

# Wrongful Living

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*ABSTRACT: Executing an advance directive that specifies a patient's wishes regarding end-of-life medical care is an exercise of self-determination—a conscious choice about the degree and type of medical intervention one wishes to receive under end-of-life circumstances. Empirical studies, however, consistently report that healthcare professionals fail to comply with advance directives; violations of a patient's interest in self-determination are alarmingly common. From a practical perspective, the conduct of either patients or healthcare professionals may make an advance directive unavailable, which results in noncompliance. Legally, courts have historically rejected claims for “wrongful living” associated with the prolongation of life that results from unwanted medical intervention. As a result, healthcare professionals fear the liability threatened by a wrongful death claim more than the legal exposure risked by keeping an individual alive despite a contrary mandate in an advance directive.*

*In response to practical concerns regarding availability, this Article proposes the creation of a nationwide registry of advance directives and argues that sanctions for violations of professional responsibility as well as the risk of liability for legal malpractice encourage utilization of the proposed registry. To realign the skewed legal incentives, this Article argues that the compensable harms associated with battery and negligence claims filed in lieu of “wrongful living” claims should include the loss of enjoyment of life. Because damages for loss of enjoyment of life are rarely mentioned by courts or scholars in the context of violating advance directives, this Article describes loss of enjoyment of life damages and argues that such damages should be compensable in the same manner that tort law compensates for similar injuries that lack an objective market value. In combination, the practical and legal proposals incentivize compliance with an advance directive and thereby expand the protection afforded a patient's interest in self-determination.*

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## I. INTRODUCTION

The Hippocratic Oath, which dates from the 4th Century BC, represents “an expression of ideal conduct for the physician.”<sup>1</sup> As part of its prescription for “ideal conduct,” the ancient Oath commands physicians to keep patients “from harm and injustice.”<sup>2</sup> Updating the traditional injunction to keep patients from amorphous “harm and injustice,” the contemporary Oath frequently commands physicians to avoid the specific “traps of overtreatment and . . . nihilism.”<sup>3</sup> Two recent physician-authored books, however, cast substantial doubt on how well medical professionals adhere to the Oath’s mandate regardless of its phrasing. In his best-selling book *Being Mortal*, Dr. Atul Gawande asserts that a physician’s default impulse is to continue treatment because “rarely is there nothing more that doctors can do.”<sup>4</sup> The consequence of medical decision-making by default can be substantial because aggressive treatment could be “devastating to a person’s life” or what is left of a person’s life.<sup>5</sup> More graphically, Dr. Jessica Nutik Zitter’s *Extreme*

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1. Peter Tyson, *The Hippocratic Oath Today*, PBS (Mar. 26, 2001), <http://www.pbs.org/wgbh/nova/body/hippocratic-oath-today.html>.

2. *Id.*

3. *Id.* Interestingly, the Hippocratic Oath is commonly thought to include the phrase “First, do no harm.” However, the Oath does not include such a phrase. See Robert H. Shmerling, *First, Do No Harm*, HARV. HEALTH PUB.: HARV. HEALTH BLOG (Oct. 14, 2015, 11:27 AM), <https://www.health.harvard.edu/blog/first-do-no-harm-201510138421>.

4. ATUL GAWANDE, *BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END* 173 (2014).

5. *Id.* at 220.

*Measures* warns that unthinking implementation of medical procedures places patients on an “end-of-life conveyor belt.”<sup>6</sup> At the end—literally—patients are “often comatose, tied down, and sedated” while “tethered . . . to machines” as part “of a mechanized death.”<sup>7</sup>

To derail the journey toward “the end of life conveyor belt,” statutory law provides individuals with an opportunity to decide how end-of-life care should proceed, if at all, by executing an “advance directive.” The generic phrase “advance directive” refers to various legal instruments—such as a living will or a durable power of attorney for healthcare—that permit an individual to document wishes regarding future healthcare decisions.<sup>8</sup> Each of these instruments is governed by state law. Predictably, state statutes vary not only in the requirements for execution but also in which specific documents are recognized as legal instruments. For example, Massachusetts is one of three states that recognizes an individual’s authority to designate a person to make future healthcare decisions on her behalf in the form of a healthcare proxy, but does not recognize living wills.<sup>9</sup> Despite differences, one basic policy serves as the foundation for all state statutes: Individuals have a right to control their healthcare decisions, including the decision to forego or cease life-sustaining treatments.<sup>10</sup> Complying with the individual’s decision respects the individual’s dignity, especially where medical treatment may serve only to prolong the process of death while “providing nothing medically necessary or beneficial to the person.”<sup>11</sup> In short, advance directives protect individual

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6. JESSICA NUTIK ZITTER, *EXTREME MEASURES: FINDING A BETTER PATH TO THE END OF LIFE* 19–26 (2017).

7. *Id.* at 33, 45.

8. *See, e.g.*, 42 C.F.R. § 489.100 (2017) (stating that “a written instruction, such as a living will or durable power of attorney for health care, recognized under State law . . . relating to the provision of health care when the individual is incapacitated”).

9. *Important Differences Between Health Care Proxies and Living Wills*, MASS. MED. SOC’Y, <http://www.massmed.org/Patient-Care/Health-Topics/Health-Care-Proxies-and-End-of-Life-Care/Important-Differences-Between-Health-Care-Proxies-and-Living-Wills/#.WfaPVkyZOYY> (last visited Feb. 17, 2019).

10. CAL. PROB. CODE § 4650(a) (West 2009); *see also, e.g.*, IND. CODE 16-36-4-6 (West 2007) (“A competent adult has the right to control the decisions relating to the competent adult’s medical care, including the decision to have medical or surgical means or procedures calculated to prolong the competent adult’s life provided, withheld, or withdrawn.”); N.J. STAT. ANN. § 26:2H-54(a) (West 2018) (“Adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care unless they lack the mental capacity to do so. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.”).

11. CAL. PROB. CODE § 4650(b); *see also, e.g.*, N.J. STAT. ANN. § 26:2H-54(b) (“Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospects for improvement or cure. For some individuals, the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes

autonomy under circumstances where an individual is most vulnerable to violations of dignity and autonomy.

Studies repeatedly conclude, however, that an advance directive is little more than a paper barrier against unwanted prolongation of life. A 1991 study published in the *New England Journal of Medicine*, for example, reported that the inclusion of an advance directive in a patient's medical record failed to promote compliance with a patient's preferences for life-sustaining care.<sup>12</sup> Worse yet, one survey analyzed physician responses to hypothetical situations involving seriously ill patients with advance directives and reported that the treatment decisions in those hypotheticals failed to comply with the advance directive 65% of the time.<sup>13</sup> To that end, the researchers concluded that other factors such as "[q]uality of life, treatment outcomes, and family preferences," trumped a patient's documented preferences for treatment.<sup>14</sup> At the far end of the extreme spectrum, another group of researchers announced that "as far as [they] could tell, advance directives were irrelevant to decision making" by medical personnel.<sup>15</sup> While studies generally do not go so far as to label advance directives as "irrelevant,"<sup>16</sup> research resoundingly finds "physicians routinely ignore patient instructions about end-of-life medical care."<sup>17</sup>

The frequency with which advance directives are ignored is alarming, but macro-level statistics elide the micro-cost of failing to comply with an individual's end-of-life wishes. A 2017 *New York Times* article illustrates the costs incurred by individuals when validly executed instruments regarding medical care are ignored. Beatrice Weisman executed an advance directive that gave her husband the authority to make medical wishes for her if she was unable to do so herself.<sup>18</sup> Following a stroke in 2013 that required lengthy hospitalizations, Beatrice's husband executed a Medical Orders for Life Sustaining Treatment ("MOLST") form that directed medical professionals

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the inherent dignity and value of human life and within this context recognizes the fundamental right of individuals to make health care decisions to have life-prolonging medical or surgical means or procedures provided, withheld, or withdrawn.").

12. Marion Danis et al., *A Prospective Study of Advance Directives for Life Sustaining Care*, 324 *NEW ENG. J. MED.* 882, 885 (1991).

13. Steven B. Hardin & Yasmin A. Yusufaly, *Difficult End-of-Life Treatment Decisions: Do Other Factors Trump Advance Directives?*, 164 *ARCHIVES INTERNAL MED.* 1531, 1532 (2004).

14. *Id.* at 1533.

15. Joan M. Teno et al., *Do Formal Advance Directives Affect Resuscitation Decisions and the Use of Resources for Seriously Ill Patients?*, 5 *J. CLINICAL ETHICS* 23, 27 (1994).

16. See Hardin & Yusufaly, *supra* note 13, at 1533 (stating that advance directives "serve an important function" in that they promote communication between patient and healthcare provider that may impact decision-making in the future).

17. Philip G. Peters, Jr., *The Illusion of Autonomy at the End of Life: Unconsented Life Support and the Wrongful Life Analogy*, 45 *UCLA L. REV.* 673, 674 (1998).

18. Paula Span, *The Patients Were Saved. That's Why the Families Are Suing.*, *N.Y. TIMES* (Apr. 10, 2017), <https://www.nytimes.com/2017/04/10/health/wrongful-life-lawsuit-dnr.html>.

to cease treatment if Beatrice's cardiopulmonary system failed.<sup>19</sup> Upon finding Beatrice suffering a cardiac arrest in her hospital bed, hospital staff "perform[ed] CPR . . . defibrillated her with electric shocks, [and] injected epinephrine" even though Beatrice's MOLST form was on the top of her medical chart.<sup>20</sup> The efforts saved Beatrice's life, but broke her ribs and caused her lungs to collapse during the process.<sup>21</sup> Subsequently, a hospital spokesperson claimed that Beatrice had "made a remarkable recovery," but Beatrice returned home "bedbound and relying on a feeding tube and catheters" and required 24-hour care while undergoing "intensive physical therapy."<sup>22</sup> Given the diminution in Beatrice's quality of life, the adjective "remarkable" is, to put it mildly, inapt. As evidence of the violation of her self-determination, Beatrice asked her son "why she's still here,"<sup>23</sup> which is a question for which there is no easy, let alone good, answer.

The physical and mental harm resulting from the failure to comply with an advance directive is the product of symbiotic incentives within the fields of medicine and law. During medical school, medical students are taught "how to save lives, not how to tend to their demise."<sup>24</sup> Indeed, medical training instructs students to identify and treat the body's pathologies with available medical technologies.<sup>25</sup> Protocols are employed "to guide [physicians] through increasing the levels of pharmacologic and technical support."<sup>26</sup> While deploying treatments, physicians adhere to "an unspoken rule that [they] resuscitate coding patients until they [are] almost in rigor mortis . . . trying everything to keep them alive."<sup>27</sup> The training, technology, and "unspoken rule," however, create an environment where death seems "optional or nonexistent."<sup>28</sup> As a result, a physician may overlook whether or not the patient wants to avoid increasingly invasive treatments.<sup>29</sup> Patients are "objectified" in a state of "custodial dehumanization"<sup>30</sup> where patient autonomy is an afterthought.

In addition to myopic focus on treatment, data collected for hospital comparisons may also impact compliance with an individual's advance directive. One of the key metrics in the calculation of such rankings is the 30-

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19. *Id.*

20. *Id.*

21. *Id.*

22. *Id.* The care is "all paid for out of pocket." *Id.*

23. *Id.* Beatrice's son has filed a lawsuit against the hospital because of its failure to comply with the MOLST form. According to the article, the trial was scheduled for November 2017. *Id.*

24. See GAWANDE, *supra* note 4, at 1.

25. *Id.* at 3.

26. See ZITTER, *supra* note 6, at 31.

27. *Id.* (noting that doing so involved "sticking large catheters into every possible orifice").

28. *Id.* at 32.

29. *Id.* at 31.

30. *Id.* at 33, 223.

day mortality rate after a given medical procedure, which is the “traditional yardstick for surgical quality.”<sup>31</sup> Some states require hospitals to publicize this statistic and Medicare uses the statistic “to penalize hospitals with poor performance and reward those with better outcomes.”<sup>32</sup> Doctors and medical researchers fear, however, that the pressure to obtain positive 30-day mortality data creates a conflict of interest between the interests of the hospital and those of the individual patient.<sup>33</sup> To obtain positive outcomes according to the 30-day mortality standard, surgeons are not only “reluctant to withdraw life support before 30 days, and less reluctant after 30 days,” but may also “override advance directives.”<sup>34</sup> For some patients the skewed decision-making results in a “sentence[e]” of a lengthy hospital stay or long-term care facility.<sup>35</sup> Given that individuals execute advance directives to address these precise possibilities, collecting data for hospital comparisons by consumers has the ironic consequence of creating an incentive to ignore the validly executed wishes of those same consumers.

Whichever medical factors are considered in cases where a physician is faced with the question of whether to comply with an advance directive, legal exposure is likely to be an important factor in the decision-making calculus. Historically, complainants have failed to obtain legal relief following a medical professional’s failure to comply with an advance directive. Numerous plaintiffs have initiated causes of action, denominated as “wrongful living” claims, against individuals and institutions whose actions prolonged the life of an individual despite the existence of a valid advance directive.<sup>36</sup> Courts,

31. Paula Span, *A Surgery Standard Under Fire*, N.Y. TIMES (Mar. 2, 2015), <https://www.nytimes.com/2015/03/03/health/a-30-day-surgical-standard-is-under-scrutiny.html>.

32. *Id.* For an example of a hospital’s notice regarding its 30-day mortality rate, see *30-Day Mortality Rates for Heart Attack, Heart Failure and Pneumonia at Cedars-Sinai*, CEDARS-SINAI, <https://www.cedars-sinai.edu/Patients/Quality-Measures/External-Rankings/Center-for-Medicare-and-Medicaid-Services/30-Day-Mortality-Rates-for-Heart-Attack-Heart-Failure-and-Pneumonia-at-Cedars-Sinai.aspx> (last visited Feb. 17, 2019) (“The Centers for Medicare and Medicaid Services, which collect these data, consider 30-day mortality rates to be an ‘outcome of care’ measure. They show what happened after patients with certain conditions received care at a medical center. Such measures show whether a hospital is doing well at preventing complications, educating patients about their care needs and helping patients make a smooth transition from the hospital to home or another type of care facility.”). For an explanation of how the metric is used, see *Hospital Compare: 30-Day Death (Mortality) Rates*, MEDICARE.GOV, <https://www.medicare.gov/hospitalcompare/Data/Death-rates.html> (last visited Feb. 24, 2019).

33. Span, *supra* note 31.

34. *Id.* (quoting Dr. Douglas White).

35. *Id.* (noting that one physician stated that “[t]here are no good published studies on this, but it’s something we see”).

36. A wrongful living claim is distinguishable from a wrongful life claim. A wrongful living claim asserts that medical treatment impeded death against the claimant’s wishes. See generally A. Samuel Oddi, *The Tort of Interference with the Right to Die: The Wrongful Living Cause of Action*, 75 GEO. L.J. 625 (1986) (explaining the wrongful living claim). A wrongful life claim, on the other hand, seeks compensation for the failure to provide information that would have prevented a specific person’s birth. See Thomas Keasler Foutz, Comment, “Wrongful Life”: The Right Not to Be

however, brush aside wrongful living claims for a variety of reasons. Some courts circumvent the issue by asserting that a claim for wrongful living is not part of the common law and any such claim should only be recognized after legislative enactment.<sup>37</sup> Other courts fail to recognize wrongful living claims because of the absence of a legally cognizable injury to the patient or the difficulty in computing damages associated with prolonged life. For those courts, “the status of being alive does not constitute an injury” even though an individual receives unwanted medical intervention that prolongs the individual’s life.<sup>38</sup> Simply put, courts are exceptionally reluctant “to weigh the value of impaired life against the value of nonexistence” because of the “existential conundrum” presented by the question.<sup>39</sup>

The judicial refusal to recognize “wrongful living” as a compensable tort claim creates a legal asymmetry that threatens an individual’s interest in self-determination as expressed in an advance directive. A patient’s death can lead to a wrongful death lawsuit,<sup>40</sup> which is a well-known, and feared, cause of action for medical professionals. By the same token, medical professionals also know that the risk of liability for ignoring an advance directive is low regardless of the law or facts.<sup>41</sup> In combination, the liability cost of an erroneous medical decision to end life could be staggering while the liability cost of an erroneous decision to prolong life in the face of an advance directive is likely to be insignificant. Therefore, the decisional balance tips in favor of erring on the side of prolonging life. As evidence of the role that risk management plays in medical treatment, one hospital administrator flatly declared that a hospital “would ‘rather have a wrongful liv[ing] claim than a wrongful death claim.”<sup>42</sup>

Despite the jurisprudential weight against holding medical personnel responsible for failing to comply with advance directives, recent developments hint at increasing recognition of harm when a patient’s documented preferences are violated. Healthcare professionals who fail to adhere to the commands of an advance directive are increasingly subject to discipline by

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*Born*, 54 TUL. L. REV. 480, 485 (1980) (observing that a “wrongful life” claim does not rely on an assertion of a doctor’s treatment but instead on the notion that a child’s birth would not have occurred “but for” the inadequate advice given by the physician to the child’s parents).

37. *Wright v. Johns Hopkins Health Sys. Corp.*, 728 A.2d 166, 179 (Md. 1999), *superseded by* 2000 Md. Laws 152, *as recognized in* *Plein v. Dep’t of Labor*, 800 A.2d 757, 765 n.5 (Md. 2002); *see also, e.g., Slawek v. Stroh*, 215 N.W.2d 9, 22 (Wis. 1974) (opining that such a tort should be the result of legislation because of its “vast social ramifications”).

38. *Cronin v. Jam. Hosp. Med. Ctr.*, 60 A.D.3d 803, 804 (N.Y. App. Div. 2009).

39. *Scheible v. Joseph L. Morse Geriatric Ctr., Inc.*, 988 So. 2d 1130, 1133 (Fla. Dist. Ct. App. 2008) (quoting a wrongful life case, *Kush v. Lloyd*, 616 So. 2d 415, 423 (Fla. 1992), and applying it to a wrongful living cause of action).

40. Nadia N. Sawicki, *A New Life for Wrongful Living*, 58 N.Y. L. SCH. L. REV. 279, 284 (2013/14).

41. *Id.*

42. *Id.* (quoting Judy Greenwald, *Medical Ethics & Risk Management: Liability at Life’s End: Providers Risk Suits in Reviving Patients*, BUS. INS. (May 20, 1996)).

sanctioning boards. And administrative penalties have been levied upon the institutions in which such violations occur.<sup>43</sup> Furthermore, some courts appear to be more receptive to claims that unwanted prolongation of life is a compensable harm. In *Doctors Hospital of Augusta, LLC v. Alicea*, a physician performed surgery on a patient with an advance directive that instructed healthcare professionals to eschew “heroic measures” to prolong her life.<sup>44</sup> Following a lung infection, a physician performed a surgery that resulted in the removal of 2/3 of the patient’s right lung, intubation, and subsequent ventilation.<sup>45</sup> After the patient’s death, the administrator of the patient’s estate filed a lawsuit alleging that the surgeon “and other medical personnel associated with the Hospital had subjected [the patient] to unnecessary medical procedures, in particular her intubation and placement on a ventilator . . . in violation of [the patient’s] Advance Directive.”<sup>46</sup> The hospital moved for summary judgment based upon the immunity provisions in Georgia’s Advance Directive Act, but the court denied the motion and the Supreme Court of Georgia affirmed.<sup>47</sup> To avoid subsequent litigation, the parties reached a settlement agreement that ended the legal dispute in May 2017.<sup>48</sup>

While professional discipline and administrative penalties may spark cautious optimism about future compliance with advance directives, neither is likely to create sufficient incentives for healthcare professionals to change end-of-life decision-making. Professional discipline penalizes an individual physician for a specific medical decision and the results of proceedings are unreported, which makes them difficult to discover.<sup>49</sup> Furthermore, administrative agencies have “mostly levied paltry fines” against facilities in which advance directives have been violated.<sup>50</sup> For example, agencies in Connecticut and Florida have assessed \$1,370 and \$16,000 fines, respectively, against nursing homes that resuscitated patients who had valid Do Not Resuscitate orders in their medical files.<sup>51</sup> Minimal monetary penalties are not

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43. Thaddeus Mason Pope, *Clinicians May Not Administer Life-Sustaining Treatment Without Consent: Civil, Criminal, and Disciplinary Sanctions*, 9 J. HEALTH & BIOMEDICAL L. 213, 286–94 (2013).

