

2010

## Death: A New Legal Perspective

Sigrid Fry-Revere

Thomas Reher

Matthew Ray

Follow this and additional works at: <https://scholarship.law.edu/jchlp>

---

### Recommended Citation

Sigrid Fry-Revere, Thomas Reher & Matthew Ray, *Death: A New Legal Perspective*, 27 J. Contemp. Health L. & Pol'y 1 (2011).

Available at: <https://scholarship.law.edu/jchlp/vol27/iss1/2>

This Article is brought to you for free and open access by CUA Law Scholarship Repository. It has been accepted for inclusion in Journal of Contemporary Health Law & Policy (1985-2015) by an authorized editor of CUA Law Scholarship Repository. For more information, please contact [edinger@law.edu](mailto:edinger@law.edu).

# DEATH: A NEW LEGAL PERSPECTIVE

*Sigrid Fry-Revere, Thomas Reher and Matthew Ray*

## I. INTRODUCTION

It is disturbing that so much of the debate surrounding the medical and legal definition of death is driven by a need to preserve medical resources and procure organs rather than by an honest scientific and philosophical inquiry about the meaning of life and death.<sup>1</sup> This Article argues that the focus should be on finding a precise definition of death and how to determine it with certainty, not how to reduce medical costs and increase the organ supply for transplantation. The issue usually debated by policymakers and healthcare ethicists is not death, but rather whether society can find a way to justify abandoning one set of dying patients to save another.<sup>2</sup> A liberal abandonment policy, however, entails ethically dangerous consequences such as using people as merely a means to an end, violating basic principles of informed consent, and disregarding patients' wishes about end of life care. Further complicating the situation, these debates are taking place in an atmosphere of public mistrust, and many of the policies being implemented add to, rather than ease, the public's sense that it is being deceived about the organ procurement process.<sup>3</sup>

Keeping the public in the dark about the realities of how organ donation affects end of life care is dishonest and manipulative, and such practices are in part responsible for the growing public mistrust of the healthcare profession in general and the organ procurement system in particular.<sup>4</sup> With proper education and fully-informed consent, more individuals would

---

1. Robert M. Veatch, *The Evolution of Death and Dying Controversies*, 39 THE HASTINGS CTR. REP. 16, 18 (2009) ("Innumerable variations on the definition of death incorporate philosophical and religious positions, many of which are not obviously wrong.").

2. John A. Robertson, *The Dead Donor Rule*, 29 THE HASTINGS CTR. REP. 6, 6 (1999).

3. R. D. Truog, *Is It Time to Abandon Brain Death?*, 27 THE HASTINGS CTR. REP. 29, 35 (1997).

4. Susan E. Morgan et al., *In Their Own Words: The Reasons Why People Will (Not) Sign an Organ Donor Card*, 23 HEALTH COMM. 23, 25 (2008).

choose to donate their organs than would otherwise do so without such education, even if doing so meant abandoning preconceived notions of death or proper end of life care. It is unknown whether this assessment is accurate, but the current approach of encouraging donation without accurately informing the public about how donation affects end of life care risks a public backlash against the whole organ procurement process.<sup>5</sup> This Article's solution is untried in the context of organ donation, but not unique; it models the already well-developed legal approach for dealing with similarly controversial decisions governing the refusal and withdrawal of treatment.<sup>6</sup>

This Article lays bare what is at stake in the modern dispute over the definition of death and argues that it is time to reconsider the legal definition of death as it has developed over the last fifty years. Certainty should take precedence over expediency, and individuals should be empowered to include organ donation in their end of life care plans based on their own personal beliefs. In short, as a matter of public policy, no patient should be declared dead until after all integrated circulatory and brain functions have ceased; but individuals should be allowed to decide for themselves, or through their surrogates, whether to donate organs based on their own concept of death and thus, if they so desire, before the official criteria for determining death are met.

A general note for this Article: the common nomenclature of "brain death" and "circulatory death" is confusing. The modifiers "brain" and "circulatory" are generally used to indicate how death was determined, not to indicate that only part of the person is dead.<sup>7</sup> Yet, a central theme of this Article is the discomfort many people feel with the exclusive use of either neurological or circulatory criteria to determine death of the person as a

---

5. Considering the possible ramifications of closer consideration of declaring patients dead by cardiac standards and transplanting their hearts into other patients as in seen in Mark M. Boucek et al., *Pediatric Heart Transplantation after Declaration of Cardiocirculatory Death*, 359 N. ENG. J. MED. 709, 709-14 (2008), <http://www.nejm.org/doi/pdf/10.1056/NEJMoa0800660>; Arthur J. Matas et al., *Morbidity and Mortality After Living Kidney Donation, 1999–2001: Survey of United States Transplant Centers*, 3 AM. J. OF TRANSPLANTATION 830, 833 (2003).

6. See *infra* Part II; see generally *Defining Death: Medical, Legal, and Ethical Issues in the Determination of Death*, PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, 1 (1981), [http://bioethics.georgetown.edu/pcbe/reports/past\\_commissions/defining\\_death.pdf](http://bioethics.georgetown.edu/pcbe/reports/past_commissions/defining_death.pdf) [hereinafter PRESIDENT'S COMM'N].

7. PRESIDENT'S COMM'N, *supra* note 6, at 3.

whole, and the use of such modifiers only contributes to the confusion beleaguering the definition of death.

## II. WHY THE DEFINITION OF DEATH BECAME AN ISSUE

In the not too distant past, the transition from life to death in the hospital setting was more gradual, but also more definite than it is today.<sup>8</sup> As hope waned, so did the efforts to bring about recovery.<sup>9</sup> When medical interventions ceased, mourning began.<sup>10</sup> Only those with the most emotional investment vigilantly searched for signs of life. Eventually the motionless patient became grey and stiff and even the most hopeful could not deny that death had occurred.<sup>11</sup> In the last century, however, dramatic advancements in medicine have brought with them a desire for a more precise definition of death.<sup>12</sup>

### *A. From Death of the Whole Organism to Death as Organ Failure*

Black's Law Dictionary lists a pre-twelfth century definition of death that is concise and hard to dispute: "The ending of life; the cessation of all vital functions and signs."<sup>13</sup> It is a definition that does not significantly differ from that given by the President's Council on Bioethics in its 2008 white paper on the definition of death,<sup>14</sup> which concludes in relevant part that

---

8. *Id.* at 21.

9. *Id.*

10. *Id.*

11. *Id.* ("Until the past few decades, comatose patients fairly rapidly either improved or died. If no other complication supervened and the patient did not improve, death followed from starvation and dehydration within days; pneumonia, apnea, or effects of the original disease typically brought on death even more quickly. Before such techniques as intravenous hydration, nasogastric feeding, bladder catheterization and respirators, no patient continued for long in deep coma.").

12. *Id.*

13. BLACK'S LAW DICTIONARY 458 (9th ed. 2009).

14. THE PRESIDENT'S COUNCIL ON BIOETHICS, CONTROVERSIES IN THE DETERMINATION OF DEATH: A WHITE PAPER BY THE PRESIDENT'S COUNCIL ON BIOETHICS, 1, 1 (2008), [http://www.thenewatlantis.com/docLib/20091130\\_determination\\_of\\_death.pdf](http://www.thenewatlantis.com/docLib/20091130_determination_of_death.pdf) [hereinafter PRESIDENT'S COUNCIL].

death is the absence of a “self-preserving commerce with the world.”<sup>15</sup> Compare these approaches to defining death of the whole organism to the legal standards developed in the 1970s and 1980s that identify the loss of a single function or organ with the determination of death.<sup>16</sup>

Even as recently as 1968, death was legally defined as “[t]he cessation of life; the ceasing to exist; defined by physicians as a total stoppage of the circulation of the blood, and a cessation of the animal and vital functions consequent thereon, such as respiration, pulsation, etc.”<sup>17</sup> The definition remains holistic, but also mentions the criteria used for determining death, namely the cessation of vital functions.<sup>18</sup>

Since 1968, the definition of death has radically changed. Now, Black’s Law Dictionary still gives the pre-twelfth century definition, but also provides a definition for brain death: “[t]he bodily condition of showing no response to external stimuli, no spontaneous movements, no breathing, no reflexes, and a flat reading (usually for a full day) on a machine that measures the brain’s electrical activity.”<sup>19</sup> With the advent of new medical technologies, we have parsed “death” into subcategories, such as brain death and cardiopulmonary death, which consequently has caused us to rethink how to determine when an organism’s life has ended. Where once “death” sufficed as an all-encompassing term, now a collection of terms exist—for brain death: whole or total brain death, total brain failure, coma depassee, irreversible coma, brain arrest, and total brain infarction (death of tissue due to lack of blood supply); and for circulatory death: heart death, heart/lung death, cardiorespiratory death, and cardiopulmonary death.<sup>20</sup>

Unlike the definitions of the pre-1970s and the recent President’s Council, which considered death to be a holistic bodily event, the standards developed from the 1970s to the 1990s targeted the cessation of specific organ functions to justify removing the person from life support, or

---

15. *Id.* at 62.

16. PRESIDENT’S COMM’N, *supra* note 6, at 62 (summarizing KAN. STAT. ANN. §77-202 (1971)).

17. BLACK’S LAW DICTIONARY, *supra* note 13.

18. PRESIDENT’S COMM’N, *supra* note 6, at 5 (“Traditionally, the cessation of heartbeat and of breathing were regarded by the lay and medical communities alike as the definitive signs of death.”).

19. BLACK’S LAW DICTIONARY, *supra* note 13.

20. PRESIDENT’S COMM’N, *supra* note 6, at 21.

procuring organs before they become unusable.<sup>21</sup> There is no doubt that the process of death is a continuum from the failure of individual organs to total system failure and then even to the breaking down of cellular processes. Yet the issue is not the inevitability of the process (if it is clear that the patient is in fact dying), but finding the point of no-return. The Nobel prize-winning surgeon Joseph Murray knew he did not have to wait for a potential donor to turn grey and stiff before harvesting the kidneys he needed for transplant, and Murray's team received organs from patients that were declared dead under the standard of the time, namely fifteen to twenty minutes after the cessation of circulatory functions.<sup>22</sup> Much has changed with how we determine death (as evidenced by the methods described herein) since Dr. Murray did his trail-blazing transplants, but one issue still remains: there is a difference between dead beyond a reasonable doubt and the point at which death becomes inevitable based on our knowledge of the statistical likelihood of recovery. In dispute is which of these two sometimes quite variable points in time should be used as the threshold for organ recovery.

The exact moment of death is elusive, but for legal reasons surgeons are legitimately hesitant to take organs from patients who have not officially been declared dead.<sup>23</sup> A tension exists between the need for certainty and the need to procure organs early enough that they are still viable for transplantation. These tensions are complicated by the fact that in the last century medicine has improved dramatically in its ability to save lives

---

21. Stuart J Youngner & Robert M Arnold, *Philosophical Debates About the Definition of Death: Who Cares?*, 26 J. OF MED. & PHIL. 527, 533 (2001), <http://www.psy.vanderbilt.edu/courses/hon182/whocares.pdf> ("Brain death served two useful purposes in 1968. First, it allowed physicians to turn off respirators without fear of legal consequences . . . ."); "When the Harvard Committee put forward its new "definition" of death in 1968, mechanical ventilators had just come into widespread use but our society had no clinical, psychological, or legal experience with turning them off. Physicians and hospitals were worried about the legal consequences of doing so." *Id.* at 534.

22. See generally, Thomas Brante & Margareta Hallberg, *Brain or Heart? The Controversy over the Concept of Death*, 21 SOC. STUD. OF SCI. 389, 389-413 (1991) (discussing the pre-transplant era, the standard for death was once considered to be "when heart beat and breathing has stopped for about 15-20 minutes, death has occurred - a so-called 'heart death.'"); THOMAS FLINT, JR., EMERGENCY TREATMENT AND MANAGEMENT 334 (3d ed. 1964) (instructing that emergency personnel should continue resuscitative efforts for an hour unless obviously futile (e.g. the person is decapitated) or doing so will put the person providing emergency services in danger).

23. See Youngner & Arnold, *supra* note 21.

previously thought to be hopeless cases.<sup>24</sup> For example, before the ventilator was invented in the 1900s, an inability to breathe meant death, and certain classes of comatose patients were destined to die within days if not hours or even minutes because the technology to sustain them did not exist.<sup>25</sup> Medical advancements made it possible to hope for recovery in increasingly unlikely situations and to parse the dying from the dead with ever greater precision.<sup>26</sup> The line between hope and despair easily becomes blurred for patients' families and medical staff, particularly when giving up on one patient may mean life for others.<sup>27</sup> Medicine and the law now find themselves at a cross-road: Does society continue encouraging that everything be done to save every life, no matter how slight the chances of recovery? Or is society ready to give up on certain classes of patients in order to save others with a more realistic chance of survival? The issues of 1) how we define death and 2) who we determine should decide the point at which we give up on one patient for the sake of others are critical to how humanity sees itself and the future of medicine.

### *B. Medical Advances and the Costs of Postponing Death*

Medical science has marched towards an ever-increasing ability to postpone death.<sup>28</sup> The advent of artificial ventilation around 1900<sup>29</sup> and subsequent improvements in its design began to blur the line between life

---

24. PRESIDENT'S COMM'N, *supra* note 6, at 21.

25. *Id.* at 15-17.

26. *Id.* at 17-18.

27. Wayne Shelton, *Respect for Donor Autonomy and the Dead Donor Rule*, 3 AM. J. OF BIOETHICS 20, 20 (2003).

28. Even the stethoscope fundamentally renovated the means for determining death. It was one of the earliest technologies that could be used to look more closely at a body to observe signs of life. The stethoscope was invented in France in 1816 by René-Théophile-Hyacinthe Laennec at the Necker-Enfants Malades Hospital in Paris. *See generally* RENE-THEOPHILE-HYACINTHE LAENNEC, DE L'AUSCULTATION MÉDIATE OU TRAITÉ DU DIAGNOSTIC DES MALADIES DES POUMON ET DU COEUR: FONDÉ PRINCIPALEMENT SUR CE NOUVEAU MOYEN D'EXPLORATION (Brosson & Chaudé 1819).

29. L.A. Geddes, *The History of Artificial Respiration*, 26 INST. OF ELECTRICAL AND ELECTRONICS ENGINEERS ENGINEERING IN MED. & BIOLOGY MAG. 38, 39 (2007); Michael J. Cawley, *Mechanical Ventilation: A Tutorial for Pharmacists*, 27 PHARMACOTHERAPY 250, 251 (2007).

and death. The Iron Lung, widely used in the United States during the 1950s, kept alive polio patients whose brains were still fully functional, but whose bodies had otherwise forsaken them.<sup>30</sup> Soon, however, ventilators were also being used to keep patients alive who had lost brain function in the hope that given time the brain would recover.<sup>31</sup> The question arose of how to deal with patients who had irreversibly lost their ability to interact with the world – patients who were kept alive by machines that supported their circulatory functions but did nothing to help them regain consciousness.<sup>32</sup> People wondered whether keeping such patients alive by mechanical means was a wise use of medical resources, whether it was undignified or cruel, and, whether given the organ shortage, we should find a way to allow such patients to become donors while their organs were still viable for transplantation.<sup>33</sup>

There was no organ shortage to speak of before the 1970s because organ transplantation was in its infancy. In 1954, Dr. Joseph Murray successfully transplanted a kidney from one identical twin brother into another. However, not until more than two decades later did life-saving transplants become a realistic option due to the development and improvement of immunosuppressant drugs.<sup>34</sup> In particular, the discovery of cyclosporine in 1978<sup>35</sup> greatly increased the survival rate of transplant recipients and made the expanded use of cadaver organs feasible. The procurement of cadaver

---

30. It is interesting to note the change in dynamics: patients using iron lungs or ventilators to compensate for broken bodies were undoubtedly alive, and though their lungs have failed, their hearts and brains remained intact. If there were a disease today where muscular degeneration could progress to the heart and lung muscles but stop there, would we put such a person on a heart/lung bypass machine or would we declare them dead? James H. Maxwell, *The Iron Lung: Halfway Technology or Necessary Step?*, 64 THE MILLBANK Q. 3, 3 (1986).

31. PRESIDENT'S COMM'N, *supra* note 6, at 21-22.

32. *Id.*

33. There is no breathing without a central nervous system (CNS), but the heart can beat without any signals at all from the CNS. See FREDERICK MARTINI & EDWIN BARTHOLOMEW, ESSENTIALS OF ANATOMY AND PHYSIOLOGY 338 (1997) (discussing heartbeat). See also *id.* at 424 (discussing the brain's role in breathing).

34. Peter L. Abt et al., *Donation After Cardiac Death in the US: History and Use*, 203 J. AM. COLL. SURGEONS 208, 208 (2006).

35. *Id.*



organs, however, was complicated by the need to do so with limited delay.<sup>36</sup> The longer the donor was dead, or rather the longer organs were without an oxygenated blood supply, the less likely it was that retrieved organs would be viable for transplant.<sup>37</sup> As the science and practice of transplantation and organ preservation techniques improved, the demand for organs surged.<sup>38</sup> As the demand for organs increased, so did the push to clarify the definition of death to allow for expeditious organ retrieval.

Laws developed to deal with three interrelated issues introduced by the advent of new ventilation and transplantation technologies: 1) how to deal with questions of human dignity and end of life choices in a pluralistic society; 2) how to deal with futile treatment and prevent the wasting of medical resources; and 3) how to maximize the supply of cadaver organs for transplant.<sup>39</sup> The law took two distinct approaches to dealing with these issues: 1) let patients decide for themselves at what point their life is no longer worth preserving; and 2) clarify the point after which there is no longer a social obligation to provide treatment and life-sustaining treatment can be stopped and/or organs can be harvested.<sup>40</sup> The first approach has the significant advantage that it helps preserve trust in the medical profession, while in hindsight the latter approach seems to have had the opposite effect.

### III. HOW THE LAW EVOLVED TO DEAL WITH END OF LIFE ISSUES

Conflicting interests are at the heart of all legal action. Recent practices regarding end of life decisions raised several legal concerns.<sup>41</sup> Healthcare

---

36. Robert Steinbrook, *Organ Donation after Cardiac Death*, 357 *NEW ENG. J. MED.* 209, 210 (2007), <http://content.nejm.org/cgi/reprint/357/3/209.pdf> (“If a patient does not die quickly enough to permit the recovery of organs, end-of-life care continues and any planned donation is canceled. At present, this may happen in up to 20% of cases.”).

37. *Id.*

38. *Id.*

39. *In re Baby K*, 16 F.3d 590 (4th Cir. 1994), *cert. denied*, 513 U.S. 825 (1994); UNIFORM ANATOMICAL GIFT ACT (2009), available at <http://www.anatomicalgiftact.org/DesktopDefault.aspx?tabindex=1&tabid=63>.

40. See, e.g., *Causey v. St. Francis Med. Ctr.*, 719 So. 2d 1072 (La. Ct. App. 1998). For law increasing patient self determination, see Oregon Death with Dignity Act, OR. REV. STAT. §§ 127.005 to 127.045 (2010); see *infra* notes 93, 97, and 98. For law describing the end of duty to treat, see UNIFORM ANATOMICAL GIFT ACT, *supra* note 39.

41. See Boucek, *supra* note 5, at 709-14.

costs were rising, and spending precious dollars on patients with no chance of recovery seemed to be a waste of money.<sup>42</sup> Some argued for a right to life, others for a right to die.<sup>43</sup> Some argued that treatment was futile or that certain groups of patients should be considered dead, while others argued that such patients should not be abandoned.<sup>44</sup> Some urged that we find a way to harvest more organs more efficiently, while others argued that it was important to honor end of life wishes even if they interfered with organ donation.<sup>45</sup> The approaches described below involve two basic methods for solving such conflicts. The first creates a legal obligation to treat but gives patients and their proxies<sup>46</sup> the right to refuse treatment and shields medical professionals from liability if they heed such requests.<sup>47</sup> The second approach creates certain legal exceptions to the physician's obligation to treat, and authorizes medical professionals to override the wishes of patients

---

42. *U.S. Health Care Costs: Background Brief*, KAISER FAMILY FOUND. (Mar. 2010), [http://www.kaiseredu.org/topics\\_im.asp?imID=1&parentID=61&id=358](http://www.kaiseredu.org/topics_im.asp?imID=1&parentID=61&id=358). Some of the data provided illustrates the staggering costs of health care spending in the United States, which:

[I]n 2008, accounted for 16.2% of the nation's Gross Domestic Product; this is among the highest of all industrialized countries. Total health care expenditures grew at an annual rate of 4.4 percent . . . , a slower rate than recent years, yet still outpacing inflation and the growth in national income.

*Id.*

43. *See generally*, Alexander M. Capron, *At Law: Death and the Court*, 27 HASTING CTR. REP. 25, 25-29 (1997).

44. PRESIDENT'S COMM'N, *supra* note 6, at 28.

45. D. Alan Shewmon et al., *The Use of Anencephalic Infants as Organ Sources: A Critique*, 261 JAMA 1773, 1775 (1989).

46. Like most courts, we will assume that when a patient's surrogate makes a decision, he or she is not exercising substituted judgment, but acting as the patient's agent, because the surrogate has unique knowledge as to what the patient would consider in the patient's own best interest. The one exception is that the substituted judgment standard is appropriate when the patient is a minor or an adult who never was competent to make healthcare decisions. To avoid cumbersome language in the text, please understand each reference to a patient's decision-making authority as implicitly including his or her surrogate decision-maker, whether that person's authority comes directly from the patient or by operation of law.

