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## A Better Death in Britain?

Barbara A. Noah

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# A BETTER DEATH IN BRITAIN?

*Barbara A. Noah\**

I. CHALLENGES IN END-OF-LIFE DECISION MAKING .....	870
II. COMPARING HEALTH CARE CONTEXTS.....	875
<i>A. U.S. End-of-Life Law and Ethics</i> .....	877
<i>B. U.K. End-of-Life Law and Ethics</i> .....	881
<i>C. System-wide Differences</i> .....	886
1. Fragmented U.S. System of Health Care Delivery ....	886
2. The National Health Service .....	887
III. THE LIVERPOOL CARE PATHWAY FOR THE DYING PATIENT: A CASE STUDY.....	890
<i>A. Description and Goals</i> .....	890
<i>B. The Demise of the LCP</i> .....	892
IV. LESSONS FROM THE LIVERPOOL CARE PATHWAY.....	898
<i>A. Barriers to Quality Improvement in the United States..</i>	899
1. Fear of liability for withholding or withdrawing life- supportive measures. ....	899
2. Disagreement about the ethical status of artificial nutrition and hydration. ....	902
3. Broader fear of “death panel” criticism.....	904
4. Debate about what is meant by “the sanctity of life.”	906
5. Focusing on cost reduction may derail efforts at improvement.....	907
<i>B. Lessons from the Liverpool Care Pathway—Implementing     Best Practices</i> .....	908
V. NOT THE END .....	914

## I. CHALLENGES IN END-OF-LIFE DECISION MAKING

International comparisons of health outcomes indicate that the United States ranks poorly among wealthy, developed countries on all measures of health, with the exception of self-reported subjective health status. In the United States, overall health is poor compared with European countries, yet Americans believe that they are in good shape.<sup>1</sup> This striking evidence of self-delusion is symptomatic of the larger problem that we face with respect to life and death—the unwillingness to confront mortality.<sup>2</sup> Patients and physicians often avoid discussing the inevitability of death and planning for it, and therefore miss opportunities to make choices that comport with their values and preferences. In the absence of such decisions, the default model is to “err on the side of life” which often results in overtreatment or inappropriate prolongation of life and avoidable suffering.

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1. See James Banks & James P. Smith, *International Comparisons in Health Economics: Evidence from Aging Studies*, 4 ANN. REV. ECON. 57–81 (2012) (reporting higher rates of diabetes, obesity, stroke, cancer, and infant mortality, as well as lower life expectancies); see also James Banks et al., *Disease and Disadvantage in the United States and in England*, 295 JAMA 2037, 2039–40 (2006) (finding the greatest health disparities between the two populations in the lowest socioeconomic status groups); Steven H. Woolf & Laudan Y. Aron, *The U.S. Health Disadvantage Relative to Other High-Income Countries*, 309 JAMA 771, 771–72 (2013) (describing data from a report by the National Research Council and the Institute of Medicine that documents lower life expectancies and higher rates of disease in the United States in all age groups compared with that in sixteen other wealthy, developed countries).

2. See generally Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 ELDER L.J. 1 (2013) (discussing cultural, legal, and other reasons why patients and physicians avoid making end-of-life decisions); see also Craig Bowron, *Our Unrealistic Attitudes About Death, Through a Doctor's Eyes*, WASH. POST, Feb. 17, 2012, [http://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR\\_story.html](http://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR_story.html) (“For many Americans, modern medical advances have made death seem more like an option than an obligation.”).

Overtreatment at the end of life arises not just from the patient's denial of mortality, but from a multiplicity of systemic influences such as lack of training in end-of-life care and the fear of accusations of hastening death.<sup>3</sup> Patients may have difficulty acknowledging that death is imminent, but worse, physicians often do not inform their patients that their prognosis is poor or even that they are dying.<sup>4</sup> In general, the medical system in the United States places much more emphasis on treatment and cure than on broader notions of patient care that include alleviation of physical and emotional suffering in the final stages of terminal illness. Many physicians still view death as a failure of medicine rather than as a natural event that requires all of the physician's skill to make it as peaceful and dignified as possible.<sup>5</sup>

Research into trends in end-of-life care documents the existence and ill effects of these interrelated phenomena. The ideal of a "good death" surely must mean different things to different people but probably includes some common elements such as avoiding physical suffering.<sup>6</sup> In addition, most patients state

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3. See *infra* notes 111 to 114 and accompanying text.

