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### The Limitations of Legislation

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# THE LIMITATIONS OF LEGISLATION

DAVID ORENTLICHER\*

## TABLE OF CONTENTS

Introduction .....	1256
I. Types of End-of-Life Statutes .....	1258
A. Living-Will Laws .....	1258
B. Durable Power of Attorney for Health Care Laws ...	1259
C. Do Not Resuscitate Order Laws .....	1260
D. Health Care Surrogate Laws .....	1260
II. Problems with End-of-Life Statutes .....	1261
A. Misleading the Public About its Rights .....	1261
1. The Absence of a Statute .....	1261
2. Statutory Limitations .....	1263
B. Ambiguous Provisions .....	1268
C. Discerning Patients' Wishes .....	1268
D. Inadequate Compensation for Physicians .....	1275
E. Socioeconomic Differences .....	1276
F. Failure of Surrogates to Represent Patients' Wishes .	1277
III. Predominance of Physicians' Values in End-of-Life Decisions .....	1280
A. Evidence of the Predominance of Physicians' Values .....	1281
B. Reasons for the Predominance of Physicians' Values .....	1288
1. Natural Lag Between Theory and Practice .....	1288
2. Fear of Malpractice .....	1289
3. Futility of End-of-Life Care .....	1289
4. Patients Do Not Want to Exercise Their Autonomy .....	1290
5. Patients Lack Authority .....	1293

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6. Preservation of Professional Authority .....	1294
C. Conflicting Evidence .....	1299
IV. Potential Solutions .....	1301
A. Reform the Laws .....	1301
B. Acknowledgement and Discussion .....	1302
C. Physician Payment Reform.....	1303
D. Strengthen Legal Doctrine of Informed Consent....	1303
E. Physicians Should Distribute Values Histories .....	1304
Conclusion .....	1305

## INTRODUCTION

When prominent court cases illuminate the difficult moral issues involved in end-of-life decisions, legislatures often respond by enacting statutes designed to help resolve the dilemmas that the cases raise. For example, shortly after the New Jersey Supreme Court decided the landmark *Quinlan* case<sup>1</sup> in 1976, California enacted the nation's first living-will statute, the California Natural Death Act.<sup>2</sup> Similarly, after the United States Supreme Court issued its first (and only) life-sustaining-treatment decision in 1990,<sup>3</sup> the federal government enacted the Patient Self-Determination Act,<sup>4</sup> and several states passed new end-of-life statutes or amended existing ones.<sup>5</sup> At this point, all states and the District of Columbia have adopted at least one of the following kinds of statutes concerning end-of-life decisions for patients who have lost decisionmaking capacity: living-will laws, durable power of attorney for health care laws, do not resuscitate order laws, and health

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1. *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied*, 429 U.S. 922 (1976) (holding that patients have a constitutional right to have life-sustaining treatment discontinued).

2. George J. Annas, *The Health Care Proxy and the Living Will*, 324 NEW ENG. J. MED. 1210, 1210 (1991).

3. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

4. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, § 4206 (1990); 104 Stat. 1388-115 (1990) (codified as amended at 42 U.S.C. § 1395cc (1988 & Supp. 1992)).

5. See generally Fenella Rouse, *The Role of State Legislatures After Cruzan: What Can—and Should—State Legislatures Do?*, 19 LAW, MED. & HEALTH CARE 83 (1991).

care surrogate laws.<sup>6</sup> Some states, including Maryland, combine two or more of these different kinds of laws into a single statute.<sup>7</sup>

This response is not surprising. Many of the court cases have arisen due to uncertainty about the law. In addition, when courts reach decisions about withdrawing life-sustaining treatment, they regularly observe that the legislatures, rather than the judiciary, should be resolving the ethical and legal dilemmas posed by end-of-life decisions. According to several courts, the issues involved are not well-suited for the adversarial process, and unlike courts, legislatures have the resources and ability to entertain and synthesize the full range of relevant perspectives.<sup>8</sup>

Without doubt, laws dealing with end-of-life decisions have generated some benefits. They have reminded the public of the importance of considering in advance how they would wish to be medically treated if they became terminally ill, and they have reminded physicians of the importance of respecting patient preferences when making life-sustaining treatment decisions for incompetent patients.

Yet, there are serious limitations to, and even disadvantages of, end-of-life statutes. The statutes may mislead patients about their rights. Even if not misleading, the statutes are unlikely to achieve the goals of their proponents. Even the best statutes cannot ensure that physicians understand the preferences of their patients regarding

6. See generally Choice in Dying, Inc., RIGHT-TO-DIE LAW DIGEST: A QUARTERLY REVIEW OF LEGISLATIVE ACTIVITY AND CASE LAW (1993) [hereinafter RIGHT-TO-DIE LAW DIGEST.] In 1990, the federal government enacted the Patient Self-Determination Act (PSDA), which requires hospitals and other health care organizations to inform patients of their rights to accept or refuse medical treatment and their rights to use advance directives. John La Puma et al., *Advance Directives on Admission: Clinical Implications and Analysis of the Patient Self-Determination Act of 1990*, 266 JAMA 402, 402 (1991).

The PSDA is beyond the scope of this article. Useful articles on the PSDA include Peter J. Greco et al., *The Patient Self-Determination Act and the Future of Advance Directives*, 115 ANNALS INTERNAL MED. 639 (1991); Jeremy Sugarman et al., *The Cost of Ethics Legislation: A Look at the Patient Self-Determination Act*, 3 KENNEDY INST. OF ETHICS J. 387 (1993); Joan M. Teno et al., *The Impact of the Patient Self-Determination Act's Requirement that States Describe Law Concerning Patients' Rights*, 21 J. L. MED. & ETHICS 102 (1993); Susan M. Wolf et al., *Sources of Concern About the Patient Self-Determination Act*, 325 NEW ENG. J. MED. 1666 (1991); *Practicing the PSDA*, Special Supplement, HASTINGS CENTER REP., Sept.-Oct. 1991, at S1; OFFICE OF INSPECTOR GENERAL, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, PATIENT ADVANCE DIRECTIVES: EARLY IMPLEMENTATION EXPERIENCE (1993); OFFICE OF INSPECTOR GENERAL, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, PATIENT ADVANCE DIRECTIVES: FACILITY AND PATIENT RESPONSES (August 1993).

7. See, e.g., MD. CODE ANN., HEALTH-GEN. §§ 5-601 to -618 (1994); FLA. STAT. ANN. §§ 765.101-.401 (West 1993); N.J. STAT. ANN. §§ 26:2H-53 to -78 (West 1993).

8. See Rasmussen v. Fleming, 741 P.2d 667, 691-92 (Ariz. Ct. App. 1986); Satz v. Perlmuter, 379 So. 2d 359, 360 (Fla. 1980); *In re Conroy*, 486 A.2d 1209, 1220-21 (N.J. 1985); *In re Hamlin*, 689 P.2d 1372, 1379 (Wash. 1984).

end-of-life care. More importantly, whether or not they are aware of patient preferences, physicians generally seem to make treatment decisions that reflect their own preferences rather than the preferences of their patients. This Article reviews the problems with end-of-life statutes and suggests measures to deal with those problems.

## I. TYPES OF END-OF-LIFE STATUTES

End-of-life statutes break down into two categories, statutes that provide for advance directives and statutes that provide for end-of-life decisionmaking for patients who have not written an advance directive. Among the statutes that provide for advance directives are living-will laws, durable power of attorney for health care laws, and do not resuscitate order laws. Health care surrogate laws provide for decisionmaking when the patient has not written an advance directive.

### A. *Living-Will Laws*

Living wills are documents in which individuals indicate whether they desire life-sustaining treatment during the final stages of life. They are termed "living" wills because they take effect while the person is still alive (but after the person has lost the ability to make medical decisions).<sup>9</sup> In their living wills, people can dictate which treatments should be provided and under what circumstances they should be provided.<sup>10</sup> For example, a person may want a feeding tube, but not a ventilator, if terminally ill or may want neither a feeding tube nor ventilator if permanently unconscious. An alternative name for a living will is a treatment directive.

Traditionally, living wills have included only general statements about life-sustaining treatment (e.g., no life-sustaining treatment if an irreversible and terminal illness develops).<sup>11</sup> More recently, legislatures and scholars have developed detailed forms in which people can provide clearer guidance. For example, in one approach, the form contains several possible illness scenarios, and people can indicate which of more than a dozen medical treatments they would want for each scenario.<sup>12</sup> Because the number of possible treatment decisions far exceeds those contained in even the most detailed document, another form asks people to provide detailed information about their values so that, when treatment decisions arise, doctors or surrogates

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9. David Orentlicher, *Advance Medical Directives*, 263 JAMA 2365, 2365 (1990).

10. *Id.*

11. See, e.g., ALA. CODE § 22-8A-4(c) (1990); ALASKA STAT. § 18.12.010(c) (1991).

12. Linda L. Emanuel & Ezekiel Emanuel, *The Medical Directive: A New Comprehensive Advance Care Document*, 261 JAMA 3288 (1989).

can make appropriate decisions from application of the patient's values to the situation at hand. This approach is termed a "values history."<sup>13</sup> In a third approach, the American Medical Association recommends that patients describe their goals of treatment (e.g., treatment should be provided only if it restores the ability to communicate with others, or treatment should be provided as long as it can maintain life).<sup>14</sup> Under this approach, when a treatment decision arises, a physician would provide treatment only if it served the patient's stated goals.

Living-will statutes tend to be limited in scope, often applying only to patients who are terminally ill or permanently unconscious and often restricting the freedom to have artificial nutrition and hydration discontinued.<sup>15</sup>

### B. *Durable Power of Attorney for Health Care Laws*

Instead of giving directions about which treatments should or should not be provided, people can dictate who should make medical decisions on their behalf in the event that they become unable to make medical decisions for themselves. In other words, an individual can appoint a proxy or surrogate decisionmaker and give the surrogate authority to make any medical decision that the patient would be entitled to make if the patient were mentally competent.<sup>16</sup> In making medical decisions for the patient, the surrogate attempts to deduce the patient's preferences from the patient's previously expressed wishes or goals of treatment and the patient's personal values.

Rather than choose between a living will or a proxy appointment, people can also combine the two kinds of advance directive into a single directive.<sup>17</sup> In such cases, a patient appoints a surrogate and instructs the surrogate to follow the patient's instructions regarding treatment.<sup>18</sup> When instructions fail to give adequate guidance, surrogates have authority to make their best judgment about the patient's preferences.<sup>19</sup>

13. Pam Lambert et al., *The Values History: An Innovation in Surrogate Medical Decision-Making*, 18 LAW, MED. & HEALTH CARE 202 (1990).

14. AMERICAN MEDICAL ASSOCIATION, *ADVANCE MEDICAL DIRECTIVES FOR PATIENTS: A GUIDE TO LIVING WILLS AND POWERS OF ATTORNEY FOR HEALTH CARE* 9, 12-13 (1992).

15. Charles P. Sabatino, *Death in the Legislature: Inventing Legal Tools for Autonomy*, 19 N.Y.U. REV. L. & SOC. CHANGE 309, 313, 330 (1991-92).

16. Orentlicher, *supra* note 9, at 2366. The patient also can limit the surrogate's authority to only certain kinds of decisions.

17. *Id.*

18. *Id.*

19. *Id.*

Most durable power of attorney statutes prescribe forms that allow for appointing a surrogate and for instructing the surrogate regarding treatment.<sup>20</sup> Proxy laws are less likely than living-will laws to limit their application to terminally ill or permanently unconscious patients. They often apply to patients with any diagnosis. Similarly, they are less likely to have restrictions on the kinds of treatment that the surrogate can order withdrawn.<sup>21</sup>

### C. *Do Not Resuscitate Order Laws*

A do not resuscitate (DNR) order allows a patient to request not to receive cardiopulmonary resuscitation (CPR) if the patient suffers a cardiac arrest. In essence, a patient's request not to be resuscitated is simply a living will requesting that the patient not receive one kind of treatment—CPR. CPR has probably been singled out for special consideration because, if it is withheld, the patient will die inevitably and immediately.

Generally, states have enacted DNR order statutes for one of two purposes. Some laws, as in New York,<sup>22</sup> were enacted to cover DNR orders for patients in health care facilities and are designed to ensure that CPR is not withheld by mistake or without proper consent.<sup>23</sup> Other laws apply to the emergency medical services setting and are designed to make clear that paramedics can respect a patient's wishes not to be resuscitated. Often these laws, as in Maryland,<sup>24</sup> are included as a provision of a comprehensive advance directive statute.

### D. *Health Care Surrogate Laws*

Despite considerable publicity about advance directives, most people do not use them. Surveys find that only between four and seventeen and a half percent of adult Americans have completed an advance directive.<sup>25</sup> Accordingly, many states have enacted statutes

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20. See, e.g., CAL. CIVIL CODE §§ 2430-2444 (West 1993); COLO. REV. STAT. §§ 15-14-501 to -502 (1989); GA. CODE ANN. §§ 31-36-1 to -13 (Michie 1993); IDAHO CODE §§ 39-4501 to -4509 (1993); MD. CODE ANN., HEALTH-GEN. §§ 5-601 to -618 (1994).

21. See *supra* note 20.

22. N.Y. PUB. HEALTH LAW §§ 2960-2979 (McKinney Supp. 1993); see also GA. CODE ANN. §§ 31-36-2 to -13 (Michie 1991).

23. See generally Russell S. Kamer et al., *Effect of New York State's Do-Not-Resuscitate Legislation on In-Hospital Cardiopulmonary Resuscitation Practice*, 88 AM. J. MED. 108 (1990).

24. MD. CODE ANN., HEALTH-GEN. § 5-608 (1994); see also ARIZ. REV. STAT. ANN. § 36-3251 (1993); VA. CODE ANN. § 54.1-2987.1 (Michie Supp. 1993).

25. La Puma et al., *supra* note 6, at 402. Not surprisingly, certain subgroups of the population are more likely to complete advance directives. For example, patients with HIV-related diseases use advance directives at a higher rate than does the general population. Joan M. Teno et al., *The Use of Formal Prior Directives Among Patients with HIV-Related*

giving authority to family members or close friends to make end-of-life decisions for patients who have not completed advance directives.<sup>26</sup>

The surrogate laws list potential surrogates (e.g., guardian, spouse, child, parent, sibling, or close friend) and prioritize them on the basis of decisionmaking authority.<sup>27</sup> Often, physicians or potential surrogates can invoke surrogate laws only when a patient has a qualifying condition—typically a terminal illness, permanent unconsciousness, or a condition in which the burdens of life markedly outweigh the benefits.<sup>28</sup>

## II. PROBLEMS WITH END-OF-LIFE STATUTES

There are a number of problems with the different types of statutes that facilitate end-of-life decisionmaking for patients who have lost decisionmaking capacity.<sup>29</sup>

### A. *Misleading the Public About Its Rights*

1. *The Absence of a Statute.*—When legislatures pass statutes that recognize advance directives or surrogate decisionmaking, they create the impression that there is no right to issue an advance directive, or be represented by a surrogate, if an enabling statute has not been passed. Otherwise, why bother with the statutes at all? Yet, the rights granted in these statutes often simply duplicate common law or constitutional rights. For example, in discussing durable powers of attorney for health care in her concurrence in the *Cruzan* case, Justice O'Connor observed that states "may well be constitutionally required"<sup>30</sup> to respect an incompetent patient's prior appointment of a surrogate decisionmaker. Similarly, even under the most stringent ev-

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*Diseases*, 5 J. GEN. INTERNAL MED. 490, 493 (1990). Seriously ill patients also appear to be more likely to complete advance directives. Joanne Lynn & Joan M. Teno, *After the Patient Self-Determination Act: The Need for Empirical Research on Formal Advance Directives*, HASTINGS CENTER REP., Jan.-Feb. 1993, at 20, 21.

26. RIGHT-TO-DIE LAW DIGEST, *supra* note 6, at "Surrogate Decisionmaking" chapter; see also Jerry A. Menikoff et al., *Beyond Advance Directives—Health Care Surrogate Laws*, 327 NEW ENG. J. MED. 1165, 1165-66 (1992) (describing the benefits of statutes that designate a "backup" surrogate decisionmaker).