44. *Doctors Hosp. of Augusta, LLC v. Alicea*, 788 S.E.2d 392, 396 (Ga. 2016).

45. *Id.*

46. *Id.* at 397–98. The claims included “breach of agreement, professional and ordinary negligence, medical battery, intentional infliction of emotional distress, and breach of fiduciary duty.” *Id.* at 397.

47. *Id.* at 405. For another case where litigation proceeded to the trial stage, see, for example, *Jones v. Ruston La. Hosp. Co.*, 71 So. 3d 1154, 1155 (La. Ct. App. 2011).

48. Sandy Hodson, *Hospital Settles Lawsuit About Failing to Honor Patient’s Wishes on Extending Life*, AUGUSTA CHRON. (May 25, 2017, 12:31 AM), <https://www.augustachronicle.com/news/2017-05-25/hospital-settles-lawsuit-about-failing-honor-patient-s-wishes-extending-life>.

49. See Pope, *supra* note 43, at 289 n.511 (“It is difficult to find these cases. State medical boards organize their publicly available information only by clinician name and license number . . .”).

50. See Span, *supra* note 18.

51. *Id.*



likely to affect the financial health of the penalized institution, but they could negatively impact the grade and reputation of the institution on Medicare's Nursing Home Compare website.<sup>52</sup> In turn, low grades affect consumer decisions regarding healthcare facilities.<sup>53</sup> Regardless of the weight placed upon grades of healthcare facilities, a grade on a website is one of a number of factors that, presumably, impact consumer decisions about nursing home care. In all likelihood, factors specific to the prospective residents/patients such as the cost of care, location of the facility, and a family's degree of comfort with facility staff outweigh a government-generated grade on a website.<sup>54</sup> While useful, website grades cannot meaningfully curb systemic failure to comply with advance directives in a world where caregiving choices are often circumscribed by money and geography.

Beyond professional and administrative sanctions, litigation that ends with a decision that establishes healthcare provider liability for noncompliance would affect end-of-life decision-making, but the signal from the end of litigation may be muted by non-judicial dispute resolution. A case like *Doctors Hospital of Augusta*, for example, could be construed as a positive development because the court declined to construe the statutory immunity provisions broadly and permitted the lawsuit to proceed beyond summary judgment.<sup>55</sup> Under those circumstances, healthcare providers are incentivized to settle cases to avoid the risk of incurring a hefty jury award. The settlement concludes the litigation between the parties but may not serve as strong a stimulus for future conduct as clear precedent because the amount of money transferred to the plaintiff and the conditions of settlement remain unknown. Moreover, parties choose to settle litigation for a wide variety of reasons—risk of liability, reduce trial costs even if a case is strong, avoid bad publicity, and privacy. Without knowing the circumstances leading to a pre-trial settlement, others facing similar situations cannot predict what the consequences are likely to be from action or inaction. Although settlements have the potential to influence future behavior, especially if they involve known transfers of large sums of money, they do not unambiguously incentivize changes in practices or policies that demonstrate commitment to end-of-life self-determination.

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52. *Id.* (quoting Dr. Pope for the comment that consumers research facilities for grades); see *Nursing Home Compare*, MEDICARE.GOV, <https://www.medicare.gov/nursinghomecompare/search.html> (last visited Feb. 17, 2019).

53. See Span, *supra* note 18.

54. Marcelo Coca Perrailon et al., *Nursing Home Response to Nursing Home Compare: The Provider Perspective*, MED. CARE RES. & REV. 1, 5 (2017) ("I think the majority of people [focus on] on the aesthetics when they walk in. The smell. How the staff is interacting. How they're being treated when they walk in. What the patients look like . . . I tend to think they go more on that than statistical data." (quoting one nursing home administrator)).

55. *Doctors Hosp. of Augusta, LLC v. Alicea*, 788 S.E.2d 392, 404 (Ga. 2016).

The purpose of this Article is to propose a framework of incentives that increases the probability of compliance with an individual's advance directive. Part II of the Article traces the legal history of advance directives and engages the philosophical debate regarding the validity of advance directives. Part III identifies the practical problems associated with accessing advance directives, describes current methods of warehousing such instruments, and proposes that a national registry of advance directives should be constructed to increase accessibility. To diminish the risk of registry underutilization, Part III asserts that attorneys should enter advance directives into the registry on behalf of clients and that the threats of professional sanctions as well as exposure to legal malpractice claims provide an incentive for attorneys to do so. Part IV of the Article counters the historical inertia against "wrongful living" damages by identifying a harm rarely addressed in the relevant literature—the loss of enjoyment of life. Furthermore, Part IV uses graphs to situate loss of enjoyment of life damages within the context of battery and negligence claims filed in lieu of a valid tort claim for "wrongful living." Recognizing the intangible nature of loss of enjoyment of life damages, Part IV also argues that the absence of a quantifiable value for such damages should be no more of an obstacle than it is for other non-market injuries compensated by existing tort doctrine. The Article concludes that the practical and legal proposals not only promote the interests of the stakeholders, but also increase the probability of compliance with advance directives and thereby advance an individual's interest in self-determination.

## II. JUSTIFYING THE LEGAL RECOGNITION OF ADVANCE DIRECTIVES

The law governing advance directives seeks to maintain a delicate balance: honoring individual autonomy at the end-of-life while respecting the medical community's goal of saving lives. Indeed, several highly visible and publicly debated cases involving the conjunction of individual autonomy and end-of-life medical decisions place the challenge of mediating that balance in bold relief. During early 2005, for example, then President Bush returned from his ranch in Texas to sign federal legislation that allowed a federal court to intervene in the controversial and much-publicized Terri Schiavo case.<sup>56</sup> Regardless of public awareness, each individual case demonstrates that the legal line between prolonging a person's suffering and saving a person's life is, at best, blurry. Given the continuing indeterminacy of legal regulation, a recurring dialogue examines the theoretical legitimacy of recognizing advance directives as reliable forms of self-expression. Predictably, then, the legal governance of advance directives unavoidably creates an intersection between legal doctrine and philosophy at the nexus of life and death.

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56. Carl Hulse & David D. Kirkpatrick, *Congress Passes and Bush Signs Legislation on Schiavo Case*, N.Y. TIMES (Mar. 21, 2005), <http://www.nytimes.com/2005/03/21/politics/congress-passes-and-bush-signs-legislation-on-schiavo-case.html>.

## A. A BRIEF LEGAL HISTORY OF ADVANCE DIRECTIVES

Over a century ago, Justice Cardozo articulated the relationship between individual autonomy, medical care, and liability in *Schloendorff v. Society of New York Hospital*.<sup>57</sup> In one of the cases passages, Justice Cardozo asserted that “[e]very human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient’s consent commits an assault, for which he is liable in damages.”<sup>58</sup> If an individual needing immediate surgery was unconscious and unable to consent to medical treatment, Justice Cardozo allowed that surgery which might otherwise constitute an assault may proceed because of the emergency.<sup>59</sup> In other words, a non-emergency medical intervention performed without an individual’s consent is an assault to which liability attaches.<sup>60</sup> Within tort law, Justice Cardozo’s statements are often considered to be the foundation for the law of informed consent.<sup>61</sup> Indeed, the modern doctrine of informed consent provides that patients, when adequately informed about their treatment options, should have the right to consent to or refuse treatment.<sup>62</sup> And in order to exercise informed consent, patients must possess a sufficiently detailed understanding of the potential harms and benefits posed by a prospective treatment, the available alternatives to that treatment, or the option of withholding treatment.<sup>63</sup> Given its patient-centric emphasis, protecting an individual’s interest in autonomy sits at the core of the doctrine of informed consent.

Despite the solid footing of informed consent law, neither common nor statutory law recognized advance directives in the form of living wills prior to the mid-20th century. Triggered by the outcomes of criminal cases where one individual aided in the death of another during that period, however, groups with foreboding names like the “Euthanasia Society” argued for a mechanism by which an individual could memorialize her end-of-life wishes and thereby inoculate others from criminal prosecution.<sup>64</sup> Using insight from informed consent law, mid-century legal commentators extrapolated “a patient’s right

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57. *Schloendorff v. Soc’y of N.Y. Hosp.*, 105 N.E. 92, 93–94 (N.Y. 1914), *abrogated by* *Bing v. Thunig*, 143 N.E.2d 3 (1957).

58. *Id.* at 129–30.

59. *Id.* at 130.

60. Erin Talati, *When a Spoonful of Sugar Doesn’t Help the Medicine Go Down: Informed Consent, Mental Illness, and Moral Agency*, 6 IND. HEALTH L. REV. 171, 175 (2009) (characterizing the holding as being “unless a patient is unable to consent and an emergency intervention is necessary, any intervention by a physician done without consent constitutes assault”).

61. *Id.* at 174–75 (pointing out that Justice Cardozo’s comments reflected earlier comments made by the Supreme Court).

62. *Id.* at 175.

63. Rebecca Dresser, *Precommitment: A Misguided Strategy for Securing Death with Dignity*, 81 TEX. L. REV. 1823, 1833 (2003).

64. Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 IND. L.J. 539, 540–44 (1969).

to consent to or to refuse treatment” to argue that “a patient may refuse treatment which would extend his life.”<sup>65</sup> In cases where a patient did not possess the “desire to be kept in a [permanent] state of indefinite vegetated animation,” a 1969 law review article proposed that a patient be permitted to include a clause in a consent to treatment form that “if his condition becomes incurable and his bodily state vegetative with no possibility that he could recover his complete faculties, his consent to further treatment would be terminated.”<sup>66</sup> In theory, the proposed clause barred a physician from taking further action to prolong a patient’s life and a “patient would be permitted to die by virtue of the physician’s inaction.”<sup>67</sup> The article denominated the proposed document by a litany of phrases—“a declaration determining the termination of life,” a “testament permitting death,” a “declaration for bodily autonomy,” a “declaration for ending treatment,” a “body trust,” “or other similar reference.”<sup>68</sup> One of the suggested monikers affixed itself to the proposed instrument and has been used to identify a declarant’s end-of-life intent since that time—“a living will.”<sup>69</sup>

Seven years after the phrase “living will” first appeared on the pages of a law review, California became the first state to enact a living will statute in 1976.<sup>70</sup> Like many pieces of legislation, the state representative who introduced the bill proposing recognition of living wills was motivated by personal experience to change the law. In 1972, a future California state representative’s mother-in-law wished to delimit the amount and degree of medical treatment she received as she faced a terminal illness, but the law did not countenance a legal right to do so.<sup>71</sup> Two years later, the newly elected state representative placed a living will statute on California’s legislative agenda, but the bill failed to gather sufficient support for passage into law.<sup>72</sup> Undeterred, the state legislator again introduced a bill proposing a living will statute two years later and the bill gained sufficient support to become law.<sup>73</sup> California’s statute created a “Directive to Physicians” that not only permitted an individual to specify the amount of medical intervention that should be

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65. *Id.* at 547.

66. *Id.* at 550–51.

67. *Id.* at 551.

68. *Id.*

69. *Id.* (emphasis omitted). We generally use the term “declarant” rather than “patient,” because “declarant” is broader and also covers the time period between execution of an advance directive and the beginning of medical treatment.

70. Charles P. Sabatino, *The Evolution of Health Care Advance Planning Law and Policy*, 88 MILBANK Q. 211, 213 (2010), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2980344/pdf/milq0088-0211.pdf>.

71. Siamak N. Nabili (ed. William C. Shiel, Jr.), *Advance Medical Directive (Living Will, Power of Attorney, and Health-Care Proxy)*, MEDICINENET, [https://www.medicinenet.com/advance\\_medical\\_directives/article.htm#advance\\_medical\\_directive\\_facts](https://www.medicinenet.com/advance_medical_directives/article.htm#advance_medical_directive_facts) (last visited Feb. 18, 2019).

72. *Id.*

73. *Id.*

administered under end-of-life circumstances, but also shielded a physician from liability if she complied with the directive.<sup>74</sup> Following California's lead, states enacted statutes that recognized advance directives in one form or another and those statutes, albeit often in amended form, remain on the code books of those states.<sup>75</sup>

While a proposal for a living will statute wound its way through the California legislature, a case on the other side of the country sparked a national dialogue about self-determination when facing end-of-life circumstances. In *In re Quinlan*, a 1976 decision that was one of the first cases to focus the public's attention on the issue,<sup>76</sup> a father of a 21-year-old woman in a persistent vegetative state asked a hospital to terminate his daughter's medical treatment, but the hospital refused.<sup>77</sup> Thereafter, the father initiated a lawsuit to enforce his request on the ground that the refusal violated his daughter's right of privacy.<sup>78</sup> After concluding that the father had standing to assert his daughter's privacy interest,<sup>79</sup> the Supreme Court of New Jersey recognized that the State possessed an "interest in the preservation of life."<sup>80</sup> However, the court also maintained that "there comes a point at which the individual's rights overcome the State interest."<sup>81</sup> More specifically, the court opined that the State and an individual's interests exist on a continuum in "that the State's interests [] weakens and the individual's right to privacy grows as the degree of bodily invasion increases and the prognosis dims."<sup>82</sup> Given its relationship to privacy,<sup>83</sup> individual autonomy forms the unwritten foundation for decisions like *Quinlan*.

A little more than a decade later, the Supreme Court offered its opinion based upon a similar set of unfortunate facts in *Cruzan by Cruzan v. Director, Missouri Department of Health*.<sup>84</sup> In *Cruzan*, Nancy Cruzan fell into a persistent vegetative state following a traffic accident and her parents sought to cease hydrating and feeding procedures on behalf of Nancy, which would result in her death.<sup>85</sup> At the time, Missouri required "evidence of an incompetent's

74. See Sabatino, *supra* note 70, at 213.

75. *Id.* at 214 ("The number of living will laws snowballed during the next ten years.").

76. Robert D. McFadden, *Karen Ann Quinlan*, 31, *Dies; Focus of '76 Right to Die Case*, N.Y. TIMES (June 12, 1985), <http://www.nytimes.com/1985/06/12/nyregion/karen-ann-quinlan-31-dies-focus-of-76-right-to-die-case.html> (observing that the case "became the center of a national debate").

77. *In re Quinlan*, 355 A.2d 647, 654-57 (N.J. 1976).

78. *Id.* at 662-63. The father asserted other claims, including an interference with the free exercise of religion and cruel and unusual punishment. *Id.* at 661-62.

79. *Id.* at 660.

80. *Id.* at 661, 665.

81. *Id.* at 664.

82. *Id.*

83. Daniel J. Solove, *A Taxonomy of Privacy*, 154 U. PA. L. REV. 477, 557-60 (2006).

84. *Cruzan by Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 270-72 (1990).

85. *Id.* at 267 (explaining Nancy had "virtually no chance of regaining her mental faculties").

wishes as to the withdrawal of [life-sustaining] treatment be proved by clear and convincing evidence.”<sup>86</sup> Because Nancy had only offered ambiguous statements about the degree of care she preferred, the hospital “refused to honor the request without court approval.”<sup>87</sup> Nancy’s father filed suit and ultimately appealed defeats in state courts to the Supreme Court.<sup>88</sup> A 5-4 Court majority held that Missouri had the power to apply a clear and convincing evidence standard to requests to discontinue life-sustaining treatment.<sup>89</sup> In so doing, the Court opined “that the Due Process Clause protects an interest in life as well as an interest in refusing life-sustaining medical treatment.”<sup>90</sup> Moreover, the Court recognized the possibility of divergence between what Nancy’s parents might desire and what Nancy would want if she could communicate; therefore, “the State may choose to defer only to those wishes [(Nancy’s wishes)], rather than confide the decision to close family members.”<sup>91</sup> *Cruzan* considered an evidentiary standard, but individual autonomy in medical decision-making again played a central role in the Court’s opinion. Nancy’s wishes—if known—controlled “[t]he choice between life and death”; such a choice “is a deeply personal decision of obvious and overwhelming finality.”<sup>92</sup>

In response to escalating public concern following decisions like *Quinlan* and *Cruzan*, Congress passed the Patient Self-Determination Act (“PSDA”) in 1990 “to reinforce individuals’ constitutional right to determine their final health care.”<sup>93</sup> Under the PSDA, healthcare facilities that benefit from Medicare or Medicaid programs are instructed to provide patients with

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86. *Id.* at 280.

87. *Id.* at 268.

88. *Id.* at 268–69.

89. *Id.* at 284.

90. *Id.* at 281. Justice O’Connor’s concurrence also noted that “the liberty guaranteed by the Due Process Clause must protect, if it protects anything, an individual’s deeply personal decision to reject medical treatment.” *Id.* at 289 (O’Connor, J., concurring).

91. *Id.* at 286–87.

92. *Id.* at 281. For another case involving similar facts, see *In re Guardianship of Schiavo*, 780 So. 2d 176, 179–80 (Fla. Dist. Ct. App. 2001) (holding that a Florida lower court had the authority to order discontinuation of medical care based upon the evidence presented). The litigation and media coverage of the Terri Schiavo case not only triggered a legal fight, but also a political battle. See, e.g., Clyde Haberman, *From Private Ordeal to National Fight: The Case of Terri Schiavo*, N.Y. TIMES (Apr. 20, 2014), <https://www.nytimes.com/2014/04/21/us/from-private-ordeal-to-national-fight-the-case-of-terri-schiavo.html> (discussing the role politicians played in the Schiavo case and their attempt to assert control over the case); Carl Hulse & David D. Kirkpatrick, *Even Death Does Not Quiet Harsh Political Fight*, N.Y. TIMES (Apr. 1, 2005), <https://www.nytimes.com/2005/04/01/politics/even-death-does-not-quiet-harsh-political-fight.html> (discussing the politicization of the Teri Schiavo case).

93. U.S. GEN. ACCT. OFF., GAO-95-135, PATIENT SELF-DETERMINATION ACT: PROVIDERS OFFER INFORMATION ON ADVANCE DIRECTIVES BUT EFFECTIVENESS UNCERTAIN 1–4 (1995); see Robert S. Olick, *Defining Features of Advance Directives in Law and Clinical Practice*, 141 CHEST 232, 233 (2012) (noting that Congress passed the Patient Self-Determination Act in the wake of the decision to incentivize advance directive completion).

materials that detail their end-of-life rights upon admission to the facility.<sup>94</sup> The materials should inform patients about the right to accept or refuse medical treatments as well as outline the healthcare facility's policies that affect that right.<sup>95</sup> Furthermore, the healthcare facility must provide patients with written advance directives and document the existence of an advance directive in a patient's medical record.<sup>96</sup> Importantly, an individual is not required to execute an advance directive as a prerequisite to receiving care.<sup>97</sup> Although Supreme Court decisions may have prompted federal action, states had a wealth of legislation governing advance directives at the time of those decisions; therefore, the PSDA deferred to existing state law while imposing new requirements.<sup>98</sup> Predictably, state law regulations varied widely.<sup>99</sup> But whatever jurisdictional variation existed in execution and recognition of advance directives, Congress intended the PSDA to serve as a "Miranda warning" for those facing end-of-life decisions.<sup>100</sup>

As an empirical matter, the PSDA proved to be a successful prompt for the execution of advance directives. According to results from a University of Michigan study, the number of individuals aged 60 years or older who created advanced directives increased from 47% in 2000 to 72% in 2010 after the enactment of the PSDA.<sup>101</sup> The problem, of course, is that merely increasing the raw number of advance directives does little to incentivize compliance with those instruments. Effectuating an individual's end-of-life wishes is, in its most basic form, a two-variable equation: end-of-life self-determination equals execution of an advance directive plus compliance. The PSDA satisfied its stated goal of increasing the number of declarants, but the second variable remained unaffected, which ultimately leads to empirical results that reveal widespread violations of self-determination under life and death circumstances.<sup>102</sup>

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94. 42 U.S.C. §§ 1395cc(f)(1)(A), 1395cc(f)(2), 1396a(w)(1)(A), 1396a(w)(2) (2012).

95. *Id.* §§ 1395cc(f)(1)(A), 1395cc(f)(2), 1396a(w)(1)(A), 1396a(w)(2).

96. *Id.* §§ 1395cc(f)(1)(B), 1396a(w)(1)(B).

