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## Two Conflicts in Context: Lessons from the Schiavo and Bland Cases and the Role of Best Interests Analysis in the United Kingdom

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**TWO CONFLICTS IN CONTEXT: LESSONS FROM THE  
SCHIAVO AND BLAND CASES  
AND THE ROLE OF BEST INTERESTS ANALYSIS IN THE  
UNITED KINGDOM**

*Barbara A. Noah\**

<b>I.</b>	<b>INTRODUCTION</b>	239
<b>II.</b>	<b>TWO CASES OF PATIENTS IN PERMANENT VEGETATIVE STATE</b>	242
	A. <i>THERESA SCHIAVO</i>	243
	B. <i>ANTHONY BLAND</i>	245
<b>III.</b>	<b>END OF LIFE LAW AND PRACTICES</b>	248
	A. <i>AMERICAN END OF LIFE LAW AND PRACTICES</i>	248
	B. <i>UNITED KINGDOM END OF LIFE LAW AND PRACTICES</i>	252
<b>IV.</b>	<b>SOME COMPARISONS AND OBSERVATIONS</b>	256
<b>V.</b>	<b>IN THE U.S.: A ROLE FOR BEST INTERESTS ANALYSIS</b>	259
<b>VI.</b>	<b>CONCLUSION</b>	263

**I. INTRODUCTION**

In the United States, we are often reluctant to talk openly about the prospect of death or our preferences regarding end of life care. Moreover, we are reluctant to memorialize our wishes about end of life care in any formal manner such as an advance directive.<sup>1</sup> The causes of this reluctance vary, but

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<sup>1</sup> A recent survey conducted in the U.S. indicated that, while 80 percent of those surveyed believed that it was important to record their end of life wishes in an advance directive, less than a quarter of them had actually done so. Only 40 percent of those surveyed indicated that they had talked with a loved one about their end of life wishes, and only 8 percent had been asked about their wishes by their physicians. See Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CTR. REP. 30, 32, 36 (2004) (noting that less than 20 percent of Americans having living wills and that studies also suggest

include discomfort about confronting mortality, a desire to avoid placing a burden on family members, and lack of prompting by physicians to consider these questions.<sup>2</sup> This denial of mortality and unwillingness to discuss end of life options negatively impacts individuals, families, and the health care system.<sup>3</sup>

One-third of Americans die in a hospital despite the fact that most patients prefer to die at home.<sup>4</sup> We spend enormous resources at the end of life—often with little or no measurable benefit to dying patients.<sup>5</sup> Many patients receive therapeutic care, cardiopulmonary resuscitation, ventilator support, or ICU care even when death is imminent.<sup>6</sup> Physicians also tend to overestimate the remaining lifespans of seriously ill patients, and are thus more likely to accede to patient requests for additional interventions.<sup>7</sup> At the

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that living wills rarely influence the level of medical care; in fact, at least a quarter of patients with living wills receive care that is inconsistent with their instructions).

<sup>2</sup> Moreover, advance directives, when they do exist, often are of little use in resolving disputes about end of life care for particular patients. As other commentators have noted, advance directives rarely resolve end of life disputes; these commentators have therefore suggested abandoning efforts to encourage the utilization of advance directives. *See, e.g.,* Fagerlin & Schneider, *supra* note 1, at 31, 38–39 (suggesting that, in an attempt to extend patients' exercise of autonomy beyond their span of competence, resources spent to make living wills routine and even universal but that this policy has not produced results that justify its costs, and it should therefore be abandoned); John A. Robertson, *Second Thoughts on Living Wills*, 21(6) HASTINGS CTR. REP. 6, 6–7 (1991) (acknowledging the benefits, at least superficially, of living wills, but questioning whether they actually provide valid guidance as to the later-incompetent patient's wishes and interests).

<sup>3</sup> *See generally* Barbara A. Noah, *In Denial: The Role of Law in Planning for Death*, 21 ELDER L. J. 101 (2013).

<sup>4</sup> *See* Yafu Zhao & William Encinosa, *The Costs of End of Life Hospitalizations*, available at <http://www.ncbi.nlm.nih.gov/books/NBK53605/> (last visited Sept. 12, 2012) (describing data from 2007). This trend is improving, however. Recent data suggests that more people died at home in 2009 than in 2000, although the rate of intensive care unit utilization has increased during the same time period. *See* Joan M. Teno *et al.*, *Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions*, 209 JAMA 470, 473 Tbl. 2 (2013).

<sup>5</sup> It is well-documented that one-third of medical expenses for the last year of life are spent in the final month and that aggressive therapies and technologies in that final month account for nearly 80 percent of these costs. *See* Baohui Zhang *et al.*, *Health Care Costs in the Last Week of Life: Associations with End of Life Conversations*, 169 ARCH. INTERNAL MED. 480, 482–84 (2009). Moreover, 30 percent of Medicare dollars spent go to care for the 5 percent of Medicare beneficiaries who die each year. *See* Amber E. Barnato *et al.*, *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 HEALTH SERV. RES. 363, 363–64 (2004).

<sup>6</sup> *See* Amresh Hanchate *et al.*, *Racial and Ethnic Differences in End-of-Life Costs: Why Do Minorities Cost More than Whites?*, 169 ARCHIVES INTERNAL MED. 493, 497–98 (2009) (surveying use of expensive end of life interventions among a large sample of Medicare beneficiaries and finding patterns of substantial expenditure on life-sustaining treatment in the final six months of life).

<sup>7</sup> Interestingly, the conundrum is more complex than it appears superficially. Physicians who communicate well with their patients and feel closer to them were more likely to over-estimate life expectancy for those patients, suggesting that a close doctor-patient relationship makes it more difficult for physicians to be frank with patients about their

same time, we under-utilize available resources for pain and symptom management and other sorts of palliative care.<sup>8</sup> These patterns are even more marked among racial and ethnic minorities in the United States.<sup>9</sup>

In the U.S., the ethical principle of individual patient autonomy has long held primary place as a guidepost for making decisions on behalf of those who have lost decisional capacity.<sup>10</sup> Generally stated, the primary goal for end of life decision making in the U.S. is to provide care according to the individual patient's wishes, either by asking the patient directly or, if the patient has lost decisional capacity, by attempting to ascertain the patient's preferences using advance directives, conversations with family members and friends, and the context of the patient's values, preferences, and beliefs. Under this approach, the ideal is to preserve the patient's autonomy even when he or she can no longer articulate a preference.

In reality, autonomy in this context is often illusory because there is insufficient information about the patient's preferences available, leaving physicians and family members in a quandary as to whether to continue providing life-sustaining care. Uncertainty about prognosis in the case of terminal illness—or possibility of some future recovery of function in the case of severe brain injury—adds to the complexity of decisions about withdrawal of life-supportive care. Too frequently, conflicts over these decisions lead to grief for families or, worse, litigation to resolve what cannot be resolved through conversation.

By comparison, in the United Kingdom, patient preferences play an important role in deciding whether to initiate or continue life-supportive measures for seriously ill or dying patients, but this principle is deliberately and openly supplemented with a careful consideration of the patient's best interests, particularly when the patient's wishes are unknown or unclear, when the physician questions the wisdom of the patient's choice on medical grounds, or when resource constraints become a factor.<sup>11</sup> Although there are

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prognoses. See Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients*, 320 BRIT. MED. J. 469, 470–71 (2000) (finding that, in predicting patients' remaining life expectancies, physicians were correct only 20 percent of the time and were over-optimistic 63 percent of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions); cf. Paul Glare, *Predicting and Communicating Prognosis in Palliative Care*, 343 BRIT. MED. J. d5171 (2011) (“Temporal predictions based on clinical judgment are notoriously inaccurate and usually overoptimistic. Although probabilistic predictions are more accurate . . . actuarial judgment of survival is now recommended. Several statistical models that predict survival have been developed . . . but none has entered routine clinical practice.”).

<sup>8</sup> See Teno, *supra* note 4, at 475–76 (describing the ongoing trend of very short hospice stays and late referrals to hospice care).

<sup>9</sup> See generally Barbara A. Noah, *The Role of Race in End-of-Life Care*, 15 J. HEALTH CARE L. & POL'Y 349–78 (2012).

<sup>10</sup> See *infra* notes 36–37 and accompanying text (discussing dying patients' rights in the United States).

<sup>11</sup> See *infra* notes 59–63 and accompanying text (describing the role that doctors play in end of life decision making in the United Kingdom).

several very significant differences between the U.S. and the U.K. in terms of health care delivery, insurance, the role of the physician, and other cultural variables, there are strong arguments for adopting aspects of the British approach to end of life decision making and disputes here in the U.S.

This essay focuses on two cases involving patients in permanent vegetative states (PVS) for whom little was known about their respective individual preferences, and it analyzes the differences in conceptualization and resolution of disputes concerning these patients' care. It includes an overview of the different approaches to end of life decision making for incapacitated patients in the United States and in the United Kingdom. Finally, the essay considers whether and how U.S. physicians and patients might more actively incorporate a "best interests" principle into end of life decision making for patients in PVS.