47. Omnibus Budget Reconciliation Act of 1990, H.R. 5835, 101st Cong. (1990).

or their proxies under certain circumstances (futility and brain death) without fear of liability.<sup>48</sup>

*A. First Approach: An Obligation to Treat and the Right to Self-Determination*

It is difficult to engender trust in a policy driven definition of death in a pluralist society such as the United States, where cultural, religious, and philosophical notions of life and death differ broadly. In a situation where patients run the risk of being treated by medical professionals who do not share their moral perspective, it is the government's obligation to protect its citizens from both healthcare personnel who may disagree with a patient's perspective and shifting societal norms that may violate a patient's religious or moral beliefs. U.S. courts, and to some extent U.S. legislatures, realized in the early 1900s that the only way to preserve both trust and the pluralist nature of this country's moral fabric would be to establish a dual standard.<sup>49</sup> The government and medical profession would indiscriminately work to preserve life, and patients would have the right to decide for themselves when to change the goals of treatment or even stop treatment all together based on their own personal assessment of the meaning of life and death. There are some aberrant decisions,<sup>50</sup> but this dualist approach has been affirmed and reaffirmed repeatedly at all levels of government.

---

48. See *Bryan v. Rectors and Visitors of Univ. of Va.*, 95 F.3d 349 (4th Cir. 1996) (upholding the district court's grant of defendant's motion to dismiss the claim brought by Cindy Bryan, administratrix of the estate of Shirley Robertson, to hold the University of Virginia Medical Center liable for failing to provide stabilizing care as required by the Emergency Medical Treatment and Active Labor Act).

49. See discussion *supra* Part III.

50. See generally *Causey v. St. Francis Med. Ctr.*, 719 So. 2d 1072, 1072 (La. Ct. App. 1998). The Louisiana Court of Appeals for the Second Circuit ruled that it was not a battery when a physician and hospital withdrew life-sustaining care from a thirty-one year-old quadriplegic comatose patient with end-stage renal failure over the express objection of the patient's family. The patient's treating physician stipulated that with continued ventilation and dialysis the patient could live another two years, but she would only have a one to five percent chance of ever regaining consciousness. The court acknowledged that questions of futility are subjective, but stressed that physicians have a right to decide when treatment is medically inappropriate and held that this particular case needed to be evaluated by a medical review panel under the state's Medical Malpractice Act to see if the physician's (and hospital's) action was outside the standard of care. *Id.*

The first prong of the dual standard - the medical profession's obligation to do its best to preserve each patient's life regardless of personal feelings about quality of life - helps engender trust in the profession but does nothing to prevent what may seem like a waste of scarce and expensive life-saving and life-preserving medical resources, and it does nothing to increase the organ supply. The second prong however, allows individuals to choose for themselves when to stop treatment that has little chance of improving their quality of life. The obvious advantage of this approach is that patients continue to trust healthcare professionals to do all they can to save a patient's life until the point where the patient himself, or through an advance directive or a proxy healthcare decision maker, requests that treatment be altered or stopped.<sup>51</sup> The locus of this trust lies in the assurance that patients' decisions are respected, whether the decision is to continue, to alter, or to stop treatment. The added benefit of personal decisions to forego or withdraw treatment, is that fewer medical resources are spent on patients with a hopelessly diminished quality of life, and more organs of higher viability become available because the dying process, at least in some cases (e.g., removal from the ventilator and/or artificial heart), is controlled enough to allow for the careful timing of organ retrieval.<sup>52</sup>

### 1. An Obligation to Treat

The physician's obligation to treat is deeply rooted in both medical and legal tradition.<sup>53</sup> First, there is the historic concept of obligations afforded by a physician's training. Second, there are the four principles dominating contemporary medical ethics.<sup>54</sup> Finally, there are duties imposed by professional associations and the legal system.<sup>55</sup>

---

51. See Susan D. Goold, *Trust and the Ethics of Health Care Institutions*, 31 HASTINGS CTR. REP. 26, 27-28 (2001).

52. See Franklin G. Miller & Robert D. Truog, *Rethinking the Ethics of Vital Organ Donations*, 38 HASTINGS CTR. REP. 38, 45 (2008).

53. HIPPOCRATES, OF THE EPIDEMICS bk. I (Francis Adams trans., Internet Classics Archive) (c. 400 B.C.E.), available at <http://classics.mit.edu/Hippocrates/epidemics.1.i.html>.

54. TOM BEAUCHAMP & JAMES CHILDRESS, PRINCIPLES OF BIOMEDICAL ETHICS, PART II 99-287 (6th ed. 2009).

55. *Opinion 10.01: Fundamental Elements of the Patient-Physician Relationship*, AM. MED. ASS'N. (1993), <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion1001.shtml>.

The origin of physicians' obligations to their patients is usually traced to the Hippocratic school of medicine. Primarily, the maxim guiding physicians is found in the phrase *Primum non nocere*, "above all, do no harm."<sup>56</sup> This aphorism provides foundation for the principle of nonmaleficence, but the *Hippocratic Oath* itself provides a more express obligation to treat: "I will apply dietetic measures for the benefit of the sick according to my ability and judgment; I will keep them from harm and injustice."<sup>57</sup> Thus, a fiduciary duty to help patients in whatever way a physician's skills allow is evident even in some of the earliest tenants of the medical profession.

In contemporary medical ethics, physicians' obligations to their patients are fourfold: respect for autonomy, nonmaleficence, beneficence, and justice.<sup>58</sup> Each of these provides an interrelated component of the doctor-patient relationship; in sum, they provide a framework for the proper practice of medicine. Respect for the autonomous choices of patients upholds the ability of the patient to make informed "choices, and to take actions based on their personal values and beliefs."<sup>59</sup> The "principle of nonmaleficence imposes an obligation not to inflict harm on others."<sup>60</sup> While the extent to which this obligation should be followed is debatable,<sup>61</sup>

---

56. HIPPOCRATES, *supra* note 53 (in which physicians agree "to abstain from doing harm").

57. ANCIENT MEDICINE: SELECTED PAPERS OF LUDWIG EDELSTEIN 6 (Owsei Temkin & C Lillian Temkin eds., 1967); *see also* BIOMEDICAL ETHICS 71 (Thomas Mappes & David Degrazia eds., 2006).

58. *See* BEAUCHAMP & CHILDRESS, *supra* note 54, at 12-13.

59. *Id.* at 103.

60. *Id.* at 149.

61. Consider the case of the use of chemotherapy to inhibit the growth of and ultimately kill a tumor: the administration of such drugs markedly harms (in the limited sense) the patients. While the (intended) outcome of that specific course of action is in the best interest of halting the growth of the tumor, the action itself denies the prima facie obligation to "do no harm," because the drugs' effects on the patient's body are devastating. It is, therefore, the requisite task of the medical team in conjunction with the patient to deliberate over and decide upon in conjunction the best course of treatment for a specific medical need, using the four principles as guideposts rather than hard-and-fast rules. LOUIS LASAGNA, PHILOSOPHICAL MEDICAL ETHICS; ITS NATURE AND SIGNIFICANCE 43-46 (Stuart Spicker & Hugo Englehardt, Jr. ed., D. Reidel Publishing Co., 1975) (discussing "Do No Harm").

the obligation accords with the traditional roles assigned to physicians. The principle of beneficence requires that physicians provide a direct benefit to their patients while simultaneously balancing the benefits and risks to produce the best overall outcome.<sup>62</sup> Finally, the principle of justice requires that “social benefits and social burdens be distributed in accordance with the demands of justice.”<sup>63</sup> Justice details, at least in part, the means by which resources that are paid for are allocated.<sup>64</sup>

U.S. physicians’ obligations to their patients are grounded in adherence to these principles as expressed through the codes of conduct advanced by their governing professional associations. For example, the American Medical Association (AMA), speaking to the duty the physician owes the patient, states that:

The patient has the right to continuity of health care. The physician has an obligation to cooperate in the coordination of medically indicated care with other health care providers treating the patient. The physician may not discontinue treatment of a patient as long as further treatment is medically indicated, without giving the patient sufficient opportunity to make alternative arrangements for care.<sup>65</sup>

This duty of nonabandonment clearly is intended to foster trust.

The physician’s obligation to treat was embodied in U.S. law through several developments. Since 1937, the law has required that physicians, after commencing treatment, continue treatment unless the physician gives “the patient sufficient notice” to “procure other medical attention if he desires.”<sup>66</sup> Furthermore, some courts have held that the locality rule (which recognizes limitations imposed on rural physicians because of a lack of

---

62. See BEAUCHAMP & CHILDRESS, *supra* note 54, at 197.

63. BIOMEDICAL ETHICS, *supra* note 57, at 27.

64. See generally NORMAN DANIELS, *JUST HEALTH: MEETING HEALTH NEEDS FAIRLY* (Cambridge University Press 2008). The “Just Health” conception proposed by Norman Daniels is a theory that physicians should be concerned with the protection of the normal range of opportunity, and disparities in health should be mitigated to protect the normal range of opportunity afforded to the statistically “healthy” person. *Id.*

65. AM. MED. ASS’N, CEJA REPORT A-90: FUNDAMENTAL ELEMENTS OF THE PATIENT-PHYSICIAN RELATIONSHIP 1 (1990), [http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja\\_aa90.pdf](http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja_aa90.pdf); see also Timothy E. Quill & Christine K. Cassel, *Nonabandonment: A Central Obligation for Physicians*, 122 ANNALS OF INTERNAL MED. 368, 370 (1995).

66. *Ricks v. Budge*, 64 P.2d 208, 211 (Utah 1937).

specialized instrumentation or resources) does not relieve healthcare professionals of the obligation to refer their patients to other specialized providers when the first cannot or will not provide the required or requested treatment.<sup>67</sup> Also, the Americans with Disabilities Act (ADA) passed by Congress in 1990, and modified in 2008, requires physicians (as individuals operating services) to provide the disabled with the same opportunities afforded to the non-disabled.<sup>68</sup>

Lastly, the Emergency Medical Treatment and Active Labor Act (EMTALA) requires that hospitals with emergency medical facilities examine all patients presenting to determine if an emergency exists, to either provide stabilizing treatment or transfer the patient to another hospital, and that specialty hospitals must accept cases requiring their specialty as capacity allows.<sup>69</sup> Specifically, the EMTALA calls for the following:

If any individual . . . comes to the emergency department and a request is made on the individual's behalf for examination or treatment for a medical condition, the hospital must provide for an appropriate medical screening examination within the capability of the hospital's emergency department, including ancillary services routinely available to the emergency department, to determine whether or not an emergency medical condition . . . exists. [If so,] the hospital must provide either . . . further medical examination and such treatment as may be required to stabilize the medical condition, or . . . for transfer of the individual to another medical facility [and that] [a] participating hospital that has specialized capabilities or facilities (such as burn units, shock-trauma units, neonatal intensive care units, . . . ) shall not refuse to accept an appropriate transfer of an individual who requires such specialized capabilities or facilities if the hospital has the capacity to treat the individual.<sup>70</sup>

Together, the ADA and EMTALA can be understood as requiring treatment for patients compromised by illness even if healthcare

---

67. See Jerald J. Director: *Malpractice: Physician's Failure to Advise Patient to Consult Specialist or One Qualified in a Method of Treatment Which Physician Is Not Qualified to Give*, 35 A.L.R.3d 349 (1971); see also Sylvia Law et al., *Notes: The Locality Rule and Quality of Care*, L. & AM. HEALTH CARE SYS. 845-47 (West Group Publishing 1999).

68. Americans with Disabilities Act Title III: Public Accommodations and Services Operated by Private Entities, 42 U.S.C. § 12186(b) (1990).

69. 42 U.S.C. § 1395dd (1986).

70. *Id.*

professionals feel there is no long-term benefit to such treatment. For example, in the case of *In re Baby K*, the Fourth Circuit Court of Appeals decided that emergency medical personnel could not refuse to provide emergency treatment for an infant over the mother's objection, even if the emergency team felt treating the anencephalic infant was futile and would only cause suffering and prolong the dying process.<sup>71</sup>

## 2. *The Right to Self-Determination*

The obligation to treat is a derivative of the right to consent or refuse treatment, not the other way around. Under common law, it was recognized early on that obtaining consent in emergency situations was impractical.<sup>72</sup> Often the patient was not well enough to give consent and, in emergency situations, healthcare providers should concentrate on treatment, not getting consent. As a result, it became public policy to assume consent in emergency situations and protect healthcare providers from an accusation of battery if they treated a patient under such circumstances without first obtaining permission.<sup>73</sup> However, there were logical exceptions: What if the patient or the patient's family was expressly and coherently objecting to treatment despite the emergency? Or what if there was disagreement among medical staff over the urgency of treatment and whether there was time to obtain consent? The need for answers to these types of questions is what led to the development of a whole body of law that deals with patient self-determination and the right to refuse or demand the withdrawal of even life-saving or life-sustaining treatment.<sup>74</sup>

### *a. Courts Uphold the Right to Refuse Treatment, Even Life-Saving or Life-Sustaining Treatment*

In the United States, where the law strives to respect the pluralistic traditions of its citizenry, "dignity" and "quality of life" are concepts most

---

71. *In re Baby K*, 16 F.3d at 590; *but see Bryan*, 95 F.3d at 349 (discussing the limited duty to treat potentially futile case, overcoming the emergency, and its immediate aftermath).

72. *See generally* Comm. on Pediatric Emergency Med., *Consent for Emergency Medical Services for Children and Adolescents*, 111 PEDIATRICS 703, 703-706 (2003), <http://aappolicy.aappublications.org/cgi/reprint/pediatrics;111/3/703.pdf>.

73. Kurt Hartman & Bryan Liang, *Exceptions to Informed Consent in Emergency Medicine*, 35 HOSP. PHYSICIAN 53, 56 (1999), [http://www.turner-white.com/pdf/hp\\_mar99\\_emergmed.pdf](http://www.turner-white.com/pdf/hp_mar99_emergmed.pdf).

74. Omnibus Budget Reconciliation Act of 1990, H.R. 5835, 101st Cong. (1990).



likely applied to broaden, not narrow, patient self-determination. In 1914, when the U.S. Supreme Court decided *Schloendorff v. Society of New York Hospital*, Justice Cardozo said, "Every human being of adult years and sound mind has a right to determine what shall be done with his own body."<sup>75</sup> Then in 1976, the U.S. Supreme Court denied *certiorari* in *In Re Quinlan, sub nom Garger v. New Jersey* and thereby let stand a New Jersey Supreme Court decision accepting the notion that the right to self-determination includes the right to have a surrogate decision-maker refuse even life-saving or life-sustaining treatment for a patient who cannot verbalize such a refusal on his or her own.<sup>76</sup> In *In Re Quinlan*, the New Jersey Supreme Court wrote:

If a putative decision by Karen [the patient] to permit this non-cognitive, vegetative existence to terminate by natural forces is regarded as a valuable incident of her right of privacy, as we believe it to be, then it should not be discarded solely on the basis that her condition prevents her conscious exercise of the choice.<sup>77</sup>

Subsequently, in *Cruzan v. Director, Missouri Department of Health*, the U.S. Supreme Court acknowledged that there was a fundamental common law and probably also a constitutional right to make one's own healthcare decisions, including the right to refuse life-saving or life-sustaining treatment, but that states had a countervailing right, derived from their obligation to preserve life, to take appropriate measures to assure that there is sufficient evidence of a patient's wishes before a surrogate may act to withdraw life-sustaining treatment.<sup>78</sup> The Court did not specify what standard of proof was required, only that it was acceptable for states to set their own standards as to how much proof should be required. In this particular instance, it was decided that Missouri's decision to use an intermediate standard of proof, the "clear and convincing" standard, as opposed to the lesser "preponderance of the evidence" or more stringent "beyond a reasonable doubt" standard, was not an unconstitutional restriction on a patient's right to due process.<sup>79</sup> Consequently, state laws in effect today range from those that only require the surrogate to have some evidence of the patient's wishes to those that specifically require a valid

---

75. *Schloendorff v. Soc'y of N.Y. Hosp.*, 211 N.Y. 125, 126 (1914).

76. *In re Quinlan*, 355 A.2d 647, 673, 684 (1976), *cert. denied sub nom Garger v. New Jersey*, 429 U.S. 922 (1976).

77. *Id.* at 41.

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

79. *Id.*

advance directive that clearly identifies which types of life-sustaining treatment the patient would want to refuse and under what circumstances.<sup>80</sup>

*b. Advance Directive Laws*

While cases like *In Re Quinlan* were working their way through the courts, many state legislatures, and eventually even the U.S. Congress, considered advance directive legislation.<sup>81</sup> Judicial decisions regarding treatment refusal or withdrawal overwhelmingly focus on patients' rights, but advance directive legislation often serves multiple purposes.<sup>82</sup> In addition to affirming a patient's right to refuse treatment, these laws also provided healthcare professionals with immunity from prosecution for following advance directives, and legislators who have ethical qualms about allowing the withdrawal of treatment were afforded an opportunity to control the circumstances under which the right can be exercised.<sup>83</sup>

In 1976, California passed the first advance directive legislation in the country, the California Natural Death Act, which stated that "[t]he

---

80. For example, Nebraska law provides that an attorney may not remove patients from artificially administered hydration and nutrition unless:

[T]he principal is suffering from a terminal condition or is in a persistent vegetative state and the power of attorney for health care explicitly grants such authority to the attorney in fact or the intent of the principal to have life-sustaining procedures or artificially administered nutrition or hydration withheld or withdrawn under such circumstances is established by clear and convincing evidence.

NEB. REV. STAT. § 30-3418 (2010). Alternatively, South Dakota seems to utilize the "preponderance of evidence" standard, although not explicitly, for the making of substituted judgment decisions. South Dakota's healthcare decisions by agent statute states: "Whenever making any health care decision for the principal, the attorney-in-fact or agent shall consider[] the decision that the principal would have made if the principal then had decisional capacity, if known, and the decision that would be in the best interest of the principal." S.D. CODIFIED LAWS § 59-7-2.5 (2008). At this point there are no states that require the most stringent "beyond a reasonable doubt" standard to permit a healthcare proxy or advance directive to make decisions about the cessation of life-sustaining treatments, although arguably, some, like Nebraska and Alabama, seem to apply a "clear and convincing" standard that is strict enough to almost qualify as "beyond a reasonable doubt." ALA. CODE § 22-8A-11 (2009).

81. See, e.g., *California's Natural Death Act*, 128 W. J. MED. 322, 322-28 (1978), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1238103/pdf/westjmed00260-0066.pdf>.

82. *Id.* at 323.

83. *Id.*

terminally ill patient, in a prospective way, makes the decision,” and that “[t]hose most affected by the prospect of dying ought to determine how their final days are to be spent.”<sup>84</sup> The California legislation also specifically protected healthcare providers who in good faith followed a “Living Will” written under the Act.<sup>85</sup> But this legislation and the legislation passed by other states since, limit the right of patients to direct end of life healthcare decisions should they become incompetent. These limitations would not be judicially acceptable for competent patients, but in the interest of protecting potentially vulnerable incompetent patients the states have imposed various restrictions. For example, the first version of California’s advance directive law was only available to patients suffering from a terminal condition, and to be valid the Living Will could not be executed any earlier than two weeks after the patient received a prognosis that death was imminent.<sup>86</sup> Arkansas followed with almost identical legislation in 1977.<sup>87</sup> Most advance directive laws today are not so restrictive regarding the declarant’s prognosis at the time the directive is executed, but they are often restrictive in other respects.<sup>88</sup>

---

84. *Id.*

85. *Id.*

86. Since 1976, the law in California has become less restrictive regarding who qualifies for relief under the statute. Before the California Natural Death Act was repealed and superseded by provisions of the California Probate Code, related to advance health care directives, it provided the following definitions: “‘Qualified patient’ means a patient diagnosed and certified in writing to be afflicted with a terminal condition by two physicians, one of whom shall be the attending physician, who have personally examined the patient,” and “‘Terminal condition’ means an incurable condition caused by injury, disease, or illness, which, regardless of the application of life-sustaining procedures, would, within reasonable medical judgment, produce death, and where the application of life-sustaining procedures, serve only to postpone the moment of death of the patient.” The Natural Death Act, CAL. HEALTH & SAFETY CODE §§ 7185-88 (repealed 1999) (The Natural Death Act in California is superseded by the provisions of the California Probate Code relating to advance healthcare directives.); see Bernard Lo & Robert Steinbrook, *Resuscitating Advance Directives*, 164 ARCH. INTERN MED. 1501, 1502 (2004); see also Med. Staff Conference, *supra* note 81.

87. ARK. CODE ANN. §§ 20-17-201 to 20-17-218 (2010).

88. *E.g.*, restrictions on the use of artificial nutrition and hydration to non-invasive forms without explicit request. *Id.* Many states, such as Colorado, include limitations of application of advance directive to exclude pregnancy. See COLO. REV. STAT. §§ 15-18-101 to 15-18-113 (2009). Similarly, a few states also include restrictions of the power of a proxy (restricting consent to abortion, sterilization, or psychosurgery). See D.C. CODE

With time, various kinds of durable power of attorney (DPA) for healthcare also became acceptable forms of advance directives. DPAs were a pre-existing legal convention that became more common as a means of appointing a proxy of one's choice instead of allowing a surrogate to be appointed by operation of law.<sup>89</sup> Most states currently have incorporated some form of DPA for health care, usually called a "healthcare proxy," into their advance directive legislation, but even in those states where no special healthcare power of attorney is available, the standard durable power of attorney used in other contexts is an option.<sup>90</sup>

In 1990, Congress passed The Patient Self-Determination Act (PSDA) with the intent of encouraging reliance on advance directives.<sup>91</sup> The PSDA requires that: (1) at the time of admission, patients be given a written summary of healthcare decision-making rights specific to the state and the facility's policies with respect to recognizing advance directives, (2) patients be asked if they have an advance directive and that their response be documented, (3) hospitals make an effort to educate staff and the community about advance directives, and (4) no discrimination based on whether or not a patient has an advance directive, and (5) providers educate themselves, their staff, and the community on issues concerning advance directives.<sup>92</sup>

### 3. *Physician Aid in Dying*

Physician aid in dying tips the balance in favor of self-determination and allows physicians to aid patients in ending their lives. The practice is legal in Oregon, Washington, and Montana.<sup>93</sup> Physician aid in dying, or physician assisted suicide as it is sometimes called, is clearly more than just a case of

---

§§ 7-621-30 (2009); *see also* Health-Care Decisions Act, D.C. CODE §§ 21-2201 to 21-2213 (2009).