4. See Nancy L. Keating, et al., *Physician Factors Associated With Discussions About End-of-Life Care*, 116 *CANCER* 998, 1001 (2010) (concluding that most physicians surveyed indicated that they would not discuss end-of-life decisions and choices with terminally ill patients until they exhibited symptoms or there were no remaining treatments available); Bethel Ann Powers et al., *Meaning and Practice of Palliative Care for Hospitalized Older Adults with Life Limiting Illnesses*, 2011 *J. AGING RES.* 1, 7 (2011), available at <http://www.hindawi.com/journals/jar/2011/406164/> (discussing the distinctions between and intersection of palliative care and end-of-life care and recommending better training of healthcare providers to understand that "end of life" is not a "well-demarcated period of time before death.").

5. See *infra* notes 67–75 and accompanying text (discussing goals of the Liverpool Care Pathway).

6. For a review of the research on the multiple dimensions that influence perceived quality of dying and death, see Sarah Hales et al., *The Quality of Dying and Death*, 168 *ARCHIVES INTERNAL MED.* 912, 912–18 (2008) (identifying several commonly identified qualities that a "good death" requires, such as freedom from pain and suffering, circumstances of death (e.g., home versus hospital), and cultural variables in different studied countries, such as maintaining independence, control, self-determination, and entrusting decisions to others). For an excellent overview of the idea of a good death and of the emotional issues surrounding death and dying, see SHERWIN B. NULAND, *HOW WE DIE: REFLECTIONS ON LIFE'S FINAL CHAPTER* (1995).

that they would prefer to die at home,<sup>7</sup> but only about 30 percent of patients in the United States do so.<sup>8</sup> Instead, we utilize significant amounts of hospital-based resources at the end of life,<sup>9</sup> including costly therapeutic care and life-prolonging tech-

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7. See GEORGE H. GALLUP INT'L INST., *SPIRITUAL BELIEFS AND THE DYING PROCESS: A REPORT ON A NATIONAL SURVEY* (1997) (reporting results of a survey of U.S. residents commissioned by the Nathan Cummings Foundation and Fetzer Institute); I.J. Higginson & G.J. Sen-Gupta, *Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences*, 3 J. PALLIATIVE. MED. 289, 297–300 (2000) (finding that despite that majority of British patients suffering from serious illnesses wish to die at home, most die in either hospital or a long-term care facility).

8. 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 in 2000, 2005, and 2009*, 309 JAMA 470 (2013) (concluding that, although only 24.6 percent of patients died in hospital in 2009 compared with 32.6 percent in 2000, percentages of deaths in long-term care facilities held steady at around 27 percent and deaths at home rose from 30.7 percent in 2000 to 33.5 percent in 2009); YAFU ZHAO & WILLIAM ENCINOSA, *THE COSTS OF END-OF-LIFE HOSPITALIZATIONS* (2009), available at <http://www.ncbi.nlm.nih.gov/books/NBK53605/> (describing data from 2007 indicating that one-third of Americans died in hospitals); Jeanne Lenzer, *Unnecessary Care: Are Doctors in Denial and is Profit Driven Healthcare to Blame?*, 345 BRIT. MED. J. 6230 (2012) (referring to another estimate that 65 percent of deaths in the United States occur in hospitals). Yet another study found that 45 percent of U.S. deaths occur in hospitals and 22 percent in long term care facilities. See NATIONAL CENTER FOR HEALTH STATISTICS, *DEATHS FROM 39 SELECTED CAUSES BY PLACE OF DEATH, STATUS OF DECEDENT WHEN DEATH OCCURRED IN HOSPITAL OR MEDICAL CENTER, AND AGE: UNITED STATES 1995-2005* (2009).

9. 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); see also Teno et al., *supra* note 8, at 473 tbl.2 (noting that, in 2009, 29.2 percent of patients who died had received care in an ICU in the previous thirty days); Donald M. Berwick & Andrew Hackbarth, *Eliminating Waste in U.S. Health Care*, 307 JAMA 1513 (2012) (describing six categories of healthcare spending waste, including overtreatment, such as use of surgery when watchful waiting is better and unwanted intensive care at the end of life, and estimating that wasteful spending in the overtreatment category accounts for between \$158 billion and \$226 billion in 2011).

nology, even when it is very likely that the benefits in terms of enhanced quality of life or increased survival time are limited or nonexistent.<sup>10</sup> Many patients in the United States receive invasive interventions such as cardiopulmonary resuscitation and Intensive Care Unit (“ICU”) care even when death is imminent.<sup>11</sup>

At the same time, we delay and then underutilize hospice and palliative care.<sup>12</sup> Most worryingly, these trends are worsen-