## II. TWO CASES OF PATIENTS IN PERMANENT VEGETATIVE STATE

The cases of Anthony Bland in the U.K. and Theresa Schiavo in the U.S. provide contrasting examples of the ways in which physicians, families, courts, and the public react to cases of young adults in PVS for whom treatment decisions must be made. Decisions about whether to continue providing care to patients in PVS are particularly challenging, in the absence of clear knowledge of the patient's wishes as previously expressed in an advance directive or conversations with family or health care providers, precisely because these patients are neither actively dying nor progressing towards recovery. The resolution of these cases therefore serves as a bellwether for the effectiveness of end of life decision making more generally in their respective countries.

PVS is a form of unconsciousness that differs from coma.<sup>12</sup> Because patients in PVS experience waking and sleeping cycles, open their eyes, move their limbs, and utter sounds,<sup>13</sup> lay observers sometimes find it difficult

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<sup>12</sup> See Multi-Society Task Force on PVS, *Medical Aspects of the Persistent Vegetative State*, (Pt. I), 330 NEW ENG. J. MED. 1499, 1501 (1994) (hereinafter, Multi-Society Task Force on PVS) ("[T]he adjective 'persistent' refers only to a condition of past and continuing disability with an uncertain future, whereas 'permanent' implies irreversibility. Persistent vegetative state is a diagnosis; permanent vegetative state is a prognosis."); see also Roger N. Rosenberg, *Consciousness, Coma, and Brain Death—2009*, 301 JAMA 1172, 1172 (2009) (describing PVS as "a syndrome with several causes in which the patient has sustained severe brain damage, and in which coma has advanced to a state of wakefulness without detectable awareness."). The persistent vegetative state is generally distinguished clinically from the 'minimally conscious state,' "in which the patient exhibits definite responsiveness that is cognitively driven, rather than unconscious reflexive responses." *Id.* at 1172.

<sup>13</sup> See Multi-Society Task Force on PVS, *supra* note 12, at 1500-01. ("Patients in a vegetative state are usually not immobile. They may move the trunk or limbs in meaningless ways. They may occasionally smile, and a few may even shed tears . . . utter grunts or, on rare occasions, moan or scream. . . . These motor activities may misleadingly suggest purposeful

to accept that the patient lacks any capacity for thought, emotion, or other activities associated with consciousness. These patients typically can breathe without assistance but cannot experience or interact with their environment. Patients in PVS require comprehensive care, including artificial nutrition and hydration, to remain alive. With comprehensive care, these patients can live for many years, yet patients with confirmed permanent vegetative state have no hope of recovering consciousness or any degree of function.<sup>14</sup>

### A. Theresa Schiavo

Several major cases involving young adults in PVS have shaped the U.S. jurisprudence addressing disputes over withdrawal of life-sustaining treatment from patients who are not actively dying. Each of these disputes involved uncertainty about the quality or quantity of evidence of the permanently incapacitated patient's presumed wishes, both because the patient had no advance directive, and because a family member or the State was disputing the appropriateness of a health care proxy decision.<sup>15</sup>

The most recent of these cases concerned the care of Theresa Schiavo. In 1990, a sudden cardiac arrest left Theresa Schiavo, aged 26, with a severe anoxic brain injury leading to PVS.<sup>16</sup> Theresa Schiavo spent fifteen

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movements . . . ."); cf. Christopher M. Booth *et al.*, *Is This Patient Dead, Vegetative, or Severely Neurologically Impaired?*, 291 JAMA 870 (2004) (evaluating data on neurological outcomes after cardiac arrest, and concluding that several clinical signs that become apparent just 24 hours after cardiac arrest serve as reliable predictors of poor neurological prognosis).

<sup>14</sup> Recent technological developments have allowed physicians to test the diagnosis of persistent vegetative state. In a small study, approximately 20 percent of recently diagnosed patients demonstrated signs of consciousness when their brain activity was measured with an electroencephalogram (EEG) test. See Benedict Carey, *Study Finds Signs of Awareness in 'Vegetative' Patients*, N.Y. TIMES, Nov. 9, 2011, at A15; see also Damian Cruse *et al.*, *Bedside Detection of Awareness in a Vegetative State: A Cohort Analysis*, 378 LANCET 2088–94 (2011) (assessing 16 patients recently diagnosed with PVS and finding that 3 of these patients demonstrated some brain response to commands). In addition to EEG, new brain imaging technologies such as functional magnetic resonance imaging (fMRI) technology allows physicians to identify localized neural activity in the brain that was previously undetectable through observable patient responses. These scans also have called into question the accuracy of diagnoses of permanent vegetative state, raising questions about the consequent appropriateness of withdrawal of life-sustaining measures from these patients. See J. Andrew Billings *et al.*, *Severe Brain Injury and the Subjective Life*, 40 HASTINGS CTR. REP. 17, 18–19 (May/June 2010); A. M. Owen *et al.*, *Detecting Awareness in the Vegetative State*, 313 SCIENCE 1402 (2006); A. M. Owen *et al.*, *Using Functional Magnetic Resonance Imaging to Detect Covert Awareness in the Vegetative State*, 64 ARCH. NEUROL. 1098–1102 (2007); Rosenberg, *supra* note 12, at 1173 (describing recent research results).

<sup>15</sup> See, e.g., *Guardianship of Schiavo*, 780 So.2d 176, 177 (2001) (disputing, among other things, whether it was appropriate for the patient's husband to continue to serve as her surrogate decision maker); *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 265 (1990); *In re Quinlan*, 355 A.2d 647, 651 (1976).

<sup>16</sup> The description of events in the *Schiavo* case is adapted from Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 U. MIAMI L. REV. 107, 107–08; 114–15; 124–25 (2005) (hereinafter, Noah, *Politicizing the End of Life*) (describing

years in a persistent vegetative state sustained by artificial nutrition and hydration, along with a host of other types of medical care, although she was not ventilator dependent. Because of ongoing legal disputes about the appropriateness of continuing this care, Theresa's feeding tube was removed and replaced twice before it was removed for a third and final time and she was allowed to die. This conflict carried on over many years despite multiple court determinations that what was known about Theresa's wishes in this regard satisfied the standard of evidence required in the state where she resided for removal of life-sustaining care.<sup>17</sup>

From 1998 until 2005, Theresa's husband, Michael Schiavo, having accepted that Theresa would not recover consciousness, sought permission from the Florida courts to have her feeding tube removed so that she could die. Michael based his request on Theresa's previously expressed wishes and values, explaining that Theresa would never have wanted to continue to exist in a vegetative state after all hope of recovery had gone. This testimony was consistent with the requirement in Florida law that decisions for incapacitated patients attempt to replicate what they would choose were they able to express their wishes.<sup>18</sup> At the same time, Theresa's parents vigorously objected to this request, arguing that the evidence of Theresa's wishes was insufficient and that its source was suspect.<sup>19</sup> Disputes about the nature of Theresa's medical condition confounded the issues. Theresa's parents found it difficult to accept that she lacked capacity for thought, emotion or other activities associated with consciousness.<sup>20</sup> Nevertheless, in a series of judicial decisions, state and federal courts repeatedly confirmed the legal propriety of acceding to Michael's request, finding the evidence of Theresa's

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the events and discussing in detail the interference from outside parties in the dispute); Barbara A. Noah, *The Role of Religion in the Schiavo Controversy*, 6 HOUSTON J. HEALTH L. & POL'Y 319, 320–29 (2006) (hereinafter, Noah, *Role of Religion*) (providing additional details about the later years of the litigation and external interference from various interest groups).

<sup>17</sup> See *supra* Noah, *Politicizing the End of Life*, note 16; see also Steve Haidar & Kathy Cerminara, *Key Events in the Case of Theresa Marie Schiavo*, UNIV. MIAMI ETHICS PROGRAM, available at [http://www6.miami.edu/ethics2/schiavo/schiavo\\_timeline.html](http://www6.miami.edu/ethics2/schiavo/schiavo_timeline.html) (last visited Feb. 1, 2013) (providing a detailed chronology of the events of the Schiavo litigation, including citations to all judicial decisions).

<sup>18</sup> The Florida statute requires that, before a proxy decision-maker may exercise an incapacitated patient's right to withdraw life-prolonging measures, the decision must be supported by "clear and convincing evidence that the decision would have been the one the patient would have chosen if the patient had been competent." See FLA. STAT. § 765.401(3) (2012).

<sup>19</sup> During the controversy, proponents of continued treatment pointed to suspected marital problems between the couple, and to Michael Schiavo's decision to live with and father two children with another woman years after Theresa's cardiac arrest and resulting brain injury. These matters became a point of argument for conservative religious groups who intervened in the case. See *Too Vigorously Assisted Suicide*, NAT'L REVIEW, Apr. 11, 2005.