97. *See* U.S. GEN. ACCT. OFF., *supra* note 93, at 3.

98. *Id.* at 40–41.

99. *Id.* at 40.

100. Edward J. Larson & Thomas A. Eaton, *The Limits of Advance Directives: A History and Assessment of the Patient Self-Determination Act*, 32 WAKE FOREST L. REV. 249, 251 (1997) (quoting Senator John C. Danforth, who introduced the bill in the United States Senate). For further discussion of the PSDA, see generally, e.g., Kelly C. Mulholland, *Protecting the Right to Die: The Patient Self-Determination Act of 1990*, 28 HARV. J. LEGIS. 609 (1991) (analyzing the creation and impact of the PSDA); and Richard E. Shugrue, *The Patient Self-Determination Act*, 26 CREIGHTON L. REV. 751 (1993) (reviewing the evolution of medical autonomy rights leading up to the creation of the PSDA).

101. *Record Number of Older Adults Completing Living Wills, Trend Had Little Impact on Hospitalization Rates*, SCI. DAILY (Apr. 2, 2014), <https://www.sciencedaily.com/releases/2014/04/140402095105.htm>.

102. *See supra* notes 12–17 and accompanying text.

*B. PHILOSOPHY AND ADVANCE DIRECTIVES*

Despite the PSDA, state statutory law, and judicial decisions, considerable philosophical debate engulfs the validity of permitting individuals to make binding decisions in the present about future medical decisions.<sup>103</sup> Advance directive advocates argue that individuals should be able to exercise precedent autonomy to make meaningful choices for their future selves in the event that they are later unable to do so.<sup>104</sup> According to legal philosopher Ronald Dworkin, an advance directive that was executed while an individual was competent generally should control her treatment if she becomes cognitively impaired before the directive takes effect.<sup>105</sup> Following the loss of mental capacity, a person's rights and interests can be thought to belong to the person either as a *presently* cognitively impaired individual "emphasizing his present situation and capacities," or as an individual who has *become* cognitively impaired thereby emphasizing "the course of his whole life."<sup>106</sup> As a result, the decision to comply with a cognitively impaired person's advance directive depends on whether her previous, competent conception of dignity factors into the decisional calculus.<sup>107</sup> Although a person without any cognitive ability has no sense of his own dignity and self-respect, his advance directive could be honored if it would "show respect for his life as a whole."<sup>108</sup> Complying with a person's advance directive, then, accounts for the person's precedent and prospective autonomy instead of viewing autonomy as a commodity in discrete units that are directly proportional to mental capacity.

Refusing to disaggregate autonomy gives individuals the ability to express their values, and "[w]e allow someone to choose death over [life-sustaining treatment], if that is his informed wish, because we acknowledge his right to a life structured by his own values."<sup>109</sup> For example, Dworkin argues that if a Jehovah's Witness's advance directive rejects blood transfusions, his instruction should be followed in the event of an accident where a transfusion would save his life whether he remains competent or the accident rendered him incompetent.<sup>110</sup> If the accident rendered him temporarily incompetent, he was given a transfusion in his "best interest," lived, and later became competent, he may "be appalled at having had a treatment he believed worse for him than dying."<sup>111</sup> Even if his family believes he would request treatment

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103. See Nancy K. Rhoden, *The Limits of Legal Objectivity*, 68 N.C. L. REV. 845, 857-61 (1990).

104. See Jukka Varelius, *Respect for Autonomy, Advance Directives, and Minimally Conscious State*, 25 BIOETHICS 505, 506 (2011).

105. RONALD DWORKIN, *LIFE'S DOMINION: AN ARGUMENT ABOUT ABORTION, EUTHANASIA, AND INDIVIDUAL FREEDOM* 221 (1993).

106. *Id.*

107. *Id.*

108. *Id.* at 221-22.

109. *Id.* at 224.

110. *Id.* at 227-28.

111. *Id.* at 227.



if competent, his previous direction should be followed because there is no competent actor who is qualified to nullify his exercise of autonomy.<sup>112</sup> Thus, Dworkin concludes that the cognitively impaired person's precedent autonomy as expressed in his advance directive should be respected.<sup>113</sup>

Respecting a cognitively impaired individual's competent exercise of precedent autonomy may make individuals uncomfortable.<sup>114</sup> A seemingly happy but cognitively impaired patient may be denied life-sustaining treatment because of an earlier decision that was made when the patient's current condition was unforeseen.<sup>115</sup> However, even if the patient's decisions were ignored to align with her current interest in comfort, as opposed to her earlier interest involving her conception of death with dignity, her autonomy would be violated.<sup>116</sup> Her precedent autonomy should be respected, even if she no longer has any concept of her sense of self, because the person who became cognitively impaired, not just the presently cognitively impaired person, deserves compassion, and the interests of the person who became cognitively impaired persist.<sup>117</sup> Failing to comply with her advance directive would be a paternalistic and uncompassionate rejection of how the patient chose to end her life consistent with her concept of dignity when she was competent to make that choice.<sup>118</sup>

In opposition to Dworkin's defense of advance directives, critics argue that precedent autonomy has no moral authority because an individual is unlikely to have the same preferences when she receives treatment as when she executed her advance directive.<sup>119</sup> The most common criticism, typically attributed to Rebecca Dresser, maintains that the person who is receiving treatment is a metaphysically different person than the one who created the advance directive.<sup>120</sup> Because the two individuals are different people, the former person exercising autonomy to direct the treatment of the latter is not an exercise of informed consent by the incapacitated person.<sup>121</sup> Dresser supports her position with empirical evidence that patients' preferences often change from the time they execute advance directives to when they enter the hospital for treatments.<sup>122</sup> Often referred to as the "Green Eggs and Ham

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112. *Id.*

113. *Id.* at 226–32.

114. *Id.* at 228–29.

115. *Id.* at 228.

116. *Id.* at 228–29.

117. *Id.* at 230–31.

118. *Id.*

119. See Rhoden, *supra* note 103, at 857–58.

120. Elisabeth Furberg, *Advance Directives and Personal Identity: What Is the Problem?*, 37 J. MED. & PHIL. 60, 61–63 (2012).

121. Jack Schwartz, *Living Wills: Time to Say Goodbye?*, 38 MD. B.J., July/Aug. 2005, at 5, 8.

122. Dresser, *supra* note 63, at 1823. For the results of studies investigating changes in patient preferences, see, for example, Peter H. Ditto et al., *Context Changes Choices: A Prospective Study of the Effects of Hospitalization on Life-Sustaining Treatment Preferences*, 26 MED. DECISION MAKING 313,

Phenomena,” Dresser and similar critics argue that individuals often believe that they do not want life-prolonging treatments, but change their minds at the moment they would receive the treatments.<sup>123</sup>

Even if one grants the premise that advance directives guide the treatment of a metaphysically different person from the individual who executed the document, not all medical ethicists view the situation as a problem.<sup>124</sup> Some philosophers believe that individuals have “surviving interests” that outlive the person who expressed them.<sup>125</sup> Accordingly, if the person who expressed the preference no longer exists in a metaphysical sense, then the personal identity problem is irrelevant. The treatment preferences expressed in an advance directive represent surviving preferences whose implementation maximize the subject’s utility by realizing the expressed preferences as best as possible.<sup>126</sup> Honoring the right to self-determination of the person who exercised the advance directive thus may be the most effective way to maximize utility, and respect for self-determination implies a respect for the right to exercise precedent autonomy.<sup>127</sup>

Contemplating how one wishes to die after experiencing a terminal illness or injury or permanent unconsciousness is a serious undertaking. If an individual has sufficiently strong preferences about his end-of-life care to execute an advance directive, then his expressed preferences should be followed. Presumably, “[s]omeone anxious to ensure that his life is not . . . prolonged by medical treatment is worried precisely because he thinks that the character of his whole life would be compromised if it were.”<sup>128</sup> Even if a person is no longer competent, preserving her life merely because it can be done without putting her in pain fails to honor her life as a whole. For some individuals, then, the decision to terminate life-sustaining medical treatment is an expression of self-definition because “[p]eople have a strong interest in shaping their own version of a dignified dying process regardless of whether they actually experience the feared degradation.”<sup>129</sup> If fully informed and correctly articulated, advance directives are desirable not just as a mechanism to suggest the treatment an incapacitated individual may want, but as a way to allow an individual to die in a manner consistent with his conception of dignity.

As a practical matter, articulating one’s specific wishes for end-of-life treatment is a significant challenge. Advance directives are often boilerplate

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316–19 (2006); and Susan Enguidanos & Jennifer Ailshire, *Timing of Advance Directive Completion and Relationship to Care Preferences*, 53 J. PAIN & SYMPTOM MGMT. 49, 54 (2017).

123. Dresser, *supra* note 63, at 1835; Pope, *supra* note 43, at 235–37.

124. See Furberg, *supra* note 120, at 61.

125. *Id.* at 66.

126. *Id.*

127. *Id.* at 68–69.

128. DWORKIN, *supra* note 105, at 228.

129. Norman L. Cantor, *The Real Ethic of Death and Dying*, 94 MICH. L. REV. 1718, 1730 (1996).

instruments that are criticized because of the ambiguous language used to describe an individual's wishes under specific circumstances.<sup>130</sup> No advance directive, of course, can address every situation that might be encountered; therefore, the language is predictably broad to permit flexible application to a variety of end-of-life situations. Moreover, criticisms based upon the language of an advance directive again fail to honor a declarant's dignity. An individual's dignity is enhanced by respecting even general statements of values in advance directives. In any event the lack-of-specificity critique is at most a problem of implementation. If advance directives are currently too general to provide meaningful guidance in particular cases, then advance directives should be made more specific, not abandoned entirely.<sup>131</sup>

Regardless of the language employed in advance directives, empirical studies suggest that individuals' preferences change over time and such results form the basis of the metaphysical argument against advance directives.<sup>132</sup> Whatever weight might be assigned to such studies, those results should be understood to demonstrate that individuals do not have fully informed preferences and not as a justification to reject the utility of advance directives as a whole. To that end, research also suggests that better informed individuals may be able to exercise informed consent through an advance directive. Older individuals, who have presumably considered their goals at the end-of-life more seriously than younger individuals, "have more stable treatment preferences."<sup>133</sup> The evolution of preferences suggests that individuals should regularly update their advance directives and have conversations about their treatment preferences with their doctors outside of rushed, emergency settings.<sup>134</sup> Accordingly, revisiting advance directives over time mitigates the problem of inconsistent preferences.

### III. IMPROVING ACCESS TO ADVANCE DIRECTIVES

From a functional and procedural perspective, advance directives and wills share many characteristics. Functionally, each instrument provides a mechanism by which an individual memorializes her intent regarding specific end-of-life issues. Procedurally, each instrument must comply with statutory formalities for due execution and the testator/declarant must possess the

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130. See, e.g., ROBERT S. OLICK, *TAKING ADVANCE DIRECTIVES SERIOUSLY: PROSPECTIVE AUTONOMY AND DECISIONS NEAR THE END OF LIFE* 102 (2001) (noting the "pragmatic criticisms . . . that directives too often are vague and ambiguous and fail to provide instructions that effectively guide care").

131. Clarifying the language typically appearing in advance directive forms is beyond the scope of this paper.

132. See generally Jeremy A. Blumenthal, *Law and the Emotions: The Problems of Affective Forecasting*, 80 IND. L.J. 155 (2005) (discussing the implications of changing emotions and the legal consequences those changes have in certain areas of the law).

133. *Id.* at 220–21 (citing Peter H. Ditto et al., *Stability of Older Adults' Preferences for Life-Sustaining Medical Treatment*, 22 HEALTH PSYCHOL. 605, 613 (2003)).

134. Enguidanos & Ailshire, *supra* note 122, at 53–54.

mental capacity to execute the instrument.<sup>135</sup> As a corollary to execution requirements, advance directives and wills may be challenged for failure to satisfy statutory execution requirements.<sup>136</sup> Beyond courtroom challenges, advance directives and wills share a practical problem—each instrument might be unavailable at the critical time for decision-making because it is lost. However, the absence of wills and advance directives expose the testator/declarant to different legal consequences. If a will is lost, the lost will presumption may provide a basis to admit the missing original instrument to probate.<sup>137</sup> If an advance directive is lost, on the other hand, issues involving compliance are irrelevant, and an individual's life may be prolonged with a concomitant decrease in enjoyment. This Section describes the shortcomings of current modes of warehousing advance directories, argues that a centralized registry would improve access to advance directives, and proposes legal mechanisms to incentivize registry utilization.

A. EXISTING METHODS TO INCREASE ACCESSIBILITY—ADVANCE  
DIRECTIVE REGISTRIES

Although the various types of advances directives are not universally recognized by state statutes,<sup>138</sup> the codes of an overwhelming majority of states establish a framework that governs advance directives from creation to implementation—and many of those statutory provisions are, more or less, identical. To execute valid advance directives, statutes generally require the declarant and two witnesses to sign the instrument.<sup>139</sup> Once executed, a declarant is charged with the responsibility to notify a physician or other service provider of the existence of an advance directive and deliver it to the provider. Illinois law, for example, recites that

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135. For an example of will execution requirements, see UNIF. PROB. CODE § 2-502 (NAT'L CONFERENCE OF COMM'NS ON UNIF. STATE LAWS 2008). For examples of execution requirements associated with advance directives, see *infra* note 139.

136. For will contests, see generally EUNICE L. ROSS & THOMAS J. REED, *WILL CONTESTS* (2d ed. 2018) (discussing the legal jurisprudence of contesting wills). For examples of challenges to advance directives based upon execution requirements, see VT. STAT. ANN. tit. 18, § 9718 (2017) (describing the process utilized to challenge an advance directive because a declarant lacked capacity to execute the instrument).

137. RESTATEMENT (THIRD) OF PROP.: WILLS AND OTHER DONATIVE TRANSFERS § 4.1 (AM. LAW INST. 1999). For a case invoking the lost will presumption, see *Estate of Turner*, 265 S.W.3d 709, 712–13 (Tex. App. 2008).

138. Massachusetts, for example, does not have a statutory provision governing living wills. See *Massachusetts Law About Health Care Proxies and Living Wills*, MASS.GOV, <https://www.mass.gov/info-details/massachusetts-law-about-health-care-proxies-and-living-wills> (last visited Feb. 23, 2019); see also *Massachusetts Living Wills*, HAMILL & GRAY, [http://www.massachusetts-wills.com/living\\_wills.html](http://www.massachusetts-wills.com/living_wills.html) (last visited Feb. 23, 2019) (identifying Michigan and New York as additional states without living will statutes).

139. See, e.g., ALA. CODE § 22-8A-4(c) (LexisNexis 2015) (enumerating execution requirements for advance directives); N.J. STAT. ANN. § 26:2H-56 (West 2018) (describing execution and mental capacity requirements for advance directives); WASH. REV. CODE ANN. § 71.32.050 (West Supp. 2018) (detailing the formalities required to execute an advance directive).

it shall be the responsibility of the patient to provide for notification to his or her attending physician of the existence of a declaration, to provide the declaration to the physician and to ask the attending physician whether he or she is willing to comply with its provisions.<sup>140</sup>

As a corollary to patient-provided notice, a physician generally does not have an affirmative statutory duty to inquire whether or not an individual has executed an advance directive.<sup>141</sup> Upon receiving notice, a physician is supposed to place the advance directive in the individual's medical record for future consultation.<sup>142</sup> Although contained in an individual's medical record, a healthcare provider is not statutorily required to comply with an advance directive.<sup>143</sup> Under those circumstances, however, the physician/provider must transfer the declarant to a different facility.<sup>144</sup> If, on the other hand, a physician complies with an advance directive "in good faith and pursuant to reasonable medical standards," the physician is not liable for the consequences associated with the cessation of treatment.<sup>145</sup>

The statutory requirements of delivery and placement in a medical record represent significant impediments to the effectuation of an individual's end-of-life intent. Ironically, fault for missing advance directives can often be assigned to the party intended to benefit from its execution—the declarant. Taking what can only be described as an extreme precaution, one person got a "DNR" tattoo on his chest, which triggered questions about the ethics of complying with the tattoo upon admission to a hospital.<sup>146</sup> Most individuals, presumably, do not permanently ink end-of-life wishes on their persons, but instead simply execute the document and either take it home or leave it with an attorney. Either course of action has its risks. Advance directives might be kept in safe deposit boxes or Bibles without telling anyone where they are housed or left with a third party (such as an attorney) who

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140. 755 ILL. COMP. STAT. ANN. 35/3(d) (LexisNexis 2010) (imposing the duty to inform on the patient "[i]f the patient is able" to undertake these tasks).

141. See, e.g., COLO. REV. STAT. ANN. § 15-18-104(1) (West Supp. 2017) (assigning responsibility for notice to the patient); IOWA CODE § 144A.3.3 (2017) (stating that the declarant must provide notice).

142. See, e.g., 755 ILL. COMP. STAT. ANN. 35/3(d).

143. *Id.*

144. *Id.*

145. *Id.* at 35/7.

146. Gregory E. Holt et al., *An Unconscious Patient with a DNR Tattoo*, NEW ENG. J. MED. (Nov. 30, 2017), <http://www.nejm.org/doi/full/10.1056/NEJMc1713344> (stating that there were "concerns about its legality and likely unfounded beliefs that tattoos might represent permanent reminders of regretted decisions made while the person was intoxicated" (footnote omitted)). Ethics consultants advised the physicians to comply with the tattoo's command and the hospital later obtained a copy of the patient's written advance directive. *Id.*

cannot be contacted at a moment's notice.<sup>147</sup> One declarant, for example, left an advance directive with his attorney, who proceeded to store the instrument in his briefcase.<sup>148</sup> Upon admission to the hospital, the declarant's healthcare proxy could not reach the attorney to obtain the advance directive because the attorney was out of the office taking a deposition with briefcase in tow.<sup>149</sup> The absence of an advance directive, of course, moots any question regarding the liability of a provider for failure to comply the instrument. And more importantly, the absence of an advance directive threatens to subvert the wishes of a declarant who likely expended a fair amount of mental energy considering difficult end-of-life questions.

Rather than being internalized to the individual, some of the costs associated with an individual's failure to ensure that an advance directive is available are externalized to parties charged with making decisions about end-of-life care. A family member, who wants to follow a patient's presumptive wishes, might permit life-prolonging treatment only to discover the existence of an advance directive to the contrary.<sup>150</sup> In other cases, missing advance directives permit survivors to input their interests into the end-of-life calculus under the stress of life or death decision-making. One patient in Florida, for example, informed a nurse that he had an advance directive after being extubated and placed on supplemental oxygen.<sup>151</sup> Although the patient's medical chart did not include the advance directive, the nurse confirmed the existence of the advance directive with the patient's spouse.<sup>152</sup> But after 53 years of marriage, the spouse informed the nurse that she did not intend to permit the hospital to suspend medical treatments and believed that the patient would recover.<sup>153</sup> During their interaction, the spouse asked the nurse, "What if . . . this was your husband, would you give up so easily?"<sup>154</sup> Given the absence of the advance directive in the patient's medical record and the insistence of the spouse, the healthcare providers decided to "do everything as long as we do not have a copy of the advance directive."<sup>155</sup> Amidst the

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147. Paula Span, *The Trouble with Advance Directives*, N.Y. TIMES (Mar. 13, 2015), <https://www.nytimes.com/2015/03/17/health/the-trouble-with-advance-directives.html> (noting that such "[s]tories abound").

148. Paula Span, *Where's That Advance Care Directive?*, N.Y. TIMES (Oct. 17, 2013, 6:00 AM), <https://newoldage.blogs.nytimes.com/2013/10/17/wheres-that-advance-care-directive>.

149. *Id.* The article does not detail what happened to the patient. *See id.*

150. *See id.*

151. Annette Tracey, *End of Shift: Missing Advance Directive Leaves Wife, and Nurse, with Moral Dilemma*, NURSE.COM (Nov. 8, 2010), <https://www.nurse.com/blog/2010/11/08/end-of-shift-missing-advance-directive-leaves-wife-and-nurse-with-moral-dilemma>.