89. *Advance Directives*, NAT'L CANCER INST. (Mar. 7, 2000), <http://www.cancer.gov/cancertopics/factsheet/support/advance-directives>.

90. *E.g.*, The Natural Death Act, ALA. CODE §§ 22-8A-1 to 22-8A-14 (2010); The Health Care Decisions Act, ALASKA STAT. §§ 13.52.010 to 13.52.395 (2010).

91. Omnibus Budget Reconciliation Act of 1990, H.R. 5835, 101st Cong. (1990).

92. *Id.*

93. *See* Oregon Death with Dignity Act, OR. REV. STAT. §§ 127.005 to 127.045 (2010); *see also* The Washington Death with Dignity Act, WASH. REV. CODE §§ 70.245.101 to 70.245.200 (2009), *available at* <http://apps.leg.wa.gov/RCW/default.aspx?cite=70.245>; *see also* *Baxter v. Mont.*, 224 P.3d 1211 (Mont. 2009).

treatment refusal because patients are authorized to request lethal medication, and physicians may assist by prescribing such medication without fear of prosecution.<sup>94</sup> Some say aid in dying is a clear violation of the obligation to treat.<sup>95</sup> Others argue that the obligation to treat includes the obligation to treat terminal patients (or those whose self-assessed quality of life falls below an acceptable threshold) by helping them through the dying process, including helping them hasten death if that is what they wish.<sup>96</sup> Aid in dying is an undeniable example of how the law, at least in the jurisdictions listed above, has found a way to preserve the general principle that all medical professionals are obligated to preserve life while simultaneously creating a safe harbor from liability for physicians who feel caring for their patients includes respecting a terminally ill patient's wish to end a life of pain and suffering or a life the patient no longer feels is worth preserving. The legalization of "aid in dying" indicates that even an extremely controversial practice can be accommodated without causing a legal breach of the general medical obligation to treat. A vital distinction to note is that "aid in dying" as practiced in Oregon and Washington State,<sup>97</sup> unlike the active euthanasia practiced in countries like the Netherlands, has effective safeguards in place to assure that the decision to end the patient's life rests squarely with the patient and never with his or her physician. The most significant safeguard is that patients must take the medication themselves. No one can assist in the administration of the lethal dose. Thus, these states allow individuals to make very controversial decisions for themselves, while preserving trust in the medical profession by having safeguards that protect the general public from even the perception that healthcare professionals could take the initiative in ending a patient's life.<sup>98</sup>

---

94. *Id.*

95. See generally Elliot N. Dorff, *Assisted Suicide*, 13 J.L. & RELIG. 263, 263-88 (1998).

96. F. M. Kamm, *Ronald Dworkin on Abortion and Assisted Suicide*, 5 J. ETHICS 221, 239-40 (2001).

97. Montana is not included because, as of this writing, the practice of "aid in dying" is legal but not regulated. See *Baxter v. Mont.*, 224 P.3d 1211, 1211 (Mont. 2009) (holding that "physician aid in dying provided to terminally ill, mentally competent adult patient, was not against public policy for purposes of exception to consent defense.").

98. The Oregon law provides the following basic safeguards: 1) the patient must be an Oregon resident; 2) an adult of sound mind, demonstrated by a consultation with a psychiatrist if needed; 3) have a terminal medical diagnosis (less than six months to live), confirmed by a second physician; 4) make multiple requests, repeated by no less than fifteen in a days' time, and one must be in writing witnessed by a non-relative of the

#### 4. Anatomical Gifts

Organ donation does not have a judicial history of preserving patient self-determination as is the situation for treatment refusal and withdrawal cases.<sup>99</sup> Under English common law, the disposal of corpses and organ donation at death was a matter of respecting the familial right of burial, not a patient's right to make end of life treatment decisions.<sup>100</sup> It is only in the last half-century that decisions about organ donation have become more patient-centered and less about burial.<sup>101</sup> This shift has created a situation in which anatomical gifts are treated more like end of life care decisions than decisions about the disposition of corpses. Thus, instructions regarding anatomical gifts are now frequently included in, or along with, a patient's advance directive, as if such decisions were end of life treatment decisions, not wishes to be carried out after death.<sup>102</sup>

The Uniform Anatomical Gift Act (UAGA), originally drafted in 1968 and revised in 1987 and 2006 suggests model legislative language for state laws governing anatomical gifts.<sup>103</sup> In the Prefatory Note of the Revised UAGA the National Conference of Commissioners for Uniform State Laws (NCCUSL) states that the Act "is promulgated . . . to address in part the critical organ shortage by providing additional ways for making organ, eye, and tissue donations."<sup>104</sup> Furthermore, the most recent update of the UAGA

patient requesting the medication; 5) have a physician inform the patient of all potential side-effects of the medication, including unintended effects and feasible alternatives; and 6) neither the physician, nor anyone other than the patient him/herself may administer the medication. See OR. REV. STAT. §§ 127.005 to 127.045 (2010).

99. See generally *Hudson v. Children's Hosp.*, 177 S.W. 3d 232 (Tex. Crim. App. 2005).

100. See *Lott v. N.Y.*, 225 N.Y.S.2d 434 (N.Y. App. Div.1962) ("The law is well settled that the surviving next of kin have a right to the immediate possession of a decedent's body for preservation and burial and that damages will be awarded against any person who unlawfully interferes with that right or improperly deals with the decedent's body.").

101. 1962 marks the beginning of cadaveric kidney transplantation. Transplant Network, HISTORY OF TRANSPLANTATION (Nov. 28, 2010), <http://thetransplantnetwork.com/faq/history-of-transplantation/>.

102. See CAL. PROB. CODE § 4701 (West 2010).

103. UNIFORM ANATOMICAL GIFT ACT, *supra* note 39.

104. *Id.* The Prefatory Note goes on to state:

adopts first person consent to specifically give physicians the authority to follow a patient's wishes with respect to organ donation over a family's objection. This most recent iteration protects physicians against civil suits from patients' families for respecting a patient's wishes, over a family's objection. The 1968 UAGA, which originally established the right to donate organs, eyes and tissues was adopted by all states,<sup>105</sup> though the 1987 version was only adopted by twenty-six states, with others creating non-uniform anatomical gift acts.<sup>106</sup> To date, forty-two states as well as the District of Columbia and the Virgin Islands have enacted the 2006 version of the UAGA, and two states are currently considering a bill to adopt the 2006 revisions.<sup>107</sup>

### *B. Second Approach: Limiting Quality of Life Decisions*

All of the developments in the courts and legislatures mentioned thus far have dealt with the scope of an individual's authority to make decisions regarding the care of his or her body during life and immediately following death. But, there is another, less individualistic, approach to preventing the waste of medical resources and increasing the organ supply. This second approach, which was being pursued simultaneously with the first, focused its efforts on redefining futility and death (as a matter of law and public policy) in such a way that, in the most extreme cases, treatment could be stopped without consideration for individual preferences.

Laws governing end of life decisions that focus on the obligation to treat and patient self-determination always try to achieve what is best for the patient, whether this includes preserving the patient's life at all costs, even against his or her will, or allowing patients and their proxies to make life and

---

First, the [act] is designed to encourage the making of anatomical gifts. Second, the [act] is designed to honor and respect the autonomy interest of individuals to make or not to make an anatomical gift of their body or parts. Third, the [act] preserves the current anatomical gift system founded upon altruism by requiring a positive affirmation of an intent to make a gift and prohibiting the sale and purchase of organs.

*Id.* at 2.

105. *Id.*

106. See UNIFORM ANATOMICAL GIFT ACT OF 1987, <http://www.law.upenn.edu/bll/archives/ulc/fnact99/uaga87.pdf>.

107. *Enactment Status Map*, NAT'L CONF. OF COMMISSIONERS ON UNIFORM STATE LAWS (Oct. 31, 2010), <http://www.anatomicalgiftact.org/DesktopDefault.aspx?tabindex=2&tabid=72>.

death decisions based on their own personal quality of life assessments. The central issue in the obligation to treat / patient self-determination area of law is always what is in the patient's interests, not cost containment or solving the organ shortage. Some argued, however, that this patient oriented approach was misguided and that more emphasis should be placed on the good of society as a whole.<sup>108</sup>

The fierce battle waged over futility and the determination of death fundamentally boils down to a debate over who will decide how to allocate two types of life-sustaining medical resources for three types of patients: emergency services for patients not likely to recover or live long, life-sustaining treatments for those suffering from significant permanent loss of brain function, and life-saving organs for patients in need of an organ transplant.<sup>109</sup>

Allocation approaches aim to legally shift certain kinds of end of life decisions away from patients and their proxies to the medical profession.<sup>110</sup> One approach entails broadening the concept of medical futility to include decisions not to treat patients with extremely poor prognoses. Another approach includes redefining death so that hopeless cases can be declared dead and removed from life support without the patient's, or the patient's proxy's, consent. Most advocates of these approaches to cost containment and increasing organ supply understand that they limit patient autonomy, but argue that such limitations are justified in service of a greater good - that is, to save money and save lives.<sup>111</sup> Few, however, seem to acknowledge that these approaches could undermine public trust in the medical profession as a whole and the organ procurement system in particular.<sup>112</sup>

---

108. Sheri Fink, *Advisory Subcommittee to CDC Approves Ethics Guidance for Rationing Ventilators*, PROPUBLICA (Nov. 23, 2009), <http://www.propublica.org/feature/advisory-subcommittee-approves-ethics-guidance-rationing-ventilators-1123>.

109. Focus on these issues has only intensified over the years. *Id.* at 1.

110. *Id.*

111. See Boucek, *supra* note 5, at 709-14; see also Truog, *supra* note 3, at 674-75.

112. *But see* Boucek, *supra* note 5. The report recognizes that certain members of the transplant community and of the public at-large may object to reframing the determination of death on the ethical principle of nonmaleficence because, as they state, "if patients are not declared dead before organ procurement, then it seems there is no choice but to conclude that the patients are being killed by their doctors." Robert D. Truog, *Role of Brain Death and the Dead-Donor Rule in the Ethics of Organ Transplantation*, 31 CRITICAL CARE MED. 2391, 2395 (2003). This consideration brings to light the fact that the public's understanding of the facts about determinations of death



### *1. Expanding the Definition of Futility*

From the 1970s to the early 1990s, a movement developed to leave determinations of “futility” to the medical community guided by the heuristic of determining whether the patient had a chance of returning to a meaningful quality of life.<sup>113</sup> The notion of “absolute” medical futility was already a part of a legally recognized medical standard of care. Under the “absolute medical futility” standard, usually just referred to as “medical futility” but referred to here as “absolute medical futility” to distinguish it from later, more subjective, interpretations of the phrase, physicians were not expected to engage in procedures that had no chance of achieving the immediate goals for which that procedure was intended.<sup>114</sup> But under the newer, broader and more subjective, definition of futility, physicians were allowed to consider not only the treatment’s ability to meet immediate goals, but also whether it would further longer term goals such as the recovery of consciousness or discharge from the hospital.<sup>115</sup> It would be absolutely futile to perform resuscitative efforts on a corpse or to operate on the lungs of a patient whose heart is failing because such procedures would not realize their immediate intended medical goal of keeping the patient alive. A physician who refused to perform such procedures under the given circumstances would be excused from legal liability on the bases of absolute medical futility regardless of whether the patient or patient’s proxy felt such procedures should be performed.

The logical leap some philosophers and physicians began suggesting to courts and state legislatures in the ‘70s, ‘80s and early ‘90s, was that life-sustaining treatment for some patients is futile, not because the patient is dead (that would be absolute medical futility), but because the patient’s chances of returning to a meaningful quality of life was too low to warrant the expenditure of medical resources it would take to keep the patient

---

are confused, and thus may severely degrade the trust placed in the medical transplantation system. *Id.*

113. See *Causey v. St. Francis Med. Ctr.*, 719 So. 2d 1072, 1075 (La. Ct. App. 1998).

114. *Id.* (“The physician has an obligation to present all medically acceptable treatment options for the patient or her surrogate to consider and either choose or reject; however, this does not compel a physician to provide interventions that in his view would be harmful, without effect or ‘medically inappropriate.’”).

115. See *Hudson v. Children’s Hosp.*, 177 S.W. 3d 232, 233 (Tex. Crim. App. 2005).

alive.<sup>116</sup> The problem with this approach is that the medical intent of life-sustaining treatment is to sustain life, without reference to its quality. Life-sustaining treatment is not medically futile, at least not in the traditional absolute sense, if it realizes its goal of keeping the patient alive. Those advocating an expansion of the concept of futility are trying to give physicians authority to stop treatment on living patients based on so-called “futility” for reasons of cost containment when traditionally such decisions were reserved for patients and their proxies.

Understandably, this newer definition of futility causes confusion.<sup>117</sup> Absolute medical futility details treatment options that will not achieve their short-term goals, for example, restart the heart or keep the blood circulating.<sup>118</sup> The newer, more subjective form of futility details those aspects of treatment modalities that capture non-isolated medical issues about a patient.<sup>119</sup> For example, treating a patient in persistent vegetative state (PVS) for years, with no signs of higher brain function, may be considered futile even from a medical standard of care perspective because, based on current medical understanding of PVS, the patient is never going to return to a meaningful quality of life. Resuscitation, if necessary, or the provision of nutrition and hydration for such a patient would not be medically futile in the absolute sense, but may be from a subjective standpoint.

Traditionally, subjective forms of futility determinations were reserved for patients and their proxies, but in a few instances, such determinations are now left up to physicians under current law.<sup>120</sup> Another important point about having physicians make subjective futility decisions is that it is very difficult in a pluralistic society to come up with a coherent medical standard for determining what is, and what is not, a potentially meaningful quality of

---

116. See generally Council on Ethical and Judicial Affairs, Am. Med. Ass’n, *Medical Futility in End-of-Life Care: Report of the Council of Ethical and Judicial Affairs*, 281 JAMA 937 (1999).

117. *Id.*

118. *Id.*

119. *Id.* at 938 (“Claims of medical futility inherently involve a value judgment. For example, I patient may consider the physical, emotional, practical, or financial burden of aggressive intervention not worth the purpose of prolonging seemingly meaningless life.”).

120. *Casey v. St. Francis Med. Ctr.*, 719 So. 2d 1072, 1072 (La. Ct. App. 1998); TEX. STAT. ANN. § 166.052 (2003).

life.<sup>121</sup> It is for these reasons that most courts still leave such decisions to patients and their surrogates, and not to healthcare professionals.

There are two notable exceptions where the law seems to have agreed to shift more subjective decisions regarding futility out of the realm of individual choice and into the realm of medical standards of care established by medical professionals. In *Causey v. St. Francis Medical Center*, the Louisiana Second Circuit Court of Appeals decided that, under state law, a medical panel, not the court, should decide whether a physician could determine when to withdraw life-sustaining care.<sup>122</sup> Specifically, the physician wanted to withdraw life-sustaining care from a thirty-one year-old quadriplegic comatose patient with end-stage renal failure over the express objection of the patient's family.<sup>123</sup> The patient's treating physician stipulated that with continued ventilation and dialysis the patient could live another two years, but she would only have a one to five percent chance of ever regaining consciousness.<sup>124</sup> The court acknowledged that such questions of futility are subjective, but stressed that physicians have a right to decide when treatment is medically inappropriate and held that this particular case needed to be evaluated by a medical review panel under the state's Medical Malpractice Act to see if the physician's (and hospital's) action was outside the standard of care.<sup>125</sup> It is, thus, in this court's opinion, the physician's prerogative to determine whether a proposed intervention would be without medical effect or medically inappropriate. Furthermore, the state court of appeals opined that, when the decision to abort treatment because of medical futility is reached by a consensus of competent, specialized physicians and affirmed by the ethics panel, the decision becomes a standard practice of care that can be utilized as precedent.<sup>126</sup>

---

121. Yitzchok A. Breitowitz, *The Brain Death Controversy in Jewish Law*, JEWISH LAW ARTICLES, <http://www.jlaw.com/Articles/brain.html> (last visited Nov. 30, 2010).

122. *Causey*, 719 So. 2d at 1075.

123. *Id.*

124. *Id.*

125. *Id.*

126. *Id.* ("The physician has an obligation to present all medically acceptable treatment options for the patient or her surrogate to consider and either choose or reject; however, this does not compel a physician to provide interventions that in his view would be harmful, without effect or 'medically inappropriate.'").

Another notable exception to patient self-determination is that portion of the Texas Advance Directive Act that transfers decision-making authority from individuals to the medical profession in certain circumstances.<sup>127</sup> The “futility” section of the state statute allows physicians to stop life-sustaining treatment on patients, even over a family’s objection, after giving the family ten days written notice to arrange to have the patient transferred to another facility.<sup>128</sup> Notably, this law does not take into consideration the patient’s personal preferences, but instead gives physicians (and their medical institutions) the right to stop treatment in order to prevent the wasting of scarce and expensive medical resources.<sup>129</sup> The validity of the Texas statute and the authority of medical professionals to unilaterally decide to stop treatment in “futile” cases was affirmed by the Texas Court of Appeals in *Hudson v. Children’s Hospital* where a family was demanding treatment for an infant with thanatophoric dysplasia and the patient’s treating physicians and the hospital (after giving the family the statutorily required time to transfer the patient) discontinued life-sustaining treatment.<sup>130</sup>

## 2. Expanding the Definition of Death

Another notable shift away from patient-self determination is evident in efforts to expand the definition of death. The NCCUSL, for example, made no claims to any new philosophical insight or scientific discovery that lead to its broadening the definition of death.<sup>131</sup> It was forthright in identifying its motives, among which are listed:

- 1) The UDDA [(Uniform Determination of Death Act)] will help assure the public that emergency equipment, such as respirators, will be available in crisis situations for patients whose lives can be saved.

---

127. TEX. STAT. ANN. § 166.052 (2003).

128. *Id.*

129. TEX. STAT. ANN. § 166.046(e) (2003). This law provides that a patient may request continued life-sustaining treatment, despite the determination of the attending physician that such treatment is inappropriate, and such treatment will be provided in preparation for the patient’s transfer to another facility. In such an event, the patient will be responsible for any costs incurred in the transfer process. *Id.*

130. *Hudson v. Children’s Hosp.*, 177 S.W. 3d 232, 232 (Tex. Crim. App. 2005).

131. *Why States Should Adopt the Uniform Determination of Death Act*, NAT’L CONFERENCE OF COMM’RS ON UNIFORM STATE LAWS, [http://www.nccusl.org/Update/uniformact\\_why/uniformacts-why-udda.asp](http://www.nccusl.org/Update/uniformact_why/uniformacts-why-udda.asp) [hereinafter NAT’L CONFERENCE OF COMM’RS] (last visited Nov. 28, 2010).

2) A state's adoption of the UDDA aids the medical profession in saving lives. Brain death determinations are important for organ transplantation because, once death occurs, viable organs begin to deteriorate. Brain death determinations make fresh organs more available to those who need them.<sup>132</sup>

Arguably, however, the transplant community (as explained further below) is trying to adopt a medical standard that construes death far more broadly than what was originally intended by the UDDA or the 1980-1983 President's Commission. Both were deliberating the issue at the same time the NCCUSL was considering replacing the Uniform Brain Death Act (UBDA) with the UDDA.<sup>133</sup> And both the NCCUSL and the President's Commission advocated for a whole organism definition of death, not the more recent position that circulatory criteria could be used as an alternative to brain death *even in situations where it is evident that brain death has not occurred*.<sup>134</sup>

Efforts to redefine death began in the late 1960s and quickly proliferated.<sup>135</sup> In 1968, the Ad Hoc Committee of the Harvard Medical School, which was created to examine the definition of brain death, first drew serious attention to the option of creating a new legal definition of

---

132. *Id.*

133. See Maxine Harrington, *The Thin Flat Line: Redefining Who is Legally Dead in Organ Donation After Cardiac Death*, 86 *DENV. U.L. REV.* 335, 361 (2009).

134. NAT'L CONFERENCE OF COMM'RS, *supra* note 131. The NCCUSL states "[A]n attending physician often waits until a patient's heart fails to declare death even though death has, in fact, already occurred." (i.e. brain death has already occurred). *Id.* See PRESIDENT'S COMM'N *supra* note 6, at 58, (stating "[a]lthough absence of breathing and heartbeat may often have been spoken of as "defining" death, review of history and of current medical and popular understanding makes clear that these were merely evidence for the disintegration of the organism as a whole."). See also Harrington, *supra* note 133. Professor Harrington agrees with our conclusion, stating:

The President's Commission also looked upon death as a unitary phenomenon. Consideration was given by the Commission to a statute that would contain only a definition of brain death but circulatory death was included as alternative criteria because 'the loss of spontaneous breathing and heartbeat are surrogates for the loss of brain functions.'