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10. In a very recent study that attempts to measure physicians’ perceptions of when they are delivering “futile” care to their patients, the data suggested that approximately 20 percent of patients in five critical care units were receiving futile or “probably futile” treatment. See Thanh N. Huynh et al., *The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care*, 173 JAMA INTERNAL MED. 1887, 1889–1890 & fig. (2013). The survey instrument defined five situations in which treatment might be considered futile or medically inappropriate: burdens grossly outweigh benefits; patient will never survive outside an ICU; patient is permanently unconscious; treatment cannot achieve the patient’s goals; death is imminent. *Id.* at 1888. See also Robert D. Truog & Douglas B. White, Commentary, *Futile Treatments in Intensive Care Units*, 173 JAMA INTERNAL MED. 1894 (2013) (critiquing the study design, arguing that legal complexities make it difficult for physicians to say “no” to futile treatment requests, and pleading for better communication and a conflict resolution process to address these situations); R. Sean Morrison et al., *When Too Much Is Too Little*, 335 NEW ENG. J. MED. 1755, 1755–56 (1996) (describing a case of aggressive treatment of an elderly patient with advanced, terminal disease despite his repeated requests that he receive no further treatment and observing that such overtreatment interferes with quality of life for these patients with little offsetting benefit).

11. 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). One palliative care specialist describes the ICU as a place “where a Wild West culture makes it a challenge for palliative care to get a foothold,” adding that it is difficult “to slow a wild horse, particularly one that believes it can outrace death.” Jessica Nutik Zitter, *They Call Me ‘Dr. Kevorkian,’* N.Y. TIMES: WELL (Nov. 14, 2013, 1:37 PM), <http://well.blogs.nytimes.com/2013/11/14/they-call-me-dr-kevorkian/> (adding that she “believe[s] in letting the dying determine how and when they die, as opposed to coaxing their organs at all costs”).

12. See Teno et al., *supra* note 8, at 474 (noting that although use of hospice services has increased during the early 2000s, only 42.2 percent of Medicare beneficiaries with dementia and 59.5 percent of Medicare beneficiaries with cancer received hospice services at time of death); Corita Grudzen & Deborah Grady, *Improving Care at the End of Life*, 171 ARCHIVES INTERNAL MED. 1202, 1202–04 (2011) (discussing overuse of therapeutic interventions

ing—the most recent data have found that, in 2009, 28.4 percent of patients received hospice care for only three days or fewer before dying, an increase from 22.2 percent nine years earlier. Moreover, 29.2 percent of Medicare beneficiaries remained in an ICU during the final month of life compared with 24.3 percent in the earlier-studied period.<sup>13</sup> Of course, the challenge is to provide treatment that both accords with patients' wishes and is clinically appropriate. Because patient preferences vary and it is difficult to predict when death is imminent, this is not a simple process.

After providing some background on the legal and ethical principles which govern end-of-life decision making in the United States and the United Kingdom, this Article will look at a particularly important U.K. response to similar concerns about overtreatment at the end of life coupled with poor palliative care for dying patients: The Liverpool Care Pathway ("LCP") was adopted in the late 1990s as a model of best practices in the care of dying patients.<sup>14</sup> The goal of the LCP is to "ensure that all dying patients, and their relatives and carers receive a high standard of care in the last hours and days of their life."<sup>15</sup> More than a dozen years after its inception, however, the LCP is being phased out, due primarily to a public backlash in response to instances of negligent or unauthorized implementation.<sup>16</sup>

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at the end of life, and advocating that better quality care often requires emphasizing palliative measures and avoiding unavailing therapies that risk unnecessary suffering and iatrogenic harm); Haiden A. Huskamp et al., *Discussions with Physicians About Hospice Among Patients with Metastatic Lung Cancer*, 169 ARCHIVES INTERNAL MED. 954, 955–56 (2009) (finding that only half of stage IV lung cancer patients discussed hospice care with their physicians in the two months before death). These patterns are even more marked among racial and ethnic minorities in the United States. See generally Barbara A. Noah, *The Role of Race in End-of-Life Care*, 15 J. HEALTH CARE L. & POL'Y 349 (2012).

13. See Teno et al., *supra* note 8, at 470–73 & tbl.2 (finding that 11.5 percent of patients were hospitalized three or more times in the three months before death, up from 10.3 percent in the previous studied period).

14. See *News Analysis: What is the Liverpool Care Pathway?*, NATIONAL HEALTH SERVICES (Nov. 27, 2012), <http://www.nhs.uk/news/2012/11november/pages/what-is-the-liverpool-care-pathway.aspx> [hereinafter *What is the LCP?*].