152. *Id.* The patient informed the nurse that the patient's physician, attorney, and spouse had a copy of the advance directive, none of those copies appeared in the patient's medical chart. No reason is given for the absence. *Id.*

153. *Id.*

154. *Id.*

155. *Id.*

uncertainty the nurse contacted the hospital's ethics committee as well as other hospital staff to determine how to proceed.<sup>156</sup> The spouse eventually delivered the advance directive and the hospital implemented the patient's wishes.<sup>157</sup> Despite eventual compliance, the patient's failure to make certain that his advance directive could be consulted at a critical time not only placed the nurse in a professional and moral conundrum, but also permitted the interests of his spouse to supersede his advance directive.

While individuals may lose advance directives and thereby place others in a decision-making quandary, the presence of an advance directive in a patient's medical record does not guarantee consultation. A 2010 study of individuals who had executed an advance directive and given it to their healthcare providers found that a majority of those individuals did not have those instruments in their medical records.<sup>158</sup> The investigators split survey participants into two groups and found that one group of 245 people had their advance directives included in their medical charts in a shockingly low 15% of cases while the second group of 566 patients had their advance directives in their medical records in an improved, but still troublingly low, 47% of cases.<sup>159</sup> And beyond the controlled environment of empirical study, examples of cases where individuals deliver advance directives to hospital personnel but those advance directives cannot be located when needed are plentiful. Indeed, the patient in *Doctors Hospital of Augusta, LLC v. Alicea* brought her advance directive with her to the hospital and it was included in her medical record.<sup>160</sup> However, hospital staff placed the advance directive in the wrong location in the patient's medical chart and it was not discovered until after unwanted medical intervention had occurred.<sup>161</sup> Upon discovery, a nurse uttered, "Boy, somebody has really messed up."<sup>162</sup> On some level, "messing up" is predictable given the volume of paperwork and stress under which advance directives are consulted. Nevertheless, the frequency with which advance directives fail to be located despite delivery to healthcare providers is alarming. An individual may conform to the law from execution to delivery and still suffer a loss of enjoyment of life because the advance directive is, in essence, lost in plain sight.

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156. *Id.* The other hospital staff members are identified as an "interdisciplinary team." *Id.*

157. *Id.* The husband died after a few days. *Id.*

158. Victoria Y. Yung et al., *Documentation of Advance Care Planning for Community-Dwelling Elders*, 13 J. PALLIATIVE MED. 861, 862–63 (2010). The two groups were divided by age as well as health issues. *Id.*

159. *Id.* at 864. Interestingly, these results are not confined to the United States. A recent study of 998 patients in Germany who had given advance directives to their healthcare providers found that only 39.6% of those patients had those instruments in their hospital records. See Geraldine de Heer et al., *Advance Directives and Powers of Attorney in Intensive Care Patients*, 114 DEUTSCHES ARZTEBLATT INT'L 363, 363–64 (2017).

160. *Doctors Hosp. of Augusta, LLC v. Alicea*, 788 S.E.2d 392, 395 (Ga. 2016).

161. *Id.* at 395–97.

162. *Id.* at 397.

To increase the accessibility of advance directives, some states have created online registries of advance directives. Some online advance directive registries are created by statute and operated by a state agency while others are privately owned and recommended by the state. Statutes in Michigan and Nevada, for example, expressly create the Peace of Mind Registry and the Living Will Lockbox, respectively.<sup>163</sup> The West Virginia legislature chose not to create a registry by statute, but instead established an agency, the West Virginia Center for End-of-Life, and it operates an “e-Directive Registry” to store advance directives for West Virginians.<sup>164</sup> Furthermore, a few states contract with private businesses to maintain advance directive registries for use by the state.<sup>165</sup> Oklahoma statutory law provides that the state “may enter into contracts with private vendors” to operate its database of advance directives.<sup>166</sup> Whether state or privately operated, the basic purpose of an advance directive registry is to make advance directives available when needed so that individuals “will have their wishes for care known and respected.”<sup>167</sup>

Regardless of the identity of the operator, computerized advance directive registries function in a fairly similar manner. To initiate the process, declarants must complete a registration agreement that simply provides the declarant’s contact information to the registry operator as well as identify the type of instrument to be placed in the registry.<sup>168</sup> After filling out the short registration form, the declarant submits the completed registration agreement as well as her advance directive to the registry operator by mail, in person at a designated office, or by uploading the documents on the registry

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163. MICH. COMP. LAWS ANN. § 400.105d(1)(g) (West Supp. 2018) (referring expressly to a “peace of mind registry”); NEV. REV. STAT. ANN. § 449.920 (LexisNexis 2015); LIVING WILL LOCKBOX, NEV. SEC’Y OF STATE, <https://www.nvsos.gov/sos/home/showdocument?id=166> (last visited Feb. 23, 2019).

164. *About the Center*, W. VA. CTR. FOR END-OF-LIFE CARE, <http://wvendlife.org/about> (last visited Feb. 23, 2019) (noting that the legislature authorized the center in 2002).

165. Preston Holmes, *A Tour of State Advance Directive Registries*, 37 BIFOCAL 122, 122 (2016) (listing those states as Washington, Vermont, and Oklahoma).

166. OKLA. STAT. ANN. tit. 63, § 3102.1 (West 2016). Information on the Oklahoma State Department of Health website directs interested persons to submit advance directives to two private services, MyDirectives and U.S. Living Will Registry. *See Advance Directives*, OKLA. STATE DEP’T HEALTH, [https://www.ok.gov/health/Data\\_and\\_Statistics/Center\\_For\\_Health\\_Statistics/Health\\_Care\\_Information/Advance\\_Directives](https://www.ok.gov/health/Data_and_Statistics/Center_For_Health_Statistics/Health_Care_Information/Advance_Directives) (last visited Feb. 23, 2019) [hereinafter OKLA. STATE DEP’T HEALTH].

167. *Make Your Treatment Wishes Known*, W. VA. CTR. FOR END-OF-LIFE CARE, <http://wvendlife.org/home> (last visited Feb. 23, 2019).

168. *See, e.g.*, ARIZ. SEC’Y OF STATE, ARIZONA HEALTH CARE DIRECTIVES REGISTRY (2019), [https://azsos.gov/sites/default/files/bsd\\_ad\\_registration\\_agreement\\_20190107.pdf](https://azsos.gov/sites/default/files/bsd_ad_registration_agreement_20190107.pdf) (allowing declarants to also change or revoke their prior registration); STATE OF CAL. SEC’Y OF STATE, REGISTRATION OF WRITTEN ADVANCE HEALTH CARE DIRECTIVE (2015), <http://ahcdr.cdn.sos.ca.gov/forms/sfl-461.pdf> (allowing declarants to also identify the storage location of an advance directive if they opt not to house the instrument within the registry).



website.<sup>169</sup> Importantly, the registry operator generally does not examine the advance directive to determine if it complies with the formal requirements for execution in the registry's jurisdiction.<sup>170</sup> Once the advance directive has been processed, the registry operator delivers a wallet card, a bracelet, and/or stickers to the declarant with information that can be used to access the declarant's file, such as a file registration number and a password.<sup>171</sup> If a declarant wishes to modify the stored instrument in the future, a declarant may use the access information provided by the registry operator to update or revoke the instrument as needed.<sup>172</sup>

If a declarant's health circumstances warrant consultation with an advance directive, the burden of communicating access information to healthcare providers generally rests with the declarant. As a general matter, healthcare providers are unable to locate a declarant's advance directive in the registry without obtaining the access information from the declarant.<sup>173</sup>

169. See, e.g., *Advance Directives*, ARIZ. SEC'Y OF STATE, <https://www.azsos.gov/services/advance-directives> (last visited Feb. 23, 2019) (permitting submission by mail or in person); *Health Care Directive Registry*, IDAHO SEC'Y OF STATE'S OFF., <https://sos.idaho.gov/hcdr> (last visited Feb. 23, 2019) (stating expressly that email submissions will not be accepted); *End of Life Registry*, MONT. DEP'T OF JUSTICE: OFFICE OF CONSUMER PROT., <https://dojmt.gov/consumer/end-of-life-registry> (last visited Feb. 24, 2019) [hereinafter MONT. DEP'T OF JUSTICE] (allowing mail submissions only); MIPEACEOFMIND, <https://www.mipeaceofmind.org/Default.aspx> (last visited Feb. 23, 2019) (allowing submissions by upload or mail); VA. DEP'T OF HEALTH, VIRGINIA ADVANCE HEALTH CARE DIRECTIVES REGISTRY: FREQUENTLY ASKED QUESTION (FAQ) 2 (2016), <http://www.connectvirginia.org/wp-content/uploads/2016/04/FAQ-Sheet.pdf> (last visited Feb. 23, 2019) [hereinafter VA. DEP'T OF HEALTH] (allowing upload submissions only).

170. See, e.g., ARIZ. REV. STAT. ANN. § 36-3294(B) (2018) (declaring that "[t]he secretary of state is not required to review a document to ensure that it complies with the particular statutory requirements applicable to the document"); N.C. GEN. STAT. ANN. § 130A-468(a) (West 2009) (stating that "[t]he Secretary is not required to review a document to ensure that it complies with the particular statutory requirements applicable to the document"). But see MONT. CODE ANN. § 50-9-503(1) (2017) (asserting that "the attorney general shall determine if the declaration is in compliance" with Montana's execution requirements).

171. See, e.g., MONT. DEP'T OF JUSTICE, *supra* note 169 (detailing the wallet card and four stickers to be placed on various pieces of identification such as a driver's license or insurance card); *End of Life Registry Programs*, LA. SEC'Y OF STATE, <https://www.sos.la.gov/OurOffice/EndOfLifeRegistries/Pages/default.aspx> (last visited Feb. 23, 2019) [hereinafter LA. SEC'Y OF STATE] (describing a "do not resuscitate" bracelet to be placed on patients); *Mich.'s Advance Directive Registry*, MICH. DEP'T OF HEALTH & HUMAN SERVS., <https://www.mipeaceofmind.org> (last visited Feb. 23, 2019) [hereinafter MICH. DEP'T OF HEALTH & HUMAN SERVS.] (describing a wallet card to be given to patients).

172. See, e.g., VA. DEP'T OF HEALTH, *supra* note 169.

173. See, e.g., *Frequently Asked Questions*, N.C. SEC'Y OF STATE, [https://www.sosnc.gov/frequently\\_asked\\_questions/by\\_title/\\_advance\\_healthcare\\_directives](https://www.sosnc.gov/frequently_asked_questions/by_title/_advance_healthcare_directives) (last visited Feb. 23, 2019) [hereinafter N.C. SEC'Y OF STATE] (suggesting that "you may want to make copies [of a registry ID card] for everyone who you would like to have access to your directives, such as your health care agent, family members and health care providers"); ARIZ. SEC'Y OF STATE, ARIZONA ADVANCE DIRECTIVE FILING GUIDE (2019), [https://azsos.gov/sites/default/files/BSD\\_AD\\_Filing\\_Guide\\_01\\_2019.pdf](https://azsos.gov/sites/default/files/BSD_AD_Filing_Guide_01_2019.pdf) [hereinafter ARIZ. SEC'Y OF STATE] (stating that "[y]ou can share your password with your appointed medical power of attorney, your doctor and the hospital or clinic where you receive medical care, and/or whoever you choose" and providing instructions regarding access);

In other words, healthcare providers cannot perform independent searches of registries to unearth a declarant's advance directive; the declarant must communicate access details to the party needing access to the advance directive. In theory, wallet cards, bracelets, and stickers are ever-present on the person of the declarant; therefore, access information is readily available to be communicated to healthcare providers when necessary. In the real world, however, declarants might be unable to communicate access information or fail to have their wallet cards on hand at a critical moment. Recognizing this real-world possibility, registry websites frequently recommend that declarants provide family members or physicians with file numbers and passwords so that they can be delivered when needed.<sup>174</sup> Provided access is obtained, registries reduce the risk that an advance directive will be unavailable due to loss by declarant or misfiling by healthcare provider.

After obtaining identification information, most registries provide that a declarant's advance directive can be viewed online. Vermont, for example, publicizes that the instruments in its registry are "electronically stored and may be accessed by providers through the Internet or by telephone."<sup>175</sup> Consulting advance directives in state-run registries, however, is not always as straightforward as reading a scanned copy of an advance directive on a computer screen. Louisiana, for example, stores advance directives in a state-operated registry, but only provides "copies of declarations when requested by any attending physician or health care facility."<sup>176</sup> The website for Michigan's Peace of Mind Registry, the name affixed to the state's advance directive storehouse, asserts that the declarant's wishes "will soon be available to your doctors and to a hospital, nursing home, or other healthcare provider when you are a patient or resident."<sup>177</sup> Such a statement suggests that healthcare providers have ready online access to advance directives, but the FAQ portion of Michigan's website states that "[a]t this time Michigan health care providers do not have electronic access to your advance directive. You may present your wallet card to a health care provider so they can request a

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VA. DEP'T OF HEALTH, *supra* note 169 (stating that "[t]o provide access, these individuals will need your *Registration Number* and *Source* from the Wallet ID card in order to view your documents online").

174. See, e.g., MONT. DEP'T OF JUSTICE, *supra* note 169; VA. DEP'T OF HEALTH, *supra* note 169. In contrast, U.S. Living Will Registry/Advance Care Plan Registry permits searches to be performed using identifiers such as name, birth date, or Social Security number. See *How the Registry Works*, U.S. ADVANCE CARE PLAN REGISTRY, <http://www.uslivingwillregistry.com/howitworksind.shtm> (last visited Feb. 23, 2019).

175. *Provider Authorization and Obligations: Definition of Terms*, VT. DEP'T OF HEALTH, <http://www.healthvermont.gov/health-professionals-systems/advance-directives/provider-authorization-and-obligations> (last visited Feb. 24, 2019); see also, e.g., ARIZ. SEC'Y OF STATE, *supra* note 173; N.C. SEC'Y OF STATE, *supra* note 173.

176. LA. SEC'Y OF STATE, *supra* note 171.

177. MICH. DEP'T OF HEALTH & HUMAN SERVS., *supra* note 171.

copy of your advance directive.”<sup>178</sup> While the majority of registries provide for online display of a declarant’s end-of-life choices, registry storage does not necessarily equate to immediate online access.

At a time when medical records are increasingly digitized for online access, the number of states that have established online advance directories is surprisingly low. Apple is initiating a feature on its Health app that permits people to see various medical records on iPhones and the American Bar Association created an app to store a user’s advance directive,<sup>179</sup> but only 13 states had created online advance directive registries as of mid-2016.<sup>180</sup> Louisiana first passed a statute creating a central repository for advance directives in 1984,<sup>181</sup> but few states have mustered the political will to codify a registry for advance directives. And when placed on agendas in state legislatures, registry proposals often fail to survive the legislative process. Legislators in Florida, for example, introduced bills to establish an advance directive registry during the 2004 legislative session, but the bills failed to gather sufficient legislative support for enactment.<sup>182</sup> Seeking to avoid legislative potholes, some state legislatures have studied the experiences of states that maintain registries in advance of placing a registry proposal on the legislative agenda. A report to Washington’s legislature announced that the Washington Department of Health had gained “national exposure” after initiating its registry as other states sought advice regarding the creation and maintenance of a registry.<sup>183</sup> Washington’s experience and advice, ironically, did not spur the creation of state-run registries in several of the inquiring states.<sup>184</sup>

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178. *Frequently Asked Questions*, MIPEACEOFMIND, <https://www.mipeaceofmind.org/FAQ.aspx> (last visited Feb. 23, 2019).

179. Natasha Singer, *Apple, in Sign of Health Ambitions, Adds Medical Records Feature for iPhone*, N.Y. TIMES (Jan. 24, 2018), <https://www.nytimes.com/2018/01/24/technology/Apple-iPhone-medical-records.html>; *New ABA Mobile App Helps with Health Care Advanced Directives*, A.B.A. (April 16, 2014), [https://www.americanbar.org/news/abanews/aba-news-archives/2014/04/new\\_aba\\_mobile\\_app.html](https://www.americanbar.org/news/abanews/aba-news-archives/2014/04/new_aba_mobile_app.html).

180. See Holmes, *supra* note 165, at 122–27.

181. LA. STAT. ANN. § 40:1151 (2016) (noting that the current code section was “[r]edesignedated from R.S. 40:1299.58.1 by H.C.R. No. 84 of the 2015 Regular Session. Added by Acts 1984, No. 382, § 1. Amended by Acts 1985, No. 187, § 1, eff. July 6, 1985”); see also *End of Life Registry Programs*, LA SECRETARY STATE, <https://www.sos.la.gov/OurOffice/EndOfLifeRegistries/Pages/default.aspx> (last visited Feb. 23, 2019).

182. STATE ADVISORY COUNCIL ON QUALITY CARE AT THE END OF LIFE, STUDY ON A STATEWIDE ADVANCE DIRECTIVE REGISTRY, at ii (2005), <http://www.marylandattorneygeneral.gov/Health%20Policy%20Documents/ADregistry.pdf>.

183. WASH. STATE DEP’T OF HEALTH, LIVING WILL REGISTRY: A REPORT TO THE LEGISLATURE 2 (2009), [https://app.leg.wa.gov/ReportsToTheLegislature/Home/GetPDF?fileName=Living%20Will%20Registry\\_g2ao7e21-6747-45eb-a8c8-f4f4988f1835.pdf](https://app.leg.wa.gov/ReportsToTheLegislature/Home/GetPDF?fileName=Living%20Will%20Registry_g2ao7e21-6747-45eb-a8c8-f4f4988f1835.pdf) (identifying Minnesota, Alaska, Oregon, Nevada, and West Virginia as inquiring states).

184. For example, Minnesota and Alaska did not create state-maintained registries.

A primary impediment to legislative enactment of advance directive registries is concern about the practical utility of such registries given start-up costs. Washington's report assessing the feasibility of creating an online living will registry described the practices of one of the major stakeholders in the system as being a barrier to successful implementation with the simple statement that "medical institutions are slow to change."<sup>185</sup> Interestingly, the slow pace of change was not necessarily due to a lack of legislative support. Washington "spent . . . \$146,000 [on] registry computer start-up costs and marketing material development" during the first year after its state-operated registry became operational.<sup>186</sup> An "in-kind donation from the Washington State Medical Association[.]" allowed the state to mail 7,500 letters to physicians, 20,000 brochures to the public, and 12,000 pamphlets, 3,000 fact sheets, and 500 posters to healthcare providers.<sup>187</sup> Despite the initial transaction costs, Washington's reporters opined that operating costs would decrease as the number of registry participants increased.<sup>188</sup> To take advantage of the economies of scale, however, the number of participants needed to increase and "[p]ractical experience has shown that doctors and hospitals have been slow to adopt the registry system; many simply do not check them when a patient is admitted."<sup>189</sup> Washington's concern about registry utilization at inception was not unfounded—both Vermont and Nevada experienced low rates of healthcare provider enrollment when each began its state-run registry.<sup>190</sup> In combination, the start-up costs and the probability that the registry will go unused by healthcare providers present a substantial disincentive for legislative action.

Although it may seem counterintuitive, one group of stakeholders that stood to benefit the most from the creation of a registry—the public—has expressed concern about storing advance directives at the state level. A number of state-run registries are maintained by the Secretary of State,<sup>191</sup> but housing the registry in that governmental agency may create a conflict of interest in the minds of possible registrants. A focus group in Arizona, for example, feared that housing the registry within the Arizona Department of Health inappropriately linked healthcare options to fiscal decision-making,

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185. WASH. STATE DEP'T OF HEALTH, *supra* note 183, at 9.

186. *Id.* at 16.

187. *Id.*

188. *Id.* ("When all slots are occupied with participants, the cost per participant is approximately \$104. As more space is purchased and occupied, the cost per participant goes down.")

189. Shae Irving, *Living Will or Advance Directive Registries: Should You Use Them?*, NOLO, <https://www.nolo.com/legal-encyclopedia/living-will-advance-directive-registries-should-you-use-them.html> (last visited Feb. 23, 2019).