27. See, e.g., ILL. ANN. STAT. ch. 755, para. 40/25 (Smith-Hurd Supp. 1992); MD. CODE ANN., HEALTH-GEN. § 5-605 (1994).

28. See, e.g., ILL. ANN. STAT. ch. 755, para. 40/20 (Smith-Hurd Supp. 1992); MD. CODE ANN., HEALTH-GEN. § 5-606(b) (1994).

29. For an informative and recent discussion of the problems with advance directive laws, see Ardath A. Hamann, *Family Surrogate Laws: A Necessary Supplement to Living Wills and Durable Powers of Attorney*, 38 VILL. L. REV. 103, 123-34 (1993).

30. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 289 (1990) (O'Connor, J., concurring).



identitary standards used in end-of-life cases—New York's<sup>31</sup> and Missouri's<sup>32</sup> clear and convincing evidence standards—a patient's prior written rejection of life-sustaining treatment would be adequate proof of the patient's wishes to allow a physician to withdraw treatment.<sup>33</sup> Indeed, in *In re Westchester County Medical Center*,<sup>34</sup> when discussing the clear and convincing evidence standard, the New York Court of Appeals stated that "[t]he ideal situation is one in which the patient's wishes were expressed in some form of a writing, perhaps a 'living will,' while he or she was still competent."<sup>35</sup> Florida's Supreme Court upheld the validity of a living will that a patient wrote nine years before the enactment of Florida's living will statute.<sup>36</sup> Arizona's Supreme Court endorsed the concept of a durable power of attorney for health care before the state had an authorizing statute.<sup>37</sup>

Although court cases may ultimately vindicate common law or constitutional rights and demonstrate that statutory authorization is not necessary, many medical decisions will be made in the meantime and may unfortunately be made on the incorrect assumption that life-sustaining treatment cannot be withdrawn or withheld without statutory authorization. The inappropriate dependence on statutory authorization is especially prevalent among emergency system personnel. Recently, emergency personnel have advocated for the enactment of statutes that specifically permit people to reject CPR when they are outside of a hospital or nursing home.<sup>38</sup> Without these special DNR statutes, emergency personnel reason that they are obligated to administer CPR in the event of a cardiac arrest outside of a hospital or nursing home, even if the person has clearly requested that CPR not be administered.<sup>39</sup> This is so even though there is nothing about the right to refuse life-sustaining treatment that confines that right to hospital or nursing home wards, and there is no reason why a person

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31. *In re Westchester County Med. Ctr.*, 531 N.E.2d 607, 613-15 (N.Y. 1988).

32. *Cruzan v. Harmon*, 760 S.W.2d 408, 415 (Mo. 1988), *aff'd sub nom. Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

33. David Orentlicher, *The Right to Die After Cruzan*, 264 JAMA 2444, 2445 (1990); Alan Meisel, *Legal Myths About Terminating Life Support*, 151 ARCHIVES INTERNAL MED. 1497, 1501 (1991).

34. 531 N.E.2d 607 (N.Y. 1988).

35. *Id.* at 613.

36. *John F. Kennedy Memorial Hosp., Inc. v. Bludworth*, 452 So. 2d 921 (Fla. 1984).

37. *Rasmussen v. Fleming*, 741 P.2d 667, 688 n.21 (Ariz. Ct. App. 1986).

38. Many states have enacted such statutes. See, e.g., COLO. REV. STAT. §§ 15-18.6-101 to 15-18.6-108; GA. CODE ANN. §§ 31-39-1 to 31-39-9.

39. Kenneth V. Iserson & Carol Stocking, *Standards and Limits: Emergency Physicians' Attitude Toward Prehospital Resuscitation*, 11 AM. J. EMERGENCY MED. 592, 593 (1993); Kenneth V. Iserson, *Foregoing Resuscitation: Should Ambulance Staff Always Resuscitate?*, 17 J. MED. ETHICS 19, 23 (1991).

should be required to have a different document for each place in which life-sustaining treatment might be administered.<sup>40</sup>

The assumption that the lack of a statute means that no rights exist is particularly troublesome when advance documents have not been written. Ordinarily, when the patient has not left an advance directive, family members are relied upon to make decisions for the patient. Indeed, physicians have historically turned to family members for medical decisions when patients are mentally incompetent, and courts generally have recognized the authority of families to make life-sustaining treatment decisions for incompetent patients.<sup>41</sup> However, since some states have adopted health care surrogate laws, physicians in other states may wonder whether they can implement a family member's decision in the absence of an enabling statute, particularly since the Supreme Court rejected a constitutional basis for family decisionmaking.<sup>42</sup> Because in the overwhelming majority of cases there is no advance directive, uncertainty about family authority could have a profound effect on end-of-life decisionmaking.

2. *Statutory Limitations.*—As a corollary to the assumption that certain rights do not exist without an enabling statute, people also may mistakenly assume that the statutes enunciate the full extent of a patient's right and that any rights not enunciated do not exist. For example, if a living-will statute applies specifically to terminally ill patients, as some do,<sup>43</sup> people are likely to conclude mistakenly that the right to use a living will does not extend to patients who, for example,

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40. To be sure, patients may want CPR for some cardiac arrests but not others. For example, a patient may not want to be resuscitated if her condition deteriorates and her heart stops beating. Conversely, if she is undergoing surgery and her heart stops beating because of a reversible anesthetic complication, she may want to be resuscitated. Consequently, patients may need to specify in their advance directives whether they want a DNR order to always apply or apply only in certain situations. See Cynthia B. Cohen & Peter J. Cohen, *Do-Not-Resuscitate Orders in the Operating Room*, 325 NEW ENG. J. MED. 1879, 1880-81 (1991) (proposing a policy of "required reconsideration" of DNR orders before surgery); see also Robert M. Walker, *DNR in the OR: Resuscitation as an Operative Risk*, 266 JAMA 2407, 2407 (1991) (arguing that intraoperative DNR orders should be permissible); Stuart J. Youngner et al., *DNR in the Operating Room: Not Really a Paradox*, 266 JAMA 2433 (1991) (discussing the medical and ethical implications of intraoperative DNR orders).

41. See Sabatino, *supra* note 15, at 319-20.

42. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 286-87 (1990).

43. See, e.g., ALA. CODE § 22-8A-4(a) (1990); DEL. CODE ANN. tit. 16, § 2503(a) (1983); KAN. STAT. ANN. § 65-28,103(a) (1993); MO. ANN. STAT. § 459.025 (Vernon Supp. 1992); N.D. CENT. CODE § 23-06.4-04 (1991); OR. REV. STAT. §§ 127.605, 127.610 (1990). Since the Supreme Court decided the *Cruzan* case, many living will statutes that were limited to only terminally ill patients now include permanently unconscious patients. See, e.g., CAL. HEALTH & SAFETY CODE § 7186(h) (West Supp. 1994); CONN. GEN. STAT. § 19a-571(a) (1986); FLA. STAT. ANN. § 765.101(17) (West Supp. 1993); GA. CODE ANN. § 31-32-3 (1991).

are permanently unconscious or have severe Alzheimer's disease, but are not terminally ill. Similarly, if a health care surrogate law applies only to patients who are terminally ill, permanently unconscious, or in an end-stage condition, people are likely to question the authority of surrogates to make decisions for patients who do not fall within these categories. In fact, researchers have documented this line of thinking in a survey in which Wisconsin physicians were asked about their attitudes toward Wisconsin's living-will law.<sup>44</sup> In the survey, only thirty-six percent of the physicians believed that the law would be effective.<sup>45</sup> Most physicians who doubted the law's efficacy explained their doubts on the basis that the statute applied only to terminally ill patients and defined a terminal condition very narrowly.<sup>46</sup> This is so even though case law clearly demonstrates that the right to refuse life-sustaining treatment applies to patients with nonterminal illnesses,<sup>47</sup> the only issue being whether the patients have expressed their wishes clearly enough.<sup>48</sup>

There are several limitations of this nature in advance directive statutes: limitations that are meaningless because either the common law or constitution already protects the right at issue. Examples include provisions that exclude mature minors from their coverage<sup>49</sup> and provisions that specifically state that advance directives that conform to another state's statute will not be honored.<sup>50</sup> With regard to

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44. Robyn S. Shapiro et al., *Living Will in Wisconsin*, 85 WIS. MED. J. 17, 20 (1986).

45. *Id.*

46. *Id.* The statute defined terminal condition as one in which the patient is likely to die within 30 days. *Id.* Since the study was published, Wisconsin has amended its definition of terminal condition. It is now defined as a condition in which injury or illness causes an incurable condition "that reasonable medical judgment finds would cause death imminently, so that the application of life-sustaining procedures serves only to postpone the moment of death." WIS. STAT. ANN. § 154.01(8) (1989).

47. See, e.g., *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990) (denying family's request to have a life-support system removed because the patient's wishes were not clearly expressed); *Deel v. Syracuse Veterans Admin. Med. Ctr.*, 729 F. Supp. 231 (N.D.N.Y. 1990) (upholding the right of a patient who had developed "graft-versus-host" disease following bone marrow treatment to refuse life sustaining medical treatment); *Gray v. Romeo*, 697 F. Supp. 580 (D.R.I. 1988) (requiring hospital to comply with husband's request to have a feeding tube and other life support removed from an unconscious patient when evidence established that to be the patient's wish).

48. Orentlicher, *supra* note 33, at 2444.

49. See ALA. CODE § 22-8A-4 (1990); ALASKA STAT. § 18.12.010(c) (1991); ARIZ. REV. STAT. ANN. § 36-3261 (1993); see also Lisa Anne Hawkins, *Living-Will Statutes: A Minor Oversight*, 78 VA. L. REV. 1581 (1992) (exploring medical consent as a vehicle to inform legislative decisions concerning the capacity of minors to execute living wills). Maryland's statute includes emancipated minors but not mature minors. MD. CODE ANN., HEALTH-GEN. §§ 5-601(f), 20-102(a) (1994).

50. Oregon, in fact, expressly states that a living will "shall" be written according to the statutory form. OR. REV. STAT. § 127.610 (1990).

the first, the common law of many jurisdictions protects the right of mature minors to make medical decisions. Mature minors likely could rely on this right to issue valid medical advance directives. With regard to the second, the constitution protects the right of people to make treatment decisions if there is clear and convincing evidence of the patient's wishes. An advance directive from another state undoubtedly would provide evidence sufficient to meet this standard.

End-of-life statutes regularly state that their provisions are cumulative and include rights derived from other sources of law,<sup>51</sup> but laypeople often fail to appreciate the significance of these provisions. In addition, courts often are influenced by the scope of end-of-life statutes when deciding the scope of a person's common law or constitutional rights. For example, an Ohio court of appeals invoked the state's durable power of attorney law in concluding that incompetent patients do not have a common law or constitutional right to have a feeding tube discontinued, even if the patients have clearly evidenced their wishes not to be artificially fed.<sup>52</sup>

Another way that the language of an end-of-life statute may mislead people about their rights is that people may assume that an advance directive is not valid if they do not use the statutory form. This assumption may exist even in cases in which the statute specifically states that the statutory form need not be used.<sup>53</sup> People are naturally skeptical of documents that do not have an "official" look to them; a handwritten, or even typewritten, advance directive is less likely to be implemented than a directive in which a patient has filled out the statutory form, even if the handwritten or typewritten document satisfies all of the statutory requirements. The situation is similar to trying to have a check accepted when the check is written on a plain piece of paper rather than a standard bank check draft. Although the plain paper check is legally valid,<sup>54</sup> it will not be readily accepted.

In some cases, advance directive statutes have provisions that are probably unconstitutional. A number of states expressly prohibit or restrict the withdrawal of artificial nutrition and hydration.<sup>55</sup> After the *Cruzan* decision, however, such restrictions are almost certainly

51. See, e.g., ALA. CODE § 22-8A-9(d) (1990); CAL. HEALTH & SAFETY CODE § 7191.5(h) (West Supp. 1992); ILL. STAT. ANN. ch. 755 para. 35/9(d) (Smith-Hurd 1992); MD. CODE ANN., HEALTH-GEN. § 5-616(a) (1994).

52. *Couture v. Couture*, 549 N.E.2d 571, 574-75 (Ohio Ct. App. 1989).

53. See, e.g., COLO. REV. STAT. § 15-18-104(3) (1993); ILL. ANN. STAT. ch. 755 para. 35/3(e) (Smith-Hurd 1992); MD. CODE ANN., HEALTH-GEN. § 5-603 (1994).

54. See, e.g., MD. CODE ANN., COM. LAW I § 3-104 (1992).

55. See, e.g., IND. CODE ANN. § 16-8-11-4 (Burns 1993); MO. ANN. STAT. § 459.010(3) (Vernon Supp. 1993); MONT. CODE ANN. § 50-9-202(2) (1992); OHIO REV. CODE ANN.

unconstitutional.<sup>56</sup> Treatment of pregnant women provides another example of potentially unconstitutional provisions. Thirty-four living will statutes expressly limit the freedom of incompetent patients to have life-sustaining treatment withdrawn if they are pregnant,<sup>57</sup> even though courts generally hold that medical treatment cannot be imposed on a pregnant woman against her will to benefit her fetus.<sup>58</sup> Until such provisions are overturned by the courts, health care providers and institutions are likely to assume that they are valid when making medical treatment decisions.

Liability concerns compound the tendency of physicians not to recognize advance directives that deviate from the statutory provisions. Although there is virtually no legal risk from discontinuing life-sustaining treatment in accordance with a patient's or surrogate's wishes,<sup>59</sup> physicians often report that their fear of legal liability affects their willingness to follow an advance directive's instructions to stop life-sustaining treatment.<sup>60</sup> Advance directive statutes respond to this

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§ 1337.13(E) (Anderson 1993); OR. REV. STAT. § 127.605(3) (1990); UTAH CODE ANN. § 75-2-1103(6)(b) (Supp. 1993).

56. Orentlicher, *supra* note 33, at 2444-45. Indeed, even though Indiana's living-will statute restricts the withdrawal of artificial nutrition and hydration, IND. CODE ANN. § 16-8-11-4 (Burns 1993), the Indiana Supreme Court concluded that there was a common law right in Indiana to refuse artificial nutrition and hydration. *In re Lawrance*, 579 N.E.2d 32, 40-41 (Ind. 1991).

57. RIGHT-TO-DIE LAW DIGEST, *supra* note 6, at "Surrogate Decisionmaking" chapter.

58. *In re A.C.*, 573 A.2d 1235, 1246 (D.C. 1990) (holding that, in deciding whether to perform a cesarean section, "the state's interest in preserving life must be truly compelling to justify overriding a competent person's right to refuse medical treatment"); *Baby Boy Doe v. Mother Doe*, 632 N.E.2d 326 (Ill. App. Ct. 1994) (holding that "a woman's competent choice to refuse" a cesarean section "must be honored" even when her choice "may be harmful to her fetus"). *But see* *Jefferson v. Griffin Spalding County Hous. Auth.*, 274 S.E.2d 457 (Ga. 1981) (upholding an order for a woman with placenta previa to undergo a cesarean section involuntarily).

59. *See* Orentlicher, *supra* note 33, at 2446 ("No person has ever been found liable for withdrawing life-sustaining treatment without court permission."); Robert F. Weir & Lawrence Gostin, *Decisions to Abate Life-Sustaining Treatment for Nonautonomous Patients*, 264 JAMA 1846, 1852 (1990) ("Every court of final decision in every jurisdiction that has addressed the question of physician liability . . . has found physicians participating in the cases to be free from civil or criminal sanctions.").