<sup>20</sup> See Noah, *Role of Religion*, *supra* note 16, at 320–21 (2006) (describing the dispute about the nature of Theresa's condition).

wishes legally sufficient to support the removal of life supportive technology.<sup>21</sup>

For over seven years, the legal battle continued between Theresa's husband and parents with significant intervention from the Catholic Church, pro-life organizations, the Florida legislature, and the U.S. Congress.<sup>22</sup> The legal and cultural battle included motions for a new trial, visits to Theresa's bedside by a conservative U.S. Senator, death threats against the judge who issued the orders to remove Theresa's feeding tube, special legislation from the Florida legislature giving then Governor Jeb Bush the power to "stay" the removal of Theresa's already-removed tube,<sup>23</sup> a subpoena from Congress for Theresa and Michael Schiavo to "testify" before it, and much political capitalization from conservative members of Congress on the pro-life aspects of the case.<sup>24</sup>

Finally, in 2005, after a series of state and federal court hearings, the Florida court once again ordered that the hospice remove Theresa's feeding tube. On March 18, 2005, the hospice complied with the court order and additional frantic legal maneuvering ensued, including motions filed with the United States Supreme Court, and several Florida courts. Ultimately, all of the courts that heard the parents' appeals declined to overturn the order directing removal of Theresa's feeding tube for the third and final time. Fifteen years after her cardiac arrest, she was allowed to die.<sup>25</sup>

### ***B. Anthony Bland***

In the United Kingdom, the case of Anthony Bland provides an apt comparison with that of Theresa Schiavo. On April 15th, 1989, 17 year-old

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<sup>21</sup> See Haidar & Cerminara, *supra* note 17.

<sup>22</sup> *Id.* See also Noah, Role of Religion, *supra* note 16, at 333–41 (2006) (focusing particularly on the role that the Catholic Church played in events and the relevance of the Papal declaration that artificial nutrition and hydration are "ordinary care" and must be provided under all circumstances).

<sup>23</sup> See House Bill 35-E, FLA. STAT. § 418 (2003). The pertinent part of the legislation provides that:

(1) The Governor shall have the authority to issue a one-time stay to prevent the withholding of nutrition and hydration from a patient if, as of October 15, 2003: (a) That patient has no written advance directive; (b) The Court has found that patient to be in a persistent vegetative state; (c) That patient has had nutrition and hydration withheld; and (d) A member of that patient's family has challenged the withholding of nutrition and hydration. (2) The Governor's authority to issue the stay expires 15 days after the effective date of this act, and the expiration of that authority does not impact the validity or effect of any stay issued pursuant to this act.

*Id.* See also Adam Liptak, *In Florida Right-to-Die Case, Legislation that Puts Constitution at Issue*, N.Y. TIMES, Oct. 23, 2003, at A14. The bill was popularly known as "Terri's Law."

<sup>24</sup> See Haidar & Cerminara, *supra* note 17; Noah, Politicizing the End of Life, *supra* note 16.

<sup>25</sup> *Id.*

Anthony Bland was injured in the Hillsborough football ground disaster.<sup>26</sup> His lungs were crushed and punctured, and the supply of oxygen to his brain was interrupted, leaving him in a permanent vegetative state. Like Theresa Schiavo, the injury to Anthony's brain was anoxic, rather than traumatic (though it resulted from trauma), and thus the injury to the brain was global rather than localized. Physicians ultimately agreed that there was no hope that he would recover consciousness. Although, unsurprisingly given his age, Anthony had never indicated his wishes with respect to life-sustaining treatment, his father gave evidence that his son would not choose to be left on life support in these circumstances.<sup>27</sup> Unlike in the *Schiavo* case, the entire family concurred. The hospital then sought a declaration that they could legally discontinue all life-sustaining treatment including artificial nutrition and hydration.<sup>28</sup>

For the first time in British law, the U.K.'s highest court<sup>29</sup> ruled that withdrawal and withholding of medical treatment, including artificial nutrition and hydration, from patients who lack decisional capacity and who have no advance directive was permissible. The House of Lords reasoned that non-consensual treatment violates the principle of self-determination and that it is only appropriate to treat incapacitated patients without their consent when their best interests require the treatment.<sup>30</sup> As to permanently unconscious patients, the court concluded that the patient's interest in being kept alive has ended (thus no longer justifying treatment), even though discontinuation of life support also does nothing to advance the patient's interests. The court argued that in these cases, the duty to provide care ceases.

Indeed, if the justification for treating a patient who lacks the capacity to consent lies in the fact that the treatment is provided in his best interests, it must follow that the treatment may, and indeed ultimately should, be

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<sup>26</sup> See *Airedale N.H.S. Trust v. Bland* 789, 795–96 (1993) (reviewing facts of the case); see also *Hillsborough Disaster and Its Aftermath*, BBC News (Dec. 19, 2012) available at <http://www.bbc.co.uk/news/uk19545126> (last visited Jan. 20, 2013) (describing the events that led to the deaths of 96 football fans and injuries to hundreds of others).

<sup>27</sup> See *Airedale N.H.S. Trust v. Bland* at 797.

<sup>28</sup> *Id.* at 796–97.

<sup>29</sup> At the time of the *Bland* ruling, the U.K.'s highest appeals court consisted of a sub-chamber of the House of Lords. The U.K.'s trial court is called the "High Court." The intermediate level is called the "Court of Appeal." And, as of October 1, 2009, the highest court is called the "Supreme Court of the U.K." It is staffed by twelve justices (beginning with former law lords).

<sup>30</sup> See *Airedale N.H.S. Trust* at 867. As Lord Goff explained, "[i]f the justification for treating a patient who lacks capacity to consent lies in the fact that the treatment is provided in his best interests, it must follow that the treatment may, and indeed ultimately should, be discontinued where it is no longer in his best interests to provide it." *Id.*

discontinued where it is no longer in his best interests to provide it.<sup>31</sup>

The court went on to explain that,

the object of medical treatment and care was to benefit the patient, but since a large body of informed and responsible medical opinion was of the view that existence in the persistent vegetative state was not a benefit to the patient, the principle of the sanctity of life, which was not absolute, was not violated by ceasing to give medical treatment and care involving invasive manipulation of the patient's body, to which he had not consented and which conferred no benefit upon him.<sup>32</sup>

Implicit in this statement is the fact that, although the court respects the principle of the sanctity of life, maintaining life alone may not be in a patient's best interests if the treatment in question does nothing to improve the patient's condition.

Less than four years after his injury, Anthony Bland's feeding tube was removed, and he was allowed to die.<sup>33</sup> There was, naturally, a good deal of public controversy surrounding the *Bland* case during and after its litigation and resolution.<sup>34</sup> However, the bulk of public reaction about the case favored the proposed withdrawal of life-supportive measures.<sup>35</sup> Moreover, the debate and a lack of consensus among health care providers about whether to continue to provide artificial nutrition and hydration to Anthony Bland never devolved into the kind of political and societal mêlée that surrounded the *Schiavo* case in the United States.

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<sup>31</sup> *Airedale N.H.S. Trust v. Bland* at 867.

<sup>32</sup> *Id.* at 789–90.

<sup>33</sup> Kieth McLeod, *Families Stand by Their Decisions*, SCOTSMAN, Mar. 27, 1997, 1997 WLNR 2473220 (quoting Anthony's father, Allan Bland, after the decision to withdraw Anthony's feeding tube and allow him to die: "It is all about quality of life, and Tony had none. He didn't recognize you, he never spoke . . . Everything was done that could be done, but there was never any hope in our son's case. Each case should be judged on its merits. It is a different choice for each family.").

<sup>34</sup> See, e.g., John Keown, *Restoring Moral and Intellectual Shape to the Law After Bland*, 113 LAW QUART. REV. 481 (1997) (criticizing the *Bland* decision both for its reasoning and its outcome).

<sup>35</sup> See, e.g., James Gosling, *Hillsborough Tragedy Doctor Retires*, ThisisBradford.co.uk, Dec. 2, 2005, 2005 WLNR 19408656 (quoting Anthony's physician, Dr. Jim Howe who described the overwhelming public support from the community, which included telling protesters outside the hospital to go away and leave the family alone, and noting that, in the years that followed, the precedent created by the case resulted in less consternation over other cases in which patients in PVS were allowed to die.).

### III. END OF LIFE LAW AND PRACTICES

#### A. American End of Life Law and Practices

Our legal rights of decision making are grounded in the ethical principle of autonomy and include the right to refuse treatment even if one is not terminally ill,<sup>36</sup> the right to refuse treatment when terminally ill, the right to continue receiving life-prolonging treatment even when terminally ill (though this value becomes subject to dispute if the treatment appears “futile”), and, in some states, the right to hasten one’s death with the assistance of a physician.<sup>37</sup> However, individuals rarely formalize their preferences, especially when they are young. Thus, in cases such as the two described above, surrogate decision makers must face the dilemma and choose whether to continue to provide life-sustaining treatment when there is no hope of recovery. For the most part, medical treatment and decision making, including end of life decision making, is a matter left to the individual states.<sup>38</sup> End of life decision making in the United States focuses on patient autonomy as the primary ethical principle and attempts to promote this autonomy, even when a patient loses decisional capacity, via inquiries into the patient’s previously expressed wishes, values, preferences, and

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<sup>36</sup> See, e.g., *Bouvia v. Superior Ct.*, 179 Cal. App. 3d 1127, 225 (1986) (stating “Petitioner sought to enforce only a right which was exclusively hers and over which neither the medical profession nor the judiciary have any veto power. The trial court could but recognize and protect her exercise of that right.” The case reverses the trial court’s denial of a 28 year old quadriplegic woman’s petition for writ of mandate to compel hospital officials to remove her feeding tube, thus allowing the patient, consistent with her express wishes, to die.); see also Alan Meisel, End-of-Life Care, in *FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK*, at 51, 51–52 (2008) (“Autonomy is paramount for patients who possess decision-making capacity, but it is also a major consideration for patients who lack this capacity. Their wishes must be respected by the relatives or other health care proxies who make decisions on their behalf.”). But see Anne Johnstone, *A Matter of Life and Death*, *GLASGOW HERALD*, Jan. 19, 2000, 2000 WLNR 3606774 (describing a bill introduced into the House of Commons by a Pro-Life group of Members of Parliament that would have allowed for the prosecution of physicians who hastened patients’ deaths by withholding “treatment or sustenance,” and the “ecstatic welcome” the bill received from the Right to Life lobby group); see also Luke Gormally, Notes on the Winterton Bill, available at <http://www.linacre.org/winterton.html> (last visited Jan. 19, 2013) (writing in support of the bill).