190. WASH. STATE DEPT. OF HEALTH, *supra* note 183, at 11.

191. See, e.g., CAL. SEC'Y OF STATE, ADVANCE HEALTH CARE DIRECTIVE REGISTRY, <http://www.sos.ca.gov/registries/advance-health-care-directive-registry> (last visited Feb. 23, 2019); IDAHO SEC'Y OF STATE, HEALTH CARE DIRECTIVE REGISTRY, <https://sos.idaho.gov/hcdr> (last visited Feb. 23, 2019).

which threatened to “limit the health care registrants receive.”<sup>192</sup> Vermonters joined Arizonans in the fear that a registry would decrease the quality of medical care offered to individuals who had advance directives in the registry.<sup>193</sup> Executing and registering an advance directive, of course, does not equate to a reduction in medical services available to a registrant. If medical care diminishes, the diminution results from healthcare professionals adhering to the individual’s documented intent rather than the decision of an official at a state agency. Nevertheless, public concern about sacrificing end-of-life care to save money reflects a deep-seated belief that has impacted other efforts to restructure healthcare, such as the Patient Protection and Affordable Care Act.<sup>194</sup>

While stakeholder objections and start-up costs represent obstacles for legislative creation of a state-run registry, the cost of maintaining the registry is an on-going concern after the registry goes live. In fact, fiscal savings associated with defunding a registry may imperil the continuing efficacy of existing registries. The national exposure generated by Washington’s passage of its advance care registry dimmed to the point that Washington ceased operating its state-run registry in 2011.<sup>195</sup> Apparently the program simply “ran out of money” and eliminating “the registry save[d] the state \$104,000 in” its budget.<sup>196</sup> Similarly, Oklahoma passed a statute in 2009 that required its Department of Health to “establish and maintain” a registry pursuant to rules developed by the State Board of Health.<sup>197</sup> Six years later, the legislature amended its statute to permit the Department of Health to contract with a private vendor to fulfill its statutory obligations.<sup>198</sup> Thereafter, the Oklahoma State Department of Health (“OSDH”) solicited contract bids to run its registry with one particularly telling requirement— “[a]ll services provided under this contract shall be provided at no cost to the OSDH.”<sup>199</sup> The OSDH webpage now provides links to two private registry services, MyDirectives and

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192. STATE ADVISORY COUNCIL ON QUALITY CARE AT THE END OF LIFE, *supra* note 182, at 17.

193. *Id.*

194. AM. BAR ASS’N COMM’N ON LAW & AGING, MYTHS AND FACTS ABOUT HEALTH CARE ADVANCE DIRECTIVES 1–2, [http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths\\_fact\\_hc\\_ad.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths_fact_hc_ad.authcheckdam.pdf) (last visited Feb. 23, 2019). *See generally* Vanessa Cavallaro, Comment, *Advance Directive Accessibility: Unlocking the Toolbox Containing Our End-of-Life Decisions*, 31 *TOURO L. REV.* 555, 584–85 (2015).

195. Associated Press, *Washington State Ends Living Will Registry*, *HERALDNET* (July 1, 2011, 1:55 PM), <http://www.heraldnnet.com/news/washington-state-ends-living-will-registry>.

196. *Id.* (quoting a spokesperson for the Washington Health Department).

197. 63 *OKLA. STAT.* § 3102.1 (A) (2016); Act of May 21, 2009, ch. 236, 2009 *OKLA. SESS. LAW* 1439 (providing for the establishing and maintaining of an advance directives registry).

198. Act of Apr. 10, 2015, ch. 43, 2015 *OKLA. SESS. LAW* 88 (altering requirements for advance directive registry).

199. *OKLA. STATE DEP’T OF HEALTH, CREATING A STATE OF HEALTH: REQUEST FOR PROPOSALS* 5 (2015), <https://www.ok.gov/health2/documents/RFP%202015%20Advanced%20Directive%20Registry%20Re-Bid.pdf>.

U.S. Living Will Registry, to satisfy its statutory obligation to “establish and maintain” an advance directive registry.<sup>200</sup>

For states like Oklahoma, as well as Washington, Vermont, and Maryland,<sup>201</sup> the availability of private vendors that build and maintain advance directive registries provides a cost-free substitute for state-run registries. Private registries not only make legislative funding concerns irrelevant, but they also offer the benefit of extending beyond state lines; they are national in scope. A declarant in South Dakota has the same access to the registry as a declarant in New Mexico. Furthermore, some nationwide health networks provide registry services for network members. Kaiser Permanente, for example, asserts that “[i]t’s important for all Kaiser Permanente members to file a copy of their advance directive forms with Kaiser Permanente” so that the forms may be scanned into its “Advance Directive Registry.”<sup>202</sup> Similarly several non-profit health information exchanges store advance directives for individuals in specific geographic regions. The Rochester Health Information Organization provides healthcare providers in New York “with immediate access to critical information that could affect your treatment—particularly in an emergency, when you may not be able to provide it yourself.”<sup>203</sup> In sum, numerous non-governmental registries have emerged to fill the vacuum of advance directive storehouses created by funding concerns on the state level.<sup>204</sup>

#### B. CENTRALIZING AN ADVANCE DIRECTIVE REGISTRY

The proliferation of state-run and nongovernmental online advance directive registries has had an unanticipated impact that might best be described as Newtonian. On the one hand, increasing the number of registries should, in theory, make advance directives more accessible to healthcare providers thereby increasing the probability that an individual’s end-of-life intent will be followed. On the other hand, increased access to advance directives using online access points risks registry underutilization. The increased number of online databases makes it difficult to know *which* registry to consult to find a declarant’s advance directive if the declarant fails to present access information on a wallet card or identification bracelet.

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200. See OKLA. STATE DEP’T HEALTH, *supra* note 166.

201. See Holmes, *supra* note 165, at 122.

202. *Advance Directives and End-of-Life Decisions*, KAISER PERMANENTE, <https://wa.kaiserpermanente.org/healthAndWellness/index.jhtml?item=/common/healthAndWellness/careDecisions/carePlanning/advancedDirectives.html> (last visited Feb. 23, 2019).

203. *Immediate Access to Critical Information*, ROCHESTER RHIO, <http://www.grrhio.org> (last visited Feb. 23, 2019). For a brief list of regional exchanges that store advance directives, see generally CTR. FOR HEALTHCARE RES. & TRANSFORMATION, *Advance Directive Registries: A Policy Opportunity* (Sept. 2011), [www.chrt.org/document/advance-directive-registries-a-policy-opportunity](http://www.chrt.org/document/advance-directive-registries-a-policy-opportunity).

204. Holmes, *supra* note 165, at 122 (listing America Living Will Registry, DocuBank, U.S. Living Will Registry, MedAlert Foundation, and MyDirective as registries that serve as alternatives to state-maintained registries).

Healthcare providers have limited time to care for seriously ill individuals and do not have time to “check the top five directories” in search of the individual’s advance directive.<sup>205</sup> Once the correct registry is located, healthcare providers do not have time to click through multiple tabs within a single registry to fish for relevant instruments.<sup>206</sup> In all likelihood, a healthcare provider will look in one online location and then return to the default position—medical treatment.<sup>207</sup> Unless the registry is easily discovered and easily used, healthcare providers are unlikely to consult them for the purpose they are intended to serve,<sup>208</sup> which threatens to frustrate a declarant’s end-of-life plan.

To counter the problems of consulting numerous registries with an equivalent number of interfaces, a nationwide advance directory could be built and maintained at the federal level. In fact, Congress has considered bills that required a governmental study of the costs and benefits of creating a national database. A section of a bill entitled The Advance Directives Improvement and Education Act of 2004 directed the Comptroller General to “conduct a study on the feasibility of a national registry for advance directives.”<sup>209</sup> The Senate referred the bill to the Senate Finance Committee, but it took no further action.<sup>210</sup> Failing to take action on the bill during the prior 2004 legislative session, the next Congress put another bill that required an identical study on its legislative agenda, but it too went nowhere.<sup>211</sup> Four years later, the Senate again considered a bill, the Advance Planning and Compassionate Care Act of 2009, that mandated an identical feasibility study and, again, the bill failed to get out of the Senate Finance Committee.<sup>212</sup> And,

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205. Shefali Luthra, *Advance Directives: Patients’ End-Of-Life Plans Often Lost at Critical Moments*, HARTFORD COURANT (April 12, 2016), <http://www.courant.com/consumer/hc-ls-health-end-of-life-records-0403-20160403-story.html>.

206. *Id.*

207. *Id.*

208. *Id.* (citing a senior Blue Shield of California manager for the proposition that registries will be underutilized unless easy to use).

209. Advance Directives Improvement and Education Act of 2004, S.2545, 108th Cong. § 6(c) (2004).

210. *Id.*

211. Advance Directives Education Act of 2005, S. 570, 109th Cong. (2005); *All Actions S. 570 – 109th Congress (2005-2006)*, CONGRESS.GOV, <https://www.congress.gov/bill/109th-congress/senate-bill/570/all-actions?q=%7B%22search%22%3A%5B%22%5C%22advance+directive+registry%5C%22%22%5D%7D> (last visited Feb. 23, 2019) (listing the bill’s legislative action).

212. Advance Planning and Compassionate Care Act of 2009, S. 1150, 111th Cong. (2009); *All Actions S. 1150 – 111th Congress (2009-2010)*, CONGRESS.GOV., <https://www.congress.gov/bill/111th-congress/senate-bill/1150/all-actions?q=%7B%22search%22%3A%5B%22%5C%22advance++directive+registry%5C%22%22%5D%7D> (last visited Feb. 23, 2019) (detailing the bill’s legislative trek). The House of Representatives considered the same bill. Advance Planning and Compassionate Care Act of 2009, H.R. 2911, 111th Cong. (2009). The House bill wound its way through committees and subcommittees, but it met the same fate as its Senate counterpart. *All Actions H.R. 2911 – 111th Congress (2009-2010)*, CONGRESS.GOV, <https://www.congress.gov/>

the story is the same during the most recent sessions of Congress: introduction of a bill that includes a mandated study and subsequent death in committee.<sup>213</sup> Apparently implementing legislation that, in part, requires the government to investigate the feasibility of a national registry of advance directives is a Sisyphean task.

Whatever circumstances caused Congress to punt meaningful consideration of a national advance directive registry over the past dozen years, demographic inertia makes finding an efficient means of accessing an individual's advance directive an imminent pressing concern. The Baby Boomer generation will soon confront healthcare issues associated with the aging process in unprecedented numbers. More specifically, the number of individuals who reach the age of 65 years is occurring at a staggering rate of 10,000 persons per day and will do so each day for the next 12 years.<sup>214</sup> By 2025, the number of people projected to be 65 years of age and older is a little over 65 million, which exceeds the 2015 number by approximately 20 million people.<sup>215</sup> Although the overwhelming majority of the 65 years and older cohort state a preference to die at home,<sup>216</sup> data compiled by the Centers for Disease Control and Prevention shows that almost two-thirds of those individuals will die in a hospital or in a nursing home.<sup>217</sup> In short, the population is aging and the majority of those people will die in a healthcare facility. As a result, providing a mechanism for ready access to an advance directive is a looming national issue, and the failure to do so threatens to subvert the autonomy of an enormous segment of the population.

bill/111th-congress/house-bill/2911/allactions?q=%7B%22search%22%3A%5B%22%5C%22advance+directive+registry%5C%22%22%5D%7D (last visited Feb. 23, 2019).

213. Advance Planning and Compassionate Care Act of 2014, S. 3009, 113th Cong. (2014); *All Actions S. 3009 – 113th Congress (2013-2014)*, CONGRESS.GOV, <https://www.congress.gov/bill/113th-congress/senate-bill/3009/all-actions?q=%7B%22search%22%3A%5B%22%5C%22advance+directive+registry%5C%22%22%5D%7D> (last visited Feb. 23, 2019) (listing the actions on the bill); see also Compassionate Care Act, S. 2961, 114th Cong. (2016); *Actions Overview S. 2961 – 114th Congress (2015-2016)*, CONGRESS.GOV, <https://www.congress.gov/bill/114th-congress/senate-bill/2961/actions?q=%7B%22search%22%3A%5B%22%5C%22advance+directive+registry%5C%22%22%5D%7D> (last visited Feb. 23, 2019) (overviewing actions on the bill).

214. Russell Heimlich, *Baby Boomers Retire*, PEW RESEARCH CTR. (Dec. 29, 2010), <http://www.pewresearch.org/fact-tank/2010/12/29/baby-boomers-retire>.

215. 2012 *National Population Projections Tables*, U.S. CENSUS BUREAU (2012), <https://www.census.gov/data/tables/2012/demo/popproj/2012-summary-tables.html> (comparing data for the 65 years of age and older cohort for the year 2015 to 2060 in Table 2).

216. *Where do Americans Die?*, STANFORD SCHOOL OF MED., <https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die> (last visited Feb. 23, 2019) (“Studies have shown that approximately 80% of Americans would prefer to die at home, if possible.”).

217. CENTERS FOR DISEASE CONTROL AND PREVENTION, U.S. DEP’T OF HEALTH & HUMAN SERVS., PUB. NO. 2011-1232, *HEALTH, UNITED STATES, 2010: WITH SPECIAL FEATURE ON DEATH AND DYING* 85 (2011), <https://www.cdc.gov/nchs/data/hus/10.pdf> (using data for decedents 65 years and over for the 2007 cohort).



In addition to demographic data, federal expenditure on care for those who have consciously chosen to forego treatment compels the construction and maintenance of a national registry of advance directives. The increasing cost of healthcare spending in the United States, particularly Medicare spending, has been the subject of endless debate and concern for members of the public and politicians alike.<sup>218</sup> A massive 25% of all Medicare spending to benefit the elderly is allocated to end-of-life care during the last year of life.<sup>219</sup> At the same time, empirical studies show an increase in the aggressiveness of treatments that are administered during the last 12 months of an individual's life.<sup>220</sup> As a result, much of this Medicare expenditure "goes for care in [the] last couple of months that is of little apparent benefit."<sup>221</sup> For those who have advance directives that are unavailable when needed, such medical intervention not only has little medical benefit, but also exacts a hidden toll by consuming scarce resources that could be used to promote the self-determined choices of others. Failing to honor an individual's considered choices because of a missing/misfiled advance directive or technical operability problems externalizes costs throughout the system.

In contrast to the problems plaguing the existing array of storage mechanisms, centralizing advance directives on a national level reduces the transaction costs of locating a declarant's advance directive. The present mix of state and private registries demands a search of multiple registries if the declarant does not identify which registry houses the instrument.<sup>222</sup> Locating an advance directive in an online registry not only depends upon which registry is searched, but also the identity of the searcher. Healthcare facilities do not employ an "advance directive registry checker;" therefore, individual knowledge of the storage options impacts the probability of location. The online search could be performed by a physician, a hospice worker, or a medical resident, and each may have different degrees of awareness about the options available for storing advance directives. A registry that is centralized

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218. *Medicare*, CONGR. BUDGET OFFICE, <https://www.cbo.gov/taxonomy/term/1585/policy-options> (last visited Feb. 23, 2019) (containing "Policy Options" tab which includes reports about the budgetary impact of Medicare).

219. Gerald F. Riley & James D. Lubitz, *Long-Term Trends in Medicare Payments in the Last Year of Life*, 45 HEALTH SERVS. RES. 565, 565-76 (2010), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2838161/#b2> (noting that this figure represents a slight decline from prior results).

220. Amber E. Barnato et al., *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 HEALTH SERVS. RES. 363, 363-75 (2004), <https://www.ncbi.nlm.nih.gov/pubmed/15032959> (noting also that the frequency of aggressive treatment could have been greater but for the increase in palliative care); see also Craig C. Earle et al., *Trends in the Aggressiveness of Cancer Care Near the End of Life*, 22 J. CLINICAL ONCOLOGY 315, 315 (2004), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2838161/#b7> (concluding that "[t]he treatment of cancer patients near death is becoming increasingly aggressive over time").

221. See GAWANDE, *supra* note 4, at 153.

222. See Luthra, *supra* note 205 (quoting an advocacy group leader for the notion that it is "really common" for healthcare professionals to fail to use an advance directive because it is difficult to access).

on the national level, on the other hand, reduces the cost of locating a declarant's advance directive by narrowing the search field to one regardless of who is undertaking the search. Reducing transaction costs of location saves time and energy in situations where those commodities are not likely to be plentiful. Quicker identification of where an advance directive is stored translates into quicker implementation of the declarant's wishes, which reduces the harm stemming from undesired medical intervention.

A national online registry of advance directives not only decreases the transaction costs of identifying which registry stores an instrument, but also reduces the costs associated with functional usage of the registry. Whatever the "top five directories" happen to be at any given time under the current system, users probably do not interface with those directories in precisely the same way. As a result, users must navigate registries with which they may be unfamiliar in search of relevant instruments, which may again consume valuable time. Storing advance directives in one online location, however, reduces the time it takes to use the registry as users become accustomed to the process of retrieving information from it over time. Simply put, users will become familiar with how to use the registry and the process will be the same for all searches undertaken within the registry; therefore, retrieving an individual's advance directive becomes a more efficient process when compared to present procedures.

To promote efficient retrieval of advance directives stored in a national registry, two features are indispensable. As an initial matter, the national registry must be searchable without reference to the access information printed on a wallet card, bracelet, or a sticker. Although the privately-run U.S. Living Will Registry permits healthcare providers to search the database using identifiers such as the last four digits of an individual's Social Security Number,<sup>223</sup> most registry searches require input from the declarant in the form of file numbers and passwords.<sup>224</sup> This mechanism of information acquisition is largely indistinguishable from current practices that require declarants to provide their advance directives to healthcare providers.<sup>225</sup> And as experience demonstrates, individuals frequently fail to provide advance directives to healthcare providers because those instruments are not physically present when needed or the declarant is unable to communicate. Wallet cards and bracelets may modestly increase the probability that an advance directive will be accessible at a critical time, but wallet cards and bracelets will not always be available. As a result, healthcare professionals must

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223. U.S. Living Will Registry, *How the Registry Works*, U.S. ADVANCE CARE PLAN REGISTRY, <http://www.uslivingwillregistry.com/howitworksind.shtml> (last visited Feb. 24, 2019). This is not uniformly the case among private registries. See *Frequently Asked Questions*, AM. LIVING WILL REGISTRY, <http://www.alwr.com/page.cfm> (last visited Feb. 24, 2019) ("The Health Care Provider will need the information on your ID card to access your files.").

224. See *supra* note 174 and accompanying text.

225. See *supra* Section II.A.

have the ability to search the national registry sans input from the declarant. Failing to expand the ability to search a registry represents an unnecessary risk to a declarant's interest in self-determination at a time when a declarant is most vulnerable.

In addition to making the national registry searchable without declarant input, the input/output interface must be accessible online. A number of state-run and private databases already have online input/output online mechanisms, but some registries require requests for advance directives to be in writing or transfer information to healthcare professionals by non-web-based means,<sup>226</sup> such as postal mail, email, or fax. Transmitting information from an advance directive database to requesting healthcare professionals by non-web-based mechanisms slows the acquisition of critical information when time is of the essence. Indeed, examples of delayed delivery abound, and the consequences can be deleterious for those receiving information in less than a timely fashion.<sup>227</sup> Furthermore, a postal mailing is not guaranteed to arrive at its intended destination; mail can be lost or delivered to the wrong address. Given that a ready alternative exists to non-web-based transfer, the failure to permit online access with viewable online results again exposes informational exchange to an unnecessary risk while a declarant's interest in self-determination hangs in the balance.

A national registry would not only lower location, search, and usage costs, but also promises to require lower start-up costs when compared to the monies expended on developing state or private registries. According to the privately-operated U.S. Living Will Registry, a governmental registry is disfavored because it will involve "start[ing] a new government bureaucracy, with increased expense to taxpayers to plan, design and implement a storage system, and then to pay personnel to run and maintain it."<sup>228</sup> As a theoretical matter, the start-up and maintenance costs for a national registry could be significant; however, the federal government has practical experience in

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226. Presumably, these are the available options because the non-web-based mechanisms are not described. See, e.g., *Frequently Asked Questions*, CAL. SECRETARY OF STATE, <http://www.sos.ca.gov/registries/advance-health-care-directive-registry/frequently-asked-questions> (last visited Feb. 24, 2019) (noting that "[a]ll requests for information must be in writing"); Mich. Dep't of Health & Human Servs., *Frequently Asked Questions*, MIPEACEOFMIND, <https://www.mipeaceofmind.org/FAQ.aspx> (last visited Feb. 24, 2019) (noting that there is no electronic access to an advance directive, and healthcare providers may "request a copy of [an] advance directive" if they have access to such information).