60. *See* Renee M. Goetzler & Mark A. Moskowitz, *Changes in Physician Attitudes Toward Limiting Care of Critically Ill Patients*, 151 ARCHIVES INTERNAL MED. 1537, 1538 (1991) (finding that physicians were more concerned in 1988 than 1981 about malpractice liability when deciding how aggressively to treat critically ill patients); Merrijoy Kelner et al., *Advance Directives: The Views of Health Care Professionals*, 148 CANADIAN MED. ASS'N J. 1331, 1335 (1993) (expressing concerns that directives are not legal documents and thus offer no legal safeguards); Joel M. Zinberg, *Decisions for the Dying: An Empirical Study of Physicians' Responses to Advance Directives*, 13 VT. L. REV. 445, 479-81 (1989) (identifying physicians' fear of potential lawsuits, prosecutions, and civil or criminal liability as the major impediment to withdrawing life-sustaining treatment).

concern by providing physicians with immunity from civil or criminal liability if they carry out in good faith an advance directive completed according to statutory requirements.<sup>61</sup> The statutory grant of immunity would not exist, however, if the advance directive went beyond statutory provisions and was based on common law or constitutional provisions. Consequently, fear of legal liability may discourage physicians from carrying out advance directives that exceed statutory boundaries. Fears of legal liability seem to be a particular concern among emergency system personnel. As a consequence, they are reluctant to honor do not resuscitate orders.<sup>62</sup>

The concern about restrictive statutory provisions may be less serious with health care surrogate acts. For certain life-sustaining treatment decisions, courts have given a narrow scope to surrogate authority. In the *Cruzan* case, the Missouri Supreme Court would not recognize a right of the family to discontinue a feeding tube from a patient who was permanently unconscious, unless the family's decision was based on clear and convincing evidence that the patient would not want the feeding tube.<sup>63</sup> The United States Supreme Court upheld the Missouri court's decision on that issue.<sup>64</sup> Since health care surrogate acts typically allow surrogates to direct withdrawal of life-sustaining treatment, including a feeding tube, from a permanently unconscious patient, a health care surrogate act is more likely than an advance directive statute to grant rights that are not already part of the constitutional or common law landscape. In addition, when surrogate acts impose limitations on surrogate authority, they are similar to the kinds of limitations that already exist in the common law and constitutional law. For example, courts generally limit the authority of surrogates to discontinue feeding tubes in patients who are neither terminally ill nor permanently unconscious (e.g., seriously demented patients).<sup>65</sup> Similarly, surrogate acts tend to limit the authority of sur-

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61. See, e.g., ALA. CODE § 22-8A-7 (1990); CAL. HEALTH & SAFETY CODE § 7190.5 (West Supp. 1994); ILL. ANN. STAT. ch. 755, para. 35/7 (Smith-Hurd 1994); MD. CODE ANN., HEALTH-GEN. § 5-609(a) (1994).

62. See Iserson, *supra* note 39, at 23 (recognizing that emergency personnel are not clearly included in statutory definitions of health care workers).

63. *Cruzan v. Harmon*, 760 S.W.2d 408, 424-26 (Mo. 1988), *aff'd sub nom. Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990).

64. *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 286-87 (1990).

65. See *In re Conroy*, 486 A.2d 1209 (N.J. 1985) (allowing a surrogate to withdraw life-sustaining treatment only under certain circumstances and only if certain procedures are followed); *In re Westchester County Med. Ctr.*, 531 N.E.2d 607 (N.Y. 1988) (holding that a surrogate was not allowed to withdraw treatment when patient's wish to do so was not clear).

rogates when the patient is not terminally ill or permanently unconscious.<sup>66</sup>

### B. *Ambiguous Provisions*

Many of the terms used in end-of-life statutes are ambiguous. For example, statutory provisions often apply specifically to terminally ill patients. Yet, it is often unclear when a patient qualifies as terminally ill. Under Illinois's living will statute, a living will would take effect when the patient has a terminal condition,<sup>67</sup> defined as "an incurable and irreversible condition which is such that death is imminent and the application of death delaying procedures serves only to prolong the dying process."<sup>68</sup> The statute, however, does not define "imminent" or give guidance for determining when a life-sustaining treatment is delaying death rather than prolonging life. The Illinois law also forbids withdrawal of artificial nutrition and hydration if the withdrawal "would result in death solely from dehydration or starvation rather than from the existing terminal condition."<sup>69</sup> Yet, the very purpose of discontinuing artificial nutrition and hydration is to allow the patient to die from dehydration and starvation.

Similarly, health care surrogate acts often apply not only to terminally ill or permanently unconscious patients, but also to those who are in an "end-stage"<sup>70</sup> or overly burdensome<sup>71</sup> condition. While these additional conditions admirably expand coverage to other patients who may no longer want treatment, the statutes do not adequately explain when a patient comes within their scope.

### C. *Discerning Patients' Wishes*

Some of the difficulty with end-of-life decisions probably reflects physician uncertainty about patient wishes. A physician may try to carry out the patient's preferences, but may not be certain what those preferences are. Indeed, studies consistently have shown that, while physicians often believe they know their patients' treatment preferences, they generally do not know those preferences.<sup>72</sup> For example, in one study, patients were given six hypothetical scenarios and asked

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66. See, e.g., ILL. STAT. ANN. ch. 755, para. 40/20 (Smith-Hurd 1992); MD. CODE ANN., HEALTH-GEN. § 5-606(b) (1994).

67. ILL. ANN. STAT. ch. 755, para. 53/3(a) (Smith-Hurd 1992).

68. *Id.* para. 35/2(h).

69. *Id.* para. 35/2(d).

70. MD. CODE ANN., HEALTH-GEN. § 5-606(b) (1994).

71. ILL. ANN. STAT. ch. 755, para. 40/10 to /15 (Smith-Hurd 1992).

72. Richard F. Uhlmann et al., *Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences*, 43 J. GERONTOLOGY, M115, M116 (1988).

to indicate their treatment preferences.<sup>73</sup> Their physicians were asked to predict the patients' preferences.<sup>74</sup> In five out of six scenarios, the physicians were no better than chance in their predictions.<sup>75</sup> Yet, in more than seventy-eight percent of cases, physicians believed their predictions were accurate.<sup>76</sup> In another study, patients were asked their treatment preferences for several hypothetical scenarios, and the patients' physicians were asked both to give their own preferences and to predict their patients' preferences.<sup>77</sup> The data from that study showed that the physicians' predictions of the patients' preferences more closely corresponded with their own preferences than with their patients' preferences; indeed, the physicians' predictions corresponded poorly with the patients' actual preferences.<sup>78</sup>

These results are not surprising; extensive discussions between physicians and patients about end-of-life care are not common.<sup>79</sup> Indeed, studies of DNR orders indicate that physicians do a poor job of eliciting patient values and preferences.<sup>80</sup> Typically, patients participate in their DNR decisions only twenty percent of the time.<sup>81</sup> It is true that patients often lack decisionmaking capacity when the DNR order is written.<sup>82</sup> This, however, is more a result of physician delay in discussing CPR than an inevitable consequence of patient illness. One study indicated that, while seventy-six percent of the patients were mentally incapacitated when the DNR order was written, only eleven percent of these patients had been incapacitated when they entered the hospital.<sup>83</sup> Even when patients have decisionmaking capacity, they may be excluded from decisionmaking. In a study involv-

73. *Id.*

74. *Id.*

75. *Id.* at M117.

76. *Id.*

77. Lawrence J. Schneiderman et al., *Do Physicians' Own Preferences for Life-Sustaining Treatment Influence Their Perceptions of Patients' Preferences?*, 4 J. CLINICAL ETHICS 28, 29 (1993).

78. *Id.*

79. See Joy M. Roe et al., *Durable Power of Attorney for Health Care: A Survey of Senior Center Participants*, 152 ARCHIVES INTERNAL MED. 292, 292 (1992).

80. Council on Ethical and Judicial Affairs, American Medical Association, *Guidelines for the Appropriate Use of Do-Not-Resuscitate Orders*, 265 JAMA 1868, 1869 (1991) [hereinafter *Guidelines*] (stating that while 93% of physicians surveyed believed that patients should be involved in making decisions about CPR, only 10% of those physicians discussed resuscitation preferences with their patients prior to cardiac arrest).

81. *Id.*

82. See *id.* (quoting a study finding that 76% of the patients studied were incapable of indicating a treatment preference at the time the DNR order was written).

83. Susanne E. Bedell et al., *Do-Not-Resuscitate Orders for Critically Ill Patients in the Hospital: How Are They Used and What Is Their Impact?*, 256 JAMA 233, 235-36 (1986).



ing fully competent patients, twenty percent of the do not resuscitate decisions were made by family members only.<sup>84</sup>

Advance directive statutes will do little to make patient preferences clearer to physicians. First, a statute would only make a significant difference if patients generally planned to write advance directives, thereby making their preferences clearer to their physicians, but refrained from doing so because they were waiting for a law that recognized advance directives. The evidence suggests, however, that advance directives are uncommon because patients are not inclined to use them, not because patients are being prevented from using them. Although every state has at least one type of advance-directive statute, surveys indicate that no more than fifteen percent of Americans have formalized their preferences through advance directives;<sup>85</sup> indeed, some studies suggest that only about five percent of Americans have completed an advance directive.<sup>86</sup>

Even when aggressive efforts are made to persuade patients to write advance directives, results usually are disappointing.<sup>87</sup> In one study, elderly persons were divided into three groups, with the groups receiving varying levels of information about advance directives.<sup>88</sup> In addition, half of the persons in each group were invited to a meeting at which they could receive counseling about advance directives and free legal assistance to complete an advance directive.<sup>89</sup> The research-

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84. Andrew L. Evans & Baruch A. Brody, *The Do-Not-Resuscitate Order in Teaching Hospitals*, 253 JAMA 2236, 2237 (1985). Conceivably, the family members were able to convey the patients' preferences to the physicians. However, studies demonstrate that family members do a poor job of predicting the preferences of patients. See Uhlmann et al., *supra* note 72, at M117, M119 ("[T]he results [of the study] suggest that the resuscitation preferences of elderly outpatients often are not understood . . . by . . . spouses of long duration.").

85. See Jeremy Sugarman et al., *Factors Associated with Veterans' Decisions About Living Wills*, 152 ARCHIVES INTERNAL MED. 343, 343 (1992) ("Only 9% to 15% of Americans have formulated their treatment preferences in a [living will].").

86. See Susan M. Rubin et al., *Increasing the Completion of the Durable Power of Attorney for Health Care: A Randomized, Controlled Trial*, 271 JAMA 209, 210 (1994) (stating that in their study only 5.8% of the participants, prior to education and intervention, had completed an advance medical directive).

87. See Dallas M. High, *Advance Directives and the Elderly: A Study of Intervention Strategies to Increase Use*, 33 GERONTOLOGIST 342, 342 (1993) (concluding that studies attempting educational interventions have only had modest success in increasing the use of advance directives).

88. *Id.* at 343. The groups were given materials in three different formats: (1) the minimum information (a cover letter, brief instructions, and copies of the state's advance directive forms); (2) moderate information (minimal information plus two short informational flyers about advance directives); or (3) the maximum information (the minimal information plus a ten page booklet about advance directives).

89. *Id.* Thus, the study ended up with six different groups.

ers found that the additional efforts doubled the use of advance directives in the group that received moderate information and an invitation to the meeting. However, researchers found no statistically significant increases in the use of advance directives in patients in the other five groups.<sup>90</sup> In another study, which involved adult patients in an internal medicine clinic, researchers divided patients into three groups.<sup>91</sup> Patients in the first group received neither written information about living wills nor discussed living wills with their physician; patients in the second and third groups were given a booklet about living wills, were instructed to direct any questions about living wills to their physicians and were encouraged to complete the state's living will document and present the completed document to their physician.<sup>92</sup> Over a four month period, whenever physicians saw patients in the third group, the physicians initiated a discussion about living wills and encouraged the patients to complete a living will.<sup>93</sup> No such discussions were initiated with group one and group two patients.<sup>94</sup> After the four month period, each group three patient was contacted by phone or letter and invited for a free clinic visit "to discuss and/or complete the living will with their physician."<sup>95</sup> No such follow-up was implemented for group one or two patients.<sup>96</sup> Ultimately, none of the patients in group one or two completed a living will, and only fifteen percent of the patients in group three completed a living will.<sup>97</sup>

A study with less intensive efforts yielded even worse results.<sup>98</sup> Researchers found no effect on the patients' likelihood of completing a living will after an intervention consisting of a twenty to thirty minute interview during which physicians discussed living wills with their geriatric patients and then gave the patients a copy of the statutory living will form and a card reminding them to discuss advance directives with their physician at their next clinic visit.<sup>99</sup> A similar study with durable powers of attorney yielded better, but still insubstantial, results.<sup>100</sup> In this study, researchers mailed patients a cover letter, an

90. *Id.* at 344.

91. Jan Hare & Carrie Nelson, *Will Outpatients Complete Living Wills? A Comparison of Two Interventions*, 6 J. GEN. INTERNAL MED. 41, 41-42 (1991).

92. *Id.* at 42.

93. *Id.*

94. *Id.*

95. *Id.*

96. *Id.*

97. *Id.* at 44.

98. Greg A. Sachs et al., *Empowerment of the Older Patient? A Randomized, Controlled Trial to Increase Discussion and Use of Advance Directives*, 40 J. AM. GERIATRIC SOC'Y 269, 272 (1992).

99. *Id.*

100. See Rubin et al., *supra* note 86, at 210.

educational pamphlet, and a durable power of attorney form; researchers also provided telephone assistance and additional information.<sup>101</sup> Four weeks later, the researchers mailed the patients follow-up letters and second copies of the power of attorney form.<sup>102</sup> The results of the study indicated that only eighteen and a half percent of the patients completed the forms.<sup>103</sup>

Perhaps the most promising results in convincing patients to fill out advance directives came from a recent study involving durable powers of attorney. In that study, approximately two-thirds of patients who were encouraged to appoint a durable power attorney did so.<sup>104</sup> The high rate of completion apparently reflected the fact that the study was limited to patients who were assessed by their physicians as having a life-threatening illness<sup>105</sup> and that the researchers expended considerable effort in encouraging patients to complete the forms.<sup>106</sup>

In short, while some approaches achieve higher completion rates than other approaches, the overall impression from the empirical literature is that, even with education and encouragement, patients generally are not likely to complete advance directives and there is therefore little reason to think that enacting advance-directive statutes will prompt many otherwise not inclined people to complete advance directives.

Why are patients reluctant to complete advance directives? There is a natural, human reluctance to confront one's mortality, and people may simply find that filling out an advance directive is too unsettling. A similar phenomenon exists with organ donation. Even though most people support organ donation in the abstract,<sup>107</sup> few have actually filled out organ donor cards.<sup>108</sup> Reluctance to confront

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101. *Id.*

102. *Id.*

103. *Id.* at 211.

104. Lawrence J. Schneiderman et al., *Effects of Offering Advance Directives on Medical Treatments and Costs*, 117 ANNALS INTERNAL MED. 599, 602 (1992).

105. *Id.* at 600. Life-threatening illness was defined to mean that the patient had no better than a 50% chance of surviving for five more years. *Id.*

106. Interview with Lawrence J. Schneiderman, lead author of study (Jan. 1994).

107. See Lloyd R. Cohen, *Increasing the Supply of Transplant Organs: The Virtues of a Futures Market*, 58 GEO. WASH. L. REV. 1, 9 (1989) (discussing a Gallup poll which found that 75% of American adults approve of the concept of organ donation, but only 17% have signed organ donor cards); Dianne L. Manninen & Roger W. Evans, *Public Attitudes and Behavior Regarding Organ Donation*, 253 JAMA 3111, 3111 (1985) (finding that while nearly 94% of the population has heard of organ transplantation, only 19% of these people carry organ donor cards).

