recovery; the same coma scenario with a physician opinion of a very slight chance of recovery; stroke resulting in partial paralysis, language deficits, total dependence in activities of daily living and a physician opinion of no chance of improvement; coma persisting six weeks after a stroke scenario with a physician opinion of a very slight chance of improvement; colon cancer with fatigue, no pain, and a life expectancy of six months; and a similar cancer scenario with pain that requires the constant use of medication. *Id.* The nine were chosen to represent a wide range of conditions varying in their severity, nature of impairment, prognosis, and level of pain. *Id.*

gates made predictions after reviewing either a scenario-based or a value-based directive completed by the patient).<sup>137</sup>

The study found no significant improvements in accuracy of surrogate-substituted judgment in any illness scenario or for any medical treatment in any of the four intervention scenarios.<sup>138</sup> The goal for using instructional advance directives is patient self-determination.<sup>139</sup> The results of this study indicate the instructional advance directives currently used to guide surrogates through the decision-making process are not as effective as they should be.<sup>140</sup> However, although current instructional advance directives have not been found to effectively assist family members, they may improve the accuracy of decision makers with little or no past relationship with the patient and may stimulate conversation between the patient and family members after completion, leading to a better understanding of the patient's desires.<sup>141</sup>

#### 4. CULTURAL REASONS

In addition to a growing elderly population, the United States is also experiencing a growth in different cultural backgrounds, thus increasing the need for culturally sensitive health care.<sup>142</sup> Advance directive completion rates for all Americans are low, but are even lower for ethnic minorities.<sup>143</sup> The nation's overall concept of advance directives and patient self-determination is driven by a general belief in autonomy and individualism.<sup>144</sup> This concept stems from the culture and belief systems of the country's European American male majority.<sup>145</sup> This focus on the individual led to several assumptions<sup>146</sup> that

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137. *Id.* at 421.

138. *Id.* Surrogate predictions were correct less than 70% of the time on average for the Alzheimer disease, coma slight chance, stroke no chance, stroke slight chance, and cancer no pain scenarios. *Id.* at 424. The overall predictive accuracy in the no-advance directive condition was 72%. *Id.*

139. *Id.* at 421.

140. *Id.* at 428.

141. *Id.*

142. Ardith Z. Doorenbos & Mary A. Nies, *The Use of Advance Directives in a Population of Asian Indian Hindus*, 14 J. TRANSCULTURAL NURSING 17, 17 (2003).

143. *Id.* at 18.

144. *Id.* at 19.

145. James L. Werth, Jr. et al., *The Influence of Cultural Diversity on End-of-Life Care and Decisions*, 46 AM. BEHAV. SCIENTIST 204, 206 (2002).

146. American Psychological Association, *End-of-Life Issues and Care*, <http://www.apa.org/pi/eol/diversity.html> (last visited Oct. 18, 2007) [hereinafter *End-of-Life Issues*]. Some assumptions made about Americans in regard to health care include "(1) the individual is the primary decision-maker, (2) the individual

shaped the health care system, and affected the use of advance directives.<sup>147</sup> However, many minority groups in the United States do not share this individualistic belief system, leading to differing opinions regarding advance directives and end-of-life care.<sup>148</sup>

Studies have found lower completion rates, less knowledge, and more negative attitudes regarding advance care planning for African Americans, Hispanic Americans, Asian Americans, and Native Americans when compared to Americans of European descent.<sup>149</sup> Additionally, African Americans and Hispanic Americans tend to express a stronger preference for life-sustaining treatment than Americans of European descent, regardless of the severity of the circumstances.<sup>150</sup> Possibly due to bad experiences with health care professionals, these groups lack trust in their advice.<sup>151</sup> Additional reasons for the disparities may include differing beliefs about whether the patient should be made aware of terminal diagnoses, differing roles of family members in decision making,<sup>152</sup> differing beliefs on male authority, and negative feelings about the discussion of dying.<sup>153</sup>

People are likely to resort to their particular cultural backgrounds and teachings when faced with end-of-life health care decisions. Their religious and cultural beliefs often help them deal with concepts of illness and dying and guide them through difficult times.<sup>154</sup> Therefore, it is important for legislators and health care professionals to recognize cultural differences and provide adequate education and opportunity for individuals to make the decisions they believe are right for them.