227. See, e.g., Liz Robbins, *Post Office Fails to Deliver on Time, and DACA Applications Get Rejected*, N.Y. TIMES (Nov. 10, 2017), <https://www.nytimes.com/2017/11/10/nyregion/post-office-mail-delays-daca-applications.html>; 'No Mail Mondays' Long-Time Postal Service Complaints Worsen During Holidays, WRAL.COM (July 13, 2018), <http://www.wral.com/-no-mail-mondays-long-time-postal-service-complaints-worsen-during-busy-holiday-season/17169253> (noting that delays involve important bills that need to be paid).

228. *Government Involvement*, U.S. LIVING WILL REGISTRY, available at <https://web.archive.org/web/20100126134726/https://www.uslivingwillregistry.com/gov.shtm> (last visited Feb. 24, 2019) (adding that the government should utilize its service as a "Partner of the Registry").

running a national registry accessible by third parties when necessary. The Organ Procurement and Transplantation Network, which is housed within the U.S. Department of Health and Human Services, maintains a “national database of all patients in the U.S. waiting for a transplant.”<sup>229</sup> Once a donor organ is available, donor information is entered into the registry and a match for the organ is found.<sup>230</sup> The registry search must occur with great dispatch because organs can only live for so long outside of the body; therefore, time is in short supply.<sup>231</sup> Given its functionality, the national organ donation registry could be used as a model for an advance directive registry. Third parties (healthcare providers) need ready access to an individual’s health-related documentation and the circumstances are time-sensitive. Rather than incurring substantial expense to create a national registry from thin air, the government’s experience with building and operating a similar registry should reduce inception costs because pitfalls can be avoided. In short, a national registry of advance directives need not be constructed from the ground up—the theoretical and practical architecture is already in place.

### C. INCENTIVIZING REGISTRATION

Regardless of the ease with which a registry might be consulted, a registry is inefficacious without declarant input. To that end, a primary challenge is getting declarants to store advance directives in a registry upon inception of the registry. The scant available data reveals that low percentages of declarants use an advance directive registry after it becomes operational. In California, for example, a mere 0.06% of its population aged 65 years or older placed an advance directive in the state’s registry following its creation in 1995.<sup>232</sup> Montana had the highest frequency of registration upon inception of its registry with 6.23% of its 65 years and older population uploading advance directives to the registry.<sup>233</sup> The reported data is imprecise in that the best figure to gauge the efficacy of registries is not represented by the percentage of registrants out of the total population of the 65 years and older cohort. Instead, a better metric would be the quotient yielded by dividing the number

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229. U.S. Dep’t of Health & Human Servs., *The Deceased Donation Process*, ORGANDONOR.GOV, <https://organdonor.gov/about/process/deceased-donation.html#matching> (last visited Feb. 24, 2019). For a description of the organizational relationship within the federal government, see U.S. Dep’t of Health & Human Servs., *Organ Procurement and Transplantation Network Policies and Reports*, ORGANDONOR.GOV, <https://www.organdonor.gov/about-dot/laws/optn.html> (last visited Feb. 24, 2019).

230. U.S. Dep’t of Health & Human Servs., *The Deceased Donation Process*, *supra* note 229.

231. U.S. Dep’t of Health & Human Servs., *Matching Donors and Recipients*, ORGANDONOR.GOV, <https://www.organdonor.gov/about/process/matching.html> (last visited Feb. 24, 2019).

232. Allison Hughes, *State Advance Directive Registries: A Survey and Assessment*, 31 BIFOCAL 23, 42 (2009).

233. *Id.*

of individuals who have entered an advance directive by the total number of individuals who have executed advance directives.<sup>234</sup>

Numerous reasons might explain the low frequency of registrations,<sup>235</sup> but the consistent underutilization of available registries suggests that a disconnect exists between the execution of estate planning documents and storage options. Although most Americans die intestate,<sup>236</sup> empirical evidence shows that the rate of testation increases with age.<sup>237</sup> Similarly, the frequency of advance directive execution also increases with age. One study of nearly 8,000 participants, for example, found that 11.8% of 18–34y participants, 19.2% of 35–54y participants, 29.3% of 55–65y participants, and 51.2% of those surveyed who were 65y or older had executed advance directives.<sup>238</sup> Both wills and advance directives have long been deemed essential for comprehensive estate planning.<sup>239</sup> And as a practical matter, both instruments are likely to be executed during the same attorney-supervised execution ceremony given the statutory signature and witnesses requirements.

Following an attorney-supervised execution ceremony, a practical issue immediately confronts all declarants/testators: where to keep the newly

234. The total number of individuals who execute advance directives, of course, is a number that is difficult, if not impossible, to ascertain.

235. For example, ignorance regarding the existence of an online registry or forgetfulness may each play a role in the failure to submit an advance directive for registration.

236. Rocket Lawyer, *Rocket Lawyer's Annual Make-a-Will-Month Survey Reveals Strong Need to Educate Consumers on Estate Planning*, MARKETWIRED (Aug. 2, 2016, 8:00 AM), <http://www.marketwired.com/press-release/rocket-lawyers-annual-make-will-month-survey-reveals-strong-need-educate-consumers-on-2147117.htm> (reporting that 64% of participants did not have a will).

237. Linda Lyons, *Last Wishes: Half of Americans Have Written Wills: Most Don't Have Living Wills*, GALLUP (June 7, 2005), <http://www.gallup.com/poll/16660/Last-Wishes-Half-Americans-Written-Wills.aspx> (reporting “that older Americans are far more likely than younger Americans to have a will” and that 71% of those surveyed over age 50 had a will).

238. Jaya K. Rao et al., *Completion of Advance Directives Among U.S. Consumers*, 46 AM. J. PREVENTATIVE MED. 65, 66, 69 (2014) (also finding that lack of awareness was the most common reason for not executing an advance directive).

239. See, e.g., Michael Chamberlain, *5 Key Estate Planning Documents to Help Avoid Family Conflicts*, FORBES (Oct. 21, 2011, 3:10 PM), <https://www.forbes.com/sites/feeonlyplanner/2011/10/21/5-key-estate-planning-documents-to-help-avoid-family-conflicts>; *Estate Planning: The Basics*, WELLS FARGO ADVISORS, <https://www.wellsfargoadvisors.com/planning/goals/estate-planning/basics.htm> (last visited Feb. 24, 2019). For planning suggestions that incorporate both wills and advance directives, see, e.g., Jane Bryant Quinn, *Making Sound End-of-Life Decisions*, AARP, <https://www.aarp.org/money/investing/info-2015/end-of-life-decisions.html> (last visited Feb. 24, 2019) (“When you make a regular will for your heirs, your attorney may provide his or her own versions of a living will or health care proxy. Modify them to suit your situation, then sign.”); Susan Fox Buchanan & James W. Buchanan, III, *Strategies for Clients in Nursing Homes*, 20 EST. PLAN. 1, 6–9 (1993); Jim Ludwick, *Do I Need a Will? What to Know About Estate Planning*, USA TODAY (May 25, 2017, 4:50 PM), <https://www.usatoday.com/story/money/personalfinance/2016/04/26/nerdwallet-wills-estate-planning/83552792>; *What is the Difference Between a Will and a Living Will*, EDWARDS ELDER LAW, P.A. (Jan. 17, 2012, 8:05 PM), <http://www.edwardselderlaw.com/Blog/2012/January/What-is-the-Difference-Between-a-Will-and-a-Livi.aspx> (noting the prudence of having both instruments).

minted instruments so that they are available at the appropriate time.<sup>240</sup> Some declarants/testators choose to depart an execution ceremony with their estate planning documents in hand and store them wherever other important documents are kept. Some attorneys even suggest that clients keep their estate planning instruments in their freezers at home to save money on a safe deposit box while adding a measure of protection against destruction by fire.<sup>241</sup> Although the price of self-storage might be right, the risks of self-storage are self-evident. Handwritten additions, cross-outs, and tears that touch some portion of the written language may lead to questions about the validity of those alterations or the instrument as a whole.<sup>242</sup> More fundamentally, the instruments may be placed in a location that is unknown to anyone but the declarant/testator and thus be unavailable when needed. In *In re Estate of Fuchs*, for example, an individual executed a will, but left documents “lying about his houses or piled in his cars.”<sup>243</sup> Three years after the individual’s death, the decedent’s family received an envelope containing the decedent’s will and thereafter offered it for probate.<sup>244</sup> The court, however, did not admit the newly discovered instrument to probate and the decedent’s estate descended by intestate succession.<sup>245</sup> Whether an advance directive or a will, the failure to have an instrument available when needed threatens to waste the time and money spent on end-of-life planning.

Instead of storing estate planning documents in freezers or cars, some declarants/testators opt to leave advance directives or wills with an attorney for safekeeping. The wisdom of leaving important instruments with an attorney is subject to varying opinions,<sup>246</sup> but the practice is generally permissible from an ethical perspective.<sup>247</sup> If an attorney retains client

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240. See generally Jennifer A. Kosteva, *Where There’s a Will, There’s a . . . Duty?: A Closer Look at the Safekeeping of Clients’ Original Estate Planning Documents*, MCGUIRE WOODS LLP (2009), [https://www.americanbar.org/content/dam/aba/publications/rpte\\_ereport/2009/april/te\\_kosteva.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/publications/rpte_ereport/2009/april/te_kosteva.authcheckdam.pdf) (listing various storage options for an individual’s estate planning documents).

241. *Where’s the Best Place to Store a Will?*, A.B.A.: SOLOSEZ, [https://www.americanbar.org/content/dam/aba/publications/solosez/storewills\\_2005\\_11.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/publications/solosez/storewills_2005_11.authcheckdam.pdf) (last visited Feb. 24, 2019).

242. See, e.g., *In re Estate of Funk*, 654 N.E.2d 1174, 1176–77 (Ind. Ct. App. 1995) (noting numerous alterations to the will by hand as well as removal and reattachment of a page of the will).

243. *In re Estate of Fuchs*, 900 N.W.2d 896, 900 (Neb. 2017).

244. *Id.*

245. *Id.* at 900, 906 (explaining that two of decedent’s children had filed for an intestate proceeding and been appointed as administrators at the time that the newly discovered will was submitted for probate).

246. Compare Abraham Shalo, Letter to the Editor, *Don’t Keep Your Will in the Lawyer’s Office*, N.Y. TIMES (Apr. 8, 1989), <http://www.nytimes.com/1989/04/08/opinion/1-don-t-keep-your-will-in-the-lawyer-s-office-314489.html>, with John W. Callinan, *Where Do I Store My Will*, LAW OFFS. JOHN W. CALLINAN (Nov. 12, 2012), <http://www.eldercarelawyer.com/blog/2012/11/where-do-i-store-my-will>.

247. THE AM. COLL. OF TRS. & ESTATE COUNSEL, ACTEC COMMENTARIES ON THE MODEL RULES OF PROFESSIONAL CONDUCT 170 (5th ed. 2016) (stating that an attorney “who has drawn

property for safekeeping, the instrument should be considered client property and subject to the requirements of Model Rules of Professional Conduct. Specifically, Model Rule 1.15 specifies that “[a] lawyer should hold property of others with the care required of a professional fiduciary.”<sup>248</sup> Although Rule 1.15 does not define “property,” the rule differentiates between client property in the form of “funds” and “other property” for safeguarding purposes.<sup>249</sup> Seeking to clarify what constitutes “property” for purposes of Rule 1.15, an American Bar Association Formal Opinion concluded that the phrase “may be fairly understood to include . . . wills . . . and . . . any documents provided to a lawyer by a client.”<sup>250</sup> Offering further illumination, the comments on the Washington Rules of Professional Conduct state that its safeguarding rule applies to “original documents affecting legal rights such as wills or deeds.”<sup>251</sup> Thus, an attorney who retains advance directives and wills must safeguard the instruments and the failure to satisfy the safeguarding obligation exposes an attorney to professional discipline.

Within the context of retaining estate planning documents, safeguarding a will should not be understood to be the same as safeguarding an advance directive. A will, of course, is inoperative until the death of the testator; therefore, third parties do not need access to the document before the testator’s death. Preservation of a will by storing it in a secure location satisfies the needs of the client and third parties with interests under the will. An advance directive, on the other hand, is needed before the declarant’s death to inform third parties of the declarant’s end-of-life choices. As a result, preserving an advance directive and a will in the same secure location may not serve the needs of the client. If both instruments are stored, for example, in a safe deposit box, neither instrument may be accessible until after the individual’s death. Post-mortem access of a will does not affect its utility, but post-mortem discovery of an advance directive eliminates its utility. Thus, the differing times at which each instrument must be available to preserve functionality suggests that advance directives and wills should be stored independently of one another.

To satisfy the duty to safeguard client property in the form an advance directive, an attorney could register the instrument in the proposed national registry of advance directives. Attorney registration of an advance directive in

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a will or other estate planning documents for a client may offer to retain the executed originals of the documents subject to the client’s instructions”).

248. MODEL RULES OF PROF’L CONDUCT r. 1.15 cmt. [1] (AM. BAR ASS’N 2016).

249. *Id.* at (a) (stating that “[f]unds shall be kept in a separate account” while “other property shall be identified as such and appropriately safeguarded”).

250. ABA Standing Comm. on Ethics & Prof’l Responsibility, Formal Op. 15-471 (2015).

251. WASH. RULES OF PROF’L CONDUCT r. 1.15A cmt. [5], WASH. COURTS, [https://www.courts.wa.gov/court\\_rules/?fa=court\\_rules.display&group=ga&set=RPC&ruleid=garpc1.15a](https://www.courts.wa.gov/court_rules/?fa=court_rules.display&group=ga&set=RPC&ruleid=garpc1.15a) (last visited Feb. 24, 2019).

the system not only preserves the instrument, but also increases the probability that the instrument will be accessible at the appropriate time.<sup>252</sup> While registration may seem to increase the burden on attorneys, the added registration obligation is no different than other professional obligations imposed under Model Rule 1.15. Indeed, Model Rule 1.15(a) mandates that “[f]unds” must be held “in a separate account . . . in the state where the lawyer’s office is situated,” which hypothesizes that an attorney must open and maintain an institutional account to hold a client’s money.<sup>253</sup> Similarly, an attorney must “deposit into a client trust account legal fees and expenses that have been paid in advance” under Model Rule 1.15(c).<sup>254</sup> Whatever added burden is imposed by the requirement to create separate accounts for client property, the advent of the digital era makes safeguarding documents easier than it has been in the past.<sup>255</sup> An instrument may be stored on a USB drive or uploaded to an online database. Storing an advance directive on a portable device, however, falls short of making the instrument available for consultation in an instant. Registering an advance directive on the proposed national registry of advance directives, on the other hand, makes the instrument accessible as needed while fulfilling the obligation to preserve client property enumerated in the Model Rules.<sup>256</sup>

The duty to safeguard an advance directive retained by an attorney not only incentivizes registration, but also confronts a persistent problem for existing registries—low numbers of registrations. An attorney who fails to register a retained advance directive risks professional discipline for violating the duty to safeguard client property, which provides a substantial incentive to comply.<sup>257</sup> Although a declarant cannot be forced to leave a newly executed advance directive with an attorney, many attorneys retain estate planning documents as a matter of course.<sup>258</sup> If the attorneys who retain advance directives satisfy the duty to safeguard client property by registering the instruments with the proposed registry, the number of registrants is likely to increase compared to the numbers associated with other registries at inception. As registrations increase, awareness of the registry increases, which, in turn, increases the likelihood of future registrations. In short, the duty to safeguard client property—backed by professional sanctions—initiates a

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252. Given that many people change their end-of-life preferences, the “appropriate time” to access an advance directive will often be well before the end of one’s life. A national registry will make it easier for declarants to access and modify their advance directives if their wishes change.

253. MODEL RULES OF PROF’L CONDUCT r. 1.15(a).

254. *Id.* r. 1.15(c).

255. James Keim, *Law Office Disaster Preparedness: The Liability and Ethics of Attorneys*, 80 FLA. B.J. 26, 30 (2006) (stating that “technology has made it easier than ever to safeguard client files and work product”).

256. Assuming the availability of an online access point.

257. As evidence of compliance, a document could be delivered to the attorney showing due registration and that document could be placed in the client’s file.

258. See ABA COMM’N ON LAW & AGING, *supra* note 194.



positive feedback loop that immunizes the proposed registry against the threat of underutilization while promoting long-term stability of the system.

The positive feedback cycle of execution and registration also responds to the philosophical criticism of advance directives based upon metaphysical differences between the precedent and future self. While empirical results show that individual preferences change over time thereby creating a schism between precedent and future preferences, updating an advance directive transforms what was once one's future self into the precedent self. But merely updating an advance directive on paper may not lead to implementation of the now precedent self's choices because those choices may not be available when needed. Simply stated, updating an advance directive does not alter practical impediments to accessibility attributable to declarants. As a result, the choices made by the now precedent self should be entered into the national registry and available for consultation thereafter. Although consultation may occur at a future time that is far removed from the time of registry entry, the later executed advance directive remains closer in time to the time of consultation when compared to the original advance directive. And, some present indication of an individual's choices is better than no indication whatsoever. Thus, allocating the burden of registry entry to an attorney narrows the temporal gap between the metaphysical precedent self and the future self; the future self is most metaphysically similar to the precedent self who last updated the advance directive.

In addition to suffering disciplinary sanctions, a lawyer who fails to enter an advance directive into a registry may be subject to a legal malpractice action. As with other torts, a cause of action for legal malpractice generally requires duty, breach, causation, and damages.<sup>259</sup> Duty here arises from the attorney-client relationship and is defined by the scope of the engagement.<sup>260</sup> An attorney must "do all things reasonably necessary to fulfill the objective of the employment," which can include "anticipating reasonably foreseeable risks of harm."<sup>261</sup> A client who engages a lawyer to prepare an advance directive intends for the advance directive to be given effect. And a lawyer preparing an advance directive can reasonably foresee that the advance directive may not be given effect if it is not available to a healthcare

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259. 4 RONALD E. MALLIN, *LEGAL MALPRACTICE* § 33:2 (2017); W. PAGE KEETON ET AL., *PROSSER AND KEETON ON THE LAW OF TORTS* § 30, 164-65 (W. Page. Keeton ed., 5th ed. 1984). Some authority holds that legal malpractice is a contract claim, not a tort claim. *O'Connell v. Bean*, 556 S.E.2d 741, 743 (Va. 2002). The type of claim does not affect the analysis below, but the characterization of the claim may impact other aspects of the case, like the statute of limitations and available damages. *Id.*

260. 1 MALLIN, *supra* note 259, § 8:5.

261. *Id.*

provider.<sup>262</sup> Registering the advance directive is therefore within the scope of the attorney's engagement.<sup>263</sup>

Given the unambiguous duty to register an advance directive, the failure to register in all but exceptional circumstances is a breach of that duty. A lawyer may counter by arguing that other lawyers in her community do not routinely register advance directives. Indeed, some courts have described the standard of care as "that degree of care, skill, and diligence commonly possessed and exercised by an ordinary member of the legal community."<sup>264</sup> The best reasoned judicial decisions, however, reject the notion that bad customs immunize deficient attorney performance. In *Gleason v. Title Guarantee Co.*, for example, the United States Fifth Circuit Court of Appeals observed that "[n]o degree of antiquity can give sanction to a usage bad in itself."<sup>265</sup> As support for the notion that a history of bad practices does not inoculate attorneys from liability, a leading treatise states that "although custom may serve to explain or expand the skill or knowledge required, it cannot and should not lower the standard of care."<sup>266</sup> Thus, failing to register an advance directive in a national registry would be a breach of an attorney's duty to a client seeking to plan for end-of-life care.

Courts often find a breach of duty when an attorney fails to record a transaction involving real property.<sup>267</sup> In *Reynolds v. Kadanoff & Haussman, P.C.*, for example, the plaintiff purchased real property at a sheriff's sale, but the plaintiff's attorney did not record the deed.<sup>268</sup> The debtor subsequently sold the property and that later deed was recorded.<sup>269</sup> The court held that these allegations stated a claim for legal malpractice.<sup>270</sup> Recording a deed is similar to registering an advance directive in the proposed registry because both are designed to put third-parties on notice of a transaction. The purpose of recording a deed is to inform buyers/third parties of interests that might affect title to land while the purpose of registering an advance directive is to inform healthcare professionals about the existence of an instrument that

262. See *supra* notes 253–60 and accompanying text.

263. Absent an agreement to the contrary by the lawyer and client.

264. See, e.g., *Cummings v. Donovan*, 828 N.Y.S.2d 475, 476 (App. Div. 2007).

265. *Gleason v. Title Guarantee Co.*, 300 F.2d 813, 814 (5th Cir. 1962).