108. Thomas D. Overcast et al., *Problems in the Identification of Potential Organ Donors: Misconceptions and Fallacies Associated with Donor Cards*, 251 JAMA 1559, 1560 (1984) ("[T]he number of card-carrying donors is 2% to 3% of all donors at most.").

issues about dying is generally cited as a basis for the paucity of organ-donor volunteers.<sup>109</sup> Even health care professionals are unlikely to complete advance directives. A survey of 500 nurses and 500 physicians found that only twenty percent had completed advance directives.<sup>110</sup> People also may assume that an advance directive will not be necessary in their individual cases. It is natural to believe that tragedy will fall elsewhere. Moreover, while a number of cases have generated substantial publicity, the vast majority of end-of-life decisions are made with little difficulty or conflict. Many persons believe that they can trust family and friends to make the decisions that they would want made and that there therefore is little need for an advance directive.<sup>111</sup>

People also may be reluctant to complete advance directives out of fear that doing so will have an adverse effect on their treatment. A common concern is that, once a patient fills out an advance directive and requests some withholding of treatment, physicians will devote less attention to that patient's care and may withhold more treatment than desired.<sup>112</sup> Indeed, in some cases in which patients have decided to forgo cardiopulmonary resuscitation (CPR), physicians have interpreted the decision as one to forgo other life-sustaining treatments.<sup>113</sup>

Even if advance directive laws caused people to start writing living wills, physicians are still unlikely to gain a clear understanding of their patients' wishes. Unfortunately, the typical living will form uses vague language that results in ambiguous guidance when specific treatment decisions arise. For example, in a case involving a patient with HIV disease, the patient, Tom Wirth, had written a living will directing that all life-sustaining treatment be withheld or withdrawn if he developed an illness such that there was "no reasonable expectation of recovering or regaining a meaningful quality of life."<sup>114</sup> When Mr. Wirth

109. See, e.g., Cohen, *supra* note 107, at 9 ("Those who refused to be organ donors cited the following reasons: (1) a fear that their death would be hastened by over-eager doctors; (2) aesthetic or religious objections to being dismembered; and (3) an unwillingness to think about their own mortality.").

110. Gene C. Anderson et al., *Living Wills: Do Nurses and Physicians Have Them?*, 86 AM. J. NURS. 271, 271 (1986).

111. Joanne Lynn, *Why I Don't Have A Living Will*, 19 LAW, MED. & HEALTH CARE 101, 103 (1991).

112. Panagiota V. Caralis et al., *The Influence of Ethnicity and Race on Attitudes Toward Advance Directives, Life-Prolonging Treatments, and Euthanasia*, 4 J. CLINICAL ETHICS 155, 157 (1993).

113. David A. Schwartz & Philip Reilly, *The Choice Not To Be Resuscitated*, 34 J. AM. GERIATRICS SOC'Y 807, 810-11 (1986).

114. Evans v. Bellevue Hosp., No. 16536/87 (N.Y. Sup. Ct. 1987) (quoting from Mr. Wirth's living will), in RIGHT-TO-DIE LAW DIGEST, *supra* note 6, at "Fact Sheets" chapter.

became stuporous from a parasitic brain infection and his physicians proposed antibiotic treatment for the infection,<sup>115</sup> Mr. Wirth's surrogate concluded that Mr. Wirth should not receive the antibiotics because his HIV infection prevented him from having a meaningful quality of life.<sup>116</sup> Mr. Wirth's physicians argued that Mr. Wirth should receive treatment because antibiotics might be able to eradicate the parasitic infection and return Mr. Wirth to his preinfection state.<sup>117</sup> In short, ambiguity surrounded the question of whether Mr. Wirth's condition was irreversible because his HIV disease could not be reversed or was reversible since the parasitic infection was potentially eradicable.<sup>118</sup>

Researchers documented the vagueness inherent in traditional living will forms in a study of patients who had completed advance directives that combined a proxy appointment with a general statement about treatment preferences.<sup>119</sup> After patients had completed their advance directives, researchers presented them with several hypothetical scenarios and asked about their treatment preferences for each of the scenarios.<sup>120</sup> The researchers found that the general instructions in the advance directive "were often inconsistent with, and poor predictors of, specific [treatment] preferences."<sup>121</sup>

Alternative living will forms have been proposed to eliminate the ambiguities inherent in traditional forms. For example, the "Medical Directive"<sup>122</sup> living will form presents patients with a decision grid that has hypothetical scenarios on one axis<sup>123</sup> and a number of different medical treatments on the other axis.<sup>124</sup> People using the form check off which treatments they would desire under which conditions.<sup>125</sup>

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115. *Id.*

116. *Id.*

117. *Id.*

118. The *Evans* court ordered treatment. *Id.* After a month of treatment produced no improvement, therapy was halted and Mr. Evans died approximately one week later. *Id.*

119. Lawrence J. Schneiderman et al., *Relationship of General Advance Directive Instructions to Specific Life-Sustaining Treatment Preferences in Patients With Serious Illness*, 152 ARCHIVES INTERNAL MED. 2114, 2115 (1992).

120. *Id.*

121. *Id.* at 2114.

122. Emanuel & Emanuel, *supra* note 12, at 3288.

123. *Id.* at 3290. For example, one such hypothetical scenario places the patient "in an irreversible coma or a persistent vegetative state but with no terminal illness." *Id.* at 3291.

124. *Id.* at 3290. These treatment categories, including use of a ventilator or feeding tube, "encompass the typical range of diagnostic and therapeutic interventions for incompetent patients." *Id.* at 3291.

125. *Id.* at 3291. According to the authors, the additional specificity "should help reflect the nuances of patient preferences." *Id.*

While alternative forms may reduce uncertainty somewhat,<sup>126</sup> they still may not adequately record patients' wishes. For example, the advance directive form may only allow an individual suffering from dementia to choose or reject antibiotics, even though the decision would likely depend on the reasons for, and the effects of, the antibiotics. If a physician prescribes antibiotics with minimal side effects to treat a painful, nonfatal skin infection, the patient would probably choose to accept the antibiotics. If, on the other hand, a physician prescribes antibiotics with serious side effects to treat a severe infection that is likely to be fatal, the patient may be much less likely to accept them.<sup>127</sup> Unfortunately, even these detailed "Medical Directive" living will forms cannot provide the patient with this degree of choice.

Maryland's statute provides another response to the lack of written advance directives by recognizing oral advance directives.<sup>128</sup> While this step should help,<sup>129</sup> it still does nothing about the failure of physicians to engage their patients in discussions about end-of-life decisions.<sup>130</sup>

#### *D. Inadequate Compensation for Physicians*

Advance directive statutes do not address another important reason why physicians have little understanding of patients' wishes. Gaining an understanding of a patient's treatment preferences takes a good deal of discussion and time. There are many possible illnesses that might develop and corresponding treatments that might be appropriate, and patients need to appreciate the different possibilities. They also need to appreciate the benefits that could and could not be accomplished through treatment. In short, considerable discussion is required to enable patients to make meaningful decisions, express their preferences to physicians, and explain how their preferences vary given different scenarios. Physicians are not inherently unwilling to take the time needed for sufficient discussion. However, under current policies, they do not receive any compensation for the time spent. Health insurance policies consider such discussions either nonreimbursable, or reimbursable at very low rates. Unless physicians are compensated for their time discussing end-of-life decisions, they

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126. William R. Mower & Larry J. Baraff, *Advance Directives: Effect of Type of Directive on Physicians' Therapeutic Decisions*, 153 ARCHIVES INTERNAL MED. 375, 377-78 (1993).

127. Allan S. Brett, *Limitations of Listing Specific Medical Interventions in Advance Directives*, 266 JAMA 825, 826 (1991).

128. MD. CODE ANN., HEALTH-GEN. § 5-602(d) (1994).

129. Orentlicher, *supra* note 33, at 2445.

130. See *supra* notes 79-84 and accompanying text.

will continue to allocate their time to activities that generate higher compensation.

### *E. Socioeconomic Differences*

While advance directives may be of great value to people who understand how to use them and are comfortable with their use, there is some evidence that socioeconomic factors affect the likelihood that people will use advance directives.<sup>131</sup> Data suggest that advance directives are less likely to be used by individuals who are not well educated<sup>132</sup> or who are financially deprived.<sup>133</sup> Similarly, preliminary data suggest that African-American and Hispanic individuals are less likely than non-Hispanic whites to complete advance directives.<sup>134</sup> A study on patient-physician communication found that nonwhite patients are less likely than white patients to discuss their end-of-life treatment preferences with their physicians.<sup>135</sup> This conclusion was found to be true even after controlling for income and education and even though there was no difference between the white and nonwhite patients' desires to discuss their preferences.<sup>136</sup>

While one can only speculate as to the reasons for these disparities, it is not surprising that a person's lack of income or education affects her likelihood of using advance directives. Such individuals may not have an adequate understanding of advance directives and may have less familiarity, and therefore less comfort, with legal documents. In addition, they may have a greater distrust of health care providers and a greater fear that signing an advance directive will result in withholding desired medical care. Ethnic differences are also not surprising. Views about death and dying vary among different cultures. Moreover, people who have experienced discrimination throughout their lives may particularly distrust health care providers. Indeed, in one study, African-American patients were most likely to

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131. See High, *supra* note 87, at 346 (relating education, race, and income to familiarity with advance directives).

132. Dallas M. High, *Why Are Elderly Patients Not Using Advance Directives?*, 5 J. AGING & HEALTH 497, 505-07 (1993).

133. High, *supra* note 87, at 346.

134. Rubin et al., *supra* note 86, at 211-12; High, *supra* note 87, at 346. However, these data were not controlled for differences in income or education. See also Caralis et al., *supra* note 112, at 156-57 (finding no statistically significant difference in the relative percentages of African-Americans, Hispanics, and non-Hispanic whites that have executed advance directives).

135. Jennifer S. Hass et al., *Discussion of Preferences for Life-Sustaining Care by Persons with AIDS: Predictors of Failure in Patient-Physician Communication*, 153 ARCHIVES INTERNAL MED. 1241, 1246 (1993).

136. *Id.*

fear that completing an advance directive would adversely affect their care.<sup>137</sup>

#### F. *Failure of Surrogates to Represent Patients' Wishes*

Proxy appointments are frequently advocated as an alternative to living wills because they avoid many of the problems associated with living wills. For example, durable power of attorney statutes typically have fewer limitations than do living will statutes.<sup>138</sup> While living will statutes often apply only when the patient is terminally ill or in a persistent vegetative state, durable power of attorney statutes usually apply whenever the patient lacks decisionmaking capacity.<sup>139</sup> Durable power of attorney statutes also address the problem of vagueness with directions for treatment in living wills. With a proxy appointment, a patient can grant a surrogate authority to resolve any ambiguities in the patient's expressed preferences.<sup>140</sup>

Health care surrogate acts are also an important advance in end-of-life decisionmaking. If an incompetent patient has not left an advance directive, a surrogate act increases the likelihood that physicians will feel comfortable relying on the patient's family members to make life-sustaining treatment decisions. In addition, health care surrogate acts often have fewer limitations than advance directive statutes. For example, in Illinois, the living-will act applies only to terminally ill patients<sup>141</sup> while the surrogate act applies to patients who are terminally ill, permanently unconscious, or in an "incurable or irreversible condition."<sup>142</sup> As a result, unlike other advance directive statutes, which may mislead patients and physicians by implying that certain common law and constitutional rights do not exist, health care surrogate acts are more likely to enumerate rights that were not clearly present under existing case law.<sup>143</sup>

137. Caralis et al., *supra* note 112, at 157.

138. See Orentlicher, *supra* note 9, at 2366 ("A method of appointing a proxy with more flexible authority is the creation of a 'durable power of attorney'. . . .").

139. *Id.*

140. *Cf. id.* ("In contrast, there is no one with legal authority other than a judge, to interpret the terms of a living will . . .").

141. ILL. ANN. STAT. ch. 755, para. 35/2(g) (Smith-Hurd Supp. 1992).

142. *Id.* para. 40/10.

143. Yet, these acts are not perfect. They fail to address many important issues. For example, many elderly patients do not have family or friends to serve as surrogate decisionmakers. Although health care surrogate acts recognize the authority of legal guardians to make life-sustaining treatment decisions, guardianship appointments are generally not carried out because they are costly and time-consuming. See Alison P. Barnes, *Beyond Guardianship Reform: A Reevaluation of Autonomy and Beneficence for a System of Principled Decision-Making in Long Term Care*, 41 EMORY L.J. 633, 680 (1992) ("[T]he cost of the creation of



Despite its benefits, proxy decisionmaking has serious limitations, the most significant being that it simply is unlikely to serve its basic purpose. Surrogate decisionmaking is premised on the belief that surrogates will make medical decisions that reflect patients' preferences. The empirical data indicate, however, that surrogates do a poor job of carrying out patients' wishes.<sup>144</sup> Several studies have examined the accuracy of surrogate decisionmakers by presenting individuals with hypothetical scenarios and asking them to indicate their treatment preferences for each scenario.<sup>145</sup> Potential surrogates are simultaneously asked to predict the preferences of the individuals.<sup>146</sup> These studies consistently demonstrate that the potential surrogates' predictions do not reach a statistically significant degree of agreement with the choices of the individuals.<sup>147</sup> This holds true even when individuals chose people that they would feel most comfortable with as surrogate decisionmakers.<sup>148</sup>

These results are not surprising. There are several reasons why agreement regarding end-of-life decisions between individuals and their surrogates is poor. First, most people do not engage in meaningful discussions of their treatment preferences with close family members or friends.<sup>149</sup> Consequently, the potential surrogates are not likely to have a good sense of the person's preferences. Second, potential surrogates tend to underestimate the quality of life of the people for whom they will be making medical decisions. For example, studies confirm that family members consistently underestimate the

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a limited guardianship is \$4000 to \$6000 for elderly people with modest, typical assets. The time from petition to adjudication . . . is seldom less than two months."). Moreover, it is not clear that guardians serve the patient's interests as much as the interests of others, such as physicians frustrated by an inability to stop treatment that they consider inappropriate. Surrogate acts also do not always reflect the changing nature of the family. Some acts recognize close friends in their hierarchy of potential surrogates, *see, e.g.*, ARIZ. REV. STAT. ANN. § 36-3231 (1993); FLA. STAT. ANN. § 765.401 (West Supp. 1993); ILL. ANN. STAT. ch. 755, para. 40/25(a)(7) (Smith-Hurd Supp. 1993); MD. CODE ANN., HEALTH-GEN. § 5-605(a)(2) (1994); N.Y. PUB. HEALTH LAW § 2965.4(a) (McKinney Supp. 1993). Others do not. *See, e.g.*, D.C. CODE ANN. § 21-2210 (Supp. 1993).

144. *See* Ezekiel J. Emanuel & Linda L. Emanuel, *Proxy Decision Making for Incompetent Patients: An Ethical and Empirical Analysis*, 267 JAMA 2067, 2069 (1992) (citing several such studies); Jeremiah Suhl et al., *Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support is Unreliable*, 154 ARCHIVES INTERNAL MED. 90 (1994).

145. *Id.* at 2069-70.

146. *Id.*

147. *See id.* at 2069 ("[T]he empirical studies . . . do suggest that proxies are not much better than chance at predicting patients' preference during incompetence.").

148. Jan Hare et al., *Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions*, 152 ARCHIVES INTERNAL MED. 1049, 1052 (1992).

149. Emanuel & Emanuel, *supra* note 144, at 2068-69.

quality of life of elderly persons.<sup>150</sup> Because they underestimate quality of life, they may conclude that treatment is not desired even when it is.<sup>151</sup> Physicians also consistently underestimate the quality of life of elderly patients.<sup>152</sup> Thus, they are likely to recommend less aggressive care to surrogates than the patient would desire.

Third, surrogates may be reluctant to authorize the withholding of life-sustaining treatment for a family member and thus mistakenly predict a person's treatment preferences. The psychological stress of feeling responsible for another person's death, particularly a loved one, may give surrogates pause when considering whether to discontinue treatment.<sup>153</sup> Indeed, although there is poor agreement between individuals and their surrogates, there seems to be a tendency for surrogates to overpredict the degree of care desired by family members.<sup>154</sup>

Thus, some factors drive surrogates toward deciding on less treatment than that which is desired by patients, while others drive them toward deciding on more than is desired. These opposing factors possibly could cancel each other out, causing surrogates to choose roughly the appropriate amount of care. Conversely, they could serve to increase the chances of a mismatch, causing some patients to receive excessive care and others to receive inadequate care. The empirical data indicate that the latter is true: opposing tendencies generally do not cancel each other out. As mentioned previously, studies consistently find that surrogates are poor predictors of their family members' preferences.<sup>155</sup>

This is not to say that we should automatically reject proxy decisionmaking. Although surrogates do a poor job of carrying out patient wishes, they may still be best situated to make decisions. Public surveys indicate that patients prefer to have family members, rather than physicians, judges, or others make their medical treatment deci-

150. *Id.* at 2069.