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has an interest in being in charge, (3) there is a clear communication and understanding between the individual and the medical team about diagnosis, prognosis, and options, (4) the individual has equal financial access to the different options offered, (5) the individual has the power and sense of entitlement to make whatever choice is desired, (6) the individual values discussing and planning for death, and (7) the individual has a spiritual orientation that does not emphasize divine interventions, and allows for choice in time and manner of death." *Id.*

147. *Id.*

148. Werth, *supra* note 145, at 206.

149. Jung Kwak & William E. Haley, *Current Research Findings on End-of-Life Decision Making Among Racially or Ethnically Diverse Groups*, 45 GERONTOLOGIST 634, 635-36 (2005).

150. *Id.* at 637-38.

151. End-of-Life Issues, *supra* note 146.

152. Kwak & Haley, *supra* note 149, at 638-39.

153. End-of-Life Issues, *supra* note 146.

154. Kwak & Haley, *supra* note 149, at 634.

## 5. DIFFERENCES BETWEEN STATES

Although the goal of ensuring advance directives are available stems from the federal Patient Self-Determination Act, advance directive documents are based on statutes that vary from state to state.<sup>155</sup> Lack of portability from one state to another creates problems because the differences between forms can cause confusion and inconsistency.<sup>156</sup> Forms executed in one state could possibly be useless in another.<sup>157</sup>

All fifty states and the District of Columbia have at least one advance directive document derived from statute.<sup>158</sup> However, the types of forms used vary.<sup>159</sup> These differences indicate a clear problem that must be addressed and illustrate the need for a uniform system that would make advance directive documents portable and eliminate the currently ineffective system.

## 6. THE LAWYER'S ROLE

Finally, there is the question of the lawyer's role in the execution of advance directives. Many people simply cannot afford the services of an attorney and do not consider obtaining a lawyer's assistance when addressing end-of-life health care.<sup>160</sup> Additionally, although some may argue that leaving the job of drafting advance directive forms to laypeople and health care professionals could lead to problems down the road, lawyers are often too busy to treat these forms and situations with the degree of care they deserve.<sup>161</sup>

Also, there may be no need for attorneys at all if a standard form were adopted by all health care providers and health care profession-

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155. Gail Gunter-Hunt et al., *A Comparison of State Advance Directive Documents*, 42 GERONTOLOGIST 51, 51-52 (2002).

156. *Id.* at 52.

157. *Id.*

158. *Id.*

159. *Id.* at 52-53. "Three states had a living will only (with limited proxy) and lacked the durable power of attorney for health care (Pennsylvania, Louisiana, and Montana; 6%). Three states had durable power of attorney for health care only (Massachusetts, New York, and Michigan; 6%). Thirty-two ([thirty-one] states plus Washington, D.C.) had both living will and durable power of attorney for health care (63%), and [thirteen] states had the combination document, advance health care directive (25%)." *Id.*

160. Rita W. Morales, Case Note, *The Twilight Zone of Nancy Beth Cruzan: A Case Study of Nancy Beth Cruzan v. Director, Missouri Department of Health*, 34 HOW. L.J. 201, 227 (1991).

161. Bruce J. Winick, *Foreword: Planning for the Future Through Advance Directive Instruments*, 4 PSYCHOL. PUB. POL'Y & L. 579, 586 (1998).

als were trained in these matters. However, there is a strong argument attorneys are essential to the process because protecting the rights of those involved and the counseling and drafting skills required demand legal knowledge.<sup>162</sup>

## B. Outside the United States

Cultural differences between residents of the United States and other countries have led to differences in the use of advance directives to guide the health care of patients. These differences are important for three main reasons. First, the United States is the most diverse nation in the world, having received over nine million immigrants between 1991 and 2000,<sup>163</sup> making it important to understand how different cultures view health care and end-of-life decisions. Understanding these differences will help the systems in the United States be more effective. Second, the United States can look to both effective and ineffective systems used in other countries in order to better develop its own programs and troubleshoot problem areas. Finally, many countries look to policies in the United States, especially in the area of health care, as a guide for their own systems.<sup>164</sup> Therefore, it is important for the United States to use its money and other resources wisely and efficiently in order to be a good example for other countries attempting to incorporate quality end-of-life care.