<sup>37</sup> See Oregon Death with Dignity Act of 1994, OR. REV. STAT. § 127.800–995; Washington Death with Dignity Act, R.C.W. 70.245; *Baxter v. Montana*, 224 P.3d 1211 (Mont. 2009).

<sup>38</sup> One notable exception, the Patient Self-Determination Act (PSDA), represents a federal effort to encourage the completion of advance directives, with very limited effectiveness. See U.S. Gov’t Accounting Office, *Patient Self-Determination Act: Providers Offer Information on Advance Directives but Effectiveness Uncertain* (1995) (concluding that “advance directives have been advocated more than they have been used” and that “in general, only 10 to 25 percent of Americans have documented their end of life choices or appointed a health care agent”); see also Fagerlin & Schneider, *supra* note 1 at 32 (commenting on the empirical studies that demonstrate the PSDA’s lack of effectiveness).

beliefs.<sup>39</sup> All fifty states have incorporated the autonomy principle into their individual laws, by acknowledging the authority of advance directives or formally appointed health care proxies,<sup>40</sup> though standards of proof for withdrawing or withholding life-sustaining treatment vary from state to state.

New York state law, for example, requires clear and convincing evidence that an incapacitated patient would refuse the treatment being offered.<sup>41</sup> New York also has no statute that formally recognizes the right of family members to make health care decisions on behalf of incapacitated patients, which makes surrogate decision making very difficult in combination with the clear and convincing evidence requirement as interpreted in that state.<sup>42</sup> Missouri,<sup>43</sup> and Michigan,<sup>44</sup> like New York, require the highest standard of civil proof, “clear and convincing evidence,” that the patient would refuse the precise life-supportive measure being used or

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<sup>39</sup> The American Medical Association (AMA) has acknowledged that patients have a right of self-determination that includes the right to refuse unwanted medical treatment, and that this right is not lost when a patient loses decisional capacity. *See* Council on Ethical and Judicial Affairs, AMA, *Decisions Near the End of Life*, 267 JAMA 2229–33 (1992); *see also* *In re Guardianship of Browning*, 568 So.2d 4 (Fla. 1990) (affirming the principle that a person’s right to refuse unwanted medical treatment including life-sustaining treatment continues even after the patient has lost the ability to express his preferences).

<sup>40</sup> *See* Meisel, *supra* note 36, at 52.

<sup>41</sup> *See* Committee on Science and the Law, *Legal Implications of Withdrawal of Care for Persistently Vegetative Patients*, 64 REC. ASS’N CITY OF N.Y. 81, 113 (2009) (hereinafter, Committee on Science and the Law) (explaining that New York courts have “reaffirmed the position that decisions to limit life-prolonging treatment for incompetent patients required clear and convincing evidence that the patient would have requested those limitations in the very circumstances and situation being considered, rather than surrogate-substituted judgment or surrogate judgment made in the patient’s best interests”); *see also* *In re Eichner*, 420 N.E.2d 64, 72 (NY 1981) (“In this case the proof was compelling. . . . There was . . . no need to speculate as to whether he would want this particular medical procedure to be discontinued under these circumstances. What occurred to him was identical to what happened in the Karen Ann Quinlan case, which had originally prompted his decision. . . . [T]he evidence clearly and convincingly shows that Brother Fox did not want to be maintained in a vegetative coma by use of a respirator.”); *In re Westchester Cnty. Med. Ctr. ex rel O’Connor*, 531 N.E.2d 607 (1988).

<sup>42</sup> *See supra* Committee on Science and the Law, note 41 at 131 (2009) (providing a detailed discussion of the law’s approach to care for these patients in the state of New York.).

<sup>43</sup> The Missouri statute explicitly excludes artificial nutrition and hydration from its definition of “death-prolonging procedure” that may be refused when one is terminally ill. Mo. R. Stat. 459.010(3). The statutory definition of terminal illness also appears to exclude PVS. Mo.R.Stat.459.010(6) (defining terminal illness as “an incurable or irreversible condition which, in the opinion of the attending physician, is such that death will occur within a short time regardless of the application of medical procedures.” As the U.S. Supreme Court confirmed in the *Cruzan* decision, the state of Missouri is constitutionally entitled to demand a standard of clear and convincing evidence that the patient would refuse artificial nutrition and hydration. *See* *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 280 (1990).

<sup>44</sup> *See, e.g.,* *In re Martin* 538 N.W.2d 399, 413 (Mich. 1995) (requiring “clear and convincing evidence” of previous statements by the now-incapacitated patient that he would refuse treatment under the precise circumstances).

contemplated under the precise medical conditions in which he or she finds him or herself. In these states, only a detailed written advance directive or well-documented and detailed conversations with a physician or health care proxy will satisfy this high evidentiary standard. In other states, a hierarchy of decision makers for the incapacitated patient, usually the spouse first followed by the majority of adult children, etc., can use a process of “substituted judgment” to express their understanding of which options the patient would choose.<sup>45</sup>

Despite this heavy emphasis on the principle of autonomy via substituted judgment, U.S. law also includes references to, and consideration of, the best interests. Many state laws already acknowledge a place for best interests analysis in making treatment decisions for incapacitated patients.<sup>46</sup> For example, courts have recognized the concept of “proportionate treatment,” and have suggested that “a treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition.”<sup>47</sup> In one New York decision, a court refused to authorize life-prolonging treatment for an incapacitated adult who had suffered several strokes and had very little cognitive ability. After she developed gangrene, the hospital wished to perform an amputation in order to save her life. The court held that incapacitated patients retain their right to refuse life-sustaining treatment and that the surgery would at best prolong the dying process while providing “no human or humane benefit” to her.<sup>48</sup> And in a well-regarded New Jersey decision, the New Jersey Supreme Court envisioned a sliding scale from pure autonomy-based decision making to pure best interests-based decision making depending on the quantity and quality of evidence of the patient’s wishes that is available.<sup>49</sup> Nevertheless, the New Jersey court was unwilling to apply either of these objective tests to

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<sup>45</sup> See, e.g., FLA. STAT. CH.765.401 (providing a hierarchy of surrogate decision makers for a patient who has lost decisional capacity in the absence of an advance directive).

<sup>46</sup> Even New York State permits an appointed health care agent to make a decision, in the absence of information about the patient’s wishes, to withdraw care in accordance with the patient’s best interests, but it contains an express exception for artificial nutrition and hydration. Only if the patient has specifically spoken on this matter may the health care agent request the withdrawal of this type of life-sustaining medical technology. See N.Y. Health Care Agents and Proxies Law, N.Y. PUB. HEALTH LAW Art. 29-C, § 2982(4).

<sup>47</sup> See, e.g., *Barber v. Superior Court*, 195 Cal. Rptr. 484 (Ct. App. 1983) (permitting withdrawal of treatment from a comatose patient).

<sup>48</sup> *In re Beth Israel Med. Ctr. for Weinstein*, 136 Misc.2d 931, 934–35; 942 (N.Y. Sup. Ct. 1987).

<sup>49</sup> *In Re Conroy*, 98 N.J. 321, 365–66 (1985) (explaining that under a “limited-objective test,” life-sustaining treatments may be withdrawn or withheld when there is some reliable evidence that the patient would wish it and when it is clear that the burdens of continued life with treatment outweigh the benefits and that under a “pure-objective test,” treatment similarly may be withdrawn or withheld in cases where the “net burdens of the patient’s life with the treatment . . . clearly and markedly outweigh the benefits that the patient derives from life” even where there is no evidence of the patient’s preferences).

patients in PVS because it argued that such patients, by definition, experience no burdens of treatment.<sup>50</sup> This conclusion deserves scrutiny because it relies on a very narrow definition of “burden” that presumes that a patient loses his interest in personal dignity when he can no longer experience its degradation.<sup>51</sup>

Despite this occasional reference to best interests analysis, with very little exception, U.S. law concerning end of life decision making favors continued life-supportive measures when the patient’s wishes are unknown or ambiguous. As the *Schiavo* dispute and other cases of its type illustrate, many individuals take the position that our end of life laws should default on the side of continued treatment whenever a patient’s choice or best interests are in dispute and should decline to assess the patient’s quality of that life in doing so.<sup>52</sup> Denying the inevitability of death increases suffering for patients and their families. Yet, many Americans wish to avoid thinking about death or quality of life issues, and so stick to the path of “doing everything” for their loved ones. As a result, U.S. courts often default to this position as well, since it represents an easy to apply rule when questions of futility arise.