15. See *id.*

16. See Krishna Chinthapalli, *The Birth and Death of the Liverpool Care Pathway*, 347 BRIT. MED. J. 4669 (2013); see also *infra* notes 86–100 and ac-

The rise and demise of the LCP provides an informative case study that illustrates the challenges in implementing guidelines for care at the end of life that respect patient autonomy while providing humane and compassionate care. Despite the United Kingdom's advantages in the form of universal health coverage and a centralized regulatory system for the practice of medicine, the LCP was thought necessary to promote best practices in end-of-life care. The LCP nonetheless suffered from implementation problems often enough to lead to its suspension, which suggests that the most significant causes of poor care at the end of life are less related to resources, access to care, or the proliferation of consensus-based guidelines than to poor communication among physicians, patients, and families about end-of-life matters. Despite the differences between the U.K. and U.S. medical delivery systems, the story of the LCP offers useful lessons to physicians and institutions in the United States that seek to provide high quality and compassionate care to dying patients. This Article will explore the underlying issues that plagued the LCP and that, similarly, pose great challenges to patients and physicians here in the United States, and will suggest lessons to be learned for the provision of end-of-life care in the United States.

## II. COMPARING HEALTH CARE CONTEXTS

A country's health care system and culture have a profound impact on the care of dying patients and many agree that care of the dying in the United States is generally not well done. In an international comparison of care at the end of life published in 2010, researchers analyzed twenty-four indicators of end-of-life care availability, quality, and cost and made comparisons among forty countries. The United Kingdom and Australia were ranked as having the highest "quality of death," while the United States tied with Canada for ninth place.<sup>17</sup> The data

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accompanying text (discussing criticisms of the LCP and reasons for its abandonment).

17. ECONOMIST INTELLIGENCE UNIT, *THE QUALITY OF DEATH: RANKING END-OF-LIFE CARE ACROSS THE WORLD*, figs.1, 5 & 6 (2010), [http://graphics.eiu.com/upload/QOD\\_main\\_final\\_edition\\_Jul12\\_toprint.pdf](http://graphics.eiu.com/upload/QOD_main_final_edition_Jul12_toprint.pdf) (ranking the United Kingdom first for overall care, for quality, and for availability).



from the United Kingdom also indicates that overall objective health status there is far better than in the United States.<sup>18</sup>

The primary goal in the United States, dictated by both law and ethical principles, is to provide end-of-life care according to the individual patient's wishes. In ideal circumstances, patients can express their preferences directly but, if the patient has lost decisional capacity, physicians must seek guidance from advance directives, conversations with family members, or proxy decision makers, and the context of the patient's values, preferences, and beliefs. Under this approach, the goal is to preserve the patient's autonomy even when he or she can no longer articulate a preference. For very ill patients who lose decisional capacity, an autonomy-based model of medical decision making is not effective unless these patients were previously willing to both discuss their preferences in advance and to document them in some form of advance directive. However, rates of advance directive completion remain low.<sup>19</sup> In reality,

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18. See Banks & Smith, *supra* note 1, at 65 (finding, in a study of self-reported rates of disease in the United States and the United Kingdom, that U.K. residents are significantly healthier than U.S. residents in the same age range and that this difference exists across all ranges of socio-economic status and education). With its substantially better overall health status, one would expect higher per capita health spending in the United Kingdom, but the opposite is true: the United States spends significantly more than double the amount per person the United Kingdom spends. *Id.* at 2037 (noting that the United States spends \$5274 per capita versus \$2164 in the United Kingdom). Part of the overspending problem in the United States has nothing to do with end-of-life decision making, but instead has much to do with the lack of control over the pricing of healthcare goods and services here compared with the rest of the world. A good portion of the spending disparity is probably attributable to the fact that Americans pay significantly more for every type of healthcare than any other country. See Elisabeth Rosenthal, *The \$2.7 Trillion Medical Bill*, N.Y. TIMES, June 1, 2013, at A1 (comparing the price of various drugs and procedures in the United States to that in other countries and explaining that the high price tag for medical goods and services in the U.S. results "not from top-notch patient care, . . . but from business plans seeking to maximize revenue [and] haggling between hospitals and insurers that have no relation to the actual costs of performing the procedure").