*Id.*

135. For one such attempt, see generally Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 *JAMA* 337, 337-40 (1968).

death.<sup>136</sup> The Ad Hoc Committee determined that patients in an “irreversible coma” should demonstrate unresponsivity and unresponsivity to all stimuli, no movements or breathing, and no reflexes.<sup>137</sup> Using different criteria, Kansas, in 1970, was the first state to pass legislation defining brain death.<sup>138</sup> The Kansas law required that “based on ordinary standards of medical practice, there is the absence of spontaneous brain functions.”<sup>139</sup> In 1972, Professor Capron and Dr. Kass proposed a substantially shorter definition of death intended to overcome the “two deaths” problem by making the two types of determinations mutually exclusive.<sup>140</sup> Only when “artificial means of support preclude” an ordinary determination of death should brain death be considered.<sup>141</sup> In 1975, the Law and Medicine

---

136. *Id.*

137. *Id.*

138. PRESIDENT’S COMM’N, *supra* note 6, at 62 (citing KAN. STAT. ANN. §77-202 (Supp. 1971)).

139. *Id.* The Kansas statute, in relevant part, states:

A person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice, there is the absence of spontaneous respiratory and cardiac function and, because of the disease or condition which caused, directly or indirectly, these functions to cease, or because of the passage of time since these functions ceased, attempts at resuscitation are considered hopeless; and, in this event, death will have occurred at the time these functions ceased; or a person will be considered medically and legally dead if, in the opinion of a physician, based on ordinary standards of medical practice, there is the absence of spontaneous brain functions; and if based on ordinary standards of medical practice, during reasonable attempts to either maintain or restore spontaneous circulatory or respiratory function in the absence of aforesaid brain function, it appears that further attempts at resuscitation or supportive maintenance won’t succeed, death will have occurred at the time when these conditions first coincide. Death is to be pronounced before artificial means of supporting respiratory and circulatory function are terminated and before any vital organ is removed for purposes of transplantation. These alternative definitions of death are to be utilized for all purposes in this state, including the trials of civil and criminal cases, any laws to the contrary notwithstanding.

*Id.*

140. PRESIDENT’S COMM’N, *supra* note 6, at 118.

141. *Id.* at 118 (“A person will be considered dead if in the announced opinion of a physician, based on ordinary standards of medical practice, he has experienced an

Committee of the American Bar Association (ABA) drafted a Model Definition of Death Act that abandoned the cardiorespiratory determination of death altogether and stated: "For all legal purposes, a human body, with irreversible cessation of total brain function, according to usual and customary standards of medical practice, shall be considered dead."<sup>142</sup> In 1978, the NCCUSL completed the UBDA based on the ABA suggestions.<sup>143</sup> The AMA, not fully satisfied with the ABA model, created its own Model Determination of Death statute in 1979.<sup>144</sup> The AMA Model Determination of Death statute offered legal protection to individuals who made end of life decisions based on the statute. And then in 1980, the NCCUSL revisited the issue, creating the Uniform Determination of Death Act, which, unlike the UBDA, included circulatory criteria as an acceptable alternative to the use of brain death criteria.<sup>145</sup>

---

irreversible cessation of respiratory and circulatory functions, or . . . irreversible cessation of total brain functions. Death will have occurred . . . when the relevant functions ceased.”).

142. PRESIDENT’S COMM’N, *supra* note 6, at 117.

143. UNIFORM BRAIN DEATH ACT, (1978). The Uniform Brain Death Act stipulates: “For legal and medical purposes, an individual who has sustained irreversible cessation of all functioning of the brain, including the brain stem, is dead. A determination under this section must be made in accordance with reasonable medical standards.” *Id.*

144. UNIFORM DETERMINATION OF DEATH ACT (Aug. 1, 1980), *available at* <http://www.law.upenn.edu/bll/archives/ulc/fnact99/1980s/udda80.htm> (approved by the American Medical Association on Oct. 19, 1980 and the American Bar Association on Feb. 10, 1981). The Act states in relevant part:

An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, shall be considered dead. A determination of death shall be made in accordance with accepted medical standards . . . . A Physician or any other person authorized by law to determine death who makes such determination in accordance with [the aforementioned] is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his acts or the acts of others based on that determination. Any person who acts in good faith in reliance on a determination of death is not liable for damages in any civil action or subject to prosecution in any criminal proceeding for his act . . . . If any provision of this Act is held by a court to be invalid such invalidity shall not affect the remaining provisions of the Act, and to this end the provisions of this Act are hereby declared to be severable.

*Id.*

145. *Id.* at 5.

The NCCUSL understood that in most settings, circulatory death and brain death are so closely linked that they are indistinguishable and that it was impractical in most situations to require more than proof of cessation of circulatory functions for a declaration of death.<sup>146</sup> It is clear in hindsight that the NCCUSL introduced brain function criteria specifically to allow the removal of brain-dead patients from life-support and to allow the harvesting of their organs, but did not anticipate (at least there is no indication in their published discussions), that circulatory criteria might someday be used to harvest organs even more expeditiously than brain criteria.<sup>147</sup>

The 1968 Ad Hoc Committee of the Harvard Medical School, however, foresaw problems with a dual-pronged approach.<sup>148</sup> It clearly stated that reliance on circulatory criteria “for the definition of death can lead to controversy in obtaining organs for transplantation.”<sup>149</sup> However, nowhere in its discussion did the Ad Hoc Committee address the NCCUSL concern that always requiring the use of brain death criteria would be impractical. Also, Jerry Menikoff, the former director of the Office for Human Research Protections, believes there is no doubt that the UDDA was meant to point to one death phenomenon, not two.<sup>150</sup> Menikoff states, “cardiopulmonary criteria were being retained [in the UDDA] precisely because they gave clear results in the *easy* cases, where it was *quite evident* that brain function had ceased . . . .”<sup>151</sup> Finally, the President’s Commission states, “the loss of spontaneous breathing and heartbeat are surrogates for the loss of brain function.”<sup>152</sup>

146. *Id.*

147. *Id.* (“A state’s adoption of the UDDA aids the medical profession in saving lives. Brain death determinations are important for organ transplantation, because once death occurs, viable organs begin to deteriorate. Brain death determinations make fresh organs more available to those who need them.”).

148. Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, *A Definition of Irreversible Coma*, 205 JAMA 85, 85-88 (1968).

149. *Id.* (“The burden is great on patients who suffer permanent loss of intellect, on their families, on the hospitals, and on those in need of hospital beds already occupied by these comatose patients. Obsolete criteria for the definition of death can lead to controversy in obtaining organs for transplantation.”).

150. Jerry Menikoff, *Doubts About Death: The Silence of the Institute of Medicine*, J. L., MED., & ETHICS 157, 160 (1999).

151. *Id.* at 164.

152. PRESIDENT’S COMM’N, *supra* note 6, at 37.



Because the two sets of criteria for determining death are so closely linked, we imagine that had the Ad Hoc Committee foreseen the current controversy, it might have proffered something like the Institute of Medicine (IOM) suggestion in its 1997 report, namely that non-heart-beating organ donation is ethically acceptable as long as there is clear evidence of irreversibility.<sup>153</sup> Although the Ad Hoc Committee would probably have added that in questionable cases, there should also be a sufficient waiting period after the end of circulatory functions to assure that brain death has occurred.

Revisions to the holistic approach to the definition of death have been controversial from the beginning, and over the years the debate has intensified rather than cooled.<sup>154</sup> Today, there still is no medical consensus as to how much time after the cessation of circulatory functions brain death occurs.<sup>155</sup> Furthermore, several circumstances (*e.g.*, immersion in cold

---

153. ROGER HERDMAN & JOHN T. POTTS, NON-HEART-BEATING ORGAN TRANSPLANTATION: MEDICAL AND ETHICAL ISSUES IN PROCUREMENT (1997).

154. PRESIDENT'S COUNCIL, *supra* note 14, at 1-2.

155. E-mail from James L. Bernat, Neurology Department, Dartmouth-Hitchcock Medical Center to Thomas Reher, (Mar. 17, 2010) (on file with author). Dr. Bernat postured that:

In most clinical settings in which the brain suffers anoxia (or hypoxia), it is accompanied by ischemia (lack of blood flow). The typical situation occurs during cardiopulmonary arrest when the brain is deprived of both blood flow and oxygen. We call that circumstance "hypoxic-ischemic" neuronal injury. When both occur together, it is hard to determine in retrospect how much neuronal injury resulted from hypoxia and how much from ischemia.

We know that during normal brain metabolic conditions, consciousness is lost after 10-20 seconds and irreversible neuronal damage begins after a few minutes. During hypothermia or treatment with central nervous system depressant medications that diminish neuronal metabolism - such as are used to induce coma therapeutically after a brain injury - the brain can tolerate loss of blood flow or oxygen for much longer periods because the neuronal metabolic demands are lessened. But no one knows the minimum duration of circulatory-respiratory arrest sufficient to produce "brain death" with destruction of essentially all neurons. Most neurologists think that it takes at least 20-30 minutes of complete cessation of circulation and oxygenation, assuming normal metabolic conditions.

The reason it is not known is there is no human model and studies on patients during cardiopulmonary arrest are complicated by the fact that a resuscitation is

water or similar sources of hypothermia, drug exposure, or metabolic or endocrine disorders) can make conventional techniques for determining death inaccurate.<sup>156</sup> While one would expect the advancement of medicine to provide more accurate means of determining death, the opposite seems to be the case. In recent years, both circulatory and brain criteria for determining death have become more, rather than less, controversial.<sup>157</sup>

#### IV. THE PHILOSOPHICAL CRISIS

Every argument about the determination of death presumes the existence of a perspective on what constitutes a human life worth saving. The UDDA is vague on this point, perhaps intentionally so, but the fundamental underlying metaphysical question has significant social and legal ramifications that cannot be ignored.<sup>158</sup>

##### *A. Balancing Respect for Persons and Maximizing Healthcare Utility*

There is much debate over how to improve the U.S. healthcare system, but there is little doubt that there is both a shortage of mechanical ventilators and organs for transplantation.<sup>159</sup> The ethos of always putting patients first has

---

underway with some degree of restoration of oxygenation and circulation, at least temporarily.

*Id.*

156. PRESIDENT'S COMM'N, *supra* note 6, at 154 ("There should be no suspicion that this state is due to depressant drugs. Primary hypothermia as a cause of coma should have been excluded. Metabolic and endocrine disturbances which can be responsible for or can contribute to coma should have been excluded.").

157. PRESIDENT'S COUNCIL, *supra* note 14, at 1-2; *see also* PRESIDENT'S COMM'N, *supra* note 6, at 3.

158. NATIONAL CONFERENCE OF COMM'NS, *supra* note 131.

159. Douglas B. White et al., *Who Should Receive Life Support During a Public Health Emergency? Using Ethical Principles to Improve Allocation Decisions*, 150 ANNALS OF INTERNAL MED. 132, 138 (2009); John L. Hick & Daniel T. O'Laughlin, *Concept of Operations for Triage of Mechanical Ventilation in an Epidemic*, 13 ACADEMIC EMERG'Y MED., 223, 224 (2006), [http://depts.washington.edu/respcare/journal\\_club/articles/20071022/Mech%20vent%20Triage%20in%20Epidemic.pdf](http://depts.washington.edu/respcare/journal_club/articles/20071022/Mech%20vent%20Triage%20in%20Epidemic.pdf) (stating that if patients expected to improve have to compete with PVS or brain dead patients without quality of life considerations, the shortage will worsen. The current number of patients waiting for organs is well over 100,000); *see generally* UNITED NETWORK FOR ORGAN SHARING, [www.unos.org](http://www.unos.org) (last visited Nov. 28, 2010).

been curtailed by notions of public responsibility and a need to balance the interests of individual patients in need of expensive emergency care against the needs of others.<sup>160</sup> It is a difficult task to both show respect for the individual patient and balance social pressures to maximize the overall availability of health care. This ethical tension between respect for individual persons and overall public health reflects the age-old conflict between deontological and utilitarian approaches to ethics.

Deontology favors respecting patients as persons capable of making their own decisions.<sup>161</sup> The obligation of physicians under this perspective requires that they think in terms of just the individual patient's best interest, not how the individual patient's interests may be superseded by general societal considerations. A deontological respect for persons is the justification for allowing advance directives to extend a person's autonomy beyond his or her capacity to decide.<sup>162</sup> Deontological thought places a paramount value on self-governance.<sup>163</sup> Court cases and statutes that allow individuals the freedom to make their own healthcare decisions, even if the majority of the population believes such decisions are a mistake or against the public interest, are motivated by the deontological principle of respect for persons.<sup>164</sup> All the right-to-die cases, the Patient Self-Determination Act, and most of the legislation about advance directives fall into this category.<sup>165</sup>

Alternatively, utilitarianism focuses on creating the greatest aggregate good.<sup>166</sup> Utilitarianism does not hesitate to balance the good of individual

---

160. Fink, *supra* note 108, at 1.

161. TOM L BEAUCHAMP & JAMES F CHILDRESS, *PRINCIPLES OF BIOMEDICAL ETHICS* 351 (5th ed. 2001) (“‘The principle of autonomy,’ [Kant] contends, is ‘the sole principle of morals,’ and autonomy alone gives people respect, value, and proper motivation. A person’s dignity—indeed, ‘sublimity’—comes from being morally autonomous.”).

162. *Id.* at 69 (“[A]s with respect for prior wishes of the now-deceased, we are, except in rare cases, *obligated to respect* the previously expressed autonomous wishes of the now severely nonautonomous person because of our *respect for the autonomy* of the person who made the decision.”) (emphasis added).

163. *Id.*

164. *Cruzan v. Director, Mo. Dep’t. of Health*, 497 U.S. 261, 268-69 (1990).

165. Omnibus Budget Reconciliation Act of 1990, Pub. L. No. 101-508, 104 Stat. 1388, *amended by* Patient Self-Determination Act of Dec. 1, 1991, Pub. L. No. 101-508, 104 Stat. 1388 (S) 4206, 1388 (1990). *See also Cruzan*, 497 U.S. at 261.

166. Julia Driver, *The History of Utilitarianism*, *STANFORD ENCYCLOPEDIA OF PHILOSOPHY* (Mar. 27, 2009), <http://plato.stanford.edu/entries/utilitarianism-history/>.

patients against the overall good to be gained by society.<sup>167</sup> When achieving the good of a particular individual carries too great a cost for society as a whole, principles of utility suggest that the individual should be denied the right to further that individual good.<sup>168</sup> Statutes that try to prevent the wasting of medical resources by denying certain categories of patients the right to those resources are a clear example of a utilitarian calculus.<sup>169</sup> Laws shifting futility determinations away from individuals to the medical profession and laws that redefine death to limit the use of scarce life-sustaining resources to those who have a chance of regaining consciousness are both examples of laws implemented to promote utilitarian principles.<sup>170</sup> Additionally, policies that clearly shift medical attention away from attempting to save the most seriously injured to harvesting organs are also motivated by a utilitarian approach to resource allocation.

It is useful to keep in mind these two major approaches to ethics and the tension between them when considering arguments for revising the definition of death.

### *B. The Metaphysics of Death*

Answering what death is and why it matters is complicated by religious and cultural pluralism.<sup>171</sup> For some, death signifies an end; others, a transition; still others, a return to the beginning.<sup>172</sup> Further complicating the issue, death is fragmented by terms such as ‘legal death,’ ‘cardiorespiratory death,’ ‘brain death,’ ‘medical death,’ and more. Even if society settles on

167. *Id.*

168. BEAUCHAMP & CHILDRESS, *supra* note 161, at 347.

169. 42 U.S.C. § 1395dd (1986) (limiting the obligation to medical screening and care or transfer only in the case of “an emergency medical condition.”).

170. TEX. HEALTH & SAFETY CODE § 166.052 (2003).

171. H. TRISTRAM ENGELHARDT, JR., *THE FOUNDATIONS OF BIOETHICS* 26 (1986) (“Absent either a general conversion to one religion, or the existence of a generally imposed orthodoxy, one will need to search for common grounds to bind rational individuals in a peaceable community.”).

172. Some believe “[d]eath is life’s ending,” yet, the relationship between death and one’s existence is controversial. While atheists generally understand death as the annihilation of the self, many world religions (eg. Christianity, Islam, Buddhism) posit that there is persistence beyond bodily death. Stephen Luper, *Death*, STANFORD ENCYCLOPEDIA OF PHILOSOPHY (May 26, 2009), <http://plato.stanford.edu/entries/death/>.

the scientific criteria necessary for medical death, individuals may doubt the sufficiency of medical death for religious or cultural purposes.<sup>173</sup>

For anyone who does not believe in an afterlife, death is the dividing point between existence and non-existence, and the reality or perception of when that transition takes place is probably thought of in very concrete terms.<sup>174</sup> For some, it may be when all brain functions that allow interaction with the world cease, while for others, it may be when higher brain functions irreversibly cease or when the body no longer can interact with the world in some fashion that is meaningful to that individual.<sup>175</sup>

For the various religions that view dying as a passageway to a new existence beyond death, the consequences of changes in the definition of death are varied. For example, Catholic tradition holds almost uniformly that determinations of death are a scientific rather than a religious matter,<sup>176</sup> but Jewish religious scholars are more divided on the issue.<sup>177</sup> Metaphysical concerns over when death occurs are not the main focus of this paper, but it is very possible that such concerns further complicate the public's general understanding of the organ retrieval process. Consider the clinical ethicist who tells healthcare staff and families that waiting five minutes after the cessation of circulatory function before declaring death, as is common medical practice in accordance with IOM recommendations, is necessary so that the soul can leave the body before organ retrieval begins.<sup>178</sup> While the IOM never mentions the soul, it does mention that the five minute rule is needed to allow emotional distance between therapeutic efforts and organ retrieval.<sup>179</sup> So when is the person dead - when death is declared or five

---

173. Breitowitz, *supra* note 121.

174. See Luper, *supra* note 172 (explaining the termination thesis).

175. *Id.* at 1.2 (discussing the conflicting concepts of animalism and mindism).

176. *Education Programs: FAQ on 'Brain Death'*, NAT'L CATHOLIC BIOETHICS CTR., <http://www.ncbcenter.org/NetCommunity/Page.aspx?pid=436> (last visited Oct. 31, 2010).

177. Some leaders require the absence of breath and a heartbeat, others accept brain death according to nuclide brain scans, still others require both cessation of cardiorespiration and detectable electrical activity of the brain. Breitowitz, *supra* note 121.

178. The ethicist in question is a friend of Sigrid's who has an active clinical ethics practice and teaches clinical ethics at a reputable program.

179. INST. OF MED., NON-HEART-BEATING ORGAN TRANSPLANTATION: PRACTICE AND PROTOCOLS, 1, 17 (2000), available at [http://www.nap.edu/openbook.php?record\\_id=](http://www.nap.edu/openbook.php?record_id=)

minutes later? In Part V., *infra*, we will explain how opting for a very conservative approach to determining death and a very liberal approach to allowing individuals to make end of life choices that include organ donation can avoid such metaphysical problems.

### C. The Dead Donor Rule

The dead donor rule is a generally unwritten, but almost universally accepted, precept of organ donation—donors must be determined to be dead before organ donation can proceed.<sup>180</sup> The dead donor rule has its implicit origins in the 1968 Harvard Medical School Ad Hoc Committee recommendation that brain criteria be recognized as the legal standard for determining death.<sup>181</sup> It is also supported by the Catholic Church's Ethical and Religious Directives.<sup>182</sup>

The rule is based in the deontological principle that it is wrong to expedite a potential donor's death in order to save potential organ recipients. Robert D. Truog, Professor of Medical Ethics at Harvard Medical School, and Franklin G. Miller, a member of the senior faculty in the Department of Bioethics, National Institutes of Health, argue that adherence to the dead

---

9700&page=17 ("The recommendation of a five-minute interval between cardiopulmonary arrest and the declaration of death is based on the acknowledged limitations of [the empirical] data.").

180. Miller & Truog, *supra* note 52, at 674-75 ("At the dawn of organ transplantation, the dead donor rule was accepted as an ethical premise that did not require reflection or justification, presumably because it appeared to be necessary as a safeguard against the unethical removal of vital organs from vulnerable patients.").

181. Norman Frost, *Reconsidering the Dead Donor Rule: Is it Important That Organ Donors Be Dead?*, 14 KENNEDY INST. OF ETHICS 249, 249 (2004), available at [http://muse.jhu.edu/journals/kennedy\\_institute\\_of\\_ethics\\_journal/v014/14.3fost.html](http://muse.jhu.edu/journals/kennedy_institute_of_ethics_journal/v014/14.3fost.html) ("Implicit in the report was the assumption that - for reasons of ethics, law, and public acceptance - a patient should be dead before vital organs were removed.").

182. William P. Fay, *Ethical and Religious Directives for Catholic Health Care Services*, U.S. CONFERENCE OF CATHOLIC BISHOPS (4th ed. 2001), available at <http://www.usccb.org/bishops/directives.shtml> (deciphering that "[t]he transplantation of organs from living donors is morally permissible when such a donation won't sacrifice or seriously impair any essential bodily function and the anticipated benefit to the recipient is proportionate to the harm done to the donor" and "[s]uch organs should not be removed until it has been medically determined that the patient has died.").

donor rule has led to definitions of death that cater to the rule.<sup>183</sup> Instead of merely protecting donors, the rule also paternalistically limited the conditions under which patients can donate organs.<sup>184</sup> The dead donor rule faces three major criticisms: 1) that there is insufficient evidence that patients have lost all brain function; 2) that the loss of brain function is not a sufficient condition for death, rather the patient must also have lost circulatory function; and 3) that death should not be a prerequisite for organ donation.<sup>185</sup>

On the other hand supporters of the rule argue that the dead donor rule protects the wishes of the donors themselves.<sup>186</sup> DuBois, who served on the Institutes of Medicine 2006 Committee on Increasing Rates of Organ Donation, points out that the rule has the great advantage that it does “not invoke concepts that are dependent on any particular religious framework; that it is consistent with and build upon the scientific evidence we have; and that we simply must engage such issues if our laws are to have any moral force and to inspire trust.”<sup>187</sup>

#### V. SCIENTIFIC UNCERTAINTIES

Despite medicine’s best efforts, pinpointing the biological moment of death is elusive. It does not matter whether someone holds that either the irreversible cessation of circulatory functions or the irreversible loss of brain function is a sufficient or necessary condition for the determination of death—both sets of criteria are fraught with medical uncertainty and fail to shed much, if any, light on what really constitutes death.