Given that several opinion polls establish that the majority of people would prefer not to receive life-sustaining treatment if they are confirmed to be in a permanent vegetative state,<sup>53</sup> and given the astonishing amount of health care resources expended in the final months of our lives,<sup>54</sup> this presumption in favor of continued life-supportive measures deserves much more scrutiny than it typically receives. Why does the law presume that,

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<sup>50</sup> See *In re Peter*, 529 A.2d 419, 424–25 (N.J. 1987) (arguing that patients in PVS “do not experience any of the benefits or burdens that the Conroy balancing tests are intended or able to appraise”).

<sup>51</sup> See *infra* note 93 and accompanying text (suggesting that dignitary harm extends to patients who have permanently lost consciousness).

<sup>52</sup> See, e.g., *Conservatorship of Wendland*, 28 P.3d 151 (2001) (upholding a trial court decision to continue life-sustaining treatment despite a proxy decision-maker’s request to withdraw it because the proxy “offered no basis for such a finding other than her own subjective judgment that the conservatee did not enjoy a satisfactory quality of life and legally insufficient evidence to the effect that he would have wished to die”); see also *In re Conservatorship of Helga M. Wanglie*, No. PX91283, (Hennepin Cnty., Minn., Prob. Ct. 1991) reprinted in *LAW & MED.* 369 (1991) (upholding the surrogate’s request for continued treatment of the patient, who was in a persistent vegetative state and who died more than a year later of sepsis); *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 281 (1990) (“a state may properly decline to make judgments about the ‘quality’ of life that a particular person may enjoy and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual.”).

<sup>53</sup> See, e.g., Press Release, Harris Interactive, *By a Near Four-to-One Margin, U.S. Adults Favor Not Taking Additional Steps to Prolong the Lives of Patients in a Persistent Vegetative State*, Apr. 12, 2005; Lydia Saad, *Americans Choose Death Over Vegetative State*, Gallop (Mar. 29, 2005), available at <http://www.gallup.com/poll/15448/americanschooseddeathovervegetativestate.aspx>, (last visited March 3, 2011).

<sup>54</sup> Cf. Andrew Stern, REUTERS, *Discussing End-of-Life Care Lowers Cost: U.S. Study*, REUTERS (Mar. 9, 2009), available at <http://www.reuters.com/article/latestCrisis/idUSN06415881> (Mar. 9, 2009).

when a patient's wishes are unknown, that patient would wish to continue treatment or life-supportive measures, in particular, given that such a presumption, when compared with the empirical evidence of people's preferences, often will constitute an abrogation of a patient's autonomous right to refuse treatment? Part of the answer is, of course, that keeping a patient alive "in error" is capable of correction in the future, should additional information about the patient's wishes or condition become available.<sup>55</sup> Implicit in this "err on the side of life" mentality is an unwillingness to make quality of life assessments. A biologic view of life is a binary view that a person is either "alive" or "dead"; it fails to account for the range of intermediate levels of unconsciousness or other sorts of disability or suffering in which a person with decisional capacity might choose to forego additional life-prolonging treatment. This purely biologic view of life certainly presents an attractive bright-line rule for courts.<sup>56</sup> But for persons to whom this approach is applied, the presumption in favor of continued treatment risks demeaning the individual and disregarding his preferences. Moreover, the argument that continuing with the provision of existing life-sustaining treatment is merely maintaining the status quo, rather than making a decision, is a fallacy.<sup>57</sup> Continuing treatment is a choice, a decision as capable of violating a person's preferences as the decision to discontinue treatment. Logically, then, the principle of autonomy is a *petitio principii* and incapable of solving the dilemma it creates (or, at least, perpetuates).

### ***B. United Kingdom End of Life Law and Practices***

The legal system and its impact on medical practice in the United Kingdom differs significantly from that of the U.S. Rather than a state-by-state patchwork of statutes and common law opinions, there is a unified approach to end of life decision making in England, Wales, and Northern Ireland, and substantively similar standards in Scotland (though with variations in required procedures). However, there is no formal legislation that directly regulates end of life care, although aspects of the Mental Capacity Act of 2005 are relevant.<sup>58</sup>

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<sup>55</sup> Of course, it seems unlikely that "new evidence" of an incapacitated patient's wishes is discovered very often.

<sup>56</sup> Cf. *In re Baby K*, 16 F.3d 590 (4<sup>th</sup> Cir. 1994) (resolving, on technical statutory grounds, a dispute about continued life supportive measures for an anencephalic infant and thus defaulting to protection of purely biologic life).

<sup>57</sup> See RONALD DWORKIN, *LIFE'S DOMINION* 205 (1993) (arguing, in response that the court has no right to choose to end care for those who have not chosen it themselves, that "the fallacy in this argument is that choice cannot be avoided. To continue treatment is as much of a choice as to discontinue it.").

<sup>58</sup> See Mental Capacity Act, available at [www.legislation.gov.uk/ukpga/2005/9/](http://www.legislation.gov.uk/ukpga/2005/9/) contents. In 2008, the U.K. government did, however, make a decision to adopt a systematic 10 year plan to improve the quality of end of life care. See Bradford H. Gray, *England's*

Under the current applicable U.K. law, which includes the Mental Capacity Act (MCA), common law precedent, and guidance documents for physician practice, the physician retains the ultimate authority to make treatment decisions for incompetent adults rather than the next-of-kin.<sup>59</sup> Even the courts do not dictate what happens except to the extent of pronouncing on the lawfulness of the treatment that the physician proposes.<sup>60</sup> However, the authority of the physician is limited; the physician must do what is in the patient's best interests.<sup>61</sup> Courts and the MCA itself have interpreted "best interests" to include not only medical interests but also the patient's own wishes, values, and preferences at the time the patient was competent.<sup>62</sup> Thus, the concept of best interests in the U.K. includes elements of concern for the patient's autonomous preferences. The Mental Capacity Act and accompanying guidance documents also include relevant provisions which require doctors to act in the best interests of incapacitated patients.<sup>63</sup>

In cases of patients in PVS, the General Medical Council (GMC) has published a Guidance for Doctors on Treatment and Care Towards the End of Life<sup>64</sup> which provides a very different picture of the approach in the U.K. to these treatment decisions compared with that of the U.S. First, it is worth noting that, although the publication is called a "guidance" and contains a disclaimer that it is not a statement of legal principles or a substitute for legal advice,<sup>65</sup> it has the effect of a series of regulatory statements. Doctors are

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*Approach to Improving End-of-Life Care: A Strategy for Honoring Patients' Choices*, The Commonwealth Fund, July 2011, at 2, available at <http://www.commonwealthfund.org/Publications/IssueBriefs/2011/Jul/EnglandsApproachtoImprovingEndofLifeCare.aspx> (last visited Jan. 18, 2013).

<sup>59</sup> See Dominic Bell, *The Legal Framework for End of Life Care: A United Kingdom Perspective*, 33 INTENSIVE CARE MED. 158, 159 (2006).

<sup>60</sup> *Id.* at 159.

<sup>61</sup> See, e.g., Re A., 1 FLR 549 (2000) (cited in Bell, *supra* note 59, at 159).

<sup>62</sup> U.K. DEP'T OF HEALTH, *Good Practice in Consent* HSC 2001/023 (2001); GEN. MED. COUNCIL, *Seeking Patients' Consent: The Ethical Considerations* (1998).

<sup>63</sup> See Mental Capacity Act, § 4. Section 4(5) adds that, with respect to decisions about life-sustaining medical treatment, the doctor "must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death." Section 4(6)(a)–(b) adds that the doctor must, in evaluating the patient's best interests, also consider the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), [and] the beliefs and values that would be likely to influence his decision if he had capacity"). According to Guidance documents, if a patient does not have a relevant advance directive, the physician may consider withdrawing life-sustaining treatment "based on a range of clinical criteria, including unresponsive physiological deterioration, overwhelming and irreversible pathology such as brainstem death, and progression of co-morbidity against a background of significant impairment of quality-of-life prior to the critical illness." GEN. MED. COUNCIL, *Treatment and Care Towards the End of Life: Good Practice in Decision-making* (May 20, 2010) (hereinafter, GEN. MED. COUNCIL) available at [http://www.gmcuk.org/static/documents/content/End\\_of\\_life.pdf](http://www.gmcuk.org/static/documents/content/End_of_life.pdf) (last visited Feb. 15, 2012).

<sup>64</sup> See GEN. MED. COUNCIL, *supra* note 63.

<sup>65</sup> *Id.* at 6. In addition to the GEN. MED. COUNCIL's Guidance, in 2007, the Department for Constitutional Affairs and the Lord Chancellor issued the Mental Capacity

informed that, in cases where the guidance states “you must,” this creates an overriding duty or principle of practice.<sup>66</sup> The nearest equivalents in the U.S. are professional organizations such as the American Medical Association or the National Hospice and Palliative Care Organization. These private groups publish standards, statements of practice or principles of treatment, but they are not binding on physicians, even on those who are members of the organizations.