151. See Joseph G. Ouslander et al., *Health Care Decisions Among Elderly Long-Term Care Residents and Their Potential Proxies*, 149 ARCHIVES INTERNAL MED. 1367, 1371 (1989) ("[A] relatively high proportion of elderly people desire intensive intervention to prolong their lives . . .").

152. Richard F. Uhlmann & Robert A. Pearlman, *Perceived Quality of Life and Preferences for Life-Sustaining Treatment in Older Adults*, 151 ARCHIVES INTERNAL MED. 495 (1991); Robert A. Pearlman & Richard F. Uhlmann, *Quality of Life in Chronic Disease: Perceptions of Elderly Patients*, 43 J. GERONTOLOGY M25, M27 (1988).

153. Emanuel & Emanuel, *supra* note 144, at 2068.

154. Uhlmann et al., *supra* note 72, at M117.

155. See *supra* notes 144-148 and accompanying text.

sions for them.<sup>156</sup> The choice of a surrogate decisionmaker is just as much an exercise of autonomy as the giving of a specific treatment instruction. As long as people understand that their surrogates may not choose exactly as they would have, the exercise in autonomy is a meaningful one. The important point is that the patient has decided how the decision will be made. Moreover, many patients seem to prefer that their surrogates choose in accordance with the surrogate's view of the patient's best interests, rather than the surrogate's view of the patient's preferences.<sup>157</sup>

Although surrogate decisionmaking may be the best possible approach when patients have lost decisionmaking capacity, we must recognize that it is not a very effective method for carrying out patient preferences.<sup>158</sup>

### III. PREDOMINANCE OF PHYSICIANS' VALUES IN END-OF-LIFE DECISIONS

In the previous sections, this Article suggested that end-of-life statutes have limited impact because they are misleading or poorly drafted, because patients do not document their preferences and physicians do not elicit patient preferences, and because surrogates do not faithfully represent the wishes of patients. One could respond

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156. See Dallas M. High, *A New Myth About Families of Older People?*, 31 GERONTOLOGIST 611, 615-16 (1991) (citing a survey that found that 94% of those who responded preferred to have family members as surrogates); Dallas M. High, *Standards for Surrogate Decision Making: What the Elderly Want*, 17 J. LONG-TERM CARE ADMIN. 8, 9 (1989) (citing an in-depth survey of 40 patients in which 90% preferred to have family members serve as surrogate decision-makers) [hereinafter High, *Standards*].

157. See High, *Standards*, *supra* note 156, at 9-10 (finding that 50% of those surveyed favored the "best interest standard" over the "substituted judgment standard."). Some commentators have observed that the family has its own interests that should not be ignored when treatment decisions are made; Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 JAMA 59, 61 (1992) (finding that 31% of those surveyed were willing to give "complete leeway" to their surrogate to override their advance directive, and another 30% were willing to give at least "a little leeway" to their surrogate). See, e.g., John Hardwig, *What About the Family?*, HASTINGS CENTER REP., Mar.-Apr. 1990, at 5 (arguing that the moral relevance of the interests of the family should be acknowledged).

158. Surrogate decisionmaking has also been criticized because of the conflicts of interest that family members have. See, e.g., *Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261, 286 (1990) ("[C]lose family members may have a strong feeling . . . that they do not wish to witness the continuation of the life of a loved one which *they regard* as hopeless, meaningless, and even degrading.") (emphasis added). However, those cases probably represent a minority of situations and can best be dealt with by implementing protective safeguards. Former Chief Justice Burger has stated: "[t]hat some [family members] 'may at times be acting against the interests of [the patient]' . . . creates a basis for caution, but is hardly a reason to discard wholesale those pages of human experience that teach that [family members] generally do act in the [patient's] best interests." *Parham v. J.R.*, 442 U.S. 584, 602-03 (1979).

that this simply reflects the need to learn from our experiences with early statutes and early end-of-life decisionmaking and build on that experience to improve the quality of end-of-life decisionmaking. However, an even more fundamental concern about the efficacy of end-of-life statutes calls into question whether even the best statutes or the most intensive educational efforts will serve the goal of ensuring that life-sustaining treatment decisions are based on the preferences of patients. The potential success of end-of-life laws is inherently limited by fundamental philosophical disagreements about the way end-of-life decisions should be made. In particular, considerable evidence suggests a major gap between the generally accepted theory that end-of-life decisions should be based on patient self-determination and the actual practice of physicians in administering end-of-life care.<sup>159</sup> The evidence suggests that physicians generally still consider it their responsibility to make treatment decisions that they believe are in the patient's best interest and that patient preferences should be ignored if they are inconsistent with the physician's view of the patient's best interests.<sup>160</sup> In other words, it appears that end-of-life decisions are frequently driven by the physician's values rather than the patient's values.

#### A. *Evidence of the Predominance of Physicians' Values*

A number of important studies demonstrate the predominance of physician values in end-of-life decisions. In the first study, nursing home patients or, if the patients lacked decisionmaking capacity, their surrogates, completed living wills.<sup>161</sup> Over the next two years, when a patient either died in the nursing home or was hospitalized, researchers examined the patient's medical records to determine whether the medical decisions made for the patient were consistent with that patient's living will.<sup>162</sup> The researchers found that seventy-five percent of the decisions were consistent with the patient's advance directive.<sup>163</sup>

At first glance, the seventy-five percent level of agreement seems impressive and suggests a general respect for patients' values. A closer examination indicates that physicians probably overrode patient pref-

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159. Much of the following discussion is an elaboration of a thesis developed in David Orentlicher, *The Illusion of Patient Choice in End-of-Life Decisions*, 267 JAMA 2101 (1992).

160. Kelner et al., *supra* note 60, at 1335-36.

161. Marion Danis et al., *A Prospective Study of Advance Directives for Life-Sustaining Care*, 324 NEW ENG. J. MED. 882 (1991). Participants consisted of 126 mentally competent nursing home residents and 49 family members of incompetent residents. *Id.*

162. *Id.* at 882-83.

163. *Id.* at 884.

erences a majority of the time when there was a disagreement between the patient and physician. For most end-of-life decisions, people generally agree on the appropriate treatment. For instance, in a survey of public preferences, eighty percent of those surveyed stated that they would not want a ventilator or feeding tube if they were permanently unconscious and over eighty percent stated that they would not want a ventilator or feeding tube if they became demented and terminally ill.<sup>164</sup> Accordingly, in most end-of-life situations, physicians and patients probably agree on whether treatment should be provided, and much of the seventy-five percent consistency between the living wills and the physicians' decisions can be explained by a sharing of values between patients and physicians. When there is disagreement between physicians and patients, however, it follows that the physicians' preferences generally prevail.<sup>165</sup> Assuming that there is a sixty percent agreement rate and a forty percent disagreement rate between patients and physicians, then a twenty-five percent override rate means that physicians prevail in 62.5 percent of the disagreements (twenty-five percent/forty percent).<sup>166</sup>

Other findings in the study also indicate that physicians were more likely to base treatment decisions on their own values rather than the patient's values. For example, in many cases, when the patient was transferred from the nursing home to a hospital, the patient's living will did not accompany the patient and was therefore not incorporated into the patient's hospital chart.<sup>167</sup> Yet, the living will's presence in the patient's chart did not increase the likelihood that physicians would follow the living will.<sup>168</sup> Similarly, when patients who had written their own living wills were compared with patients whose living wills were written for them by their surrogates, there was no

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164. Linda L. Emanuel et al., *Advance Directives for Medical Care—A Case for Greater Use*, 324 NEW ENG. J. MED. 889, 893 (1991).

165. See, e.g., Panagiota V. Caralis & Jeffrey S. Hammond, *Attitudes of Medical Students, Housestaff, and Faculty Physicians Toward Euthanasia and Termination of Life-Sustaining Treatment*, 20 CRITICAL CARE MED. 683, 686 (1992) (explaining that study results show that 31.3% of a combined group of caregivers found the patient's right to choose only a moderately important or unimportant factor in end-of-life treatment decisions).

166. In a survey of family physicians in Ontario, Canada, only 44% of the physicians reported that they always followed their patients' advance directives. David L. Hughes & Peter A. Singer, *Family Physicians' Attitudes Toward Advance Directives*, 146 CANADIAN MED. ASS'N J. 1937, 1941 (1992).

167. Danis et al., *supra* note 161, at 884. The hospital received the advance directive and incorporated it into the patient's chart in only 25 of 71 hospitalizations. *Id.*

168. *Id.* at 885-86.

difference in the likelihood that physicians would follow the living will.<sup>169</sup>

Another study on advance directives corroborates these results. As part of this second study, researchers randomly assigned patients to either an experimental group that completed a durable power of attorney or to a control group that did not.<sup>170</sup> The researchers tracked the patients for at least two years and compared the care of the patients in the advance directive group with that of the patients in the control group.<sup>171</sup> The researchers found no statistically significant differences in the medical treatment that the patients in the two groups received.<sup>172</sup> While the lack of any difference in treatment might suggest that advance directives fail to give meaningful guidance, it also suggests that physicians base end-of-life treatment decisions primarily on their own values.

In the first advance directive study,<sup>173</sup> the researchers tried to discover why living wills were sometimes disregarded. After reviewing the medical records and interviewing the physicians, the researchers concluded that physicians often overrode living wills when they disagreed with the wisdom of the patients' choices.<sup>174</sup> In some cases, the physicians provided undesired treatment because they felt that the treatment was appropriate.<sup>175</sup> In other cases, they withheld desired treatment because they believed that the treatment would not benefit the patient.<sup>176</sup> In short, physicians often overrode patient choice when they believed that respecting patient preferences would not be in the patient's best interests.<sup>177</sup> If physicians continue to believe that they are obligated to make end-of-life medical decisions based on their sense of the patient's best interests rather than on their understanding of the patient's wishes, living wills will have little effect on medical decisionmaking. They will be respected only when they are consistent with the physician's views of the patient's best interests.

Another study similarly demonstrates physicians unwillingness to comply with patient choices that are inconsistent with their views of

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169. *Id.*

170. Schneiderman et al., *supra* note 104, at 599-600.

171. *Id.* at 600-01.

172. *Id.* at 603.

173. See *supra* notes 161-169 and accompanying text.

174. Danis et al., *supra* note 161, at 886-87.

175. *Id.* at 886.

176. *Id.*

177. *Id.* at 887. The researchers concluded that "the data suggests that in caring for incapacitated patients, physicians balance respect for autonomy with other competing ethical principles in order to make what they believe are the wisest decisions." *Id.*

the patient's best interests.<sup>178</sup> This third study relied on hypothetical scenarios, asking physicians whether they would comply with a number of potential patient decisions regarding end-of-life care, such as withholding life-sustaining treatment or performing euthanasia.<sup>179</sup> The scenarios involved four patients of varying ages and varying medical problems.<sup>180</sup> When the researchers asked the physicians whether they would comply with the patient's request to have a ventilator withdrawn, the physicians' likelihood of compliance depended upon the prognosis of the patient.<sup>181</sup> Over half of the physicians would withdraw a ventilator upon request from a patient with widely metastatic breast cancer or a patient bedridden from severe emphysema.<sup>182</sup> Conversely, less than a third of the physicians would withdraw a ventilator upon request from a mildly demented, though competent, elderly woman with pneumonia.<sup>183</sup> This difference likely reflects the fact that, unlike the other two patients, the elderly woman had a reversible respiratory problem and an expected survival of several more years.<sup>184</sup>

An important question is whether the physicians in these studies acceded to patient choice only when the patient chose what the physician considered to be the best decision or whether the physicians were willing to accept a patient's decision as long as it was within a reasonable range of treatment options. The latter alternative cannot explain the results of these studies. In end-of-life situations, the alternatives of both treatment and no treatment are almost always within the reasonable range of choices for patients to make.<sup>185</sup>

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178. Caralis & Hammond, *supra* note 165, at 683.

179. *Id.*

180. The patients included a 29-year-old male with AIDS, a 62-year-old male who was bedridden with severe emphysema, a 78-year-old female with mild dementia (but still mentally competent) and acute pneumonia, and a 37-year-old female with widely metastatic breast cancer. *Id.*

181. *Id.* at 687-88.

182. *Id.*

183. *Id.* at 686-87 (Table 5). In another study that presented physicians from seven countries, including the United States, with hypothetical scenarios, over 40% of the physicians' decisions differed from the care that had been requested by the hypothetical patient. Efreem Alemayehu et al., *Variability in Physicians' Decisions on Caring for Chronically Ill Elderly Patients: An International Study*, 144 CANADIAN MED. ASS'N J. 1133, 1138 (1991).

184. Caralis & Hammond, *supra* note 165, at 684. Commentators have been quick to point out that sometimes when physicians base their treatment decisions on the perceived benefit of the treatment to the patient, they err about the actual likelihood of benefit. Donna L. Miller et al., *Factors Influencing Physicians in Recommending In-Hospital Cardiopulmonary Resuscitation*, 153 ARCHIVES INTERNAL MED. 1999, 2002 (1993). The data reveal a tendency to overestimate the likelihood of patient survival after in-hospital cardiopulmonary resuscitation. *Id.*

185. As discussed below, there may be situations in which a medical treatment desired by the patient would be futile and therefore not a reasonable choice. However, truly futile

Another important study examining physician respect for patient values focused on treatment decisions for patients in intensive care units (ICUs).<sup>186</sup> In this study, researchers considered all patients treated in one of two intensive care units over a twelve-month period and found that seven percent had had life-sustaining treatment withheld or withdrawn.<sup>187</sup> The researchers then examined how the decisions to withhold or withdraw treatment came about.<sup>188</sup> The issue of withholding or withdrawing care usually arose during the physicians' work rounds when they were discussing their patients' treatment plans.<sup>189</sup> Indeed, only six percent of the decisions to withhold or withdraw treatment resulted from patient or surrogate requests.<sup>190</sup> Moreover, patients or their surrogates ultimately rejected the physician's recommendation to withhold or withdraw care in only two percent of cases.<sup>191</sup> In short, physicians almost always decided whether to consider stopping treatment, and the ultimate decisions were almost always in accordance with the physicians' views.<sup>192</sup>

Researchers reached similar results in an earlier study limited to do not resuscitate orders.<sup>193</sup> In ninety percent of cases, the physician raised the question of a DNR order.<sup>194</sup> In addition, the decision to issue the DNR order occurred within twenty-four hours of being raised in more than sixty percent of cases.<sup>195</sup> Because the patient or her surrogate rarely raised the question of a DNR order and the final decision to issue a DNR order occurred soon after the discussion be-

treatments represent only a very small percentage of treatments desired by patients at the end of life. See *infra* notes 221-224 and accompanying text.

186. Nicholas G. Smedira et al., *Withholding and Withdrawal of Life Support from the Critically Ill*, 322 NEW ENG. J. MED. 309 (1990).

187. *Id.* at 310.

188. The researchers gathered data through observation of patients and through completion of standardized, closed-format questionnaires by critical care fellows, research nurses, and family counselors. *Id.* at 309-10.

189. *Id.* at 311.

190. *Id.* at 312.

191. *Id.* Nine percent of the families, or 10 of the 106 studied, initially disagreed with the physicians' suggestions to cease artificial life support, but eight of those families eventually capitulated. *Id.*

192. In the study, only 4% of the patients who had treatment withheld or withdrawn had decisionmaking capacity at the time the decisions were made. *Id.* at 311. Thus, the physicians' dominant role in the decisionmaking process possibly reflected the patients' inability to participate in the process, rather than the physicians' dominance over the process. However, it is likely that physician dominance explains the study results. If physician dominance was not strong, the study should have documented a greater role for the family members in the decisionmaking. They, after all, were the patients' surrogates.

193. Schwartz & Reilly, *supra* note 113, at 807.

194. *Id.* at 809.

195. *Id.*



gan, there is good reason to believe that the physicians' values drove the decisions. If the values of the patients were driving the decisions, researchers would likely have found patients and their surrogates raising the issue of a DNR order more frequently; in addition, it is likely that patients and surrogates would have taken more time to reach a decision once the issue was raised by the physician.