### 1. JAPAN

In Japan, advance directives are not a legally endorsed expression of a patient's end-of-life health care wishes and are not legally binding on the health care provider.<sup>165</sup> Therefore, an advance direc-

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162. *Id.*

163. CARLTON MARTZ ET AL., CONSTITUTIONAL RIGHTS FOUND., CURRENT ISSUES OF IMMIGRATION, 2006, at 14 (2006), available at [http://www.crf-usa.org/immigration/Issues\\_of\\_Immigration\\_Ole\\_Final.pdf](http://www.crf-usa.org/immigration/Issues_of_Immigration_Ole_Final.pdf).

164. See Anthony S. Kessel & J. Meran, *Advance Directives in the UK: Legal, Ethical, and Practical Considerations for Doctors*, 48 BRIT. J. GEN. PRAC. 1263, 1263 (1998), available at <http://www.pubmedcentral.nih.gov/pagerender.fcgi?artid=1410166&pageindex=1#page>.

165. Rihito Kimura, *Death, Dying, and Advance Directives in Japan: Socio-Cultural and Legal Point of View*, in ADVANCE DIRECTIVE AND SURROGATE DECISION MAKING IN TRANSCULTURAL PERSPECTIVE (Hans-Martin Sass et al., eds., 1998), available at [http://www.bioethics.jp/licht\\_adv8.html](http://www.bioethics.jp/licht_adv8.html) (located in Section III: Advance Directives as a Non-Legal Document in Japan).

tive is simply a private document.<sup>166</sup> Several sociocultural traditions and mentalities have led to this form of advance directive usage. First, the physician-patient relationship in Japan is based on the tradition of the patient's complete and unquestioning trust in the physician—leaving any decision making to the physician.<sup>167</sup> Second, while in the United States respect for autonomy and self-determination drive the nation's moral beliefs regarding advance directives,<sup>168</sup> the Japanese tradition is focused on the family or other socially related group rather than on the individual.<sup>169</sup> Third, and likely the most influential, although patients' families are told of terminal diagnoses, health care providers in Japan often do not inform patients of their bleak circumstances.<sup>170</sup> One cannot make decisions and express wishes regarding end-of-life health care when one does not know the circumstances of one's own health.

However, discussions concerning advance directives have increased during the past decade<sup>171</sup> and recently there has been a push for the use of advance directives by several organizations.<sup>172</sup> The Japan Society for Dying with Dignity has made a general form available for patients to express their wishes for avoiding unwanted medical treatment.<sup>173</sup> The Citizen's Group in Thinking of Terminal Care has

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166. *Id.* (located in Section IV: Some Unique Elements in Japanese Advance Directives).

167. *Id.* (located in Section 3.1: Socio-Cultural Aspects). A survey found that 84.9% agreed the patient's will is not indispensable, meaning a patient's physician and family members would be granted the authority to make end-of-life health care decisions in "Do Not Resuscitate" circumstances. *Id.* Additionally, 68.4% agreed to have a decision made by the attending physician, showing the patient's lack of involvement in the decision-making process in those difficult situations. *Id.*

168. Akira Akabayashi et al., *Perspectives on Advance Directives in Japanese Society: A Population-Based Questionnaire Survey*, BMC MED. ETHICS, Oct. 2003, at 9, available at <http://www.biomedcentral.com/content/pdf/1472-6939-4-5.pdf>.

169. Kimura, *supra* note 165 (located in Section 3.1: Socio-Cultural Aspects). The focus on family and socially related groups stems from the traditional Japanese mentality of "Amae," which is a sense of interdependence. *Id.*

170. *Id.* "A mixture of Shinto, Confucian, and Buddhist beliefs wherein death should not be hastened to avoid disturbing the harmony of the universe also muddle the issue, as does a commonly-held view that life and one's body are to be regarded as gifts from one's parents to be treated with traditional filial piety." *Id.*

171. Akabayashi et al., *supra* note 168, at 1.

172. Kimura, *supra* note 165 (located in Section IV: Some Unique Elements in Japanese Advance Directives).

173. *Id.* ("The 'Dying with Dignity Declaration' requests that medical technology not be used to artificially prolong life in irreversible or incurable situations, asks that effective pain reduction methods be used even though they may hasten death, and permits the withdrawing of life-sustaining technologies in the case of a persistent vegetative state of several months duration.").