In situations where there is uncertainty about the continued care of patients who lack decisional capacity and who are in PVS or similar conditions, the GMC’s guidance strongly emphasizes the patient’s best interests and recognizes that many patients have not formally stated their wishes concerning care under these circumstances. The guidance instructs doctors to use their own “specialist knowledge . . . and clinical judgment, together with evidence about the patient’s views (including advance statements, decisions, or directives), to identify which . . . treatments are clinically appropriate and are likely to result in overall benefit for the patient.”<sup>67</sup> In England and Wales, even though the doctor retains ultimate treatment decision authority, the GMC guidance also requires the doctor to request the appointment of an advocate to participate in the decision making process when there is no legal proxy or close relative who is willing to stand in that role for the patient.<sup>68</sup>

Where there is disagreement about whether a particular treatment or intervention would be of overall benefit (either between doctors, or among the doctor, his or her patient, or the patient’s family or proxy), the Guidance sets out a process to resolve the dispute. Interestingly, the Guidance specifically addresses situations in which the proxy or decision maker requests treatment that the doctor believes would not be clinically

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Act Code of Practice. This code provides practical guidance to physicians, proxies, paid carers, independent advocates, and others for the implementation of the MCA’s provisions, including a thoughtful discussion about what the MCA means by “best interests.” See DEPT. FOR CONST’L AFFAIRS, *Mental Capacity Act of 2005 Code of Practice* (2007) 64–91, available at <http://www3.imperial.ac.uk/pls/portallive/docs/1/51771696.PDF> (last visited Jan. 12, 2013). The Code of Practice informs physicians that the MCA does not impose a duty of compliance with the Code; “it should be viewed as guidance rather than instruction.” It nevertheless goes on to say that if one has “not followed relevant guidance contained in the Code then they will be expected to give good reasons why they have departed from it.” *Id.* at 1.

<sup>66</sup> *Id.* By contrast, in the U.S., doctors are regulated in the state in which they practice by state boards of medicine, which occasionally work with state legislatures to promulgate specific standards of practice (often addressing the prescribing of addictive drugs) and to discipline doctors who violate standards or mistreat or abuse patients. The U.S. state boards of medicine do not, however, routinely promulgate general standards of practice for end of life care or any other area of medicine.

<sup>67</sup> *Id.* at 16.

<sup>68</sup> *Id.* at 18 (explaining that the Mental Capacity Act of 2005 requires the appointment of an Independent Mental Capacity Advocate (IMCA) in such circumstances). The IMCA has “authority to make enquiries about the patient and to contribute to the decision by representing the patient’s interests but cannot make a decision on behalf of the patient.” *Id.*

appropriate or of overall benefit to the patient. In these circumstances, the doctor should explain the reasons for this opinion and discuss it with the patient's family. The doctor is not, however, obligated to provide such treatment.<sup>69</sup>

In disputed cases, the Guidance recommends various non-legal approaches as a first step, including involving an independent advocate, seeking advice from a more experienced colleague or obtaining a second opinion, holding a case conference, or using local mediation services in order to work toward consensus.<sup>70</sup> If none of these steps effectively resolves the disagreement, the Guidance instructs doctors to seek legal advice by applying to the appropriate statutory body for review (in Scotland) or to an appropriate court for an independent ruling.<sup>71</sup> The Guidance adds that, in England, Wales and Northern Ireland, the court should consider "whether treatment is in the patient's 'best interests'" whereas in Scotland the courts should consider "whether treatment is of benefit to the patient."<sup>72</sup>

The Guidance expressly addresses particularly complex end of life scenarios as well, including questions about the provision of artificial nutrition and hydration and issues arising with patients in PVS or who otherwise lack decisional capacity.<sup>73</sup> For patients in PVS or similar conditions, the Guidance instructs doctors in England, Wales, and Northern Ireland to approach the appropriate court for a ruling before withdrawing nutrition and hydration.<sup>74</sup> Overall, the Guidance suggests that physicians have significant authority and even the obligation to decide whether or not artificial nutrition and hydration are of overall benefit for particular patients.

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<sup>69</sup> *Id.* at 18–19 (providing that the decision maker or proxy can at this point request a second opinion or seek review from the appropriate statutory body in Scotland or and appropriate court in the rest of the UK).

<sup>70</sup> *See* GEN. MED. COUNCIL Guidance at 30 (adding that in seeking consensus, the physician "should take into account the different decision-making roles and authority of those you consult, and the legal framework for resolving disagreements.").

<sup>71</sup> *See id.* at 30.

<sup>72</sup> *See id.* at 30, n. 22.

<sup>73</sup> *See generally* GEN. MED. COUNCIL Guidance, §§ 112–27 (discussing the provision of clinically assisted nutrition and hydration generally, for patients who have capacity, for adults who lack capacity with varying prognoses, and for adults in PVS). With respect to adults who lack capacity and who are not expected to die within hours or days but who are in the end stage of a disease or condition, the Guidance instructs doctors to provide artificial nutrition and hydration if it would be of overall benefit to the patient and to take into account the patient's wishes and values. *See* GEN. MED. COUNCIL Guidance at 57 (adding that "[t]he patient's request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor."). In these circumstances, if the doctor believes that artificial nutrition and hydration would not be of overall benefit to the patient, it can be withheld or withdrawn, but the doctor must obtain a second opinion from another doctor who is familiar with the patient's condition but is not directly caring for the patient. *Id.* at 57–58 (stating that the doctor should also consider seeking legal advice).

<sup>74</sup> *Id.* at 59 (adding that, although courts in Scotland have not announced this requirement, doctors would be wise to seek legal advice on whether a court ruling might be necessary in individual cases).

#### IV. SOME COMPARISONS AND OBSERVATIONS

Case law from the United Kingdom suggests that physicians and courts confronting difficult end of life choices in the U.K. are significantly more pragmatic about these tragic cases. Beginning with the *Bland* case, and continuing in successor cases,<sup>75</sup> there is evidence of a genuine willingness to consider openly not only the express wishes of the patient (if they are known), but also, and only together with, the patient's best interests and quality of life.

It is important to note that the court in the *Bland* case took pains to characterize a doctor's removal of life-supportive measures as an omission (not motivated by a desire to bring about the patient's death) rather than an act intended to cause the patient's death. As Lord Goff suggested:

I agree that the doctor's conduct in discontinuing life support can properly be categorised as an omission . . . . discontinuation of life support is, for present purposes, no different from not initiating life support in the first place. In each case, the doctor is simply allowing his patient to die in the sense that he is desisting from taking a step which might, in certain circumstances, prevent his patient from dying as a result of his pre-existing condition; and as a matter of general principle an omission such as this will not be unlawful unless it constitutes a breach of duty to the patient.<sup>76</sup>

Many in the United States agree with this argument for the withdrawal of life-supportive care. Courts and medical ethics commentators have argued, persuasively, that withdrawing life support is not "killing" the patient, but rather allowing the patient to die of the underlying disease or injury which led to the life support in the first place. It is ceasing to place an artificial obstacle in the way of what would otherwise be a natural death.<sup>77</sup>

But the U.K. court's willingness to speak directly of the patient's "best interests" and to acknowledge that it is not always in a patient's best

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<sup>75</sup> The view of the House of Lords as expressed in the Anthony Bland case was later confirmed by the House of Lords in 2001 in *National Health Service Trust A. v. M. and N.H.S. Trust B. v. H.*, 1 All E.R. 801 (2001); 1 F.C.R. 406; 2 W.L.R. 942; 2 F.L.R. 367 (concurring with the House of Lords' decision in *Bland*, taking into account the European Convention on Human Rights and Fundamental Freedoms (ECHR)); see also Danuta Mendelson & Timothy Stoltzfus Jost, *A Comparative Study of the Law of Palliative Care and End-of-Life Treatment*, 31 J. L. MED. & ETHICS 130, 131 (2003) (discussing these cases).

<sup>76</sup> *Id.* at 866 (distinguishing from this situation the case of "an interloper who maliciously switches off a life support machine.").

<sup>77</sup> See, e.g., *In Re Conroy*, 486 A.2d 1209, 1224 (1985) (explaining that the refusal of medical treatment "merely allows the disease to take its natural course; if death were eventually to occur, it would be the result, primarily, of the underlying disease.").

interests to continue receiving care which keeps him alive would cause consternation among many people in the U.S., particularly those who describe themselves as conservative Christians or “pro-life.” As an example, Lord Browne Wilkinson in the *Bland* case expressed the view that physicians have a responsibility to withdraw life-sustaining medical care when such treatment is considered futile:

[i]f there comes the stage where the responsible doctor comes to the reasonable conclusion (which accords with the views of a responsible body of medical opinion) that further continuance of an intrusive life-support system is not in the best interests of the patient, he can no longer lawfully continue that life-support system: to do so would constitute the crime of battery and tort of trespass to the person.<sup>78</sup>

This view has been confirmed repeatedly as a matter of public policy in the practice of medicine in the U.K.<sup>79</sup>

The co-existence of principles of autonomy and beneficence creates disagreements about the futility of life-supportive medical technology, and these disputes are embedded into many end of life conflicts. Physicians, patients, or families may question whether and when further treatment or life-sustaining measures are no longer medically or ethically appropriate.<sup>80</sup> The futility conundrum is obvious (futility is in the eye of the beholder), and families, patients, and health care providers may fail to agree on an appropriate point to discontinue technological interventions. Without guidance about an individual patient’s beliefs regarding continued life-supportive measures, it is difficult to know when to cease providing support to a person whose condition will not improve. In such circumstances, the U.S. health care system and its providers are reluctant to opine about an incapacitated patient’s best interests or, underlying that inquiry, quality of life.<sup>81</sup> Instead, courts in these cases generally will revert to erring on the side of continued treatment.<sup>82</sup>

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<sup>78</sup> *Bland* at 883 (Lord Browne-Wilkinson).