Another important study looked at the issuance of DNR orders for patients with one of four serious diagnoses—AIDS, metastatic lung cancer, advanced liver cirrhosis, or severe congestive heart failure.<sup>196</sup> Researchers selected these four diagnoses because all had roughly the same likelihood of death both in the short term (after one year) and the long term (after five years).<sup>197</sup> Despite the similarities in prognosis, there were marked differences in likelihood of DNR orders. Approximately fifty percent of the AIDS and lung cancer patients had DNR orders; only five to fifteen percent of the cirrhosis and heart failure patients had DNR orders.<sup>198</sup> The researchers examined the hospital charts to see whether the differences could be explained by differences among the patients in terms of their mental status or on the basis that the patients' severity of illness varied from that predicted by their diagnostic category.<sup>199</sup> Neither of these possibilities explained the disparities.<sup>200</sup>

Moreover, differences among the patients in terms of their preferences also could not explain the disparities. If patient preferences were responsible for the differences, one would expect to see either that patients with AIDS and lung cancer were more likely to request a DNR order or that patients with cirrhosis and heart failure were less likely to agree to a physician's suggestion of a DNR order. However, as discussed earlier, two studies have shown that decisions to withhold or withdraw life-sustaining care are almost always initiated by physicians.<sup>201</sup> Consequently, it is unlikely that the patients varied in their tendency to request a DNR order. It is also unlikely that the patients varied in their likelihood of agreeing to a DNR order. Among the cirrhosis and heart failure patients who did not have a DNR order, the records of fewer than five percent documented any discussion about

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196. Robert M. Wachter et al., *Decisions About Resuscitation: Inequities Among Patients with Different Diagnoses but Similar Prognoses*, 111 ANNALS INTERNAL MED. 525, 525 (1989).

197. *Id.* at 526.

198. *Id.* at 528.

199. *Id.* at 529.

200. *Id.*

201. Schwartz & Reilly, *supra* note 113, at 809 (finding that the physician initiated the DNR discussion in 90% of all cases); Smedira, *supra* note 186, at 311 (finding that the decision usually originated with primary and intensive care teams on work rounds).

CPR.<sup>202</sup> Therefore, it appears that the physicians approached the question of CPR differently with AIDS and cancer patients than with cirrhosis and heart failure patients.

The results of these studies are not at all surprising. The dominance of physician values in medical treatment decisions is not unique to end-of-life decisions. Studies of other treatment decisions show similar results. For example, in a study of treatment for lung cancer, the choice of surgery versus radiation was influenced more by physician risk preferences than by patient risk preferences.<sup>203</sup> Surgery has a higher short-term risk of death but a lower long-term risk of death.<sup>204</sup> The patients were more risk averse than the physicians, but the treatment choices between surgery and radiation were more consistent with the risk preferences of the physicians.<sup>205</sup> Additionally, in a study of cesarean section rates among physicians at a single hospital, the different obstetricians varied in their use of cesarean sections by a factor of more than two.<sup>206</sup> Medical or socioeconomic differences among the patients could not account for the disparities; instead, the disparities appeared to reflect idiosyncratic differences among the physicians.<sup>207</sup> Likewise, studies of racial and gender disparities in clinical decisionmaking have found differences in treatment of coronary artery disease and chronic kidney failure according to race and gender that cannot be explained by variations in age, severity of disease, income, or type of insurance.<sup>208</sup> After controlling for these potentially confounding variables, blacks are only fifty-five percent as likely as whites to receive a kidney transplant,<sup>209</sup> and women with

202. Wachter et al., *supra* note 196, at 530.

203. Barbara J. McNeil et al., *Fallacy of the Five-Year Survival in Lung Cancer*, 299 NEW ENG. J. MED. 1397, 1401 (1978).

204. *Id.* at 1397.

205. *Id.* at 1401 ("Clearly . . . most patients today are treated with operation because of the overwhelming belief of most physicians that operation is 'better.'").

206. The frequency of cesarean sections varied from a low of 19.1% to a high of 42.37%. Gregory L. Goyert et al., *The Physician Factor in Cesarean Birth Rates*, 320 NEW ENG. J. MED. 706, 707 (1989).

207. *Id.* at 708 ("The implication of our findings is that individual variation among physicians could be an important factor underlying the increasing cesarean-section rates.").

208. Council on Ethical and Judicial Affairs, American Medical Association, *Black-White Disparities in Health Care*, 263 JAMA 2344 (1990); Council on Ethical and Judicial Affairs, American Medical Association, *Gender Disparities in Clinical Decision Making*, 266 JAMA 559 (1991).

209. P.J. Held et al., *Access to Kidney Transplantation: Has the United States Eliminated Income and Racial Differences?*, 148 ARCHIVES INTERNAL MED. 2594 (1988); SCHOOL OF PUBLIC HEALTH, STATE UNIV. OF NEW YORK AT ALBANY & NEW YORK STATE DEP'T OF HEALTH, END STAGE RENAL DISEASE IN NEW YORK STATE 183, 209 (1991).

symptoms of coronary artery disease are much less likely than men to be evaluated for heart disease.<sup>210</sup>

Use of a surrogate would not address the problem of physicians making decisions on the basis of their own values rather than the patients' values.<sup>211</sup> In the studies that demonstrated a predominance of physician values, many of the patients were represented by their surrogates. Indeed, in the first advance directive study discussed, physicians overrode advance directives written by surrogates to the same extent that they overrode directives written by patients.<sup>212</sup>

### *B. Reasons for the Predominance of Physicians' Values*

There are several possible explanations for the predominance of physician values in end-of-life decisionmaking, including the natural lag between theoretical acceptance and functional implementation of a change, the fear of malpractice, the futility of implementing patients' choices, patients' reluctance to make decisions, patients' lack of authority, and physicians' desire to preserve professional authority.

1. *Natural Lag Between Theory and Practice.*—With any theoretical development, there is a natural lag between theoretical acceptance and the practical implementation of the change. Physicians, like others, do not change established practices immediately, and it makes sense to subject new theories to the test of time to ensure their validity.

Nevertheless, this is not a sufficient explanation for the failure of physicians to respect patient values. Most of the studies discussed in this Article were conducted at major teaching hospitals where interns and residents are responsible for much of the decisionmaking.<sup>213</sup> Accordingly, physicians who were still in the midst of their postgraduate training and within a few years of graduation from medical school made most of the treatment decisions. These physicians received all of their medical training after principles of patient self-determination had received widespread recognition. In addition, ample evidence indicates that physicians are perfectly capable of making rapid changes in their modes of practice when they so desire. For example, within five years of its introduction into the United States, laparoscopic cho-

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210. J.N. Tobin et al., *Sex Bias in Considering Coronary Bypass Surgery*, 107 ANNALS INTERNAL MED. 19 (1987).

211. See *infra* notes 250-251 and accompanying text.

212. See *supra* text accompanying note 169.

213. See, e.g., Smedira et al., *supra* note 186, at 309 (conducting a study at the Moffit-Long Hospital of the University of California and San Francisco General Hospital).

lecystectomy replaced more traditional methods of surgery in approximately eighty percent of operations to remove the gall bladder.<sup>214</sup> This rapid adoption of the newer method is particularly striking given the absence of any rigorous studies comparing the two methods<sup>215</sup> and the fact that laparoscopic surgery requires very different techniques than the traditional method of gall bladder surgery.<sup>216</sup>

2. *Fear of Malpractice.*—Physicians often cite concerns about liability risk as a deterrent to practicing good medicine. These physicians may fear retaliatory suits from family members if life-sustaining treatment is withdrawn or withheld from a patient. Indeed, this fear of liability, though unfounded,<sup>217</sup> appears to influence physician willingness to discontinue life-sustaining treatment.<sup>218</sup> This alone, however, does not adequately explain the predominance of physician preferences in end-of-life treatment decisions. Often, when physicians impose their own values and override patient choice, they withhold or withdraw treatment that a patient desires. For example, in the nursing home study examining adherence to living wills, seventy-five percent of the overrides of the patient's choice resulted in denial of treatment that had been requested in the living will.<sup>219</sup> In addition, some skepticism is appropriate when physicians attribute life-sustaining decisions to fear of liability. First, there are no reported cases of successful prosecution or suit against a physician for withdrawing life-sustaining treatment.<sup>220</sup> Second, physicians may simply prefer to attribute their reluctance to carry out patient wishes to a "neutral" explanation like the law, rather than to disclose that their objection really stems from personal philosophical views. It is often easier to deal with moral conflicts by couching disagreements in morally neutral terms.

3. *Futility of End-of-Life Care.*—Physicians might override patient choices and ignore patient values because they are exercising what they feel is their right to reject patient demands for treatment that is medically futile.<sup>221</sup> This theory would explain why patients are denied treatment that they desire, but would not explain the provision of

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214. NIH Consensus Development Panel on Gallstones and Laparoscopic Cholecystectomy, *Gallstones and Laparoscopic Cholecystectomy*, 269 JAMA 1018, 1018 (1993).

215. *Id.*

216. Barak Gaster, *The Learning Curve*, 270 JAMA 1280 (1993).

217. Orentlicher, *supra* note 33, at 2446.

218. Zinberg, *supra* note 60, at 479-81.

219. Danis et al., *supra* note 161, at 884-85.

220. See Orentlicher, *supra* note 33, at 2446; Weir & Gostin, *supra* note 59, at 1852.

221. *Guidelines*, *supra* note 80, at 1870.

services that are undesired. Even if perceived medical futility explained most cases in which physicians overrode patient values, however, the overrides still reflect the imposition of physician values. Judgments about futility almost never reflect impersonal opinions that no medical benefit is possible; rather, they reflect personal value judgments that the benefits of treatment are not worth their costs.<sup>222</sup> For example, when Helga Wanglie's family requested that she be maintained on a ventilator, despite her permanently unconscious state, her physicians argued that there was no medical benefit to be gained by keeping her alive.<sup>223</sup> Yet, the preservation of life is always a medical benefit. To be sure, there may be reasons not to consider the preservation of life a *worthwhile* medical benefit. For example, when health care resources are limited, it may not make sense to spend them on patients who will never regain consciousness. That, however, is a judgment about allocating resources, not a judgment about futility.<sup>224</sup>

4. *Patients Do Not Want to Exercise Their Autonomy.*—Some have argued that patients really do not want to make their own medical decisions. Although patients very much want to be fully informed about the decisions that need to be made, it has been observed that they ultimately want their physicians to make the decisions for them.<sup>225</sup> There is a good deal of intuitive sense to this argument. When physicians describe treatment options and then leave the final choice to the patient, many patients feel that the physicians are abdicating their professional responsibility to exercise their medical judgment.<sup>226</sup> Indeed, a number of studies suggest that patients do not want to make medical decisions,<sup>227</sup> particularly when their illnesses

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222. Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561, 1563 (1992).

223. Steven H. Miles, *Informed Demand for "Non-Beneficial" Medical Treatment*, 325 NEW ENG. J. MED. 512, 513 (1991). Ironically, Ms. Wanglie's family had to fight in court to receive ventilatory treatment for a permanently unconscious patient while Karen Quinlan's family previously had to fight in court to withdraw ventilatory treatment for a permanently unconscious patient. *In re Quinlan*, 355 A.2d 647 (N.J.), cert. denied, 429 U.S. 922 (1976).

224. Truog et al., *supra* note 222, at 1563.

225. Jack Ende et al., *Measuring Patients' Desire for Autonomy: Decision Making and Information-Seeking Preferences Among Medical Patients*, 4 J. GEN. INTERNAL MED. 23, 28 (1989).

226. This is my anecdotal experience from discussions with friends and family members.

227. William M. Strull et al., *Do Patients Want to Participate in Medical Decision Making?*, 252 JAMA 2990 (1984); David S. Krantz et al., *Assessment of Preferences for Self-Treatment and Information in Health Care*, 39 J. PERSONALITY & SOC. PSYCHOL. 977 (1980); Linda Pendleton & William C. House, *Preferences for Treatment Approaches in Medical Care: College Students Versus Diabetic Outpatients*, 22 MED. CARE 644 (1984); Ilan B. Vertinsky et al., *Measuring Consumer Desire for Participation in Clinical Decision Making*, 9 HEALTH SERVICES RES. 121 (1974).

are severe.<sup>228</sup> On the other hand, other studies indicate that patients do in fact want to make medical decisions for themselves.<sup>229</sup>

Ultimately, the argument that patients prefer to exercise their autonomy by ceding medical decisionmaking to their physicians fails to withstand scrutiny. First, it is not clear that the studies reaching this conclusion are accurately measuring the patients' desires to make medical decisions. For example, researchers in one study concluded that patients do not want to make medical decisions by asking whether people agreed or disagreed with statements such as: "It's almost always better to seek professional help than to try to treat yourself."<sup>230</sup> Yet, the desire for professional advice is a very different issue than the desire to make the ultimate decision. Another study asked questions such as whether the doctor or patient should decide "[w]hen the next visit to check your blood pressure should be."<sup>231</sup> Such questions may yield misleading results because, at first glance, they seem to be clearly technical in nature. But consider the following example. A pregnant woman, after an appropriate discussion, agrees to delivery by cesarean section. Her physician then asks her to decide the type of incision to be used to pierce her abdomen. She is likely to respond that the choice of incision is a medical decision for the physician to make. However, if the physician informs her that a lower midline incision gives greater exposure and can therefore accommodate a malpresentation or an unusually large child, but leaves a noticeable scar, while a transverse abdominal incision leaves no noticeable scar but gives less exposure,<sup>232</sup> she is much more likely to want to make the decision herself. Indeed, patient preference for a better cosmetic result has led obstetricians to use the transverse abdominal incision more frequently.<sup>233</sup>

Studies by John Wennberg and others suggest that, when given enough information to fully understand the issues at stake, patients do want to make medical decisions.<sup>234</sup> To accommodate patients,

228. Ende et al., *supra* note 225, at 26-27.

229. Barrie R. Cassileth et al., *Information and Participation Preferences Among Cancer Patients*, 92 ANNALS INTERNAL MED. 832 (1980); Ruth R. Faden et al., *Disclosure of Information to Patients in Medical Care*, 19 MED. CARE 718 (1981); Marie R. Haug & Bebe Lavin, *Practitioner or Patient—Who's in Charge?*, 22 J. HEALTH & SOC. BEHAVIOR 212 (1981).

230. Krantz et al., *supra* note 227, at 980.

231. Ende et al., *supra* note 225, at 29.

232. Richard Depp, *Cesarean Delivery and Other Surgical Procedures*, in OBSTETRICS: NORMAL AND PROBLEM PREGNANCIES 635, 643 (Steven G. Gabbe et al. eds., 2d ed. 1991).

233. LEO J. DUNN, *CESAREAN SECTION AND OTHER OBSTETRIC OPERATIONS* in DANFORTH'S OBSTETRICS AND GYNECOLOGY 639, 644 (James R. Scott et al. eds., 6th ed. 1990).

234. Joseph F. Kasper et al., *Developing Shared Decision-Making Programs to Improve the Quality of Health Care*, 4 QUALITY REV. BULL. 183 (1992).

Wennberg and his colleagues have pioneered the concept of "shared decision-making programs." As part of the programs, physicians give patients interactive video programs that present detailed information about their treatment alternatives and include outcome probabilities for the different types of treatments based on the patient's specific characteristics.<sup>235</sup> Patients who use the shared decisionmaking programs generally take more control over their medical decisions. For example, preliminary data indicate that the use of the programs with prostate-surgery candidates results in a forty-four to sixty percent reduction in the rate of surgery.<sup>236</sup> In short, in the studies that suggest that patients have little desire to make medical decisions, the patients probably did not realize that seemingly technical questions are in fact intrinsically value laden. If they had realized this, the studies likely would have come out differently.

One important study, however, strongly suggests that many patients prefer to cede some of their decisionmaking authority.<sup>237</sup> In this study, patients receiving chronic kidney dialysis treatment were asked whether they would want the dialysis continued if they developed advanced Alzheimer's disease.<sup>238</sup> The patients were then asked "how much leeway their physician and surrogate should have to override . . . [their decision] if overriding were in their best interests."<sup>239</sup> While thirty-nine percent of the patients would give no leeway, thirty-one percent would give complete leeway and the remaining thirty percent would give intermediate degrees of leeway to their surrogates and physicians to override their own decision.<sup>240</sup>

There are two weaknesses to this study. First, of the patients who would permit overrides, it is unclear whether they were giving authority primarily to their surrogate or to their physician since they were only asked how much leeway they would want their surrogate *and* physician to have.<sup>241</sup> Second and more importantly, it is unclear how patients interpreted "best interests."<sup>242</sup> Presumably, they had some concept of an objective judgment as to the best treatment for them. If

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235. *Id.* at 183. With patient-specific outcome probabilities, a patient would be given, for example, an individual figure for the likelihood that prostate surgery would relieve his specific symptoms, rather than an average figure that would apply to a large group of men with similar symptoms. *Id.*

236. *Id.* at 184.