also issued a type of advance directive, which attempts to simplify the process with a check mark system and combines the characteristics of a living will and a durable power of attorney.<sup>174</sup> Finally, the Student Bioethics Study Group at Kyoto Women's University created an advance directive document for pregnant women.<sup>175</sup>

## 2. CANADA

Much like the United States' state-specific legislation on advance directives, Canadian legislation on advance directives falls under provincial jurisdiction with eleven approaches corresponding to the ten provinces and one territory.<sup>176</sup> Also like the United States, the courts and general public of Canada acknowledge the importance of advance directives and the public wishes to effectively implement them into their lives.<sup>177</sup> However, also like the United States, the use of advance directives is not widespread.<sup>178</sup> In 1998, only 10% of Canadians had completed an advance directive.<sup>179</sup> However, an increasing number of Canadians are beginning to document their end-of-life health care wishes through advance directive documentation, and it is predicted Canadian health care will continue to see an increase in advance directive utilization.<sup>180</sup>

Unlike the United States, Canada's national government has not encouraged the use of advance directives.<sup>181</sup> However, individual health care providers, local hospitals, medical schools, nursing schools, and other private organizations have promoted the documentation of end-of-life care wishes.<sup>182</sup> Recently, the Let Me Decide pro-

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174. *Id.*

175. *Id.* For example, one statement says, "if a guardian for the unborn baby had previously been designated, the document specifying this should be retracted and the best medical treatment for continuation of pregnancy and delivery should be performed." *Id.*

176. Alister Browne & Bill Sullivan, *Advance Directives in Canada*, 15 CAMBRIDGE Q. HEALTHCARE ETHICS 256, 256 (2006).

177. *Id.*

178. Canadian Association of Critical Care Nurses, *Advance Directives*, <http://caccn.ca/new/index.php?fuseaction=view.content&item=56> (last visited Oct. 18, 2007) [hereinafter *Advance Directives*]. "A 1997 survey conducted at the Canadian Association of Critical Care Nurses national conference found that eighty percent of respondents had cared for at least one patient with an advance directive and that eighty-nine percent of respondents were in favor of advance directives." *Id.*

179. Browne & Sullivan, *supra* note 176, at 259.

180. *Advance Directives*, *supra* note 178.

181. Browne & Sullivan, *supra* note 176, at 260.

182. *Id.*

gram was developed and has had promising results to date.<sup>183</sup> This system gives patients and family members the opportunity to record health care choices regarding levels of care, nutritional support, and cardiopulmonary resuscitation.<sup>184</sup> A recent study of the program indicated a higher rate of planning and, more specifically, that the “plans were more specific, residents were less likely to die in the hospital, fewer resources were used, and families were more satisfied with the process than were family members . . . using more traditional advance care planning.”<sup>185</sup>

### 3. BRITAIN

Unlike the United States, Britain does not have statutory regulation regarding advance directives for end-of-life health care.<sup>186</sup> Instead, the requirements for a legally valid, anticipated refusal of medical treatment stem from case law.<sup>187</sup> According to precedent, for an anticipated refusal to be legally valid, the patient must be competent at the time of the declaration, informed in broad terms about the nature and effect of the procedure, have anticipated and intended the refusal to apply to the circumstances that subsequently arose, and be free from undue influence when issuing the declaration.<sup>188</sup>

In response to the United States’ passage of the Patient Self Determination Act, the British Medical Association (BMA) published a report on advance directives to provide guidance for those in Britain.<sup>189</sup> The BMA intended to encourage dialogue regarding individuals’ future medical treatment and proposed six types of advance directives.<sup>190</sup> As a result, the BMA supports the use of advance directives

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183. Hickman et al., *supra* note 15, at S27.