---

183. Miller & Truog, *supra* note 52, at 674-75 (“[T]his ongoing reliance suggests that the medical profession has been gerrymandering the definition of death to carefully conform with conditions that are most favorable for transplantation.”).

184. *Id.*

185. Frost, *supra* note 181, at 251.

186. James M. DuBois, *Is Organ Procurement Causing the Death of Patients?* 18 *ISSUES IN LAW & MED.* 21, 24 (2002), available at <http://www.jstor.org/stable/3527567>.

187. *Id.*; see also James L. Bernat, *A Defense of Whole-Brain Concept of Death*, 28 *HASTINGS CTR. REP.* 14, 16-17 (1998). “As a matter of public policy, respecting the dead donor rule is essential to maintaining public confidence in the medical profession’s role in organ procurement. Continuing to require the dead donor rule frees patients from the fear that physicians will declare them dead prematurely for the purpose of procuring their organs.” *Id.* at 22.

### A. Accuracy of Determining Death by Circulatory Criteria

The permanent cessation of circulation and respiration is by far the oldest and easiest method for determining that a person is dead. The presence of so-called “vital functions” is the historic marker of life, and conversely, their absence is the historic marker for death. Until recently, when a person’s heart stopped beating and chest stopped moving, there was little doubt that the person was dead. Death was confirmed when the body became grey and rigid. In today’s world the criteria have not changed but there is less willingness to wait for confirmation of death, because every minute that a patient’s/corpse’s organs are without oxygen, the viability of organs decreases.

Historically, little significance was placed on the causal relationship between the permanent cessation of cardio-pulmonary function and the irreversible cessation of all bodily functions.<sup>188</sup> When a person’s heart stopped beating and/or his or her breathing stopped, it was impossible to restart them.<sup>189</sup> Not until the mid nineteenth century were there any techniques for artificial respiration (Dr. Silvester’s method was introduced in 1858), and not until the mid twenty century did artificial respiration combined with chest compression as it is in modern Cardiopulmonary Resuscitation (CPR) become the preferred resuscitative practice.<sup>190</sup> Methods that make it possible to restart a person’s heart beat or respiratory function understandably seem miraculous and beg the question of how long does one try to restart these functions when they have stopped.<sup>191</sup> The most commonly accepted standard is still applied by emergency medical teams when they come across a heart attack victim - at least thirty minutes if the

---

188. *History of CPR*, AM. HEART ASS’N, <http://www.americanheart.org/presenter.jhtml?identifier=3012990> (last visited Oct. 29, 2010).

189. *Id.*

190. Not until the 1700s was mouth-to-mouth resuscitation officially recommended. The 1900s brought about chest compressions, and finally the combination of respirations and compressions. *Id.*; see also *Silvester’s Method*, UNIVERSITY COLLEGE OF LONDON, <http://www.ucl.ac.uk/slade/slide/ShortStory/7b.html> (last visited Oct. 31, 2010).

191. *Know the Facts, Get the Stats: 2007*, AM. HEART ASS’N (Dec. 2006), [http://www.americanheart.org/downloadable/heart/116861545709855-1041KnowTheFactsStats07\\_loRes.pdf](http://www.americanheart.org/downloadable/heart/116861545709855-1041KnowTheFactsStats07_loRes.pdf) (“In cities with ‘community AED programs,’ when bystanders provide immediate CPR and the first shock is delivered within 3 to 5 minutes, the reported survival rates from VF sudden cardiac arrest are as high as 48 to 74 percent.”).



patient is an adult and no physician is accessible to advise.<sup>192</sup> But there are many factors that affect whether the patient's circulatory system will ever regain function, such as age, the general health of the person, whether the damage suffered due to illness or trauma can be repaired, and the length of time the person has gone without a self-sustained heartbeat.<sup>193</sup> The problem is that all these and other variables interact to make it very difficult to come up with a clear rule as to how soon it is appropriate to give up on trying to save a patient and turn to salvaging organs for transplantation.<sup>194</sup> The trick is finding the point at which the person as an integrated organism is irreversibly lost, but individual organs can still be restarted (even the heart) in another patient.<sup>195</sup> This becomes understandably difficult for the public to grasp when people have determined death for centuries, if not millennia, based on the *irreversible* loss of heart function.<sup>196</sup>

Equally confusing is the debate over how long to wait to see if the heart "auto-resuscitates" after efforts to save a person are stopped and organ retrieval is begun.<sup>197</sup> Simply put from a layman's perspective, if the heart could auto-resuscitate there would be no need for artificial resuscitative efforts in the first place. The whole point of emergency medical treatment is that the patient needs medical support to survive and to have even a chance at recovery. The common misconception is that emergency support will not be withdrawn until it is clear that the patient is in fact dead, not just when the medical team feels reasonably sure that the patient will die despite their best efforts.<sup>198</sup> This perspective is not only a public misconception; it is also the underlying premise in the emergency medical services protocol described above.<sup>199</sup>

---

192. *Cardiopulmonary Resuscitation Protocol*, U.S. COAST GUARD, [http://uscg.mil/hr/cg112/docs/pdf/SAR\\_CPR\\_protocols.pdf](http://uscg.mil/hr/cg112/docs/pdf/SAR_CPR_protocols.pdf).

193. AM. HEART ASS'N, *supra* note 191; U.S. COAST GUARD, *supra* note 192.

194. *See* Bernat, *supra* note 155.

195. *Id.*

196. PRESIDENT'S COMM'N, *supra* note 6, at 5 ("Traditionally, the cessation of heartbeat and of breathing were regarded by the lay and medical communities alike as the definitive signs of death.").

197. *Id.*

198. U.S. COAST GUARD, *supra* note 192.

199. *Id.*

The modern medical standard for determining cardiac death for potential organ donors is clearly convoluted. Imagine a person whose circulatory system is so severely damaged that it cannot be repaired, for example, someone who has uncontrolled bleeding in too many places to even try to repair them all, yet that person's heart is still beating, albeit with the assistance of resuscitative efforts, and although the patient is unconscious, his brain is not damaged or not severely damaged. If resuscitative efforts are stopped and the person's heart does not beat on its own, is that person dead or only dying? Will that person be dead seventy-five seconds to five minutes later, at the moment when his heart is removed and restarted in another person? Does it make any difference if you know that neurologists believe it takes approximately fifteen to twenty minutes of anoxia to the brain to halt higher neurological function, even longer to cause total brain death?<sup>200</sup> Does the fact that the heart is virtually worthless for transplantation purposes if it is not removed within ten minutes after oxygenation stops or that all major organs deteriorate rapidly if not oxygenated by a beating heart change whether the person described above is dead?<sup>201</sup> There is no doubt that the standards for determining cardiac death are evolving not because of new discoveries about the dying process, but because of a desire to find ever more efficient ways to harvest the most viable organs possible. The question is how should the law adapt to deal with these changes?

#### *B. Accuracy of Determining Death by Brain Criteria*

Brain death, unlike cardiac or circulatory death, is being challenged because of new scientific discoveries.<sup>202</sup> The use of brain death as a prerequisite for organ donation necessitates: 1) an acceptance that a cessation of a certain neurological functions can be equated with death of the person as a whole (a precept which has gained wide acceptance both in law and in public opinion over the last fifty years); and 2) that our ability to test for those functions is accurate (a precept which is increasingly challenged). The science behind brain death remains insecure in its ability to directly examine brain death/life, and medical experts are divided over whether brain death can be generalized to death of the organism as a whole.<sup>203</sup>

---

200. James L. Bernat, *Contemporary Controversies in the Definition of Death*, 177 PROGRESS BRAIN RES. 21 (2009) [hereinafter *Contemporary Controversies*]; see also Bernat, *supra* note 155.

201. See *Contemporary Controversies*, *supra* note 200.

202. PRESIDENT'S COUNCIL, *supra* note 14, at 6.

203. *Id.*

The President's Council on Bioethics' 2008 White Paper on "Controversies in the Determination of Death" raises questions about the efficacy of the use of "brain death" criteria.<sup>204</sup> Specifically, the report raises the question of what, exactly, the term "brain death," used both colloquially and medically, indicates; whether "'brain death' is, indeed, the death of the human being;" and what to make of reports of patients with evidence of ongoing integrated bodily activities (a requisite of the determination of death cited earlier in the Council's paper) who meet criteria of "whole brain death?"<sup>205</sup> None of these challenges are answered in the Council's report, and evidence a need for further exploration into the meaning and use of "brain death" criteria for the determination of death.<sup>206</sup>

The concept of "brain death" thus seems to be a convenient legal fiction rather than a scientific fact. There is no other potential pool of organ donors whose treatment is more obviously futile both from a personal and a public perspective than brain dead patients. Yet, to decide that life without significant brain function is not worth living is not the same as to say a person whose brain is severely and irreparably damaged is dead. There is life even with an irreversibly damaged brain; however, it is just not a life most people feel is worth preserving, given the futility of further medical intervention and the unlikelihood of meaningful recovery.<sup>207</sup> The notion of "brain death" was not discovered, but was rather invented to allow healthcare professionals to unilaterally remove such patients from life-support without fear of liability.

---

204. *Id.*

205. *Id.*

206. See *Medical Subject Headings*, NAT'L LIBRARY OF MED. (2009), [http://www.nlm.nih.gov/mesh/2010/mesh\\_browser/MBrowser.html](http://www.nlm.nih.gov/mesh/2010/mesh_browser/MBrowser.html) (search "persistent vegetative state" and see information listed under heading "Scope Notes"). A permanent vegetative state (PVS) "refers to the neurocognitive status of individuals with severe brain damage, in whom physiologic functions (sleep-wake cycles, autonomic control, and breathing) persist, but awareness (including all cognitive function and emotion) is abolished." Additionally, functional MRI examinations have been utilized in "detecting covert signs of residual cognitive function" in vegetative state patients. *Id.* See also Martin M. Monti et al., *Willful Modulation of Brain Activity in Disorders of Consciousness*, 362 N. ENG. J. MED. 579, 588 (2010). Also, "misdiagnosis of brain death is possible if a locked-in syndrome, hypothermia, or drug intoxication is not recognized." Eelco F.M. Wijdicks, *The Diagnosis of Brain Death*, 344 N. ENG. J. MED., 1215, 1218 (2001).

207. J.L. Bernat et al., *Report of a National Conference on Donation after Cardiac Death*, 6 AM. J. TRANSPLANTATION 281, 282 (2006).

What all these difficulties make evident is that death itself has not changed only our willingness to declare people dead earlier in the dying process, and the ultimate question is has doing so really benefited society particularly given the growing trust crisis and the recent downward trend in organ donation?

## VI. INCONSISTENCIES IN LAW AND PRACTICE

One goal of the UDDA, which it has in common with all NCCUSL documents, is an attempt to create uniformity in practices across state lines.<sup>208</sup> While the NCCUSL did succeed relatively well in creating a semblance of uniformity in determination of death laws,<sup>209</sup> the implementation of those laws, even those that seem similar in substance, is far from uniform, and the policies of individual medical institutions are even less consistent. A person who is legally dead according to the statute of one

---

208. NATIONAL CONFERENCE OF COMM'RS, *supra* note 131.

209. Today, all states have established legal standards for determining death that includes brain death criteria, but not all states have uniformly adopted the UDDA. Forty-three governing bodies (thirty-six states, District of Columbia, Puerto Rico, and the Virgin Islands) have determination of death acts almost identical to the UDDA. *A Few Facts About the Uniform Determination of Death Act*, NAT'L CONFERENCE OF COMM'RS ON UNIFORM STATE LAWS, [http://www.nccusl.org/nccusl/uniformact\\_factsheets/uniformacts-fs-udda.asp](http://www.nccusl.org/nccusl/uniformact_factsheets/uniformacts-fs-udda.asp) (last visited Nov. 30, 2010). Three states have legal standards for brain death determined through court precedent, which usually identify the UDDA criteria as a nationally recognized standard even if the act itself is not cited. Arizona and Washington both follow the UDDA and Massachusetts follows the UBDA. *See*, Arizona v. Fierro, 603 P.2d 74, 74 (Ariz. 1979); Commonwealth v. Golston, 366 N.E. 2d 744, 744 (Mass. 1977); and *In Re Bowman*, 617 P.2d 731, 731 (Wash. 1980). Only Virginia retains the language of the original Kansas law for determining death. VA. CODE ANN. § 54.1-2972 (2010). Hawaii, Iowa, Kentucky, Louisiana, and Texas use the Capron-Kass standards. *See* HAW. REV. STAT. § 327C-1 (2010); IOWA CODE § 702.8 (2010); KY. REV. STAT. ANN. § 446.400 (LexisNexis 2010); LA. REV. STAT. ANN. § 9:111 (2010); TEX. HEALTH & SAFETY CODE ANN. § 8.761.001 (West 2010). Florida, Illinois, and Massachusetts maintain the UBDA criteria for determining death. FLA. STAT. §382.009 (2010); 755 ILL. COMP. STAT. § 50/1-10 (2010); *Golston*, 366 N.E. 2d at 744. New Jersey and New York follow the general verbiage of the Capron-Kass standard but includes exemption from brain death based on religious beliefs. *See* N.J. STAT. ANN. § 26:6A-1 et seq. (West 2010); *Guidelines for Determining Brain Death*, N.Y. STATE DEP'T OF HEALTH (Dec. 2005), [http://www.nyhealth.gov/professionals/doctors/guidelines/determination\\_of\\_brain\\_death/docs/determination\\_of\\_brain\\_death.pdf](http://www.nyhealth.gov/professionals/doctors/guidelines/determination_of_brain_death/docs/determination_of_brain_death.pdf). New York requires each hospital to formulate written policies that specify the process for determining brain death, using the Department of Health's manuscript as a guideline for making the policy. *Id.*

state is alive according to the statutes of another, and, even within a state, a person found dead according to the policies of one medical institution might be considered alive according to the policies of another.

#### *A. Legal Inconsistencies*

The UDDA so far has been adopted legislatively in 38 states and two U.S. territories, and judicially in two additional states.<sup>210</sup> The ten states that have not adopted the UDDA are Florida, Hawaii, Illinois, Iowa, Kentucky, Louisiana, Massachusetts, New Jersey, Texas, and Virginia.<sup>211</sup> Dissenting states follow one of four alternative approaches: (1) the Uniform Brain Death Act (UBDA),<sup>212</sup> (2) the Capron-Kass Model,<sup>213</sup> (3) the Kansas model,<sup>214</sup> or (4) those that follow a model that creates a religious exception to reliance on brain death criteria for determining death.<sup>215</sup>

It is worth noting that some of these statutes clearly express a mistrust of the NCCUSL criteria for determining death.<sup>216</sup> For example, in Virginia,

210. See sources cited *supra*, note 209; see also DC CODE §7-601 (2010); V.I. CODE ANN. tit. 19, § 869 (2010).

211. *Id.*

212. Florida, Illinois, and Massachusetts follow the UBDA standard, wherein only the standard of brain death is explicit and the traditional cardiorespiratory standard is unwritten. See FLA. STAT. §382.009 (2010); 755 ILL. COMP. STAT. § 50/1-10 (2010); *Golston*, 366 N.E. 2d at 744.

213. Hawaii, Iowa, Kentucky, Louisiana, and Texas follow the Capron-Kass Model, which provided a concise and clarified revision to the Kansas version. See HAW. REV. STAT. § 327C-1 (2010); IOWA CODE § 702.8 (2010); KY. REV. STAT. ANN. § 446.400 (LexisNexis 2010); LA. REV. STAT. ANN. § 9:111 (2010); TEX. HEALTH & SAFETY CODE ANN. § 8.761.001 (West 2010).

214. Virginia follows the Kansas Model: the original, wordy and somewhat nebulous text accused of creating a situation of two deaths. VA. CODE ANN. § 54.1-2972 (2010).

215. New Jersey and New York both allow for a person to not be declared dead based on religious exemption. See N.J. STAT. ANN. § 26:6A-1 et seq. (West 2010); see also *Guidelines for Determining Brain Death*, *supra* note 209.

216. *E.g.*, VA. CODE ANN. § 54.1-2972 (West 2010) (“A person shall be medically and legally dead if . . . there is the absence of spontaneous respiratory and spontaneous cardiac functions and . . . attempts at resuscitation would not . . . be successful in restoring spontaneous life-sustaining functions . . . [or] there is the absence of brain stem reflexes, spontaneous brain functions and spontaneous respiratory functions.”).

circulatory criteria may only be relied upon if any attempt at CPR would not restore such functions or if used in conjunction with brain criteria.<sup>217</sup> In Connecticut, the language used in its determination of death statute is different than what is used in its anatomical donations statute, the former using the UDDA standard, and the latter explicitly accepting only a brain death determination of death, while allowing for “other method[s] of determining death,” without specifying if those other methods are circulatory criteria or something else.<sup>218</sup> Hawaii restricts the use of brain criteria to cases involving organ donation or the cessation of artificial life-sustaining treatment, at all other times circulatory criteria suffice.<sup>219</sup> In Illinois - for purposes of the Health Care Surrogate Act - death is defined according to the UDDA, clearly applying circulatory and brain criteria in the alternative, but elsewhere Illinois law identifies brain death as the only acceptable means of determining death for organ and tissue donation.<sup>220</sup>

Furthermore, note that various statutes describe the preponderance of evidence for death differently: The Kansas model required that death be

---

217. *Id.*

218. Compare CONN. GEN. STAT. ANN. § 19a-504a (West 2010), with CONN. GEN. STAT. ANN. § 19a-279h(b) (West 2010). The language of the Determination of Death Statute stipulates that for a qualifying hospital to determine whether to remove a patient from life support there must be “either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead. Determination of death shall be made in accordance with accepted medical standards.” Whereas the Anatomical Donations Statute directs that a donor be pronounced dead if “in accordance with . . . customary standards of medical practice, the donor has suffered a total and irreversible cessation of all brain function. A total and irreversible cessation of all brain function shall mean that the heart and lungs . . . cannot function, and are not functioning, without artificial supportive measures.”).

219. HAW. REV. STAT. ANN. § 327C-1 (LexisNexis 2010) (“The determination of death in all other cases [non-donor cases] shall be made [based on cardio-respiratory functions].”).

220. Compare 755 ILL. COMP. STAT ANN. § 40/10 (West 2010) (“‘Death’ means when, according to accepted medical standards, there is (i) an irreversible cessation of circulatory and respiratory functions or (ii) an irreversible cessation of all functions of the entire brain, including the brain stem.”), with 755 ILL. COMP. STAT ANN. § 50/1-10 (West 2010) (“‘Death’ means for the purposes of the Act, the irreversible cessation of total brain function, according to usual and customary standards of medical practice.”).

“based on ordinary standards of medical practice,”<sup>221</sup> which is what was suggested by the Capron-Kass model.<sup>222</sup> The ABA model uses “according to usual and customary standards of medical practice.”<sup>223</sup> The UBDA states “made in accordance with reasonable medical standards.”<sup>224</sup> The AMA prefers “made in accordance with accepted medical standards,”<sup>225</sup> as does the UDDA, and the forty states that follow the UDDA.<sup>226</sup> Other states use significantly different terminology. For example, Illinois uses “usual and customary standards.”<sup>227</sup> Idaho law states “in accordance with accepted medical standards which mean the usual and customary procedures of the community in which the determination of death is made.”<sup>228</sup> Idaho’s legislation acknowledges the nation-wide fact that there is no clear standard in most areas; standards vary not only from state to state but also from community to community. In reality, standards even vary from one medical institution to another within the same community.

Finally, note that altering treatment plans for a hopelessly injured patient can do just as much to expedite organ retrieval as declaring that patient dead. It is possible, given current medical practices, independent of statutory requirements, to cease curative efforts and prepare a patient for organ

221. Compare KAN. STAT. ANN. §§ 65-101-09, 58-625 to 58-32 (2009) (“based on ordinary standards of medical practice, there is the absence of spontaneous brain function; and if based on ordinary standards of medical practice, during reasonable attempts to either maintain or restore spontaneous circulatory or respiratory function in the absence of aforesaid brain function . . .”), with HAW. REV. STAT. ANN. § 327C-1 (LexisNexis 2010) (basing its determinations of death on “ordinary standards of current medical practice”).

222. See Alexander M. Capron & Leon R. Kass, *A Statutory Definition for the Standards for Determining Human Death: An Appraisal and A Proposal*, 121 U. PA. L. REV. 87, 111 (1972).

223. PRESIDENT’S COMM’N, *supra* note 6, at 64.

224. *Id.* at 143.

225. *Uniform Determination of Death Act*, *supra* note 144.

226. *Id.* at 5.

227. As previously mentioned, “death” is defined twice in Illinois legislature. 755 ILL. COMP. STAT ANN. §§ 40/10, 50/1-10 (West 2010) (using both “accepted medical standards” and “customary standards of medical practice”).

228. IDAHO CODE ANN. § 54-1819 (2010).

donation quite some time before a declaration of death. So it is possible, and some believe even probable, that a patient's status as a potential organ donor can influence pre-death treatment decisions independent of when it is legally appropriate to declare the patient dead. If legislators in Virginia, Connecticut, Hawaii and Illinois intended to prevent premature determinations of death for organ donors by requiring a determination of death through the use of brain criteria, and not circulatory criteria, then that intent can in many instances be thwarted by altering the end of life care of potential organ donors to include preparation for organ retrieval prior to a declaration of death. In other words, the significant moment for the protection of dying patients is not the actual declaration of death, but the point at which life-saving efforts cease and preparation for organ retrieval begins. Legislators in Virginia and other states that rejected the UDDA language may have found a way to help avoid the possibility that organ donors are declared dead prematurely, but they have not prevented, if that was their intention, the practice of treating donors as if they were dead well in advance of an actual declaration of death.