237. See Sehgal et al., *supra* note 157, at 59-63 (concluding that not all patients prefer to have their advance directives strictly followed).

238. *Id.* at 60.

239. *Id.*

240. *Id.* at 61.

241. *Id.* at 60.

242. *Id.*

the patients envisioned an objective judgment, however, their responses did not take into account the possible imposition of someone else's values. Thus, even this study does not provide physicians with a defense for basing treatment decisions on their own values, rather than on the values of the patient.

5. *Patients Lack Authority.*—To a certain extent, physicians appear to believe that patient preferences can be justifiably ignored on the ground that patients lack appropriate authority. There are two possible reasons for this view. First, physicians may simply believe that, because patients lack medical training and expertise, they are not capable of making the kinds of complex medical decisions that arise with life-sustaining treatment. Indeed, studies have found that many physicians question the ability of patients to participate meaningfully in any medical decisionmaking at the end of life.<sup>243</sup> Although this belief may explain some physician behavior, it does not justify such behavior. As discussed below, decisions regarding life-sustaining treatment are inherently value-laden and do not require medical knowledge.

Second, when patients have lost decisionmaking capacity, physicians may take the view that the patients have different interests than their previously competent selves and that the preferences expressed by the patient while competent should not be implemented when they would undermine the best interests of the currently incompetent patient.<sup>244</sup> For example, a person may have written in a living will that all life-sustaining treatment should be withdrawn in the event of advanced dementia. At that time, the person may have felt that there is no value to life when it is no longer possible to read, converse, or even recognize friends and family. After reaching his or her demented state, however, the patient might seem happy and content, responding with smiles to various activities or stimuli. If the patient seems to gain pleasure from life and experiences little suffering, then it would seem to be in the patient's best interests to maintain life-sustaining treatment. This view is supported by the study of dialysis patients,

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243. See, e.g., Kent W. Davidson et al., *Physicians' Attitudes on Advance Directives*, 262 JAMA 2415, 2416 Table 3 (1989) (indicating that 58.8% of responding doctors strongly agreed that "[a] potential problem with advance directives is that patients could change their minds about 'heroic' treatment after becoming terminally ill" and 32.4% strongly agreed that "[t]he training and experience of physicians gives them greater authority than patients in decisions about withholding 'heroic' treatment").

244. Rebecca S. Dresser & John A. Robertson, *Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach*, 17 LAW, MED. & HEALTH CARE 234, 240-41 (1989).



many of whom indicated that they wanted their decisions overridden if to do so was in their best interests.<sup>245</sup>

In addition, there is some empirical evidence that healthy patients underestimate the quality of life that comes with having a disabling condition. For example, cancer of the rectum is usually treated with surgical therapy, but for some patients radiation therapy is an alternative approach.<sup>246</sup> If surgical therapy is used, the patient ends up with a colostomy. With radiation therapy, a colostomy is not necessary.<sup>247</sup> In a study of patient values, researchers found that patients who had received radiation therapy perceived the quality of life with a colostomy as lower than did the patients who had received surgical therapy and were living with a colostomy.<sup>248</sup>

These data demonstrate the need for better patient education. The studies of Wennberg and others<sup>249</sup> indicate that effective educational methods can greatly enhance patient understanding of the implications of alternative medical treatment options.

I will not try to settle the debate regarding whether an incompetent patient's treatment should be guided by the patient's previous instructions or the patient's current best interests. Even if we accept the best interests argument, it only provides support for overriding the patient's preferences. It does not support substituting the physicians' preferences for those of the patient.

6. *Preservation of Professional Authority.*—The real explanation for the dominance of physician values in end-of-life decisions seems to be a professional resistance to a loss of authority. If patient autonomy is taken seriously, its impact will extend far beyond end-of-life decisions. Every medical decision, from prescribing an antibiotic to performing bypass surgery, ultimately comes down to a balancing of benefits and detriments.<sup>250</sup> Medical decisions based on such balancings do not require any particular medical expertise and therefore could be made by patients based on their personal benefit and risk preferences. In

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245. Sehgal et al., *supra* note 157, at 61.

246. Norman F. Boyd et al., *Whose Utilities for Decision Analysis?*, 10 MED. DECISION MAKING 58, 60 (1990).

247. *Id.*

248. *Id.* at 63, 65. These differences could not be explained on the grounds that patients who did not want a colostomy chose radiation therapy and patients who did not mind a colostomy chose surgical therapy. The decision to use radiation therapy was generally not made on the basis of patient preferences. *Id.* at 65-66.

249. See *supra* notes 234-236 and accompanying text.

250. See Tom Tomlinson & Howard Brody, *Futility and the Ethics of Resuscitation*, 264 JAMA 1276, 1277 (1990) (asserting that every medical determination involves a judgment regarding the potential harms and benefits of intervention).

other words, if we take seriously the principle that only patients have the right to decide which benefits are worthwhile and which risks are too serious, then it is not clear what authority physicians have to decide when a treatment should or should not be provided. Indeed, a survey of physicians in California and Vermont suggests that many physicians object to advance directives because they believe advance directives will curtail physician control of treatment decisions.<sup>251</sup>

The following example illustrates the issue regarding physician authority. Until recently, medical textbooks included the standard recommendation that physicians offer amniocentesis to check for Down syndrome to women with no family history of the syndrome only if the women were thirty-five or over.<sup>252</sup> While several factors contributed to this recommendation, one of the most important was the view that amniocentesis made sense only when the risk of having a Down syndrome child was comparable to the risk that the amniocentesis would cause the pregnancy to abort.<sup>253</sup> However, women who have strong feelings against having a Down syndrome child might choose amniocentesis even if the risk of an abortion from the procedure was several times greater than the risk of having a Down syndrome child without the procedure.<sup>254</sup> These women might reason that, even if they lose a fetus from the amniocentesis, they can always become pregnant again. Whether this is a reasonable choice cannot be settled by appealing to any principles derived from medical knowledge.

Consideration of two other examples leads to the same conclusion. The first example is that of coronary artery bypass surgery. Because of concern that many bypass surgeries were being performed unnecessarily, the American College of Cardiology and American Heart Association convened an expert panel to develop guidelines for

251. Zinberg, *supra* note 60, at 482.

252. PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: A REPORT ON THE ETHICAL, SOCIAL, AND LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING, AND EDUCATION PROGRAMS 75, 76 (1983) [hereinafter SCREENING AND COUNSELING]. Some textbooks still include this recommendation. See, e.g., Joe L. Simpson, *Genetic Counseling and Prenatal Diagnosis*, in OBSTETRICS, NORMAL AND PROBLEM PREGNANCIES 269, 278 (Steven G. Gabbe et al. eds., 2d ed. 1991) ("[Genetic] screening is now offered routinely for . . . women aged 35 years or older to detect . . . Down Syndrome.").

253. SCREENING AND COUNSELING, *supra* note 252, at 77. In other words, there are two significant risks being balanced. The risk of not doing an amniocentesis and giving birth to a Down syndrome baby, and the risk of doing an amniocentesis and losing a normal fetus through iatrogenic abortion. *Id.* at 80.

254. *Id.*

the use of bypass surgery.<sup>255</sup> The panel concluded that physicians should offer bypass surgery to patients only if the surgery could provide longer survival or less compromise of wellbeing<sup>256</sup> than medical therapy. Like the policy for amniocentesis, this restriction on bypass surgery reflects a nonmedical value judgment. Some patients might prefer surgery to medical therapy, even if there is no difference in outcome, because of the inconvenience of daily medical therapy. A similar value judgment underlies the consensus guidelines for coronary angioplasty.<sup>257</sup> The panel for angioplasty concluded physicians should not offer the procedure when the chances of success are less than sixty percent.<sup>258</sup> Yet, medical expertise does not dictate that a sixty percent cutoff rate should be used, rather than a fifty percent or seventy percent cutoff rate.

In sum, it is not surprising that end-of-life treatment decisions largely reflect physician rather than patient values. Physicians routinely make value judgments when making medical judgments. To yield to patient values in end-of-life decisions would require a radical change in the way physicians practice medicine. This is not to suggest that there is anything unseemly about physicians imposing their own values. In imposing their values, physicians are trying to ensure that the patient receives the best possible outcome. The problem, as indicated, is that the best possible outcome can only be determined by the patient's values.

Some commentators have argued that an obligation to respect patient values would require physicians to compromise their professional values and that principles of patient self-determination do not necessarily require such a compromise.<sup>259</sup> When treatment provides no medical benefit—a rare occurrence—this argument may be

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255. ACC/AHA Task Force, Subcommittee on Coronary Artery Bypass Graft Surgery, *Guidelines and Indications for Coronary Artery Bypass Graft Surgery: A Report of the American College of Cardiology/American Heart Association Task Force on Assessment of Diagnostic and Therapeutic Cardiovascular Procedures*, 17 J. AM. C. CARDIOLOGY 543 (1991).

256. Compromise of wellbeing is measured by frequency and magnitude of chest pain or shortness of breath and the degree to which the patient's ability to engage in exercise or other physical exertion is limited.

257. See ACC/AHA Task Force, Subcommittee on Percutaneous Transluminal Coronary Angioplasty, *Guidelines for Percutaneous Transluminal Coronary Angioplasty: A Report of the American College of Cardiology/American Heart Association Task Force on Assessment of Diagnostic and Therapeutic Cardiovascular Procedures*, 12 J. AM. C. CARDIOLOGY 529 (1988) (outlining a series of recommendations and guidelines for the use of coronary angioplasty).

258. *Id.* at 538-42.

259. See Frank A. Chervanek & Laurence B. McCullough, *Justified Limits on Refusing Intervention*, HASTINGS CENTER REP., Mar.-Apr. 1991, at 12, 13-15 (arguing that a patient's demand for alternative medical intervention may be unreasonable because it is inconsistent with that patient's best interests and asserting that physicians can preserve their profes-

valid.<sup>260</sup> In the vast majority of cases, it is not. There are only three potential bases for taking the decision away from the patient: (1) a physician's treatment decision reflects the patient's best interest; (2) health care resources are scarce and abiding by a patient's directive may deprive others of health care; and (3) the physician has conscientious objections to carrying out the patient's wishes. None of these justifies substituting physicians' values for patients' values. With regard to the first, principles of self-determination make clear that patients are in the best position to determine their best interests. Physicians therefore have no legitimate justification for overriding the patient on the basis of the patient's best interests. Although there are limits on the kinds of risks that society allows people to assume, there is no reason why physicians should decide which medical risks are too great for the patient to assume any more than they should decide which environmental or workplace risks are too great for people to assume. Similarly, while it may not be appropriate for an incompetent patient's treatment to be determined by the previously competent self, why should physicians—as opposed to family members—have the authority to decide what is in a patient's best interests? In short, there may be a best interests argument for overriding patient values; it, however, is not an argument for substituting physician values.

Likewise, although it is true that society cannot provide every patient with every beneficial treatment and that someone must decide which treatments will be available and which will not, these choices should not be based on the personal preferences of physicians. Physicians agree: they traditionally have rejected bedside rationing on the ground that allocation decisions should be made on a societal level,

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sional values in such a situation with strategies designed to educate the patient about why their preference is unreasonable from a clinical perspective).

260. See generally Truog et al., *supra* note 222, at 1560-63 (discussing the meaning of futility when discussed in connection with medical treatment). The debate about the meaning of futility is an important one, though beyond the scope of this Article; see also Leslie J. Blackhall, *Must We Always Use CPR?*, 317 NEW ENG. J. MED. 1281, 1282 (1987) (asking whether a physician is obligated to perform CPR on a patient who wants it when the physician believes that CPR will not be beneficial and may be harmful); See *Guidelines*, *supra* note 80, at 1869 ("The frequent performance of CPR on patients who are terminally ill or who have little chance of surviving for more than a brief period of time has promoted concern that resuscitation efforts may be employed too broadly."); John D. Lantos et al., *The Illusion of Futility in Clinical Practice*, 87 AM. J. MED. 81, 81-84 (1989) (discussing the implications of the claim that a medical treatment is futile); Lawrence J. Schneiderman et al., *Medical Futility: Its Meaning and Ethical Implications*, 112 ANNALS INTERNAL MED. 949, 949 (1990) ("[W]e propose that when physicians conclude . . . that in the last 100 cases a medical treatment has been useless, they should regard that treatment as futile."); Tomlinson & Brody, *supra* note 250, at 1276-80 (arguing in support of futility judgments).

rather than an individual level.<sup>261</sup> To maintain patient trust, physicians must remain advocates for their patients, not divide their loyalties between their patients and society.<sup>262</sup> Moreover, if physicians make rationing decisions on an individual basis, the decisions will reflect their own biases rather than the shared values of society as a whole.

Finally, even a physician's valid conscientious objections to a course of treatment<sup>263</sup> does not justify the physician interjecting her values to override a patient's treatment decision. If a physician has a

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261. See Norman G. Levinsky, *The Doctor's Master*, 311 NEW ENG. J. MED. 1573, 1575 (1984) ("[I]t is society, not the individual practitioners, that must make the decision to limit the availability of effective but expensive types of medical care.").

262. See *id.* at 1574 (arguing that physicians who withhold treatment because they believe it is wasteful lose the faith of their patients).

263. In many cases, physicians may simply disagree about the moral acceptability of a proposed course of action. For example, although ethicists consider the withholding and withdrawing of life-sustaining treatment to be morally equivalent, many physicians believe that it is less acceptable to withdraw than to withhold life-sustaining care. See Council on Ethical and Judicial Affairs, American Medical Association, *Decisions Near the End of Life*, 267 JAMA 2229 (1992) [hereinafter *Decisions*] ("There is . . . no ethical distinction between withdrawing and withholding life-sustaining treatment."); see also Caralis & Hammond, *supra* note 165, at 688 ("[I]n this group of physicians and students, the clear majority (73%) feel that withdrawing treatment is different than withholding . . ."); Mildred Z. Solomon et al., *Decisions Near the End of Life: Professional Views on Life-Sustaining Treatments*, 83 AM. J. PUB. HEALTH 14, 19 (1993) ("Most [physicians] . . . asserted that withdrawing treatment is ethically different than deciding not to initiate treatment."). Physicians also seem to perceive a distinction in the law between withholding and withdrawing care, Philip G. Peters, Jr. et al., *Physician Willingness to Withhold Tube Feeding After Cruzan: An Empirical Study*, 57 MO. L. REV. 831, 838-39 (1992), even though there is no such distinction. Meisel, *supra* note 33, at 1499 ("It is sometimes said that although it might be permissible not to start a particular treatment for a critically ill patient, once begun, it is impossible to stop . . . [I]t is a myth that there is a legal requirement to continue treatment if it is properly refused."). In one study, only 59% of the physicians reported that they would carry out a ventilator-dependent patient's request to have the ventilator turned off, even though 98% of the physicians stated that they would agree not to place the patient on the ventilator in the first place if the patient did not want ventilatory treatment. Terri R. Fried et al., *Limits of Patient Autonomy: Physician Attitudes and Practices Regarding Life-Sustaining Treatments and Euthanasia*, 153 ARCHIVES INTERNAL MED. 722, 723-24 (1993). Physicians also seem to disagree with the dominant ethical view that the patient's refusal of life-sustaining treatment should be respected regardless of the kind of treatment and regardless of whether the treatment involves a ventilator or a feeding tube. *Decisions*, *supra*, at 2230-31 (asserting that the decision of whether life-sustaining treatment should be initiated or maintained depends on the patient's problems, not the nature of the treatment). In one study, physicians were more willing to withhold CPR, ventilation, or surgery than antibiotics or feeding tubes. Mower & Baraff, *supra* note 126, at 380 Table 3. In another study, more than 35% of physicians agreed with the proposition that "even if life supports such as mechanical ventilation and dialysis are stopped, food and water should always be continued." Solomon et al., *supra*, at 18 Table 4. The researchers found that the reluctance to discontinue feeding and hydration would not have been different if the proposition had used the language "medically supplied nutrition and hydration" rather than "food and water." *Id.* at 18.

moral or ethical objection to carrying out a patient's wishes, the physician should transfer care of the patient to someone who does not.<sup>264</sup> Any other course of conduct would inevitably lead to treatment in contravention of the patients' directives.<sup>265</sup>

In sum, physicians seem unwilling to respect patient values and choice for the main reason that they desire to preserve professional authority. This, however, is not a valid justification for doing so. While there must be some limits to patient choice, those limits should be set by society as a whole, not by individual physicians.