184. *Id.*

185. *Id.*

186. Kessel & Meran, *supra* note 164, at 1263.

187. *Id.*, e.g. *In re T*, (1992) 3 W.L.R. 782 (A.C.). A twenty-year-old woman, thirty-four weeks pregnant, told a nurse she did not want a blood transfusion due to religious reasons after being injured in a car accident before any need for one arose. *Id.* The court ruled that the woman’s request was invalid because she had a false sense of security and was misinformed as to the availability and effectiveness of alternative procedures. *Id.*

188. Kessel & Meran, *supra* note 164, at 1263.

189. *Id.*

190. *Id.* The six different types of advance directives discussed are a requesting statement reflecting an individual’s aspirations and preferences, a statement of general beliefs and aspects of life that the individual values, a statement naming a proxy, a directive giving clear instructions refusing some or all treatment(s), a statement specifying a degree of irreversible deterioration after which no life-sustaining treatment should be given, and a combination of the above. *Id.*

and recognizes their legally binding effect on health care professionals when the four conditions noted above are met.<sup>191</sup> Additionally, despite a lack of legislation from Parliament, there is a general understanding of what cannot be legally requested through an advance directive, including the refusal of food or drink by mouth and the request of anything that is against the law, such as euthanasia, and assisting suicide.<sup>192</sup>

Therefore, it seems as though Britain is trailing the United States in its use of advance directives, but has acknowledged the importance of their use and is encouraging further implementation.

#### 4. THE NETHERLANDS

The Netherlands takes a much more liberal view of end-of-life care in comparison to the United States and the other countries previously discussed. Like the United States, the Netherlands recognizes the right to refuse life-sustaining treatment.<sup>193</sup> Unlike most countries, however, in the past the Dutch permitted assisted suicide and even more active forms of euthanasia, such as physician-administered lethal injection.<sup>194</sup> These practices were regulated, but not completely outlawed, until the introduction of a new law in April 2002.<sup>195</sup> The law states that euthanasia and assisted suicide are criminal offenses unless they are performed by a physician who follows six specified rules of due care and reports the case to an assessment committee.<sup>196</sup>

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191. *Advance Decision: Explanatory Information and Form*, ALZHEIMER'S SOCIETY, June 2007, [http://www.alzheimers.org.uk/After\\_diagnosis/PDF/463\\_advance\\_decision.pdf](http://www.alzheimers.org.uk/After_diagnosis/PDF/463_advance_decision.pdf).

192. *Id.* Additional limitations on advance directives include refusal of basic nursing care essential to keep one comfortable, refusal of the use of measures designed to maintain comfort such as painkillers, and any demand for care the relevant health care team considers inappropriate. *Id.*

193. Vicki Lens, *Natural Death Acts*, ENCYCLOPEDIA OF DEATH AND DYING, <http://www.deathreference.com/Me-Nu/Natural-Death-Acts.html> (last visited Oct. 18, 2007).

194. *Id.*

195. J.J.M. van Delden, *The Unfeasibility of Requests for Euthanasia in Advance Directives*, 30 J. MED. ETHICS 447, 447 (2004), available at <http://jme.bmj.com/cgi/reprint/30/5/447.pdf>.

196. *Id.* The six rules are: the physician must be convinced the request of the patient was voluntary and well considered; the physician must be convinced the suffering of the patient was unbearable and without prospect of relief; the patient must be informed about his/her situation and prospects; the physician, together with the patient, must be convinced there was no reasonable alternative solution for the situation; at least one other physician must have seen the patient and must have given a written statement containing his evaluation of the four previous re-

This new law also addresses advance directives that request the end of life in certain circumstances where an incompetent patient made the request while still competent.<sup>197</sup> A physician is allowed to act upon that written request, as long as the physician follows the other rules of due care.<sup>198</sup> Similar to laws in the United States, the new Dutch laws permit the use of, and adherence to, advance directives.<sup>199</sup> However, the Dutch laws go one large step further than any legislation found in the United States by allowing limited assisted suicide. In addition to questions about the effectiveness and prevalence of assisted suicide in the Netherlands, much debate surrounds the moral issues of the practice and whether assisted suicides have actually been involuntary.<sup>200</sup> Despite opponents' claims, some contend euthanasia rates are just as high in other countries as in the Netherlands, just not as evident.<sup>201</sup>

#### IV. Resolution and Recommendation

The United States has the most expensive health care system in the world, estimated to cost \$2.2 trillion, or \$7,129 per person, in 2006.<sup>202</sup> This does not necessarily mean the United States has the best system, though it is arguably superior to the majority of health care systems throughout the world, particularly in regard to advance directives and end-of-life care planning. However, improvements can still be made. The great majority of the public recognizes the importance of advance care planning and an efficient system to carry out patients' documented wishes.<sup>203</sup> Our legislators' and health care professionals' goal should be to ensure all Americans receive their desired

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quirements; and the ending of life must be performed in a professional and careful way. *Id.*

197. *Id.* at 449.