<sup>79</sup> For example, in 2000, the then-chairman of the British Medical Association’s Medical Ethics Committee spoke strongly in support of the view that treatment should not be continued when it becomes more of a burden than a benefit to the patient. “Deliberate over-treatment can be as detrimental as under-treatment.” See Anne Johnstone, *The Arguments Behind Attempts to Legislate on the Most Agonizing Decision Doctors Have to Make; A Matter of Life and Death*, GLASGOW HERALD, Jan. 19, 2000, 2000 WLNR 3606774 (quoting Dr. Michael Wilks).

<sup>80</sup> Futility questions arise in two categories: questions of the subjective value of the medical intervention and questions about the probability that the medical intervention will be successful. See Robert D. Truog *et al.*, *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561 (1992).

<sup>81</sup> See, e.g., *Cruzan v. Dir.*, Mo. Dept. of Health, 497 U.S. 261, 282 (1990) (“[W]e think a State may properly decline to make judgments about the quality of life that a particular

With the continual advancement of life-supportive technologies, we add to our arsenal for delaying death. A decision to maintain the status quo and continue life-supportive measures may help assuage feelings of helplessness on the part of families and care givers, and it may align with the interests of “pro-life” organizations, but it is not necessarily in the individual patient’s best interests, nor does it necessarily reflect the patient’s authentic choice.<sup>83</sup> As explained above, a purely biologic view of life presents an easy to apply bright-line rule for U.S. courts.<sup>84</sup> Any willingness to look beyond mere biologic existence would require that physicians and families consider whether technologies that extend life provide a benefit to patients in cases in which the patient will experience no improvement in function. Too often, rather than address uncomfortable quality of life questions, we in the U.S. sidestep these ethically challenging decisions. The problem with this preference in the direction of continued treatment is that it is just as likely to offend an individual’s autonomy as to err in the opposite direction and withdraw treatment.

Part of the particular difficulty with discussing death in the U.S. probably stems from the heterogeneity of its culture. While the United States takes pride in its religious and cultural pluralism, it struggles with the resultant differences when attempting to reach a collective, societal consensus on end of life matters. The mainstream culture in the U.S. is

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individual may enjoy, and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual.”); *Conservatorship of Wendland*, 28 P.3d 151 (2001) (upholding a trial court decision to continue life-sustaining treatment despite a proxy decision maker’s request to withdraw it because the proxy “offered no basis for such a finding other than her own subjective judgment that the conservatee did not enjoy a satisfactory quality of life and legally insufficient evidence to the effect that he would have wished to die”); *In re Conservatorship of Helga M. Wanglie*, No. PX91283, (Hennepin Cnty. Prob. Div., Minn. 1989) (upholding the surrogate’s request for continued treatment of the patient, who was in a persistent vegetative state and who died more than a year later of sepsis).

<sup>82</sup> See, e.g., *Cruzan* at 283 (“An erroneous decision not to terminate [life-supportive measures] results in a maintenance of the status quo; the possibility of subsequent developments such as advancements in medical science, the discovery of new evidence regarding the patient’s intent, . . . at least create the potential that a wrong decision will eventually be corrected . . . . An erroneous decision to withdraw life-sustaining treatment, however, is not susceptible of correction”); see also Alicia R. Ouellette, *When Vitalism is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 IND. L. J. 1 (2004) (arguing that people in the U.S. err on the side of life by defining it as biological life in order to avoid having to draw the line between euthanasia and determining that the patient’s best interests might involve ceasing life-sustaining care).

<sup>83</sup> Cf. Sean Palfrey, *Daring to Practice Low-Cost Medicine in a High-Tech Era*, NEW ENG. J. MED. (2011), available at <http://www.nejm.org/doi/pdf/10.1056/NEJMp1101392?source=hcrc> (last visited Mar. 3, 2012) (commenting on the mistaken belief that “‘doing everything’ is the best practice and the way to prevent harm”).

<sup>84</sup> Cf. *In re Baby K*, 16 F.3d 590 (4<sup>th</sup> Cir. 1994) (resolving, on technical statutory grounds, a dispute about continued life supportive measures for an anencephalic infant and thus defaulting to protection of purely biologic life).

heavily divided on the most challenging issues in end of life care. This divisiveness, with respect not only to end of life care but also reproductive autonomy, is often referred to as the “culture wars.” The mechanisms of legal adjudication go some way to creating consensus by recognizing some fundamental rights of decision making, but when an individual’s wishes are unclear and a dispute reaches the judicial system, our cultural heterogeneity adds fuel to the ensuing conflict.<sup>85</sup>

In the U.S., many hold the view that life begins at conception and that all life is sacrosanct, even if the person in question is permanently and irretrievably unconscious. By contrast, British courts have taken the position that “a view that life must be preserved at all costs does not sanctify life.”<sup>86</sup> As Lord Justice Hoffmann wrote in the *Bland* case, “[t]he choice which the law makes must reassure people that the courts do have full respect for life, but that they do not pursue the principle to the point at which it has become almost empty of any real content and when it involves the sacrifice of other important values such as human dignity and freedom of choice.”<sup>87</sup> This is a difficult line to draw, but well worth the effort.

#### V. IN THE U.S.A.: ROLE FOR BEST INTERESTS ANALYSIS

Although there are many differences between the U.S. and the U.K. law governing decision making for incapacitated patients, two stand out. First, the primacy of the autonomy principle in the U.S. means that physicians are rarely called upon to make the actual decision about whether to withdraw life sustaining medical treatment. Physicians are asked to implement decisions made by patients (via advance directives) or their proxies, but they rarely possess the responsibility or authority to decide (although of course physicians must provide the necessary information on which to base the decision and they also retain the right to refuse to implement a patient’s or proxy’s request to withdraw care).<sup>88</sup> In contrast, physicians in the U.K. are expressly charged with the responsibility to

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<sup>85</sup> Cf. Douglas B. White & Thaddeus M. Pope, *The Courts, Futility, and the Ends of Medicine*, 307 JAMA 151, 151-52 (2012) (discussing the collateral benefits of judicial adjudication of end of life disputes).

<sup>86</sup> *In re a Ward of the Court*, 2 I.R.L.M. 401 (S.C.) (Ir. 1995) (adding that “sanctity of life was not a principle on which legal structures should be based since it depended on a religious outlook that not everyone shared.”); also cited in Bell, *supra* note 59, at 160.

<sup>87</sup> See *Airedale NHS Trust v. Bland*, at 830.

<sup>88</sup> The Texas Advance Directives Act is a rare example of a statute that allows health care facilities to discontinue life-sustaining medical treatment in cases where the treating physicians believe that continuing such care is medically or ethically inappropriate. See Texas Advance Directives Act, Section 166.046(e) (1999). Three other state medical associations also have expressed support for similar legislation. See White & Pope, *supra* note 85, at 151.

determine whether continuing life-sustaining medical treatment is appropriate under the law.

Second, as explained above, the principle of autonomy, despite its inherent weaknesses, is frequently interpreted by courts in the U.S. to exclude any consideration of best interests, including quality of life or the concept of dignitary harm, except to the extent that the patient or proxy has included these considerations in their expressed wishes. The autonomy principle may be understood to include best interests analysis, but only if the individual patient wants it so. In contrast, the best interests principle is paramount in the U.K. and includes within it the wishes of the patient (autonomy). The British approach therefore adds a layer of pragmatism into the decision, by taking into account the best available information about the patient's prognosis and the likely effectiveness of proposed therapeutic interventions.

What does it really mean to do "what the patient would choose if able"? In the current U.S. approach, when we do not know a patient's wishes, we either 1) err on the side of continued treatment as a default position or 2) make a mixed autonomy and best interests decision or a pure best interests analysis without necessarily being explicit about it. In other words, autonomy often is simply not enough to make a determination about the ethical propriety of continuing life-supportive measures for a patient in PVS. Increasing the rate at which patients make advance directives also will not solve the problem of treatment of patients in PVS because, even when these documents are available, they may have limited application under state law.<sup>89</sup> About one-third of states exclude permanent unconsciousness as a condition for which advance directives can be drafted to direct the withdrawal of care.<sup>90</sup> And at least three-quarters of states allow individual health care providers to refuse to carry out a patient's wish for withdrawal or withholding of life-sustaining treatment, either for reasons of conscience, or for no reason at all.<sup>91</sup> Finally, advance directives made in the past may not be accurate predictors of what a now-capacitated individual would actually choose under the exact circumstances when later incapacitated by illness.<sup>92</sup>

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<sup>89</sup> States frequently limit applicability of advance directives to terminal illness, leaving patients who suffer from chronic and debilitating disease (including PVS) with more limited options, such as the appointment of a health care proxy. See Robertson, *supra* note 2, at 6; see also Fagerlin and Schneider, *supra* note 1, at 31.

<sup>90</sup> See Stephen Arons, Current Issues in End-of-Life Care, in BERZOFF & SILVERMAN, *LIVING WITH DYING*, 730, 734 (Joan Berzoff and Phyllis R. Silverman, eds., 2004).