266. 2 MALLIN, *supra* note 259, § 20:8 (footnote omitted); see also *Berman v. Rubin*, 227 S.E.2d 802, 806 (Ga. Ct. App. 1976) ("Of course, the fact that the defendant has followed customary procedures will not always insulate him from liability.").

267. 4 MALLIN, *supra* note 259, § 34:30; *Benedict v. Estate of Noumair*, 289 A.D.2d 71, 71 (N.Y. App. Div. 2001); *Brown v. Walker*, 555 S.E.2d 223, 224 (Ga. Ct. App. 2001); *Gold v. N.Y. State Bus. Grp. Inc.*, 255 A.D.2d 628, 630 (N.Y. App. Div. 1998); *Reynolds v. Kadanoff & Haussman, P.C.*, 248 A.D.2d 607, 608 (N.Y. App. Div. 1998); *Hundley v. Robinson*, 569 So. 2d 55, 58 (La. Ct. App. 1990).

268. *Reynolds v. Kadanoff & Haussman P.C.*, 218 A.D.2d 732, 732 (N.Y. App. Div. 1995).

269. *Id.*

270. *Id.* at 733.

guides end-of-life care.<sup>271</sup> When attorneys fail to take reasonable steps to provide notice of an advance directive when the issue and consequences of inaccessibility are foreseeable, they should answer to a claim of legal malpractice.

The next element of legal malpractice, causation, presents a more significant obstacle to liability when compared to the first two elements of a claim. The client will have to establish that but for the attorney's failure to register the advance directive, the advance directive would have been given effect.<sup>272</sup> As discussed above, an abundance of evidence demonstrates that healthcare providers often disregard instructions in advance directives even when they are aware of them.<sup>273</sup> Whether healthcare providers would have complied with an advance directive in a particular case in which the advance directive was not discovered because it was not entered into the registry will be a factual question. A plaintiff could, for example, compare the provider's actions to the policies and practices outlined in the material required to be supplied to patients upon admission under the language of the Patient Self-Determination Act ("PSDA").<sup>274</sup> A deviation between the facts and a facility's written policies could, in part, lead a jury to conclude that the advance directive would have been honored if it had been available to healthcare providers. Although the causation element is a barrier to a legal malpractice claim, the difficulty of proof should not serve to insulate attorneys from liability when their omissions have foreseeably deleterious consequences.

If a client surmounts the obstacle created by the causation requirement, then a plaintiff must specify the damages suffered as a result of the defendant's conduct. In all likelihood, the damages resulting from the failure to register an advance directive will be noneconomic in nature. Statutory law often defines what is covered by the broad phrase "noneconomic damages," but, as a general matter, noneconomic damages are intended to compensate for intangible, nonpecuniary losses.<sup>275</sup> The Florida Code, for example, defines "[n]oneconomic damages" to "include[e] pain and suffering, inconvenience, physical impairment, mental anguish, disfigurement, loss of capacity for enjoyment of life, and other nonfinancial losses to the extent the claimant is

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271. 26A C.J.S. *Deeds* § 159 (2018); 66 AM. JUR. 2D *Records and Recording Laws* § 46 (2019).

272. See *Cummings v. Donovan*, 36 A.D.3d 648, 648 (N.Y. App. Div. 2007) ("A cause of action to recover damages for legal malpractice requires proof . . . that, but for the defendant's negligence, the plaintiff would have been successful in the underlying action.").

273. See *supra* notes 12–17 and accompanying text.

274. Patient Self-Determination Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388-115, 1388-204 (1990) (codified as amended at 42 U.S.C. §§ 1395cc(f)(1)(A), 1395cc(f)(2), 1396a(w)(1)(A), 1396a(w)(2) (2012)).

275. See generally Harry Zavos, *Monetary Damages for Nonmonetary Losses: An Integrated Answer to the Problem of the Meaning, Function, and Calculation of Noneconomic Damages*, 43 LOY. L.A. L. REV. 193 (2009) (arguing that noneconomic damages in tort suits serve more as a symbolic reparation).

entitled to recover such damages under general law.”<sup>276</sup> Some authority states that noneconomic damages are not allowed for legal malpractice claims.<sup>277</sup> The bulk of authority, however, prohibits noneconomic damages only when they are a consequence of other, economic, injuries.<sup>278</sup> One court explained:

There are cases in which the original claim negligently handled by the attorney will not be predicated upon an economic loss, such as cases involving issues of contested child custody or visitation, confinement to a mental hospital, imprisonment, adoption, etc. Not to allow mental anguish damages under these limited circumstances would leave such a client without a remedy and virtually immunize the negligent attorney. This would certainly be contrary to public interest and would not constitute sound public policy.<sup>279</sup>

Mental anguish damages are not premised on any economic injury; therefore, non-economic damages are recoverable in a legal malpractice action. Moreover, failing to permit an award of noneconomic damages in these cases would effectively leave individuals without a remedy. After all, the damages incurred are those associated with continued life following unwanted medical intervention. Noneconomic damages defy exact calculation because no objective measure can be utilized, but awards should be “fair and just.”<sup>280</sup> Although they may be criticized as arbitrary,<sup>281</sup> awarding noneconomic damages in legal malpractice cases involving an attorney’s failure to register an advance directive not only capture a portion of the harm suffered by declarants, but also promotes the public interest by providing a remedy for foreseeable harm.<sup>282</sup>

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276. FLA. STAT. § 766.202(8) (2011). For examples of other definitions of “noneconomic damages,” see IDAHO CODE ANN. § 6-1601(5) (Supp. 2018); and MICH. COMP. LAWS ANN. § 691.1416(f) (West 2015).

277. *Smith v. McLaughlin*, 769 S.E.2d 7, 20 (Va. 2015) (“A legal malpractice plaintiff may recover only pecuniary damages proximately caused by an attorney’s breach of the contractually implied duties.”).

278. *Gavend v. Malman*, 946 P.2d 558, 563 (Colo. App. 1997).

279. *Jarrell v. Miller*, 882 So. 2d 639, 647 (La. Ct. App. 2004).

280. *See, e.g.*, VA. CODE ANN. § 8.01-52 (2017) (describing the amount of damages available).

281. *See Zavos, supra* note 276, at 250–54 (cataloguing various comments regarding the arbitrary nature of noneconomic damage awards).

282. Legal malpractice exposure might attach earlier during the representation if an attorney fails to advise an individual about advance directives. Indeed, a New Jersey court explained that immunizing attorneys from liability for non-economic harm would inappropriately leave clients without a remedy for a variety of engagements, including “[d]rafting a living will.” *Kohn v. Schiappa*, 656 A.2d 1322, 1324 (N.J. Super. Ct. Law Div. 1995). Specifically, a plaintiff in this context would have to prove (1) that her estate planning attorney failed to suggest an advance directive during the planning process, (2) that she would have executed an advance directive if informed, (3) that her healthcare provider would have been made aware of the advance directive, and (4) that because there was no advance directive (5) the healthcare provider administered unwanted life-saving treatment (6) that caused harm. 1 RONALD E. MALLEN, *LEGAL MALPRACTICE* § 8:20 (2019). Importantly, the fact that harm would not have

## IV. COMPENSATION FOR VIOLATIONS OF ADVANCE DIRECTIVES

Although case and statutory law authorizes advance directives, awarding damages based upon a novel claim of “wrongful living” is unlikely to gain widespread acceptance in the near future. Existing common law principles, however, may provide a mechanism to award damages that have the potential to impact future behavior without wholesale acceptance of “wrongful living” into the common law. As an initial option, a court could construe the violation of an advance directive as a dignity tort and award damages based upon harm to the dignity of declarants.<sup>283</sup> Indeed, sizable dignity awards would, in theory, promote greater compliance with advance directives. But given their rejection of “wrongful living” as a viable theory, courts seem unlikely to broaden the scope of dignity torts to include violations of advance directives. Furthermore, courts have largely failed to award dignity damages in analogous settings involving informed consent,<sup>284</sup> which again does not augur well for dignity as a basis for signaling damages in cases where an advance directive is violated.

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occurred but for the healthcare provider’s life-saving intervention does not preclude recovery from the estate planning attorney. RESTATEMENT (SECOND) OF TORTS § 905 cmt. i (AM. LAW INST. 1977). To the contrary, the plaintiff can succeed by showing that care consistent with her wishes (non-intervention) would have achieved her desired medical condition (death). RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL AND EMOTIONAL HARM § 26 cmt. n (2010).

Much of the factual support for such a claim is identical to that which supports a malpractice claim for failure to use the proposed registry; therefore, we omit discussion in the body of the paper to avoid repetition. However, the first three elements of the claim create evidentiary challenges for plaintiffs. First, proving element (1) involves a post-hoc review of evidence that is largely, if not entirely, within a defendant attorney’s knowledge. To ameliorate the issue, the burdens of production and persuasion for this element could be reallocated to the attorney. *Nader v. Allegheny Airlines, Inc.*, 512 F.2d 527, 538 (D.C. Cir. 1975) (shifting the burden to the defendant in part because it “will be in a better position to develop any needed documentation”); Jody S. Kraus, *Decoupling Sales Law from the Acceptance-Rejection Fulcrum*, 104 YALE L.J. 129, 146 (1994) (stating that one “rationale for allocating burden of proof . . . is to provide the party best able to create cost-effective evidence with the incentive to do so”). Second, element (2) requires a plaintiff to show counter-factually that, if properly advised by the attorney, she would have executed an advance directive refusing care. A plaintiff may offer evidence on this point. Such testimony may be self-serving, but that goes to weight, not admissibility. *See Connolly v. Smith*, No. 03-03-00575-CV, 2004 WL 1898220, at \*5 (Tex. Ct. App. Aug. 26, 2004). Lastly, proving that a healthcare provider would have known about the individual’s advance directive might stymie many claims given the problem of inaccessibility. Nevertheless, a plaintiff might, for example, submit hospital policies/protocols as evidence that the provider would have been aware of the advance directive. The final elements are factually straightforward—the absence of an advance directive led to unwanted medical intervention and associated harm.

283. Calvert Magruder, *Mental and Emotional Disturbance in the Law of Torts*, 49 HARV. L. REV. 1033, 1034 (1936).

284. *See* E. Haavi Morreim, *Medical Research Litigation and Malpractice Tort Doctrines: Courts on a Learning Curve*, 4 HOUS. J. HEALTH L. & POLY 1, 73–79 (2003) (arguing that courts should recognize dignitary harm for violations of informed consent in the context of medical research in the form of “medical research battery” and “invasion of bodily integrity”). *But see* Lugenbuhl v. Dowling, 701 So. 2d 447, 455–56 (La. 1997) (recognizing dignity harm for “disregard[ing] the patient’s expressed wishes” after a physician performed a medical procedure despite the patient’s objection).

Thus, a more granular examination of claims within existing tort doctrine and the associated harms suffered by declarants is necessary to increase the probability of trial or settlement awards that realign the current incentive structure.

Because courts routinely refuse to entertain lawsuits premised on “wrongful living,” plaintiffs have asserted a wide range of tort claims seeking compensatory damages from responsible parties.<sup>285</sup> For example, individuals have filed claims based upon just about everything from traditional intentional infliction of emotional distress to more attenuated claims grounded upon §1983 and the False Claims Act.<sup>286</sup> One of the most straightforward claims, however, asserts that defendants are liable for battery after administering medical treatment in violation of an advance directive. A person can be liable for battery if the person through intentional and non-consensual affirmative conduct makes contact with another person that causes bodily harm or is offensive.<sup>287</sup> Presumably, a healthcare provider makes some form of contact with the declarant, such as inserting tubes or moving from one bed to another for treatment, and that contact is non-consensual given the existence of a valid advance directive. Even if the touching does not cause bodily harm, it is almost certainly “offensive” as an interference with “autonomy, dignity, and freedom from emotional harm” as memorialized in the advance directive.<sup>288</sup>

In addition to filing a complaint alleging that wrongful medical intervention constitutes battery, a plaintiff may ground a complaint for compensatory damages on the law of negligence. As a general matter, showing that a healthcare provider is liable for negligence requires a showing that a provider had a duty to adhere to an advance directive, a breach of that duty, the plaintiff suffered damages, and that the breach caused the damage.<sup>289</sup> The choice between battery or negligence comes down to the presence or absence of intent because negligence does not require a plaintiff to show that the defendant’s conduct was intentional. As a result, negligence is often the claim of choice in cases where a healthcare provider was ignorant of the existence of an advance directive.<sup>290</sup> A plaintiff might assert that a healthcare provider was negligent, for example, if the healthcare provider overlooked an advance

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285. See Pope, *supra* note 43, at 260–61. Professional sanctions are also possible. If these sanctions were consistently imposed and serious enough, they could mitigate the need for more expansive tort liability and the public law proposal set forth below. The problems with AD completion and compliance outlined above suggest that current professional sanctions are insufficient.

286. *Id.*

287. RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL AND EMOTIONAL HARM § 101 (AM. LAW INST., Tentative Draft No. 1, 2015).

288. *Id.* § 101 cmt. b.

289. RESTATEMENT (THIRD) OF TORTS: LIAB. FOR PHYSICAL AND EMOTIONAL HARM § 3 (AM. LAW INST. 2005).

290. See Pope, *supra* note 43, at 268.

directive in a patient's medical record, treated the patient in violation of the advance directive, and the patient suffered harm in form of prolonged life because of the treatment. In reality, the risk of a claim of negligence in cases involving violations of advance directives is likely to be inversely proportional to the quality of medical record-keeping and the protocols by which those records are consulted. Effective record-keeping and review practices decrease the risk of negligence.

Interestingly, plaintiffs may opt to combine assertions of negligence and battery to account for both intentional and unintentional wrongs when seeking compensation for unwanted life-prolonging medical intervention. In *Anderson v. St. Francis-St. George Hosp., Inc.*, for example, the Supreme Court of Ohio considered battery and negligence claims asserted by an individual who was resuscitated via defibrillation following an episode of ventricular tachycardia despite an order not to do so.<sup>291</sup> Analyzing the negligence claim, the court recited that an alleged cause is not a cause upon which compensation is awarded "if the particular event would have occurred without the doing of the act."<sup>292</sup> In this case, the court concluded that the stroke was a foreseeable occurrence after surviving heart problems and that no evidence existed to show that the resuscitative efforts caused the stroke.<sup>293</sup> And although the court noted that a plaintiff could recover for battery, only nominal damages could be granted if the battery was "physically harmless."<sup>294</sup> The plaintiff did not suffer physical harm as a result of the defibrillation; therefore, only nominal damages could be awarded.<sup>295</sup> Soberly, the court declared that "[t]here are some mistakes, indeed even breaches of duty or technical assaults, that people make in this life that affect the lives of others for which there simply should be no monetary compensation."<sup>296</sup>

Despite judicial non-recognition of "wrongful living" and the "nominal damages" that may be granted to battery/negligence plaintiffs, a return to first principles points the way to improved damage awards in cases involving violations of advance directives. Whether "wrongful living," battery, or negligence serves as the foundation of a plaintiff's complaint, the primary damages claim will take the form of compensatory damages. The definition varies, but compensatory damages generally represent the "actual damages

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291. *Anderson v. St. Francis-St. George Hosp., Inc.*, 671 N.E.2d 225, 228 (Ohio 1996). The patient suffered a stroke and became partially paralyzed following medical treatment. *Id.* at 226. The patient/original plaintiff died, and the administrator of plaintiff's estate pursued the claim on behalf of the decedent. *Id.*

292. *Id.* at 228.

293. *Id.*

294. *Id.* at 229. The court's statement casts further doubt over the ability of dignity damages to channel future behavior because damage to dignity is also "physically harmless;" therefore, a possibility exists that dignity damages will be insufficiently large to alter decision-making.

295. *Id.* (noting that there were "no tissue burns or broken bones").

296. *Id.* at 228.

... awarded for the loss, injury, or deterioration to a person caused by the negligence, design, or accident of another.”<sup>297</sup> Because they compensate for “actual damages,” compensatory damages exclude punitive damages.<sup>298</sup> Thus, the fundamental goal of compensatory damages is to “put the plaintiff back in the same position [he/she] was in prior to the occurrence in question so that thereafter the plaintiff would be no richer and no poorer than” before the act causing the harm.<sup>299</sup>

For plaintiffs seeking compensatory damages based upon a theory of “wrongful living,” the essence of the claim is that life following unwanted medical intervention is an injury that merits compensation. In other words, wrongful living plaintiffs seek damages for continued life, which is graphically depicted in Figure 1. The solid horizontal line in Figure 1 represents a plaintiff’s quality of life and the vertical line that bisects the horizontal line represents medical intervention that prolongs a plaintiff’s life. By seeking compensation for post-intervention life, plaintiffs seek a monetary award for area B in Figure 1. Courts have traditionally refused to recognize “wrongful living” as a basis for compensation on the ground that life is always a benefit, never an injury. As a general matter, then, plaintiffs asserting a wrongful living claim do not receive any compensation for harm contained in area B following medical intervention that prolongs life in violation of an advance directive.

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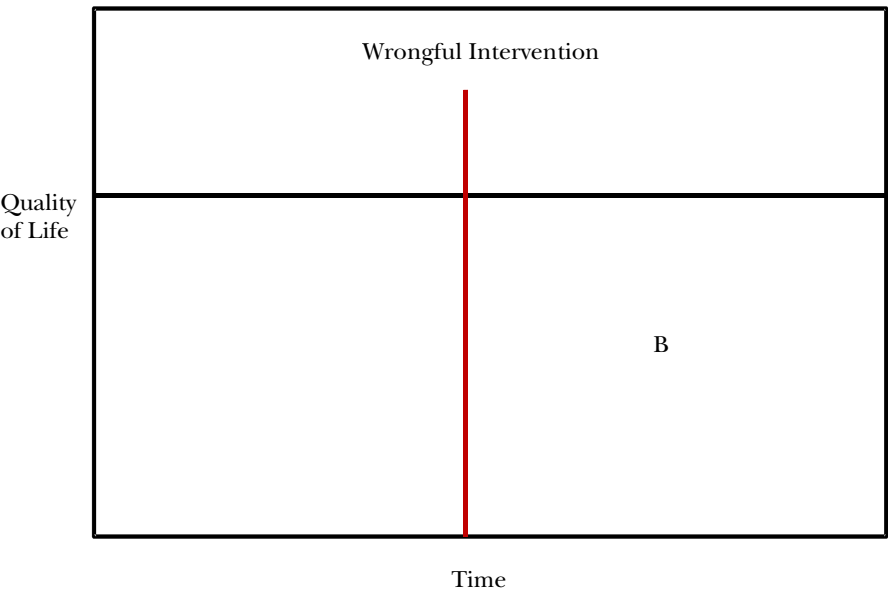
297. 17 FLA. JUR. 2D *Damages* § 7 (2018) (footnotes omitted); *see also, e.g.*, 22 AM. JUR. 2D *Damages* § 24 (2018) (“Compensatory damages are intended to redress the concrete loss that the plaintiff has suffered by reason of the defendant’s wrongful conduct. Their objective is to repair the damage caused to one party by the wrong of another. In both contract and tort actions, compensatory damages are awarded for the purpose of making the injured party whole by reimbursing, compensating, or indemnifying him or her for the loss or harm suffered, to the extent that it is possible to measure his or her injury in terms of money. The term covers all loss recoverable as a matter of right and includes all damages (beyond nominal damages) other than punitive or exemplary damages.” (footnotes omitted)).

298. STUART M. SPEISER ET AL., 2A AMERICAN LAW OF TORTS § 8:60 (Monique C.M. Leahy ed., 2018) (stating that “punitive damages may not be awarded unless the party seeking them has sustained actual harm or damages sufficient to support an underlying cause of action”); *see also, e.g.*, 22 AM. JUR. 2D *Damages* § 24 (“The term [compensatory damages] covers all loss recoverable as a matter of right and includes all damages . . . other than punitive or exemplary damages.”).