### *B. Implementation Inconsistencies*

Variations in legal standards beget inconsistencies in implementation. Even with commonly shared statutes such as the UDDA, individual institutional policies exhibit a wide range of troubling differences. Common discrepancies include: when death is declared, what interventions are initiated without consent, what procedures are allowed before death is declared, and what is communicated to patients and families regarding the organ retrieval process, particularly the preparations that take place before the donor's death.

#### *1. Declaring Death*

Although state statutes mandate the basic criteria necessary for a determination of death, implementation standards are left up to the medical community. Unfortunately, there is considerable discord within the medical community regarding both the specifics of declaring death and the appropriateness of using certain procedures and practices in temporal proximity to a declaration of death.

Marin County, California has a policy that allows emergency medical service (EMS) workers to declare death.<sup>229</sup> The policy states that a patient

---

229. *Determination of Death in the Prehospital Setting: ALS Personnel*, MARIN CNTY. EMERGENCY MED. SERVS. 1 (2001), <http://www.co.marin.ca.us/depts/hh/main/ems/documents/Policies/8110.pdf>. The Policy, in part, states:

Paramedics may not pronounce death, they may declare apparent death. [Patient may be declared dead if] 1. Patient is in cardiac arrest (pulseless and non-



discovered in a state of cardiac arrest AND not known to be alive in the preceding fifteen minutes may be declared dead.<sup>230</sup> The policy also allows EMS workers to take into account social considerations such as “resuscitative efforts are not wanted or appropriate, terminal disease, family request, etc.” in determining the appropriateness of non-action.<sup>231</sup> By contrast, the protocol provided by the United States Coast Guard provides that unless the patient is obviously dead, or after ten minutes of CPR it is determined that the patient has not revived and higher level medical care is more than thirty minutes away and contact with a physician is impossible and the patient is at least eighteen years of age, CPR must be continued.<sup>232</sup>

Compare the above protocols to the “Brigham and Women’s Hospital Policy on Declaration of Death by Brain Criteria” which is consistent with many hospital protocols. The procedure section begins with “An attending physician must assume the responsibility for the determination and declaration of death by brain criteria.”<sup>233</sup> In addition, the policy details that

breathing) 2. The patient was discovered in a state of cardiac arrest AND was not known to be alive in the preceding fifteen (15) minutes. If Do Not Resuscitate advance directive is present, witness to the arrest does not preclude declaration of death 3. Asystole has been documented in two monitoring leads for one (1) minute.

*Id.*

230. *Id.*

231. *Id.*

232. See U.S. COAST GUARD, *supra* note 192, at 2. The Coast Guard noted that:

2. Obviously dead patients include those that are decapitated, incinerated, have major organs (heart, lungs, brain or liver) separated, or for whom rigor mortis or lividity is present.

...

4. This is a SAR or MedEvac Mission, where higher level medical care is more than 30 minutes away, contact with a physician is impossible and the patient is 18 years of age or older.

5. When patient is not obviously dead, CG EMS providers will start and continue CPR until: Patient revives, EMS provider becomes physically exhausted and cannot continue, EMS provider is relieved by another qualified aid provider, death is determined by a physician, or aid provider directed to stop by a physician.

*Id.*

233. BRIGHAM & WOMEN’S HOSP. LEGAL STAFF, GUIDELINES FOR DECLARATION OF DEATH BY BRAIN CRITERIA (2004).

it is intended to “assist members of the medical staff in determining death by brain criteria,” and not “to replace physician judgment in individual cases.”<sup>234</sup> Noteworthy differences include the focal responsibility of the attending physician, as well as the focus on diagnosing and declaring brain death without mention of social factors, such as those discussed in the Marin County EMS policy.

Finally consider the “University of Texas Medical Branch (UTMB) Policies and Procedures” which state, on the one hand, “[d]eclare death after 2-5 minutes of no pulse, apneic and unresponsive to verbal stimuli,” and, on the other hand, allowing death to be declared two to five minutes after “irreversible cessation of all spontaneous brain function,” but gives no indication as to how these two sets of criteria relate to the decision to stop resuscitative efforts.<sup>235</sup> Both these policy statements presuppose a valid determination to give up on resuscitative efforts.

Allowing the exclusion of various types of brain activity is counterintuitive to the UDDA’s notion of “whole brain death”, yet it is common medical practice to exclude many different types of brain activity from interfering with a declaration of death. The UTMB policy which allows a determination of brain death on clinical observations alone, without “confirmatory tests,”<sup>236</sup> lists all of the following as *not inconsistent* with a determination of brain death:

---

234. *Id.*

235. UNIV. OF TEXAS MED. BRANCH HOSP. ADMIN., INSTITUTIONAL HANDBOOK OF OPERATING PROCEDURES (2007), available at [http://www.utmb.edu/Policies\\_And\\_Procedures/Clinical/PNP\\_005024](http://www.utmb.edu/Policies_And_Procedures/Clinical/PNP_005024). Policy 9.15.9, provides:

- (a) A person is dead when, according to ordinary standards of medical practice, there is irreversible cessation of the person’s spontaneous respiratory and circulatory functions. (Patient is pulseless, apneic and unresponsive to verbal stimuli for a period of at least 2 - 5 minutes).
- (b) If artificial means of support preclude a determination that a person’s spontaneous respiratory and circulatory functions have ceased, the person is dead when, in the announced opinion of a physician, according to ordinary standards of medical practice, there is irreversible cessation of all spontaneous brain function. Death occurs when the relevant functions cease.
- (c) In cases of brain death, death must be pronounced before artificial means of supporting a person’s respiratory and circulatory functions are terminated.

*Id.*

236. *See id.* (“Conventional cerebral angiography, Electroencephalography, Transcranial Doppler ultrasonography, Technetium—99m hexamethylpropyleneamineoxime, (Tc-HMPAO) brain scan, Somatosensory evoked potentials”).

- Spontaneous movements of the limbs not caused by pathologic flexion or extension response.
- Respiratory-like movements characterized by shoulder elevation and adduction, back arching, and intercostal expansion without significant tidal volume.
- Sweating, blushing, and tachycardia.
- Normal blood pressure without pharmacologic support or sudden increase in blood pressure.
- Absence of diabetes insipidus.
- The presence of deep tendon reflexes, triple flexion response, and superficial abdominal reflexes.
- Babinski's reflex.<sup>237</sup>

These are only a few examples of how confusing the standards for determining death can be. The truth is that there are almost as many variations in how declarations of death are made in and out of the hospital setting as there are healthcare teams who make them.

## 2. *Before Death*

Keeping the care for the living patient and the recovery of organs separate is crucial in avoiding real and perceived conflicts of interest,<sup>238</sup> yet for many institutions it is difficult to maintain a clear separation.

The Louisiana State University Health Sciences Center–Shreveport, has policies that aim to maintain separation between patient care and the donation process, but nevertheless condones (albeit with reservations) the insertion of an intravenous or arterial catheter before the patient dies.<sup>239</sup> The

237. *Id.*; but see Michael Cooperman, *Diabetes Insipidus*, EMEDICINE CLINICAL KNOWLEDGE BASE, INSTITUTIONAL EDITION. (2009) (“Central diabetes insipidus is characterized by decreased secretion of antidiuretic hormone (ADH) . . . ADH is produced in the hypothalamus [which is located above the brain stem].”).

238. AM. MED. ASS'N, OPINION 2.157 - ORGAN DONATION AFTER CARDIAC DEATH (2005), available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2157.shtml> (“The health care professionals providing care at the end of life should be distinct from those participating on the transplant team. No member of the transplant team may have any role in the decision to withdraw life support or in the process leading to pronouncement of death.”).

239. LA. STATE UNIV. HEALTH SCI. CTR., ORGAN DONATION AFTER CARDIAC DEATH (DCD) PROTOCOL: LOUISIANA ORGAN PROCUREMENT AGENCY (LOPA), 1, 3 (2008), [http://www.sh.lsuhs.edu/policies/policy\\_manuals\\_via\\_ms\\_word/hospital\\_policy/h\\_5.7.1](http://www.sh.lsuhs.edu/policies/policy_manuals_via_ms_word/hospital_policy/h_5.7.1)

catheter insertion has no curative or palliative benefit - its only purpose is to prepare the dying patient for post-death organ retrieval. What if the patient is an organ donor but also has an advance directive that says he or she wants to die peacefully without any invasive end of life measures?

The Arkansas Children's Hospital protocol allows the organ procurement team to ask the clinical attending physician for changes in care to accommodate organ donation before the declaration of death but informing and getting consent from the family of the patient is required.<sup>240</sup> Also, the policy acknowledges the importance of comfort care, including a statement that the sedation and analgesia usually used during the withdrawal of life support may also be necessary when making preparations for organ retrieval implying that such preparations may cause discomfort to donors.

St. Vincent Hospital provides a "Donor Maintenance" list of what should be done post-donation consent, but before the withdrawal of life-support takes place. The types of interventions that are allowed without specific consent (all that is needed is consent to donate in general) include performing blood draws, obtaining X-rays, and placing an arterial line.<sup>241</sup> While the policy goes on to prohibit more invasive procedures such as cold perfusion before a declaration of death, the policy also states that just before removing life support measures, "[t]he ICU RN or physician will administer Heparin 300 units/kg IV push," which is administered to help preserve the donor's organs, without mentioning any need for consent for such a procedure.<sup>242</sup>

The literature on declaring death is replete with evidence of widespread inconsistencies. One study conducted at the University of Utah School of Medicine provides an extensive review of 105 institutional Donation after

---

.pdf ("Should the patient require the insertion of any intravenous and or arterial-line catheters, necessary measures will be taken to minimize patient discomfort.").

240. ARK. CHILDREN'S HOSP., DONATION OF ORGANS AFTER CARDIAC DEATH K-17, 1, 3 (Jan. 2009), [http://www.pediatricethics.org/index.php?option=com\\_docman&task=doc\\_download&gid=7&Itemid=](http://www.pediatricethics.org/index.php?option=com_docman&task=doc_download&gid=7&Itemid=) ("Care of the patient will continue . . . as it would for any patient on comfort care. Suggestions may be made by the ARORA staff regarding medical therapies to improve organ function. The family must be informed (and consent obtained), if additional therapies are used.").

241. ST. VINCENT INDIANAPOLIS HOSP., ST. VINCENT INDIANAPOLIS HOSPITAL: POLICIES AND PROCEDURES, ANATOMICAL GIFT AND DONATION AFTER CARDIAC DEATH, (2009). See the section titled "Donor Maintenance" for a complete list of the attending physician's responsibilities and tests performed once consent has been obtained. *Id.*

242. *Id.*

Cardiac Death Protocols (referred to at various times as “donation after cardiac death,” “non-heartbeating donation” and more recently and more accurately “donation after the cessation of circulatory functions” policies), finding that seventy-two percent of institutions have policies, and eighty-four percent of those policies specify criteria for determining death.<sup>243</sup> Of the majority of hospitals (eighty-five percent) that expressly declare a waiting period, ninety percent require five minutes from declaration of death to the beginning of organ harvesting, with only four outliers (varying from less than two and longer than five minutes).<sup>244</sup> Antommara and his coauthors, however, also state that while some specified waiting period between the determination of death and organ retrieval is common, “[m]ost supporters of DCD do not require additional time for the donor to also fulfill neurological criteria for death.”<sup>245</sup>

James L. Bernat, a well-published neurologist of Dartmouth-Hitchcock Medical Center, reports that participants in a 2005 national conference on DCD agreed with the Society of Critical Care Medicine that the wait time from onset of asystole to declaration of death should be at least two minutes and at most five minutes.<sup>246</sup> Additionally, the article notes that some procurement teams advocate requiring asystole of only “75 seconds on the grounds that 60 seconds was the longest reported duration of asystole that had been followed by autoresuscitation and that the sooner death can be declared after asystole, the less damage from warm ischemia will occur in the organs.”<sup>247</sup> Bernat is concerned about ever shortening wait times, but more concerned about practices that ignore the intent of such waiting periods by waiting for the actual retrieval but not waiting with the preparations necessary for retrieval. In particular, Barnat is concerned by efforts to improve organ perfusion following the removal of life-sustaining treatment.<sup>248</sup> He found that “several hospitals” in his survey provided

---

243. Armand H. Matheny Antommara et al., *Policies on Donation After Cardiac Death at Children's Hospitals: A Mixed-Methods Analysis of Variation*, 301 JAMA 1902, 1903 (2009).

244. *Id.*

245. *Id.* at 1906.

246. James L. Bernat, *The Boundaries of Organ Donation after Circulatory Death*, 359 N. ENG. J. MED. 669, 671 (2008).

247. *Id.*

248. *Id.*

Extracorporeal Membrane Oxygenation (ECMO) to the donor immediately after death is declared. He states:

If ECMO adequately provided circulation and oxygenation of the donor's entire body, it would retroactively negate the death determination by preventing the loss of circulation and respiration from becoming permanent and irreversible, potentially 'reanimating' the heart and preventing the progression to brain destruction on which the circulatory criterion of death is predicated.<sup>249</sup>

Further indicating the propensity to manipulate procedures to allow for the declaration of death before total organ failure, Bernat found that some institutions favored the use of an ECMO combined with an intraaortic occlusion balloon, used to block blood flow above the diaphragm (preventing perfusion of the brain and thoracic organs) because it spares the abdominal organs without perfusing the heart and brain, allowing those organs critical to the determination of death (heart and brain) to deteriorate while preserving other organs for transplant.<sup>250</sup>

Do such procedures undo the findings used for declaring death by interfering with the otherwise inevitable progression to brain death? How do these procedures affect the irreversibility requirement that is central to every legal definition of death?

### 3. Before Consent

While some advocate a switch to presumed consent for organ donation,<sup>251</sup> the current U.S. legal standard is that informed consent is required before organ donation and pre-death preparations for donation.<sup>252</sup> For this reason, preparations taken before consent to donation violate the standard that consent must be obtained. Even if a general consent to donation is obtained, there certainly is no "informed" consent for the types of pre-death organ

249. *Id.*

250. *Id.*

251. See, e.g., Alberto Abadie & Sebastien Gay, *The Impact of Presumed Consent Legislation on Cadaveric Organ Donation: A Cross Country Study*, 25 J. HEALTH ECON. 599, 613 (2005); C. Cohen, *The Case for Presumed Consent to Transplant Human Organs After Death*, 24 TRANSPLANTATION PROCEEDINGS 2168, 2169 (1992); Veronica English, *Is Presumed Consent the Answer to Organ Shortages? Yes*, 334 BRIT. MED. J. 1088, 1088 (2007).

252. OPINION 2.157, *supra* note 238 ("In cases of uncontrolled DCD, prior consent of the decedent or consent of the decedent's surrogate decision maker is ethically required. Perfusion without consent to organ donation violates requirements of informed consent for medical procedures and is not permissible.").

preserving procedures discussed in the last section. Such pre-death preparations clearly violate the legal disclosure requirement of informed consent, but they also potentially can conflict with a patient's express end of life treatment preferences. It is also evident that the medical community is well aware of these problems.

The AMA raised informed consent and disclosure concerns in its discussion of the 1993 Regional Organ Bank of Illinois (ROBI) Protocol. The AMA noted that perfusion was initiated before consent could be obtained from surrogates,<sup>253</sup> and further that, at least in its first iteration, the protocol allowed catheters to be inserted without consent and directed that catheters be concealed from families under the bed sheets.<sup>254</sup>

By way of contrast, consider the Beaumont Hospitals protocol, which provides a comprehensive list of what informed consent must include.<sup>255</sup>

253. AM. MED. ASS'N, CEJA REPORT 3-I-94—ETHICAL ISSUES IN ORGAN PROCUREMENT FOLLOWING CARDIAC DEATH: IN SITU PRESERVATION OF CADAVERIC ORGANS, 1, 2 (1993), [http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja\\_3i94.pdf](http://www.ama-assn.org/ama1/pub/upload/mm/369/ceja_3i94.pdf) (“[W]hen the original design was implemented, none of the initial 35 surrogates consented to perfusion . . . To enable a trial of in situ preservation, the protocol was revised to allow the commencement of perfusion without consent of the decedent’s surrogate decision-maker.”).

254. *Id.* at 3 (acknowledging that benefits of obtaining more organs for transplantation outweigh the harm done by perfusion to the cadaver, since the patient has already been declared dead and does not suffer harm. Due to the minimal level of intrusion and discrete manner in which perfusion is performed, it was observed that most grieving families were unable to identify that perfusion occurred. As a result, “[n]one of the families, even those who ultimately refused organ retrieval, objected when they learned that perfusion had occurred without their consent.”).

255. BEAUMONT HOSPITALS INSTITUTIONAL ETHICS COMMITTEE (IEC) AND LEGAL AFFAIRS, BEAUMONT HOSPITALS: PATIENT CARE POLICIES—CORPORATE, ORGAN DONATION FOLLOWING CARDIAC DEATH (DCD) (2009). The procedures for documenting the surrogate’s decision should be conducted as follows:

An explanation of DCD and the opportunity for donation.

An explanation of the medical and ethical rationale for DCD.

A clear statement that the surrogate is free to agree to or refuse donation.

An explanation of where and how support will be withdrawn and of the measures used to maintain patient comfort.

A period of time for questions about the donor process.

A period of time for the surrogate to consider the decision.

An explanation of any additional procedures needed for DCD, including pre-mortem procedures that may not be for the benefit of the patient (e.g., use of drugs, cannulation, bronchoscopy, liver biopsy, and other similar

The protocol states that “[f]amilies should be permitted to consent to, or refuse to consent to, the use of measures to restore circulation and oxygenation to the organs of a candidate for DCD if cardiovascular arrest occurs during testing.”<sup>256</sup> This type of openness and respect for the informed consent process, however, is more the exception than the rule among the protocols we reviewed.

#### 4. Disservice of Information

With all the inconsistencies in laws, professional standards, and institutional policies, it is not surprising that the public is confused about the relationship between declarations of death and the organ procurement process. To make things worse, even healthcare professionals charged with communicating about such issues at times lack clarity on these issues.<sup>257</sup>

While there seems to be, in at least a few instances, a conscious effort to conceal,<sup>258</sup> or at least not fully disclose, the details of the organ procurement process, there also seems to be a profound lack of consistency in communicating with the public on the interplay between determinations of death and organ harvesting. The ROBI protocol discussed above, as originally drafted, is an example where the consent process was intentionally thwarted and evidence of organ retrieval preparations were intentionally concealed.<sup>259</sup> Other less severe transgressions involve the unintentional dissemination of potentially misleading information.

No doubt the Southwest Transplant Alliance meant to inform the public when it created a brochure describing the organ donation process, but some

---

procedures), and their risks and complications and measures used to maintain patient comfort.

*Id.* at 4.

256. *Id.*

257. See Stuart Youngner et al., “Brain Death” and Organ Retrieval: A Cross-Sectional Survey of Knowledge and Concepts Among Health Professionals, 261 *JAMA* 2205, 2209 (1989) (regarding the health professionals’ confusion about the declaration of death and its implications in organ transplantation); see also Laura A. Siminoff et al., *Death and Organ Procurement: Public Beliefs and Attitudes*, 59 *SOC. SCI. & MED.* 2324, 2326 (2004).

258. See CEJA REPORT 3 –I -94, *supra* note 253 (discussing ways medical teams may mislead or conceal certain aspects of perfusion after the declaration of death but before the decision by the decedent’s family to donate).

259. *Id.* at 2.



of that brochure's content is confusing and potentially misleading.<sup>260</sup> The brochure which divides the organ procurement process into chronological steps, discusses how death is declared in its fifth step, but then in its sixth step discusses providing medication for organ viability and comfort care. Why would comfort care be needed after a patient is dead? Also, in one place, the brochure tells patients and their families that donation does not take place until after five minutes of asystole, but elsewhere the same brochures states that donation takes place after *two to* five minutes of asystole.<sup>261</sup> Then immediately following a discussion of organ procurement, the brochure state that "if the patient does not expire within one hour, the medical staff transfers the patient to a location [...]," allowing for the possible misconception that patients are expected to expire during the organ procurement process.<sup>262</sup> Far from catering to a fourth grade reading level, the information provided requires extensive familiarity with the organ procurement process to decipher what is meant. Such confusing statements have the potential to unsettle family members, and are more likely to create mistrust in the organ procurement system than to educate the public effectively about the process.

---

260. See SOUTHWEST TRANSPLANT ALLIANCE, ORGAN DONATION AFTER CARDIAC DEATH: SAVING MORE LIVES, [http://www.organ.org/v2/assets/documents/brochures/Brochure\\_DonationAfterCardiacDeath.pdf](http://www.organ.org/v2/assets/documents/brochures/Brochure_DonationAfterCardiacDeath.pdf) (last visited Nov. 30, 2010).

261. Information provided by Southwest Transplant Alliance to potential donors and recipients states:

During transfer to the OR, the donor is supported on a ventilator and monitored by the surgical team and hospital staff. Once in the OR, medications are administered for organ viability and comfort care. When the team is ready, the donor is extubated. As in all settings where support is withdrawn, comfort measures for the donor are of the utmost importance.

A hospital staff member declares cardiac death. The OPO surgical team waits an additional two to five minutes to ensure the patient's heart does not start beating again. Research has shown that a patient's heart will not start beating again beyond two minutes after the declaration of cardiac death. After waiting five minutes, the organ recovery begins. If the patient does not expire within one hour, the medical staff transfers the patient to a location as outlined according to hospital policy and the attending physician is contacted.

*Id.* at 6.