198. *Id.*

199. Suzanne Daley, *The Dutch Seek to Legalize Long-Tolerated Euthanasia*, N.Y. TIMES, June 20, 2000, at A1.

200. See Lens, *supra* note 193.

201. *Id.*

202. Julie Appleby, *Consumer Unease with U.S. Health Care Grows*, USA TODAY, Oct. 15, 2006, [http://www.usatoday.com/money/industries/health/2006-10-15-health-concern-usat\\_x.htm](http://www.usatoday.com/money/industries/health/2006-10-15-health-concern-usat_x.htm).

203. See Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 258 (1997) (indicating data shows "a huge majority of the public are in favor of the concept of advance directives, but that only 10-to-15 percent of them had prepared one") (citation omitted).

treatment at such critical moments. Two major, yet not overly costly or difficult, actions should be taken to assist in accomplishing that goal.

First, the ADIEA should be passed. Increased education and discussion about advance directives, and decreased costs for consultation with physicians would result from the ADIEA and help accomplish the greater goal of making it easier for patients and their family members to receive their desired end-of-life care. However, one key aspect of the ADIEA would be particularly beneficial. The current state statute-based system ultimately limits the effectiveness of prior-executed advance directives forms when the patient moves from one state to another. If the executed form does not meet the statutory requirements of the treating state, it will not be honored by the health care professionals and the patient's documented wishes regarding end-of-life care will be ignored. The ADIEA's requirement to honor advance directives executed in another state would greatly improve the effectiveness of advance directives and make it easier for everyone involved to ensure one's important end-of-life care wishes are carried out.

The implementation process, rather than the actual law and attitudes of individuals, may explain advance directives' low usage rate. Therefore, even if the ADIEA is not passed and the law does not change, a change in how advance directives are used under current law may produce the desired results. Although statutes regarding advance directives differ from state to state, the nation would benefit from adopting one, all-encompassing advance directive form. As noted above, several forms distributed by private organizations have proven to be effective in producing the desired results of patients and their family members.<sup>204</sup> If Congress were to choose one of these forms, or a combination thereof, thereby eliminating the wide variety of forms used throughout the country, it would solve several problems.

A well-designed form with clear instructions would eliminate confusion where the listed wishes are ultimately either too vague or too specific. It would also eliminate the need for costly attorneys because proper legal wording and instructions for end-of-life care would no longer be an issue. Additionally, using one form and making it

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204. See *supra* Part II.C.

standard procedure for all patients to execute one at a particular time would ensure an ever-increasing amount of people would be knowledgeable about their options and have their wishes documented.

Problems regarding the physician-patient relationship would also be diminished. Specifically, physicians would no longer have to initiate an uncomfortable conversation regarding the patient's end-of-life care. However, they would still be available for any questions the patient may have regarding the form. Finally, one standard form could eliminate some of the cultural reasons that so many people in the United States do not execute advance directive forms. For example, Aging with Dignity recently enacted a new initiative to translate their Five Wishes form into twenty new languages.<sup>205</sup> The translations will increase the use of the Five Wishes form, already widely distributed and receiving praise, and make it easier for the increasing number of immigrants to the United States to document their wishes.

## V. Conclusion

The ability to choose how one would like to be treated at the end of life is a constitutional right that is greatly underused. Despite the lack of prevalence of advance directive execution in the United States, most Americans agree that it is an important right that should be utilized. Fortunately, U.S. legislators have recognized this dilemma and are attempting to pass the Advance Directives Improvement and Education Act. The ADIEA would likely assist in bringing the significance of advance directive documents to the forefront of the minds of many Americans. However, the low rate of execution will likely continue unless the ADIEA is supplemented with one standard form that is readily available to everyone.

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205. Aging with Dignity, Five Wishes Translations, <http://www.agingwithdignity.org/translations.html> (last visited Oct. 18, 2007).