### C. *Conflicting Evidence*

If physicians are imposing their own values in end-of-life decisionmaking, it is difficult to explain why today's decisions seem to be made differently than in the past. For example, today life-sustaining treatments are being withdrawn when in the past they would have been imposed on patients.<sup>266</sup> According to one recent study, from 1988 to 1990 almost twice as many intensive care unit patients had do not resuscitate orders as did patients from 1979 to 1982.<sup>267</sup> Patients and physicians may suggest this phenomenon indicates that, today, treatment decisions are based on patient values despite physician disagreement. Rather than indicating a heightened physician respect for patient values, however, the evidence demonstrating changes in treatment decisions may indicate a change in physician values. Patients may be receiving less aggressive care at the end of life because physicians are less inclined to see value in such care. Indeed, as Daniel Callahan has observed, end-of-life treatments often follow a trend of first being mandatory, then becoming optional, and finally becoming unavailable.<sup>268</sup> In other words, certain treatments at first are imposed

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264. See MD. CODE ANN., HEALTH-GEN. § 5-613 (1994) (allowing a health care provider to decline to carry out the instruction of a health care agent or surrogate as long as the provider makes every reasonable effort to transfer the patient to another health care provider).

265. There may be a small percentage of cases in which the physician objects to providing care on the grounds that to do so would be inhumane.

266. See Robert L. Jayes et al., *Do-Not-Resuscitate Orders in Intensive Care Units: Current Practices and Recent Changes*, 270 JAMA 2213, 2215 (1993) (discussing the increases in the frequency of do not resuscitate orders).

267. *Id.*

268. See Daniel Callahan, *On Feeding the Dying*, HASTINGS CENTER REP., Oct. 1983, at 22, 22 (asserting that in 1973 it was uncommon to turn off respirators, but that in 1983, when the respirator does the patient no good, it was often discontinued).

on patients and then ultimately come to be denied to patients, regardless of the preferences of the patient or the patient's family.<sup>269</sup>

For example, at one time, there was automatic treatment for patients who had lost all brain function but whose heart function could be maintained.<sup>270</sup> Then it became permissible to discontinue life-sustaining treatment from such patients. Now these patients are considered legally dead,<sup>271</sup> and treatment to maintain heart function is denied even when families request continuation of treatment.<sup>272</sup> Treatment for cardiac arrest has undergone a similar progression. At one time, when a patient's heart ceased beating, CPR was automatically administered. However, because many of these patients cannot be resuscitated, or, if they can, they may live for only a brief time and with a poor quality of life, DNR orders were developed so patients could decline CPR.<sup>273</sup> Now, many patients are not even offered CPR, on the ground that CPR is futile.<sup>274</sup>

Perhaps the most striking progression has occurred in the treatment of patients in persistent vegetative states or other permanently unconscious conditions. In *In re Quinlan*,<sup>275</sup> the New Jersey Supreme Court granted an unconscious patient's physician, with the concurrence of the patient's family, permission to turn off the ventilator that was keeping the unconscious woman alive.<sup>276</sup> Before *In re Quinlan*, however, it was generally assumed that such patients must be given life-sustaining, ventilatory treatment.<sup>277</sup> Since then, patients and families have had the authority to decline ventilators. Currently, there is a vigorous movement to declare ventilators unavailable for permanently unconscious patients. For example, in 1991, a Minneapolis hospital

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269. *Id.* (indicating that today respirators are routinely turned off even if the patient's family wants the treatment continued).

270. *Id.*

271. See *In re Bowman*, 617 P.2d 731, 737-38 (Wash. 1980) (noting that at least 25 state legislatures adopted brain death as the standard of death and holding that a person who has sustained irreversible cessation of brain functions is legally dead).

272. See Callahan, *supra* note 268, at 22 ("It is no longer customary to allow a person who has suffered brain death of the whole brain to be maintained on a respirator simply because the family wants that done."). Under New Jersey law, however, patients are entitled to treatment after brain death if the desire for treatment is motivated by religious reasons. N.J. STAT. ANN. § 26:6A-5 (Supp. 1993).

273. See Jayes et al., *supra* note 266, at 2213-17 (discussing the history of DNR orders and their increased use).

274. See *id.* at 2216 (suggesting that the increase in the use of DNR orders indicates that physicians and families are setting limits to therapy in cases when a poor outcome is likely).

275. 355 A.2d 647 (N.J. 1976).

276. *Id.* at 671-72.

277. See Callahan, *supra* note 268, at 22 (discussing how, before *Quinlan*, it was uncommon to turn off respirators).

went to court unsuccessfully to disconnect a ventilator from a permanently unconscious patient over the family's objections.<sup>278</sup> Many commentators also have argued that all life-sustaining treatment should be withheld or withdrawn from permanently unconscious patients, either because the treatment is futile<sup>279</sup> or because the patients should be considered dead.<sup>280</sup>

In short, while patients today are less likely to receive certain kinds of end-of-life care than patients ten or twenty years ago, the change in treatment more likely reflects changes in physicians' values than a greater respect by physicians for patients' values.

#### IV. POTENTIAL SOLUTIONS

##### A. *Reform the Laws*

Should we abolish advance directive statutes because of their tendency to mislead patients about their rights? While there might be good theoretical reasons for doing so, this is not a practical solution. The statutes are too well-established within our legal system for there to be any likelihood of their revocation. They could, however, be improved by amending them to correct their ambiguous, unconstitutional or otherwise problematic provisions. Additionally, health care surrogate acts should be passed in all states. Because it is unrealistic to expect that advance directives will become common place, there must be a default regime for patients without directives, just as we have a regime of default rules for people who die intestate.<sup>281</sup>

The new Uniform Health Care Decisions Act provides an excellent model for both advance directive and surrogate laws with its unitary statutory approach.<sup>282</sup> In particular, the Act responds to the lack of written documentation of patient wishes by expressly recognizing

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278. Miles, *supra* note 223, at 512-15. In the case, the family of an 85-year-old woman insisted on continued life support treatment even though many health care professionals had determined that the woman was at the end of her life and that the respirator was nonbeneficial. *Id.* at 513. The court appointed the woman's husband as her representative and refused to rule on the legality of a stop treatment order, noting that the husband had not made a stop treatment request. *Id.*

279. Schneiderman et al., *supra* note 260, at 949 (arguing that physicians should withhold treatment that they deem to be futile).

280. See generally Stuart J. Youngner & Edward T. Bartlett, *Human Death and High Technology: The Failure of the Whole-Brain Formulation*, 99 ANNALS INTERNAL MED. 252 (1983).

281. James Lindgren, *Death by Default*, 56 LAW & CONTEMP. PROBS. 185, 195 (1993).

282. See Charles P. Sabatino, *The New Uniform Health Care Decisions Act: Paving a Health Decisions Superhighway?*, 53 MD. L. REV. 1238, 1254 (1994) ("Perhaps the most compelling fact in favor of acceptance of the Uniform Act is the fragmentation and variability of state health decisions law.").



that oral instructions are just as valid as written instructions.<sup>283</sup> In addition, the Act does not have limitations according to patient diagnosis or type of treatment,<sup>284</sup> it acknowledges close friends as potential surrogate decisionmakers,<sup>285</sup> and it expressly recognizes advance directives executed outside of the state.<sup>286</sup>

As indicated previously, however, not all of the problems will be addressed by even the best set of end-of-life statutes. We will still have to deal with the problem of physicians imposing their own values. The following recommendations address that concern.

### *B. Acknowledgement and Discussion*

Physicians simply may not recognize the extent to which they are injecting their values into the decisionmaking process. Studies suggest that physicians believe that they are implementing their patients' preferences even when implementing their own.<sup>287</sup> Therefore, a renewed focus on patient autonomy during medical school instruction, postgraduate training, and continuing medical education should improve end-of-life decisionmaking. While ethics instruction is much more common than in the past,<sup>288</sup> it is still at the periphery of medical education and is usually concentrated in the first two years of medical school.<sup>289</sup>

Education alone will never be a sufficient answer. If it were, the more than two decades of emphasis on patient rights of self-determination would have changed physician behavior by now. Experience has repeatedly shown that changes in the behavior of physicians (or other persons) does not occur from the dissemination of information alone. Rather, the dissemination of information must be accompanied by financial incentives, regulatory mandates, or encouragement by trusted, local opinion leaders.<sup>290</sup> Accordingly, the next two recommendations exploit the effectiveness of financial incentives and regulatory mandates.

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283. UNIF. HEALTH-CARE DECISIONS ACT § 2(a) (1993). The Act, however, inexplicably fails to recognize oral proxy appointments. *Id.* § 2(b).

284. *Id.*, §§ 2, 4-5.

285. *Id.* § 5(c).

286. *Id.* § 2(h).

287. Uhlmann et al., *supra* note 72, at M117; Schneiderman et al., *Do Physicians' Own Preferences*, *supra* note 77, at 29.

288. Edmund D. Pellegrino et al., *Relevance and Utility of Courses in Medical Ethics: A Survey of Physicians' Perceptions*, 253 JAMA 49, 49 (1985).

289. *Id.*; Daniel P. Sulmasy et al., *Medical House Officers' Knowledge, Attitudes, and Confidence Regarding Medical Ethics*, 150 ARCHIVES INTERNAL MED. 2509, 2509 (1990).

290. This point is developed at length in David Orentlicher, *The Influence of a Professional Organization on Physician Behavior*, 57 ALBANY L. REV. 583, 591-605 (1994).

### C. Physician Payment Reform

To the extent that physician ignorance of patient preferences and values reflects inadequate compensation for time spent talking to patients, payment reform could have an important impact. Currently, physicians are discouraged from learning their patients' views because they are not compensated for doing so. Higher reimbursement rates for discussions about end-of-life care would undoubtedly lead to more discussion. This could be accomplished by compensating physicians based on time spent with the patient, rather than on whether they performed an invasive procedure.<sup>291</sup>

### D. Strengthen Legal Doctrine of Informed Consent

Because principles of informed consent are not seriously enforced by the law in other contexts,<sup>292</sup> it is not surprising that physicians are insufficiently respectful of patient preferences in the context of end-of-life decisions. Currently, there is little force to the legal doctrine of informed consent. For example, a suit for lack of informed consent will succeed only if physical injury occurs.<sup>293</sup> Therefore, if a patient is not warned of a significant risk and the risk does not materialize, a legal cause of action does not even arise. Yet, even without physical injury, this patient has been wronged.<sup>294</sup> Since the risks usually will not materialize and patients rarely sue even when they are injured by malpractice,<sup>295</sup> there is little deterrent effect to informed consent law.

The deterrent effect is also weakened because liability exists only if a "reasonable" patient given greater information would have made a decision different than that made by the patient.<sup>296</sup> Since most medical treatments are widely accepted, however, it is extremely difficult to show that a "reasonable" patient would have refused the physician's recommendation to accept the treatment. Further, the reasonable patient standard ignores the fundamental principle of self-determina-

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291. See generally Tom J. Wachtel & Michael D. Stein, *Fee-for-Time System: A Conceptual Framework for an Incentive-Neutral Method of Physician Payment*, 270 JAMA 1226 (1993).

292. See JAY KATZ, *THE SILENT WORLD OF DOCTOR AND PATIENT* 48-84 (1984) ("The legal vision of informed consent, based on *self-determination*, is still largely a mirage.").

293. DAVID W. LOUISELL & HAROLD WILLIAMS, *MEDICAL MALPRACTICE* ¶ 22.01 (1989).

294. Alan Meisel, *A "Dignitary Tort" as a Bridge Between the Idea of Informed Consent and the Law of Informed Consent*, 16 LAW, MED. & HEALTH CARE 210, 210 (1988).

295. See A. Russell Localio et al., *Relation Between Malpractice Claims and Adverse Events Due to Negligence: Results of the Harvard Medical Practice Study III*, 325 NEW ENG. J. MED. 245, 245 (1991) (finding in one study that only 8 of 260 patients who had adverse events caused by medical malpractice filed claims).

296. LOUISELL & WILLIAMS, *supra* note 293, at ¶ 22.13.

tion: that each patient's values should be respected no matter how idiosyncratic.

There are three important ways that informed consent law could be strengthened. First, a violation of informed consent law could be found when there is a failure to disclose information material to the *individual* patient. Second, patients could be given a dignitary cause of action for violation of informed consent law even if there is no bodily harm suffered.<sup>297</sup> Third, medical licensing boards could exercise their authority to discipline physicians for violations of professional standards of conduct by penalizing breaches of informed consent.<sup>298</sup>

### *E. Physicians Should Distribute Values Histories*

While all efforts should be made to persuade physicians to honor patient values, it will take time for physician behavior to change. In addition, as discussed, it may not always be possible for physicians to discern their patients' preferences.<sup>299</sup> Therefore, patients should take it upon themselves to inquire about their physicians' values when choosing their primary care physicians.<sup>300</sup> If patients choose physicians whose values coincide with their own, it is much more likely that treatment decisions will coincide with the patient's values and preferences.

Patients can discover their physicians' values by simply inquiring about them. In addition, this process could be facilitated if physicians prepare their own values histories or other detailed advance directive forms and distribute them to current and prospective patients. Indeed, since end-of-life decisions tend to accord more with physician values than patient values,<sup>301</sup> patient self-determination might be better facilitated if patients chose physicians according to the physicians' values rather than assuming that their preferences would be followed by any physician whom they chose.

In addition, there are other benefits to be gained by relying on physician rather than patient documentation of values and treatment preferences. Since most patients will never complete an advance di-

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297. See Meisel, *supra* note 294, at 216 ("Perhaps the recognition of a cause of action for the dignitary affront of nondisclosure unaccompanied by bodily injury will help the law of informed consent to approximate more nearly the idea of informed consent.").

298. Wendy K. Mariner, *Informed Consent in the Post-Modern Era*, 13 LAW & SOCIAL INQUIRY 385, 404 (1988).

299. See *supra* notes 72-78 and accompanying text.

300. I am indebted to Professor Robert Aronson of the University of Washington School of Law for this point.

301. See *supra* notes 159-210 and accompanying text.

rective, use of physician documentation will cover a higher percentage of patient-physician relationships. Second, physician documentation is likely to be more reliable than patient documentation. Since physicians have a greater familiarity with the course of serious illnesses and the advantages and disadvantages of various medical treatments, their treatment preferences are more likely to be effective in fulfilling their wishes. A patient, on the other hand, is more likely to choose or refuse a treatment due to a misunderstanding about the benefits and risks of the treatment.

Having patients consider their physicians' values and preferences would not require a complete overhaul in physician-patient relations. It is already common for some patients to consider whether a physician takes an aggressive or a conservative approach to treating medical problems. But because patients are not accustomed to questioning their physicians about their values and may be uncomfortable with the idea, it is important that physicians volunteer the information and not wait for their patients to request it.

#### CONCLUSION

It is natural for lawyers and legislatures to respond to social problems with legal solutions. And, the public has benefited from legal activity in end-of-life decisionmaking. Nevertheless, when end-of-life decisions fail to correspond to patient preferences, the primary problem is not the absence of an end-of-life statute or the existence of a poorly drafted statute. Rather, the failure reflects more deeply rooted problems, particularly that end-of-life decisions, like other medical decisions, are driven primarily by physician preferences and values, rather than patient preferences and values. Until the dominance of physician values is addressed, no end-of-life statute can ensure that patient wishes will be fulfilled.