262. *Id.*

The most glaring lack of informed consent takes place where most people sign up to be donors -- at their state department of motor vehicles (DMV).<sup>263</sup> Most DMV websites provide no information about the organ procurement process, nor do they provide links to outside resources that might be able to answer potential donors' questions.<sup>264</sup> For example, a search on the Wisconsin DMV site for the word 'organ,' brought up information on how to register to be a donor, but non-active links to fact sheets about organ donation itself.<sup>265</sup> Even if DMV websites were more informative, most people would probably appreciate having information available at the DMV itself when they are asked to make the decision to donate, not through a computer at another time and place. Consent given under such circumstances may be voluntary, but it is far from "informed."

## VII. THE TRUST CRISIS

There is a well-documented crisis in the public's trust in all types of authority, including healthcare professionals.<sup>266</sup> Current organ procurement policies need to be analyzed against the background of this crisis. The problem is severe enough that the Harvard School of Public Health has a "Healthcare Trust Initiative" which recently published *The Trust Crisis in Healthcare: Causes, Consequences, and Cures*,<sup>267</sup> and has several ongoing

---

263. See generally Sandra Woien et al., *Organ Procurement Organizations Internet Enrollment for Organ Donation: Abandoning Informed Consent*, 7 BIOMED CENTRAL MED. ETHICS 1, 7 (2006), <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1764895/pdf/1472-6939-7-14.pdf> (discussing how the enrollment programs for organ donation do not meet informed consent standards).

264. See, e.g., *Becoming an Organ Donor*, WIS. DEP'T OF TRANSP., DEP'T OF MOTOR VEHICLES, <http://www.dot.wisconsin.gov/drivers/drivers/apply/donor.htm> (last visited Oct. 25, 2010).

265. *Organ Donor: Facts and Figures 2008*, WIS. DEP'T OF TRANSP. 1 (2009) <http://www.dot.wisconsin.gov/drivers/docs/organdonor.pdf>; *Organ Donor Recipient Discusses Issues To Being An Organ and Tissue Donor*, WIS. DEP'T OF TRANSP., <http://www.dot.wisconsin.gov/drivers/docs/audio-organdonation.doc> (last visited Nov. 30, 2010).

266. See generally DAVID A. SHORE, *THE TRUST CRISIS IN HEALTHCARE: CAUSES, CONSEQUENCES, AND CURES* (2007).

267. *Id.*

projects dealing with how to help physicians regain the trust of their patients and the general public.<sup>268</sup>

#### *A. Trust in the Organ Procurement System is Failing*

The last half-century has brought significant advances in organ transplantation, but it also has traded the personal relationship of general practitioner and patient for a medical-industrial complex.<sup>269</sup> The impersonal nature of modern medicine makes mistrust inevitable, especially among the poor and minorities where such lack of trust is far from unfounded.<sup>270</sup> The situation is aggravated by constant reminders that healthcare costs are too high<sup>271</sup> and that the organ shortage is reaching desperate proportions,<sup>272</sup> both

---

268. *Forces of Change: New Strategies for the Evolving Health Care Marketplace*, HARVARD SCH. OF PUB. HEALTH, <http://www.hsph.harvard.edu/ccpe/programs/Forces.html> (last visited Oct. 31, 2010).

269. *See generally*, Arnold S. Relman, *The New Medical-Industrial Complex*, 303 N. ENG. J. MED. 963 (1980); *see also* James W. Jones et al., *Consultation or Corruption? The Ethics of Signing on to the Medical-Industrial Complex*, 43 J. VASCULAR SURGERY 192, 193 (2006).

270. Recent studies into the donation and transplantation practices by minorities in the U.S. is vastly underrepresented, especially among the African-American community, when compared with the Caucasian community. Comparing the 2000 Census report and data from the UNOS, while the US population is roughly 75% white and 12% black, about 38% of the patients on the kidney waiting list are white and 34% of them are black. *See* U.S. CENSUS BUREAU, POPULATION BY RACE AND HISPANIC OR LATINO ORIGIN (2001), <http://www.census.gov/population/www/cen2000/briefs/phc-t1/tables/tab01.pdf>. This illustrates the inordinate burden to find matched organs present on the African-American minority community. Furthermore, disparities in use of renal transplantation as treatment for ESRD are exacerbated between whites and blacks, considering 30.9% of whites for whom dialysis would be sufficient were placed on the waiting list, and 29% of black patients for whom transplantation was recommended were directed to continue dialysis. Arnold M Epstein et al., *Racial Disparities in Access to Renal Transplantation - Clinically Appropriate or Due to Underuse or Overuse?*, 343 N. ENG. J. MED. 1537, 1541 (2000). Finally, it has been shown that black patients are less likely to donate due to their distrust of the medical system. L. Ebony Boulware et al., *Understanding Disparities in Donor Behavior: Race and Gender Differences in Willingness to Donate Blood and Cadaveric Organs*, 40 MED. CARE 85, 89 (2002). Due to this distrust, the result is fewer organ donations to black patients in need. *See generally* Wayne B. Arnason, *Directed Donation: The Relevance of Race*, 21 HASTINGS CTR. REP. 13, 13-19 (1991).

271. *See e.g.*, Lesley Alderman, *Doctors Offer Thoughts on Cutting High Health Care Costs*, N.Y. TIMES (Mar. 20, 2010), <http://www.nytimes.com/2010/03/27/health/27patient.html>.

of which can be perceived as motivating healthcare professionals to give up on dying patients sooner than patients or their families would like.

In a recent article, James DuBois, who served on the Institutes of Medicine 2006 Committee on Increasing Rates of Organ Donation, discusses a finding that “25 percent or more of the members of groups surveyed expressed fears that if they signed a donor card, then physicians would do less to save their lives.”<sup>273</sup> One 2006 study reported in *Critical Care Medicine* shows that healthcare workers have concerns that the need for transplantable organs may cause a conflict of interest between the care given dying patients and the care needed to preserve organs for transplantation.<sup>274</sup> Numerous other articles and newspaper reports echo similar concerns over the zeal with which organ procurement organizations attempt to increase donations.<sup>275</sup>

Traditionally the courts have relied on the judgment of medical professionals anytime death determinations were in question.<sup>276</sup> But, increasingly that reliance has come under scrutiny because of an ever growing potential for conflicts of interest. Cost containment and organ retrieval are potentially inconsistent with doing everything possible to save

---

272. UNITED NETWORK FOR ORGAN SHARING, [www.unos.org](http://www.unos.org) (last visited Nov. 15, 2010). As of 7:20 am on Monday, November 15, 2010, there are 109,673 candidates on the waiting list for an organ transplantation listed on UNOS' website. *Id.*

273. J.M. DuBois, *Increasing Rates of Organ Donation: Exploring the Institute of Medicine's Boldest Recommendation*, 20 J. CLINICAL ETHICS 13, 19 (2009).

274. See Maxine Harrington, *The Thin Flat Line: Redefining Who is Legally Dead in Organ Donation after Cardiac Death*, 86 DENV. U. L. REV. 335, 364 (2009) (discussing the conflict of interest the medical profession is faced with when it is supposed to give equal consideration to the patient in need of emergency room care and the potential organ recipient).

275. See, e.g., Rob Stein, *Project to get transplant organs from ER patients raises ethical questions*, WASH. POST, Mar. 15, 2010, at A1; see generally David Crippen, *Donation After Cardiac Death: Should We Fear the Reaper?*, 36 CRITICAL CARE MED. 1363, 1363-1364 (2008); Rob Stein, *New Zeal in Organ Procurement Raises Fears. Donation Groups Say They Walk a Fine Line, but Critics See Potential for Abuses*, WASH. POST (Sept. 13, 2007), <http://www.washingtonpost.com/wp-dyn/content/article/2007/09/12/AR2007091202681.html>; Laura A. Siminoff et al., *Racial Disparities in Preferences and Perceptions Regarding Organ Donation*, 21 J GEN. INTERNAL MED. 995, 999-1000 (2006).

276. See, e.g., *Youngberg v. Romeo*, 457 U.S. 307 (1982) (adopting the professional judgment standard for determinations about the adequacy of care).

the lives of patients dying of causes other than organ failure. Given that one patient's demise can save or prolong the life of as many as nine patients waiting for transplants,<sup>277</sup> the medical profession is faced with a dilemma - the longer efforts are expended on saving a potential organ donor, the lower the quality of that donor's organs for transplant.<sup>278</sup> This potential conflict means both the courts and society at large can no longer see the medical profession as an unbiased arbiter of the determination of death - thus as financial concerns increase and the organ shortage worsens, the public's suspicion of the medical profession inevitably increases as well.

The confusion, misinformation and lack of informed consent discussed in this article understandably compound the trust issues created by potential conflicts of interest. As mentioned above, studies show that a significant portion of the public fears that being an organ donor might induce healthcare professionals to discontinue emergency treatment earlier than otherwise because of their interest in preserving organs for transplant.

It is also relevant to note that in 2009, for the first time in twenty years, the United Network for Organ Sharing (UNOS) reported that the rate of voluntary organ donations decreased. This could be an indicator of just how pervasive mistrust of the organ procurement system has become.<sup>279</sup>

#### *B. How Current Organ Procurement Practices Are Contributing to the Trust Crisis*

New medical developments have made retrieving and preserving organs more efficient, in part through methods that require changes in end of life care rather than just changes in how cadavers are handled. These new techniques are making the current legal definition of death obsolete by blurring the line between life-saving measures and organ retrieval. And public trust in the transplant community is likely to continue to decline as

---

277. *Donation in the News*, LA. ORGAN PROCUREMENT AGENCY, <http://www.lopa.org/>, (last visited Nov. 14, 2010) ("While one donor can save up to nine lives and enhance the lives of over 50 people, there remains a critical shortage."). This number varies from seven to nine depending in part on whether kidneys are considered life-saving. Patients on dialysis can survive for years, but on average only live four years. A patient's survival rate, particularly if a live donor can be found, is much higher, some claim. See SIGRID FRY-REVERE, QUICK FACTS ABOUT KIDNEY DISEASE AND THE ORGAN SHORTAGE (2009), <http://ethical-solutions.org/wp-content/uploads/2009/10/Quick-Facts-Kidney-Disease-and-the-Organ-Shortage2.pdf>.

278. Harrington, *supra* note 274, at 364.

279. Jim Warran, *Living, Deceased Donations Decline for First Time*, NEPHR ONLINE (Apr. 28, 2009), [http://www.nephronline.com/features.asp?F\\_ID=429](http://www.nephronline.com/features.asp?F_ID=429).

current legal standards fail to cope with changing organ procurement practices.

### *1. The Information Gap and Informed Consent*

The conceptual divide between what the average person intuitively thinks of death and organ donation and the medical realities of both may give rise to a sense that there is a concerted attempt by the medical community to manipulate the public's end of life choices. While fears that organ donors will be declared dead prematurely may be unfounded, the exuberance with which organ procurement agencies and physicians treat the prospect of new donors only exacerbates the problem.<sup>280</sup> When perception and reality conflict, the public may understandably get the impression that they are being deceived in an attempt to collect more organs for transplant.

When individuals sign advance directives or talk to their relatives and friends about end of life options, they probably do not consider how the implementation of those wishes may be affected if they are a potential organ donor. Similarly, when people agree on their driver's license applications/renewals to be an organ donor, can it honestly be said that they are giving informed consent for what will be done to them both before and after they are declared dead should they qualify as a donor? Do individuals fully understand what they are agreeing to when they agree to be an organ donor?<sup>281</sup>

Healthcare professionals and researchers are also sensitive to the fact that the general public is not aware of, and might be disturbed by, the invasiveness of preparations for organ retrieval. The AMA's discussion of the ROBI protocol mentions that researchers concealed the arterial catheter inserted into the groin of the patient from the family with a bed sheet.<sup>282</sup> This concealment may have been intended to prevent questions from the family before efforts could be made to procure consent. Alternatively, the researchers may have concealed the catheter to spare relatives and proxies distress from seeing the tubing, although the AMA discussion states that

---

280. See *supra* text accompanying note 275.

281. Some of these questions pertain to considerations that apply to the practice of uncontrolled donations after cardiac death, which is a practice most potential donors may not be aware of. See *supra* Part VI.B.2.

282. See CEJA REPORT 3-I-94, *supra* note 253 ("The perfusion catheter, which is inserted in the groin, was hidden from view under a sheet and was not considered disturbing by the families. None of the families, even those who ultimately refused organ retrieval, objected when they learned that perfusion had occurred without their consent.").

researchers found that families were not disturbed by the catheter once it was revealed.<sup>283</sup>

While some of the procedures described in this Article may seem alien, if not unintelligible, to some donors and their families, the problems caused by lack of transparency are exacerbated by institutional inconsistencies. Building on the IOM's 1997 discussion of the vast disparity in transplantation protocols between hospitals,<sup>284</sup> Maxine Harrington, who is Professor of health law, torts, medical malpractice, and bioethics at Texas Wesleyan University School of Law, echoes what we have found in the protocols we have collected: there is no doubt that different hospitals pronounce death at different times for identical cases.<sup>285</sup>

In this climate, extreme caution is needed to prevent the perception that physicians are establishing organ procurement policies to benefit certain patients at the expense of others. Education and transparency may be a step in the right direction, but more needs to be done to increase the supply of organs without violating basic principles of respect for persons and without risking diminished public trust in the transplant community.

## *2. Retrieving Organs from the Dying, But Potentially Not Dead Yet Patient*

Current practices in organ donation create a trust crisis by inadequately delineating between the duty to preserve the life of a dying potential organ donor and the duty to save the lives of potential organ recipients. In particular, trends in donation after cardiac death are creating the perception that organs are being retrieved from the dying, but not yet dead, patient.<sup>286</sup>

### *a. From DCD to Brain Death and Back Again*

"Donation after Cardiac Death," (DCD) at first called "Non-Heartbeating Donation" and more recently and more accurately called "donation after the cessation of circulatory functions," was the original protocol for cadaveric organ retrieval.<sup>287</sup> When cadaveric transplants first became practical on a

283. *Id.*

284. HERDMAN & POTTS, *supra* note 153.

285. Harrington, *supra* note 274.

286. *See Contemporary Controversies*, *supra* note 200.

287. Murray performed the first kidney transplant between identical twins in 1954. *A Tribute to the Pioneers of Transplantation: Remarks by Dr. Murray at the U.S. Transplant Games*, NAT'L KIDNEY FOUND., [http://www.kidney.org/recips/athletics/50yrs/50yrs\\_firstTransplant.cfm](http://www.kidney.org/recips/athletics/50yrs/50yrs_firstTransplant.cfm) (last visited Oct. 31, 2010). His first successful kidney

larger scale in the 1960s because of the development of immunosuppressive drugs, all organs that were not taken from live patients came from patients who had recently been declared dead after a cessation of circulatory function.<sup>288</sup> Ischemia affecting the organs during the slow donor-to-donee transition resulted, however, in low quality organs for transplantation. As brain death criteria were written into law in many jurisdictions in the 1970s and 80s, transplant teams shifted their focus from DCD to brain dead donors because organs from brain dead donors could be retrieved immediately upon a declaration of death and thus were of higher quality.<sup>289</sup> If brain death criteria were met, organs could be retrieved regardless of whether circulatory functions had stopped and thus before the organs suffered from oxygen deprivation as they did in traditional DCD organ recovery situations.<sup>290</sup> But nevertheless it is common practice to wait until after circulation has stopped to harvest organs even from brain dead patients.

The common practice of waiting for a brain dead patient's circulatory functions to stop before retrieving organs indicates uneasiness with sole reliance on brain death criteria. In many, but not all, jurisdictions, it is legal to begin organ retrieval immediately upon a declaration of brain death, yet in every protocol we found, the transplant team has the option of starting preparations for organ retrieval immediately upon declaration of brain death, or even before, but may not actually remove organs until after the donors circulation has stopped.<sup>291</sup> The policy of waiting for a brain dead patient's circulation to stop before harvesting organs indicates a willingness to risk decreased organ viability for more certainty with respect to the

---

allograph was in 1959 and first cadaveric kidney transplant was in 1962. *Joseph E Murray: The First Successful Organ Transplants in Man*, OFFICIAL WEB SITE OF THE NOBEL PRIZE (Nov. 1, 2010), [http://nobelprize.org/nobel\\_prizes/medicine/laureates/1990/murray-lecture.html](http://nobelprize.org/nobel_prizes/medicine/laureates/1990/murray-lecture.html).

288. See CEJA REPORT 3-I-94, *supra* note 253, at 1 (“Prior to adoption of neurological criteria for death in the . . . 1970s, the medical community defined death solely as the cessation of cardiopulmonary function. Organs for transplantation had to be retrieved and cooled quickly after death to minimize warm ischemia until the period between circulatory arrest and commencement of cold storage.”).

289. *Id.* (“The organs of these cadavers continued to receive an ample supply of oxygenated blood through artificial support up until the actual moment of retrieval. This minimized ischemic damage and generated better organ functioning in transplant recipients.”).

290. *Id.*

291. See Antommaria et al., *supra* note 243.



determination of death of organ donors. Or perhaps it reflects acceptance of the philosophical perspective that it is futile to treat brain dead patients and that therefore it is acceptable to let them die, but not acceptable to retrieve their organs until they are in fact dead.

As the organ shortage worsened dramatically in the early twenty-first century and the transplant community continued to search for more efficient ways to procure organs, the notion of returning to DCD gained popularity.<sup>292</sup> Organs from DCD would be of better quality if death could be legitimately declared sooner rather than the traditional conservative standard of waiting at least five to ten minutes.<sup>293</sup> Since all determinations of death statutes left the exact timing used for DCD up to some variation of “medical standards,” transplant teams began to push the limits on how early after the cessation of circulatory functions organs could be harvested. With this shift came the totally predictable debate over whether waiting ten minutes, five minutes, two minutes or even a mere seventy-five seconds after circulatory failure was enough time to ensure the patient was really dead.

So far, this Article has primarily focused on “controlled” DCD, but “uncontrolled” DCD is even more controversial. Controlled DCD involves situations where a decision has been made to discontinue life-sustaining treatment and healthcare professionals can anticipate and control the dying process. All organ retrieval from brain-dead donors are controlled DCD, but so are cases where a patient is not brain dead but the family has decided continuing treatment is futile. For example, controlled DCD can take place when terminally ill patients are taken of life-support based on their own wishes as expressed in an advance directive or through their surrogates. Such situations involve a “controlled” donation after cardiac death because the timing of the patient’s death is somewhat predictable once life-support is removed and the organ retrieval team can be ready and waiting to proceed the moment death is declared. “Uncontrolled” DCD is different in that the death is unanticipated. For example, uncontrolled DCD takes place when patients suffer catastrophic events that cause their circulatory functions to stop. For such patients, death comes after the medical team fails to stabilize

---

292. See Peter L. Abt et al., *Donation After Cardiac Death in the US: History and Use*, 203 J. AM. C. SURGEONS 208, 208 (2006).

293. Traditionally, death would be declared when the heart and lungs cease functioning. Without motivation of organ preservation for donation, little if any literature addresses a waiting time for the determination of death following onset of “surrogate” symptoms until organ donation becomes keynote. N.Y. STATE TASK FORCE ON LIFE & THE LAW, DONATION AFTER CARDIAC DEATH: ANALYSIS AND RECOMMENDATIONS (Apr. 17, 2007), [http://www.health.state.ny.us/regulations/task\\_force/donation\\_after\\_cardiac\\_death/docs/donation\\_after\\_cardiac\\_death.pdf](http://www.health.state.ny.us/regulations/task_force/donation_after_cardiac_death/docs/donation_after_cardiac_death.pdf).

the patient and thus death is less predictable than with controlled DCD where removal from life-support precipitates the cessation of circulatory functions. In neither of these situations, controlled DCD (the specific situation where the patient is not brain-dead but the patient or proxy makes a quality of life decision) or uncontrolled DCD, is it practical to apply brain death criteria for the determination of death because the use of brain death criteria is more time-consuming than the use of circulatory criteria; so time consuming, as a matter of fact, that the organs would be useless if conventional methods for determining brain death were used.<sup>294</sup> While determinations based solely on clinical observations of brain death are not necessarily time consuming, they are not reliable early in the dying process, and taking the time to confirm brain death through an electroencephalogram (EEG), a cerebral blood flow (CBF) study, or other more technical means can take hours.<sup>295</sup> Thus, if there is going to be any chance of retrieving viable organs from such patients (those for whom life-support is terminated based on principles of self-determination and those who die despite emergency care), healthcare professionals must rely on circulatory criteria without any concern for whether brain criteria are met.

The NCCUSL probably did not have donation after cardiac death the way it is practiced today in mind when it updated the Uniform Brain Death Act with the Uniform Determination of Death Act.<sup>296</sup> Before the 1970s, organs retrieved after cardiac death were of very poor quality, in part, because of the time it took to orchestrate organ retrieval - it took time to obtain consent from families, to collect health information on the donor, and to notify and assemble the organ procurement team.<sup>297</sup> During the 1960s through 1980s,

---

294. Abt et al., *supra* note 292.

295. Confirmatory tests such as angiography and radionuclide brain scans require an injection of a dye into the blood stream thirty minutes to one hour in advance of the testing. The Electroencephalography (EEG) requires the placement of electrodes on the head and also usually requires at least an hour wait from set-up to results. The American Academy of Neurologists recommends a session of “no electrical activity during at least 30 minutes” for an EEG confirming brain death, as well as a repeat six hours later of any confirmatory test. See AM. ACADEMY OF NEUROLOGY, PRACTICE PARAMETERS: DETERMINING BRAIN DEATH IN ADULTS 3 (1994), <http://www.aan.com/globals/axon/assets/4462.pdf>.