299. 8 AM. JUR. PLEADINGS & PRACTICE FORMS ANNOTATED *Damages* § 155 (2018).



Figure 1. Wrongful Living Damages from Wrongful Life-Saving Treatment



In contrast to the failure to receive compensation in “wrongful living” actions, some battery and negligence plaintiffs have received compensatory damages after the administration of unwanted life-prolonging medical treatment.<sup>300</sup> A closer examination of the list of compensable harms, however, reveals that the list is incomplete. Compensating plaintiffs for harms such as “broken bones” and “mental anguish” is unquestionably appropriate for claims of battery and negligence.<sup>301</sup> And in addition to physical and mental harms experienced by declarants whose advance directives are violated, courts also award damages for out-of-pocket costs such as “medical expenses” or “the

300. One commentator rejects compensatory damages altogether, arguing instead for no recovery of subsequent medical expenses by the HCP. Kellen F. Rodriguez, *Suing Health Care Providers for Saving Lives: Liability for Providing Unwanted Life-Sustaining Treatment*, 20 J. LEGAL MED. 1, 6 n.28 (1999).

301. *Anderson v. St. Francis-St. George Hosp., Inc.*, 671 N.E.2d 225, 229 (Ohio 1996) (describing “tissue burns” and “broken bones” as examples of compensable damages); *Anderson v. St. Francis-St. George Hosp.*, No. C-930819, 1995 WL 109128, at \*5 (Ohio Ct. App. March 15, 1995) (listing as compensable damages “medical expenses,” “the costs of the nursing home,” “any extraordinary expenses,” and “pain, suffering and emotional distress”), *rev’d*, *Anderson*, 671 N.E.2d 225 (Ohio 1996); *see also* Pope, *supra* note 43, at 265 (describing 1996 case in which jury awarded \$16.5 million in damages for pain and suffering for “the patient’s pain and suffering, the mother’s mental anguish, a sister’s mental anguish, and future medical expenses”).

costs of the nursing home” associated with wrongful medical intervention.<sup>302</sup> But one harm is generally absent from most enumerations of compensable harms associated with a violation of an advance directive—loss of enjoyment of life. In fact, damages for diminished enjoyment of life have rarely been mentioned in cases where life is prolonged after violating an advance directive or any of the literature exploring the topic.<sup>303</sup>

The frequent absence of loss of enjoyment of life damages from the list of compensable harms is striking because an award of damages for loss of enjoyment of life is inherent in the harm suffered by declarants.<sup>304</sup> Numerous studies have found that individuals who receive medical attention under dire health circumstances may not recover a suitable quality of life. A 2004 study, for example, found that only one in four patients who was intubated for stroke recovered good function and quality of life.<sup>305</sup> Similarly, an earlier investigation concluded that:

Patients who have recovered from circulatory arrest in an ICU environment after CPR find their capacity for resuming work diminished after discharge from the hospital and experience a postponed negative effect on their mental functioning, especially those functions that are related to their awareness of the environment.<sup>306</sup>

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302. *Anderson*, 1995 WL 109128, at \*5.

303. *But cf. Pope*, *supra* note 43, at 266 (describing a Louisiana case in which the plaintiffs sought damages for “the medical expenses attributable to [the patient’s] post-resuscitation care, physical and mental pain and suffering, loss of enjoyment of life, and cognitive decline”).

304. *E.g.*, Stephan A. Mayer et al., *Cost and Outcome of Mechanical Ventilation for Life-Threatening Stroke*, 31 *STROKE* 2346, 2349 (2000) (finding that half of six-month survivors who had received mechanical ventilation for stroke “were severely disabled and completely dependent”). A more recent review paints a rosier picture:

One study showed that all successfully resuscitated patients (7 out of 41) of 70 years and older enjoyed a level of independence similar to their level before the resuscitation, measured 1 month after the resuscitation. Another study with 42 successfully resuscitated patients (54% of total) of 70 years and older also found that there were no significant differences in the functional level of the survivors at the time of hospital discharge compared with their pre-arrest status.

Myke S. van Gijn et al., *The Chance of Survival and the Functional Outcome After In-Hospital Cardiopulmonary Resuscitation in Older People: A Systematic Review*, 43 *AGE & AGEING* 456, 460 (2014) (footnotes omitted). However, the same review included a third study of 24 CPR survivors over 80, in which only 20% “were capable of independent functioning outside of institutionalised care.” *Id.* And it must be noted that quality and enjoyment of life depend on many more factors than just independent functioning. Still, the review article suggests that life-saving interventions and post-intervention care have improved in recent years. *Id.* at 461–62. While that would reduce the amount of recovery, it does not affect the calculations or underlying principles.

305. C. Foerch et al., *Survival and Quality of Life Outcome After Mechanical Ventilation in Elderly Stroke Patients*, 75 *J. NEUROLOGY, NEUROSURGERY, & PSYCHIATRY* 988, 988 (2004).

306. Dinis Reis Miranda, *Quality of Life After Cardiopulmonary Resuscitation*, 106 *CHEST* 524, 529 (Aug. 1994).

Furthermore, palliative care studies demonstrate that such care does not accelerate “death, but often prolongs life with better quality.”<sup>307</sup> Given such results, declarants whose end-of-life wishes are violated experience a diminution in the enjoyment of life—and that harm is largely unrecognized and almost always uncompensated.

Fundamentally, failing to identify the loss of enjoyment in life as a cognizable harm in battery and negligence claims associated with violating an advance directive ignores the core decision declarants make in advance directives—choosing to end life rather than prolong it in an unwanted condition. Damage awards that include pain and suffering compensate for failing to honor a declarant’s wishes for comfort care only, but do not address the harm from continuing to live in a state that the declarant finds unacceptable. People may not want to remain alive if it means being unable to speak, eat by mouth, and being alone with only “the rhythmic sounds of [a] breathing machine providing the new soundtrack to . . . life.”<sup>308</sup> Indeed, some individuals witness the “bad” deaths of friends or relatives and make a conscious decision to avoid living under such circumstances by executing an advance directive that prohibits such a death.<sup>309</sup> For declarants, medical intervention only prolongs death;<sup>310</sup> remaining alive after unwanted medical intervention is not equivalent to living.

Formally, Figure 2 presents a more nuanced view of the damages suffered by declarants following the prolongation of life in violation of an advance directive. The horizontal line represents quality of life, which drops precipitously in the moments before wrongful intervention. Because intervention is successful, quality of life rises from this nadir. The exact trajectory of improvement will vary widely. Figure 2 assumes a steep initial recovery, followed by a gradual and marginally diminishing improvement. In Figure 2, then, enjoyment of life damages equal the difference between pre-intervention quality of life and post-intervention quality of life (area A in Figure 2). As a doctrinal matter, damages for loss of enjoyment of life are traditionally limited to nonpecuniary harms, such as humiliation, fear and anxiety, loss of companionship, and loss of freedom.<sup>311</sup> Each of these area A harms is readily identifiable as a consequence of violating an advance directive.<sup>312</sup> Furthermore, these nonpecuniary harms are not necessarily

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307. Jeremy Topin, *The “Good” Death that Could Have Been Much Better*, STAT (May 31, 2017), <https://www.statnews.com/2017/05/31/end-of-life-death-icu>.

308. See ZITTER, *supra* note 6, at 148.

309. *Id.* at 121.

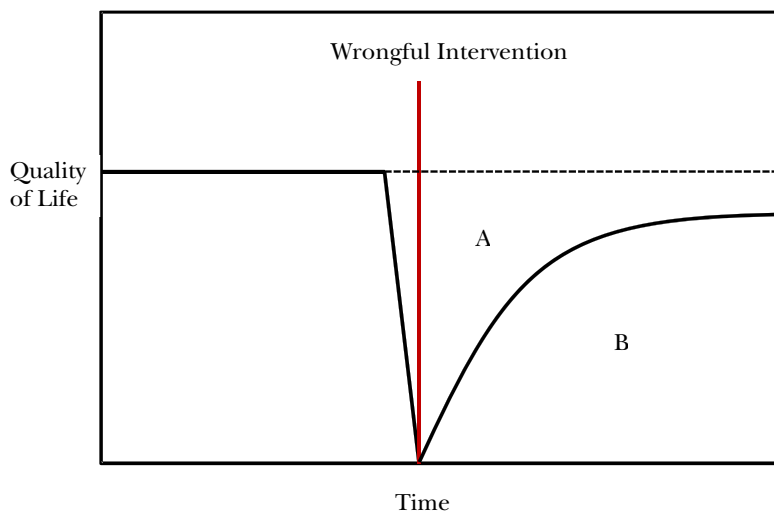
310. See Topin, *supra* note 307.

311. RESTATEMENT (SECOND) OF TORTS § 905 (AM. LAW INST. 1979).

312. At least one court ruled out humiliation damages where there is no contemporaneous witness. *Porter v. Children’s Health Care-Minneapolis*, No. C5-98-1342, 1999 WL 71470, at \*3 (Minn. Ct. App. Feb. 16, 1999) (“If he suffers from humiliation and embarrassment, his

included in battery and negligence compensatory awards. The damages that result from non-consensual touching or a breach of duty may not capture the fear and humiliation of losing meaningful contact with the world while being “stuck in a ventilator facility forever.”<sup>313</sup>

Figure 2. Enjoyment of Life Damages from Wrongful Life-Saving Treatment



Enjoyment of life damages are distinct from the “wrongful living” damages long debated in the literature (area B in Figures 1 and 2).<sup>314</sup> Enjoyment of life damages assume that continued life has positive value; “wrongful living” damages assume that continued life has negative value, which is one reason courts reject them.<sup>315</sup> In other words, “wrongful living” damages assume life itself is an injury, and courts reject the notion that continued life is harmful. Conversely, loss of enjoyment of life damages assume only that a good life is better than a bad life. The assumption that even unwanted life has value implicitly carries over into all categories of damages in wrongful prolongation of life cases. For example, assume the horizontal line represents baseline pain

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condition is a result of a subsequent telling of a version of the facts and not a consequence of the incident itself.”).

313. See ZITTER, *supra* note 6, at 125.

314. The seminal articles are Oddi, *supra* note 36 (arguing on behalf of these damages); and Adam A. Milani, *Better Off Dead Than Disabled?: Should Courts Recognize a “Wrongful Living” Cause of Action When Doctors Fail to Honor Patients’ Advance Directives?*, 54 WASH. & LEE L. REV. 149, 227–28 (1997) (disputing the legitimacy of these damages). For a more recent article, see Sawicki, *supra* note 40, at 293.

315. Pope, *supra* note 43, at 256 (explaining that some courts have rejected “wrongful living” damages because “continued life is necessarily a benefit, not harm”). In other words, area B in Figure 1 has positive value.

and suffering (or absence thereof).<sup>316</sup> The acute event depicted just to the left of the wrongful intervention generates extreme discomfort. After intervention, the patient experiences continued pain and suffering (though perhaps not indefinitely, which Figure 2 assumes).

One reason courts reject “wrongful living” as a theory for recovery is that the damages are not measurable.<sup>317</sup> To that end, the same criticism could be aimed at damage awards based upon the loss of enjoyment of life after unwanted medical intervention. Although no objective measure can place a dollar value on the loss of enjoyment of life, tort law routinely quantifies the difference *between* two states of well-being: the pre-accident level and the post-accident level. Quantification is not easy, but it is unavoidable in cases that juxtapose unambiguous harm with an ambiguous compensation calculation. Nevertheless, courts, juries, and industries place dollar values on lost limbs as well as other intangible harms. Courts and juries, for example, have awarded monetary damages for lost legs and toes while worker’s compensation plans place the average value of a lost arm at \$169,878.<sup>318</sup> In short, the difficulties of quantification are no greater for the enjoyment of life damages outlined here than they are for much of tort law generally.<sup>319</sup> And more importantly in this context, failure to quantify such damages is unfair to declarants and sets the wrong incentives for the future.

While Figure 2 depicts the loss of enjoyment of life damages available to compensate declarants following violations of advance directives, the next figure, Figure 3, illustrates counterarguments available to defendants seeking to reduce those damages. Assuming that baseline quality of life would have remained constant but for the acute event (the horizontal dotted line in Figure 3), a defendant can show contributory negligence that justifies a reallocation of responsibility and concomitant reduction in the damage award.<sup>320</sup> Specifically, a defendant has two options to show how the plaintiff’s

316. Pain and suffering could be filed under enjoyment of life, but they are generally classified instead as a separate variety of bodily harm. RESTATEMENT (SECOND) OF TORTS § 905 cmt. b (AM. LAW. INST. 1977).

317. Pope, *supra* note 43, at 256 (“Second, even if wrongful prolongation were a legally cognizable injury, it is incapable of quantification.”).

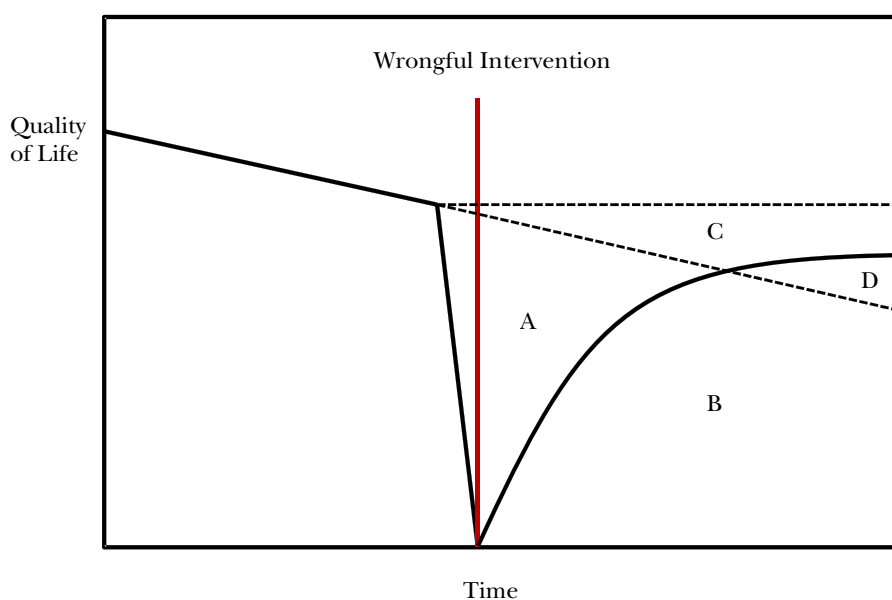
318. Lena Groeger et al., *Workers’ Comp Benefits: How Much is a Limb Worth?*, PROPUBLICA (Mar. 5, 2015), <https://projects.propublica.org/graphics/workers-compensation-benefits-by-limb>; Ronald V. Miller, Jr., *Settlement Value of an Amputated Toe*, MD. INJ. LAW. BLOG (June 3, 2016), [https://www.marylandinjurylawyerblog.com/value\\_of\\_an\\_amputated\\_toe.html](https://www.marylandinjurylawyerblog.com/value_of_an_amputated_toe.html) (including descriptions of awards for lost toes and one case involving a lost leg).

319. This is true even though diminished enjoyment of life may extend into the future. RESTATEMENT (SECOND) OF TORTS § 905 cmt. i (“The length of time during which pain or other harm to the feelings has been *or probably will be experienced* and the intensity of the distress are factors to be considered in assessing the amount of damages.” (emphasis added)).

320. Joseph H. King, Jr., *Causation, Valuation, and Chance in Personal Injury Torts Involving Preexisting Conditions and Future Consequences*, 90 YALE L.J. 1353, 1393 (1981) (“If a defendant seeks to reduce his liability by asserting that part of the harm is not attributable to his tortious

conduct contributed to the harm. First, a defendant might offer proof that the plaintiff was negligent in delaying medical treatment and earlier medical care could have prevented the acute event. Second, a defendant could reduce the damage award by showing that the plaintiff's baseline quality of life was declining before the acute event and the decline was likely to continue (Figure 3). Graphically, this is represented by the downward sloping dotted line in Figure 3. Evidence showing either a plaintiff's delay in seeking treatment or a progressive decline in health rebuts the presumption that an individual's life would have approached the pre-intervention quality of life represented by the dashed horizontal line in Figure 3.

Figure 3. Enjoyment of Life Damages from Wrongful Life-Saving Treatment in Declining Patient



The areas in Figure 3 above the dotted line with a negative slope (areas C and D) would not be compensable. Indeed, area D represents a windfall and could offset the damages defined by area A. The burden to show declining health should be placed on the defendant, and if the defendant fails to meet this burden, the damage award would be areas A plus C.<sup>321</sup>

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conduct, the burden of proving both that the plaintiff's injury is capable of apportionment and what the apportionment should be should rest on the defendant.").

321. *Id.*; cf. Peters, *supra* note 17, at 700-01 (advocating that the burden be shifted to the defendant to prove the benefits of continued life). The approach taken by Peters, unlike ours, does not avoid the need to put a value on continued life (area B in Figure 1).

An additional counterargument to imposing damages for loss of enjoyment of life following unwanted medical intervention is that the defendant is being held liable for damages that were caused by the acute event, not by the intervention. Focusing on the acute event as the cause of harm, however, misconceives the nature of the claim. First, the acute event, by precipitating death, would actually have eliminated, not caused, post-intervention damages. The intervention alone is responsible for the experience of diminished quality of life after the intervention. Furthermore, the acute event is not sufficiently “attached” to the plaintiff to reduce damages.<sup>322</sup> In other words, the plaintiff’s damages were entirely avoidable until the defendant intervened. Thus, the violation of the advance directive—not the precedent acute health crisis—caused the loss of enjoyment of life for which compensatory damages should be granted.<sup>323</sup>

## V. CONCLUSION

Although judicial decisions and statutes have recognized advance directives for over 40 years, the law has failed to generate an adequate response to well-known accessibility and compliance problems. One basic reason for the law’s passive response to the practical problem of accessibility, as well as its failure to compensate for wrongful prolongation of life, is the disparate interests of attorneys, healthcare professionals, and patients. Under the present legal construct, attorneys and healthcare professionals benefit by having limited liability exposure. Given their common interest in decreasing the potential for liability, attorneys and healthcare professionals form a single-issue interest group with little incentive to push for change. On the other hand, patients/declarants simply want to have their advance directives given effect but consist of a widely dispersed group of individuals without a meaningful ability to form a powerful and cohesive interest group. Given the singularity on one side of the equation and the scatter on the other side of the equation, the law remains static, and the legal protection of self-determination at the end-of-life remains inchoate.

In addition to addressing the practical and legal problems that impede compliance with advance directives, creating a national advance directive registry and expanding tort liability recalibrates the balance of interests between individuals and attorneys and healthcare providers. The basic interest of declarants in having their advance directives honored is

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322. King, *supra* note 320, at 1357 (“Generally, a preexisting condition may be defined as a disease, condition, or force that has become sufficiently associated with the victim to be factored into the value of the interest destroyed, and that has become so before the defendant’s conduct has reached a similar stage.”).

323. See *Lounsbury v. Capel*, 836 P.2d 188, 196 (Utah Ct. App. 1992) (“Damages for pain, suffering, ‘psychological problems’ and the like, however, may of course be recovered only to the extent that [the plaintiff] proves they were a proximate result of his undergoing the surgery to which he did not consent, rather than a result of his original injury.”).

unchanged by this paper's proposals. The interests of attorneys and healthcare professionals, on the other hand, are altered in that both groups are exposed to increased liability for either failing to register an advance directive or failing to comply with an advance directive. If these two groups lose the common law battle against increased potential liability, their professional self-interests will flip in favor of a well-functioning registry and the safe-harbor it can provide. By utilizing the proposed registry, an attorney advances a client's intent, which is the ultimate goal of representation in an end-of-life setting. Furthermore, registering an advance directive makes it readily available to healthcare providers treating patients facing end-of-life health crises. Once retrieved from the national registry, a physician's compliance with a declarant's advance directive not only satisfies the Hippocratic Oath's modern command to avoid "overtreatment,"<sup>324</sup> but also promotes what Justice Cardozo long ago described as a legal "right to determine what shall be done with his own body."<sup>325</sup>

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324. See Tyson, *supra* note 1.

325. Schloendorff, *supra* note 57, at 93.