<sup>91</sup> *Id.* at 734; see also Neil J. Farber *et al.*, *Physicians' Decisions to Withhold and Withdraw Life-Sustaining Treatment*, 166 ARCH. INT. MED. 560, 563 (2006) (describing research that indicated that nearly half of a cohort of physicians surveyed would refuse to comply with patient's wishes to withdraw or withhold life supportive technology under some circumstances).

<sup>92</sup> See Robertson, *supra* note 2, at 8 (noting that those who execute advance directives are "rarely . . . told that the directive they make reflects their current interests and

By incorporating an additional layer of consideration of a patient's best interests in situations where there is little or nothing known about the patient's actual wishes, U.S. physicians can, consistent with existing law in many states, initiate conversations with more content about the desired versus realistic ends of continuation of care. Because autonomy is still very much part of the conversation, those patients or surrogates who believe that any life, even permanently unconscious life, is preferable to death can continue to request life-supportive measures. A best interests approach could add consideration of the benefits and burdens of continued treatment (including in a concept of burdens that includes dignitary harm) into the mix, and can help the physician and family or surrogate move toward a plan of treatment or non-treatment. For example, in the *Bland* case, it was argued, in support of withdrawing artificial nutrition and hydration, both that continuing treatment would be of no benefit because it could not reverse his condition and that keeping Anthony alive under these circumstances, when he would most likely not wish it, diminished his dignity.<sup>93</sup>

This is not to suggest that a U.S. physician impose his or her assessment of the patient's best interests and then dictate the course of treatment (or non-treatment) accordingly. What is recommended here is that U.S. physicians learn to move beyond the autonomy conversation (what would your loved one choose if she were able?) to articulate the facts about the patient's chances for meaningful recovery and the benefits and burdens of continued treatment and life-supportive measures for patients in PVS with a medically confirmed diagnosis. The data suggest that, when discussing the prognosis of seriously ill patients with patients and their family members, physicians frequently shy away from disclosing these details spontaneously.<sup>94</sup>

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may not be a good indicator of their interests as an incompetent patient"); *see also* Fagerlin & Schneider, *supra* note 1, at 33 (arguing that people will have difficulty predicting their preferences in advance because they misunderstand illnesses and treatments, think about their "choices" only superficially, and change their minds over time).

<sup>93</sup> *See Airedale NHS Trust v. Bland*, at 883. In response to those who object that it cannot burden a person's dignity to keep him alive if he cannot feel pain or humiliation, commentators have pointed out, quite persuasively, that this argument "assumes that we have no interests except in those things of which we have conscious experience. But this does not accord with most people's intuitive feelings about their lives and deaths." *See* DWORKIN, *supra* note 57, at 206 (adding, with respect to Anthony Bland's interests, that it is "demeaning to the human spirit to say that, being unconscious, he can have no interest in his personal privacy and dignity, in how he lives or dies.").

<sup>94</sup> Physicians also tend to over-estimate the remaining life spans of seriously ill patients and to convey prognosis in overly optimistic terms. *See* Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients*, 320 *BRIT. MED. J.* 469, 470-71 (2000) (finding that, in predicting patients' remaining life expectancies, physicians were correct only 20 percent of the time and were over-optimistic 63 percent of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions). Even worse, a surprising number of physicians acknowledge deliberate deception of patients in discussing patients' prognoses. In

All of this, of course, will require some physicians to develop better communication skills and a willingness to use them, even in circumstances that are emotionally challenging for physician, patient, and family. Ultimately, if the permanently vegetative patient has no relevant advance directive and conversations about what the patient would choose are unavailing, and the family member or surrogate decision maker is unable or unwilling to make a decision about continued treatment or life-supportive measures, the physician or medical team should take more initiative in having the necessary conversation. When a patient's diagnosis of permanent vegetative state is confirmed and life supportive measures are the only thing standing between that person and death, physicians can do more to honor a patient's choices and dignity by including truthful conversations about prognosis and quality of life. As one commentator recently suggested, physicians should ask what the patient or family wants to know and then tell the truth in an understandable and clear way about the time that the patient has left and what he or she can expect.<sup>95</sup> Physicians who undertake these conversations acknowledge that they are difficult, and that it is often easier to let the patient be swept away by "the powerful momentum of modern medicine."<sup>96</sup> Better physician training regarding communication and understanding of legal and ethical standards for withdrawal and withholding of life-sustaining care is sorely needed.<sup>97</sup> Although it is also the case in the U.S. (as in the U.K.) that physicians have no ethical or legal obligation to provide clinically inappropriate treatment, the combined force of disagreement about what might be clinically appropriate, fear of malpractice liability, and emotional pressure from a family will frequently lead to continued treatment. In other words, in the U.S., the doctor may take the path of least resistance.

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a recent survey of physicians, one in ten physicians admitted to lying to a patient within the previous year and over half of those surveyed acknowledged that they had been unreasonably optimistic about a patient's prognosis. See Lisa I. Iezzoni *et al.*, *Survey Shows That at Least Some Physicians Are Not Always Open or Honest with Patients*, 31 HEALTH AFFAIRS 383, 383–88 (2012); cf. *Arato v. Avedon*, 858 P.2d 598 (1993) (involving a claim by a deceased patient's family that the physicians' failure to disclose specific information about survival rates and times with pancreatic cancer and related cases impaired the patient's ability to get his financial and business affairs in order).

<sup>95</sup> See Thomas J. Smith & Dan L. Longo, *Talking With Patients About Dying*, 367 NEW ENG. J. MED. 1651, 1652 (2012).

<sup>96</sup> See Mark Vierra, *Death Panels*, 156 ANN. INTERNAL MED. 394, 395 (2012) (describing a case in which he explained to a dying patient's wife why he would not recommend additional life-prolonging surgery and adding that "[e]very one of my patients is going to die one day. Like it or not, I should have these conversations earlier, more often, and more comfortably. If that makes me part of a death panel, well, I suppose I can live with that.").

<sup>97</sup> See Neil J. Farber *et al.*, *Physicians' Decisions to Withhold and Withdraw Life-Sustaining Treatment*, 166 ARCH. INT. MED. 560, 563 (2006) (noting that lack of training about the ethical and legal issues may lead to dissent among physicians when patients request that care be withheld or withdrawn).

Of course, completely abandoning the principle of autonomy in U.S. end of life decision making law is unwise and unnecessary. There is no need to revise state laws that emphasize the role of patient autonomy. It is essential, however, to recognize that autonomy alone, as an ethical and legal principle, represents an insufficient basis for end of life decision making in many instances. While it is true that, in the end, we must each confront death individually in our own way, the “good death” envisioned by most requires that patients surrender control over the externalities of medical care at some point and trust that those who provide that care will do what it takes to ease the path and not to prolong it in conflict with a patient’s best interests.<sup>98</sup>

## VI. CONCLUSION

How we die matters on multiple dimensions. Although this paper focuses on patients in PVS and similar conditions, it obviously matters to all patients. Addressing death in a compassionate but pragmatic manner has the potential to make the experience of physicians who care for dying patients more meaningful and complete, exert a positive impact on health care systems (both in terms of the economic bottom line and the allocation of resources in ways that maximize health for all), and benefit the societies in which we live.

In general, it seems that, while both the U.S. and the U.K. systems respect autonomy as a fundamental principle of health care decision making, once a patient has lost decisional capacity and the patient’s wishes are unknown or uncertain, the U.K. system is much more willing openly to consider the patient’s best interests, especially the benefits versus burdens of continued treatment and the risk that continuing treatment with no hope of improvement burdens a patient’s dignity. And unlike in the U.S., in the U.K. there is much less of a pattern of erring on the side of continued treatment if the patient has no hope of making any significant recovery.

Of course, there will be some who worry that leaving too much decision making authority in the hands of physicians allows for paternalism and the risk of discrimination. In the case of withdrawing life-sustaining measures from patients in PVS, it appears that the safeguards recommended by the GMC address these concerns effectively. The emphasis on autonomy in the U.S., and the unwillingness of many doctors to say, definitely, that further life-sustaining care is inappropriate, generates financial and psychological costs to U.S. patients, the health care system, and society as a whole. Allowing a patient to languish in a vegetative state over a period of

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<sup>98</sup> Cf. MARTHA ALBERTSON FINEMAN, *THE AUTONOMY MYTH* (2005) (arguing that, because each individual in society is “inevitably dependent” at various stages of life such as childhood and old age, society should recognize and promote “caretaking relationships” rather than traditional family structures and should acknowledge that traditional American values of individualism do not reflect the reality of societal interdependence).

many years after it has been confirmed that there is no chance of recovery does that patient an injury to his dignity and, most likely, his autonomy even if the patient is unaware of his condition.

Some aspects of the British approach to incorporating a best interests analysis into end of life decision making can and should receive more explicit consideration in American health policy, especially via medical training and continuing medical education for physicians and other health care providers. Although it is unlikely that the U.S. legal framework will change substantially in matters of end of life care, we can, as physicians, patients, and families learn to think differently about these difficult questions. And, if we truly value autonomy, our laws and the end of life practices that operate within them must do more to protect incapacitated patient's choices from those who may by default or deliberation impose their personal views about the sanctity of life on others.