296. Harrington, *supra* note 274.

297. Dr. Murray spoke about having up to forty minutes after death to get a kidney procurement organized:

On the evening of April 5, 1962, a 30-year-old male died in the hospital after open heart surgery. He had been on a by-pass oxygenator at 20°C (68°F) during this time and 3 hours prior to death had been hypotensive with little urinary

the concern was not how soon organs could be harvested after death, but rather how much time did the team have to organize transplant surgery before the organs became useless. With improved communication between hospitals and organ procurement agencies regarding potential donors, less of a need to consult with family for permission to retrieve organs (because of first person consent), and more efficient retrieval techniques, the focus shifted from lessening the time between death and transplantation to declaring death as soon as possible and doing as much as possible in preparation for organ retrieval before death is even declared.

Current DCD practices are troubling to anyone who believes the cessation of brain functions is integral to death because the sooner after circulatory functions cease that organ retrieval begins, the more likely that the donor's brain is still functioning when the retrieval takes place.<sup>298</sup> The American Heart Association states that “[b]rain death starts to occur four to six minutes after someone experiences cardiac arrest if no CPR and defibrillation occurs during that time.”<sup>299</sup> Estimates of how long after circulatory functions cease brain death criteria are met vary drastically depending on the overall condition of the patient and the severity of the ischemia. If the onset of brain death only begins after four to eight minutes of anoxia,<sup>300</sup> even a conservative ten-minute standard may be unacceptable to someone who considers the total loss of brain function a necessary condition for death. We have also heard people ask questions along the lines of, “[i]f the patient is not brain dead, does he or she feel pain or have some subconscious sense of what is going on?” The issue at hand, and one for which this article seeks remedy, is not whether such concerns have medical merit, but that it is not illogical for the public to ask such questions. The information gap between the medical community and the public is

---

output. The left kidney was removed and placed in a refrigerator at 4°C (39.2°F) within 40 min after death.

J.P. Merrill et al., *Transplantation of Kidney from a Human Cadaver*, 185 JAMA 347, 348 (1963).

298. See *Contemporary Controversies*, supra note 200.

299. *CPR Facts and Statistics*, AM. HEART ASS'N, <http://www.americanheart.org/presenter.jhtml?identifier=3034352> (last updated May 8, 2008).

300. Therese S. Richmond, *Cerebral Resuscitation After Global Brain Ischemia: Linking Research to Practice*, 8 AM. ASS'N CRITICAL-CARE NURSES 171, 173 (May 1997), available at <http://classic.aacn.org/AACN/jrn/nci.nsf/0/a522e8311772eca188256576007821ab?OpenDocument> (“A cascade of injurious events begins within minutes of ischemia. Within 6 to 8 minutes, permanent neuronal injury and death occurs in the central ischemic area.”).

disconcerting and needs to be addressed both for the sake of informed consent and to begin rebuilding public trust in the organ procurement system.

*b. The Irreversibility Conundrum*

Further complicating the debate are concerns over “irreversibility.”<sup>301</sup> All definitions of death include the requirement that the function used to determine death be irreversibly lost. But, if the loss of circulatory function must be irreversible, and the heart is an integral part of the determination of circulatory function, how is it possible to retrieve a heart from a “dead” patient and then restart it in another? Could not that same heart have been restarted in its original owner?<sup>302</sup> And, even if the original owner’s life could not be saved, isn’t the fact that the heart could be restarted in another patient evidence that the donor wasn’t dead when the heart was removed? If the heart can be started in another patient, perhaps the medical team did not try hard enough to restart the heart in its original owner or wait long enough before declaring death. These types of questions may indicate a lack of understanding of the medical status of such patients, but they nevertheless are questions we can expect the public to ask. In the realm of public perception, the scientific merit of such concerns is less important than how they affect trust in the medical profession and the organ procurement system.

Also, we are not convinced that perception is the only problem. Educating the public will not solve anything if the medical community is divided over what is appropriate. The irreversibility problem must be solved before progress can be made either in presenting accurate information to the public or in establishing clearer legal standards for the determination of death. Within the context of organ retrieval, primarily three approaches to when irreversibility may be assumed are common:

- (1) When the patient’s surrogate or family has decided to cease medical interventions (including any resuscitation efforts). This creates a situation where reversibility, even if possible, is against public policy;
- (2) When circulation cannot be restored even if resuscitative efforts are initiated or continued, in other words, there is a clear case of absolute medical futility;<sup>303</sup> or

---

301. See *Contemporary Controversies*, *supra* note 200; see also Menikoff, *supra* note 150 (discussing the difficulties and uncertainties in determining irreversibility with respect to cardiopulmonary function and organ donation).

302. Harrington, *supra* note 274.

303. See *supra* Part V.B. (discussing medical futility).

(3) When the patient will not auto-resuscitate if nothing is done.

Option (1) leaves the decision up to patients and their surrogates and is generally not controversial. The transplant community, in general, favors option (3) and rejects option (2). Yet, the American Heart Association's (AHA) resuscitation guidelines state all heart attack patients should be resuscitated unless they have a DNR order (option (1) has been exercised), there is evidence of rigor mortis (option (2)), or there is no physiological benefit to be expected from CPR (option (2) again).<sup>304</sup> The AHA standard only accepts options (1) and (2), but not option (3). The same can be said definitively of the law in Oklahoma and Virginia.<sup>305</sup> Option (2) is also the rule adopted by several courts for death determinations in non-transplant contexts.<sup>306</sup> Much hinges on which of these three approaches for defining

---

304. AM. HEART ASS'N, ECC GUIDELINES PART 2: ETHICAL ASPECTS OF CPR AND ECC (2000), available at [http://circ.ahajournals.org/cgi/content/full/102/suppl\\_1/I-12](http://circ.ahajournals.org/cgi/content/full/102/suppl_1/I-12). The guidelines state, in relevant part:

Physicians are not obliged to provide such care when there is scientific and social consensus that such treatment is ineffective. Some examples are CPR for patients with signs of irreversible death, such as rigor mortis, decapitation, dependent lividity, or decomposition. In addition, healthcare providers are not obliged to provide CPR if no benefit from CPR and advanced cardiovascular life support (ACLS) can be expected. For example, CPR would not restore effective circulation in a patient whose cardiac arrest is terminal and occurs despite optimal treatment for progressive septic or cardiogenic shock.

*Id.*

305. OKLA. STAT. tit. 63, § 63.3101.3 (2006) (“‘End-stage condition’ means a condition caused by injury, disease, or illness, which results in severe and permanent deterioration indicated by incompetency and complete physical dependency for which, to a reasonable degree of medical certainty, treatment of the irreversible condition would be medically ineffective.”); VA. CODE ANN. § 54.1-2990 (2009) (“[I]f the physician’s determination is contrary to the request of the patient, the patient’s advance directive, the decision of an agent . . . or a Durable Do Not Resuscitate Order, the physician shall make a reasonable effort to inform the patient or the patient’s agent . . . of such determination.”).

306. The Michigan Court of Appeals discussed irreversibility in a case where a child who had no heart-beat at the scene of an auto accident was later revived. The court held that the fact that medical intervention was required to restore circulation did not mean the child was dead before such resuscitative efforts proved effective. “Otherwise . . . the use of the word ‘irreversible’ becomes meaningless.” *People v. Selwa*, 543 N.W.2d 321, 322-23 (Mich. Ct. App. 1995). The Idaho Court of Appeals gave a similar common sense conclusion when it held that the fact that resuscitative efforts failed does not mean the patient was dead before those efforts began. Quite the contrary, the patient died

“irreversibility” becomes the legal standard. Option (1) arguably pushes the limits of the dead donor rule but we argue should be incorporated into the legal standard for determining death as a recognized exception to the general obligation to treat. Option (2) is a common sense option unless increasing the organ supply takes precedence over certainty in determinations of death. Finally, option (3) is questionable because not only is there no consensus on what that medical standard is, but there is evidence of ever growing mistrust in the medical community’s ability to set an unbiased standard.

To what extent will society tolerate the removal of organs from people we are not certain are dead in order to meet the ever-growing need to procure organs? How will the public react when it discovers preparation for organ retrieval is taking place before a person is dead and possibly even before the medical staff knows the patient or his or her family has consented to donate?

The lack of public information regarding the actual process of organ donation is compounded by hospital secrecy. Several hospitals refused to share their donor protocols with us, particularly when we asked for their uncontrolled donation after cardiac death policies. Why would they not want their protocols available for public scrutiny? One possible answer is that they were concerned that their protocols would be misunderstood. Another possibility is that they were worried about how the public would react if they knew the realities of the organ procurement process. There probably are many more possibilities for why hospitals did not want to share their policies, including the possibility that the requested policies were in flux, outdated or not being followed, but regardless of whether insidious motives are involved, the lack of transparency on these issues logically leads to public mistrust.

#### VIII. WHY PURSUING A DEFINITION OF DEATH THAT ENCOMPASSES MORE POTENTIAL DONORS IS NOT THE RIGHT APPROACH

It would be easy to avoid most of the difficult questions of autonomy encountered in this article if we could just find a definitive answer to the exact moment of death. Science has repeatedly shattered cultural and social perceptions of the world and perhaps it will do so again for death. Unfortunately, our current scientific understanding of the dying process

---

despite such efforts and was only dead once such efforts were discontinued - irreversibility only became a reality once efforts to resuscitate the patient ceased. *Jefferson v. E. Idaho Reg'l Med. Ctr.*, 883 P.2d 1084 (Idaho Ct. App. 1994). Finally, the Connecticut Supreme Court in *Finnegan v. Finnegan* held that a person who has a heart attack and then recovers with resuscitation efforts was not dead at any point during the resuscitative efforts because clearly the stoppage of his heart was not irreversible. *Finnegan v. Finnegan*, No. FA074031514, 2008 WL 642627 at \*1 (Conn. Super. Ct. Feb. 19, 2008).

seems to add to, rather than clear up, our confusion about death. In the 1970s and 1980s, there seemed to be a growing medical consensus that “brain death” signaled death of the entire organism, but in recent years the accuracy of techniques for determining brain death have come under increased criticism, as have standards for determining how much and what kinds of brain activity can be present in a “brain dead” person (as discussed above). Similarly, techniques for finding a person dead under more traditional circulatory criteria are also under scrutiny. There is considerable scientific disagreement as to how long after the heart stops functioning a person is dead.<sup>307</sup> To complicate matters, there is also a growing concern that brain death and circulatory death do not identify the same phenomenon.<sup>308</sup> Dying is clearly a process, but death for legal purposes needs to be an event identifiable by a specific instance in time - as a society we need to choose a point in time regardless of our ability to accurately identify such a point in time scientifically. All possible physical signs for when life becomes death and their practical, social, and legal consequences need to be evaluated thoroughly and a politically viable solution that both engenders trust in the medical community and allows for a potential increase in viable organs for transplant needs to be developed.

The inconsistent and at times contradictory nature of medical standards and statutory policies contribute to public misunderstanding and mistrust. Coming to a consensus, or legislating a new uniform standard, would help prevent confusion, but whether or not it will also prevent mistrust depends on how much of the public agrees with the definition. The more the public believes that organs are being harvested from non-dead patients, the greater the mistrust, regardless of how clear and precise the definition of death. If the goal is to regain some of the trust in the transplant community that has been lost due to the definition of death debate, the solution is to create a clear and concise definition that defines death in such a way that most of the public will agree that the donor in question is in fact dead. For example, a definition that requires that both circulatory and brain criteria are met would undoubtedly satisfy the vast majority of U.S. citizens. But such a policy would also dramatically decrease the organ supply so it must be coupled with an addition change in policy, such as the one described below.

---

307. See Bernat, *supra* note 155.

308. See Menikoff, *supra* note 150.

IX. WHY ALLOWING MORE PATIENT AUTONOMY IS THE SOLUTION (A GENTLER, MORE RESPECTFUL APPROACH)

Under current law patients can hasten death by requesting removal from life support or otherwise refusing treatment, but cannot hasten death by consenting to preparation for organ procurement or the actual harvesting of organs before an official declaration of death even if their prognosis is imminent death. It may seem macabre, but it is worth asking: If someone can decide to let themselves die, or even actively kill themselves through physician aid in dying, why can someone not decide to die in such a fashion as to preserve as many organs as possible for donation? The key to answering this question is not to be found in the definition of death but in the determination of who has authority to make end of life care decisions.

*A. The Honest Approach to Dealing With High Cost Life-Sustaining Treatment*

In most jurisdictions, a social consensus reached through legislative action has decided that people who are brain dead are not worth keeping alive at public expense, and can be a valuable source for organs because the organs can be maintained in their natural environment (the body on life-support) until they can be harvested.<sup>309</sup> The use of “brain death” to define death in such cases is a legal fiction, designed precisely to prevent the wasting of expensive medical resources and to allow the procurement of organs from patients who may not be dead by everyone’s standard, but who from a social perspective, are not worth keeping alive. Brain death criteria clearly help prevent futile treatment and legally protect physicians willing to harvest (and patients and families willing to donate) organs from such hopeless cases. This is not to deny that some (if not the great majority) of U.S. citizens believe brain death indicates death of the entire person, but there is a significant, and ever growing, number of Americans who question the validity of brain death criteria as a reliable indicator of death. The solution is to return to letting patients (and their proxies) decide the controversial issue of when it is appropriate to harvest organs. The general legal standard should be to err on the side of life, but there should also exist a safe harbor from liability for those medical professionals willing to act in accordance with clear and convincing evidence of a potential donor’s personal attitudes about death and the proper time frame for organ retrieval.

---

309. See Siminoff et al., *supra* note 257 (discussing a research study indicating people’s implicit understanding and adherence to the paradigm of the dead donor rule, which implicitly acknowledges the futility of maintaining a life through artificial support and the worth of organ transplantation to the community-at-large).



Some might criticize this approach, claiming it will increase healthcare costs because more patients and families will demand that brain dead patients be kept alive. But who pays for the upkeep of a “brain dead” or otherwise heavily brain damaged patient is a separate question from whether society should give individuals more latitude in how they personally define death. This Article is not necessarily advocating this approach, but states already have the authority to decide whether certain treatments are too expensive to cover at public expense. Consider *Hudson v. Children’s Hospital*, the case where a Texas hospital refused to continue caring for a thanatophoric dysplasia patient.<sup>310</sup> Under state law, the court found it was permissible for the hospital to give the family ten days to transfer the patient to another institution, and if the family did not do so, the hospital was within its right to cease treatment. This is an instance where the citizens of Texas, through their legislature, decided that severely and irreversibly brain damaged patients, like brain dead patients, should not be kept alive at public expense. The law in question, which is part of the Texas Advance Directives Act, speaks misleadingly in terms of “futility,”<sup>311</sup> but the net effect of such a law is that it codifies a utilitarian calculus that limits public healthcare expenditures on hopeless cases. In Texas, anyone who would want to be kept alive despite a determination under the Act that doing so would be against public policy would need to take measures to secure funding for such treatment in some way other than at public expense. Perhaps, people who felt strongly about being kept alive under such circumstances could work to create non-public emergency healthcare funding through personal savings, charity contributions or some form of specialized insurance that would help cover expenses should they find themselves suffering from a condition considered “futile” under the Act. Such state laws might possibly conflict with the federal Americans with Disabilities Act (ADA) or the Emergency Medical Treatment and Active Labor Act (EMTALA), but that is an issue that needs to be addressed elsewhere. In the meantime, let it suffice to say that at least such laws take a more honest approach to cost containment than trying to define severely brain damaged patients as dead.

#### *B. The Respectful Approach to End of life Care Related to Organ Donation*

The legal precedents set forth in right to die cases in the organ donation context should be applied. The same focus on patient self-determination could be used to increase the number and quality of organs without risking further erosion of public trust. Public policy should err on the side of life,

---

310. See *Hudson v. Children’s Hosp.*, 177 S.W. 3d 232, 232 (Tex. Crim. App. 2005).

311. TEX. HEALTH & SAFETY CODE ANN. § 166.045 (West 2009).

but individuals should be free to decide the following for themselves: 1) when to forego further treatment; 2) when to allow end of life care to shift focus from trying to save the dying individual to preserving organs for transplantation; 3) when to permit the harvesting of organs in accordance with the individual's personal definition of death; or, 4) when to allow the individual to die by the removal of organs, rather than the removal of life-sustaining treatment.<sup>312</sup>

This is not to suggest that organ removal before death should become standard practice any more than should physician aid in dying. This Article is simply suggesting that individual preferences be respected, even if they violate a generally accepted public understanding of death and proper end of life care, just as the removal of any patient from life-sustaining treatment who is not dead is allowed as an exception to the general public policy in favor of preserving life if there is enough evidence that doing so is what the patient would want. There clearly are some individuals (the medical literature is replete with accounts<sup>313</sup>) who do not think it immoral, but rather see it as an altruistic act, for an irreversibly dying patient (or his or her proxy) to allow organ removal before an official determination of death. But allowing such people to follow their moral conscience does not imply that others should do the same any more than letting terminally ill Oregonians who wish to do so to avail themselves of aid in dying obligates others to do so.

Respect for professional autonomy is also important. There undoubtedly will be physicians who consciously object to participating in preparation for organ retrieval or organ procurement before death, and there should be no obligation on their part to participate in such activities. On the other hand, those physicians who, in the interest of saving the lives of potential organ recipients, would be willing to respect a patient's decision (expressed

---

312. See CEJA REPORT 3-1-94, *supra* note 253. It is interesting to note that the AMA states that consent is necessary if perfusion begins before death occurs. This is the only ethical and legal way to proceed because if the patient is not dead yet, informed consent is required for all non-emergency treatment intended to save the life of the patient. Preparation of organ donation clearly does not fall into this exception, so preparing a body for donation without the patient's consent, through an advance directive, or his or her surrogate's permission is a battery for which healthcare providers and the hospital could be criminally liable. *Id.*

313. See, e.g., Truog & Miller, *supra* note 52; see generally Robert M. Veatch, *Donating Hearts after Cardiac Death - Reversing the Irreversible*, 359 N. ENG. J. MED. 672 (2008); see generally Michael Cook, *Abolish Dead Donor Rule For Executions and Euthanasia, Say Bioethicists*, BIOEDGE: BIOETHICS NEWS FROM AROUND THE WORLD (Oct. 26, 2009), [http://www.bioedge.org/index.php/bioethics/bioethics\\_article/8718/](http://www.bioedge.org/index.php/bioethics/bioethics_article/8718/).

through an advance directive or healthcare proxy) to proceed with donation before an official determination of death, should be protected from liability if they do so. The law should adapt to accommodate healthcare professionals at both ends of the definition of death debate in the same way it has evolved to accommodate healthcare professionals and patients at both ends of the physician aid in dying debate, or less controversially, the debate over the withdrawal of nutrition and hydration or the refusal of any other form of life-sustaining treatment.

#### X. CONCLUSION

If medical resources were unlimited, and a dying patient's organs did not deteriorate so quickly, families could be given as much time as they needed to decide when efforts to sustain life should cease, and when the harvesting of organs, if at all, should begin. In a world of limited resources and patients who could be saved by the expeditious procuring of cadaver organs, however, there is intense pressure to take authority away from patients and their proxies and shift the locus of decision making to medical professionals. But instead of reaching a public consensus on the point at which treatment efforts become futile and organs should be harvested, the argument over the line between life and death has become increasingly divisive. Aggravated by inconsistent scientific evidence and a growing schism between what the public believes and the realities of the organ procurement process, mistrust in the transplant community is growing and, for the first time in twenty years, the rate of organ donation in the United States is on the decline.

Ultimately, the social and legal battle over the definition of death is about who should decide at what point in the dying process it is appropriate to either discontinue emergency medical treatment or to begin the organ procurement process (i.e., should the patient through an advance directive, the patient's proxy, the patient's family, the medical profession, or state legislatures decide?). Traditionally, the courts have deferred end of life care decisions to patients and their surrogates, but legislatures, through the adoption of various legal definitions of death, have given the medical profession authority over the point when expensive medical resources like ventilators can be withheld and when in the dying process organ procurement may legally begin. In recent years, the medical profession has been torn between its obligation to try everything to save the life of all patients equally regardless of their affliction, and its obligation to preserve scarce medical resources on the one hand and its ability to save those in need of transplants on the other. The public trust placed in "medical standards" has permitted medical professionals to drift into questionable territory with respect to the criteria used for determining death. Almost dead, or certain-to-die-soon, patients are excellent candidates for organ procurement, but they are not dead. For medical teams to begin the organ retrieval process before donors are dead creates public suspicion and mistrust as well as a

potential for legal liability. It is time to reevaluate whether the medical profession, beleaguered by real and perceived conflicts of interest, is the appropriate guardian of the definition of death.

It is shortsighted policy to trade patients' trust for a convenient definition of death. The entire medical community suffers when physicians bow to political pressures to cut costs and harvest more organs at the expense of patients in need of emergency care or life-sustaining treatment. Ultimately, it is not the physician's role to make quality of life decisions. Yet quality of life decisions are exactly what physicians are making when they rely on subjective measures of futility to deny dying patients life-sustaining treatment, or when they begin organ retrieval on patients whose hearts are still beating or brains are still functioning. Yet, it is not these acts themselves that disturb us as much as the fact that these things are done subversively, under the guise of having medical expertise in determining death. It is no wonder that trust in the medical profession, and the transplant community in particular, is plummeting. It is noble and highly praiseworthy when individuals decide to change their end of life care plans to prevent the waste of scarce medical resources or to donate organs, but it borders on authoritarianism when public policy allows physicians to make such decisions without their patient's consent.

The answer is to follow the example of most court cases and legislation dealing with life-saving or preserving treatment; namely, empower individuals, but do not require them, to make choices that benefit society as a whole. This Article's recommendation - particularly so long as medical science cannot conclusively determine death or agree on the significance of a brain death diagnosis - is that the power to determine what happens to dying patients and their organs should rest with the patients themselves. In the same way that allowing individuals more freedom to direct end of life treatment has resulted in fewer people demanding very invasive and expensive end of life care, similarly, we predict, allowing individuals more freedom to determine the conditions for organ donation, will create an atmosphere of trust and respect where more people will donate, and donate earlier in the dying process.