19. A recent survey of 1700 California adults indicated that 80 percent of the participants believed it was important to record their end-of-life wishes in an advance directive, but less than one-quarter had actually done so. See CALIFORNIA HEALTHCARE FOUNDATION, FINAL CHAPTER: CALIFORNIANS' ATTITUDES AND EXPERIENCES WITH DEATH AND DYING (2012), <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/F/PDF%20FinalChapterDeathDying.pdf>. Only 42 percent of those surveyed indicated

autonomy at the end of life is often illusory because patients frequently are reluctant to articulate their wishes about end-of-life care or even to acknowledge to themselves or to their families the fact that they are dying.

In the United Kingdom, although patient autonomy plays an important role in deciding whether to initiate or continue life-supportive measures for seriously ill or dying patients, this principle is supplemented with an explicit 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 relevant.<sup>20</sup> Of course, there are several very significant differences between the United States and the United Kingdom, including structural aspects of health-care delivery, the role of the physician, and cultural variables.<sup>21</sup> Nevertheless, whether by necessity or design, medical law in the United Kingdom reflects a greater willingness to consider the patient's best interests and quality of life, in addition to the express wishes of the patient if they are known, compared with the autonomy-dominated model of practice in the United States.<sup>22</sup>

#### *A. U.S. End-of-Life Law and Ethics*

In the United States, individual patient autonomy, as implemented in law via the doctrines of informed consent and substi-

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that they had talked with a loved one about their end-of-life wishes, and only 7 percent had discussed these wishes with their physicians. *Id.* Other sources indicate similarly low rates of advance directive completion. See U.S. GOV'T ACCOUNTABILITY OFF., GAO-95-135, PATIENT SELF-DETERMINATION ACT: PROVIDERS OFFER INFORMATION ON ADVANCE DIRECTIVES BUT EFFECTIVENESS UNCERTAIN 2 (1995) (concluding that "advance directives have been advocated more than they have been used" and "only 10 to 25 percent of Americans have documented their end of life choices or appointed a health care agent"); Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 HASTINGS CTR. REP. 31, 32-36 (2004) (noting that less than 20 percent of Americans have living wills, that studies suggest living wills rarely influence the level of medical care, and that at least a quarter of patients with living wills receive care that is inconsistent with their instructions).

20. See *infra* notes 38 to 40 and accompanying text.

21. See *infra* notes 51 to 66 and accompanying text.

22. See generally Barbara A. Noah, *Two Conflicts in Context: Lessons from the Schiavo and Bland Cases and the Role of Best Interests Analysis in the United Kingdom*, 36 HAMLINE L. REV. 239 (2013).

tuted judgment, is the primary principle that governs decisions on behalf of those who have lost decisional capacity.<sup>23</sup> However, insufficient evidence of the patient's wishes often will leave physicians and family members in a quandary as to whether to continue providing therapeutic treatment or life-sustaining care. Uncertainty about prognosis in the case of terminal illness, or the possibility of some recovery of function in the case of severe brain injury, adds to the complexity of decisions about withdrawal of treatment or life-support measures. Even when a patient retains decisional capacity (making substituted judgment unnecessary), the patient's choice may be irrational, unreasonable or unwise, but the doctrine of autonomy, with limited exceptions, protects these choices.

As for U.S. law, for the most part, medical treatment and decision making, including end-of-life decision making, is a matter left to the individual states.<sup>24</sup> U.S. end-of-life law attempts to implement the autonomy principle via various mechanisms, including advance directives, informed consent, and surrogate decision-making. Each of the fifty states has its own statutory and common law addressing health care decision-making, and this fragmented system of regulation leads, not surprisingly, to inconsistent standards, procedures, and results in the decision-making process.<sup>25</sup> All fifty states have incorporated the auton-

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23. See Alan Meisel, *End-of-Life Care*, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK, 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 healthcare proxies who make decisions on their behalf."). The American Medical Association ("AMA") has acknowledged that patients have a right of self-determination that includes the right to refuse unwanted medical treatment, which is not lost when a patient loses decisional capacity. See Council on Ethical and Judicial Affairs, AM. MED. ASS'N, *Decisions Near the End of Life*, 267 JAMA 2229 (1992).

24. 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 ACCOUNTABILITY OFF., *supra* note 19; Fagerlin & Schneider, *supra* note 19, at 32 (commenting on empirical studies that demonstrate the PSDA's lack of effectiveness).

25. For more detailed discussion on the U.S. end-of-life law, see generally ALAN MEISEL & KATHY L. CERMINARA, *THE RIGHT TO DIE* (2004); Noah, *supra* note 22, at 249-52 (describing varying standards of evidence for purposes of allowing a surrogate decision-maker to refuse treatment on behalf of an incapacitated patient).

omy principle into their individual laws by acknowledging the authority of advance directives or formally appointed healthcare proxies,<sup>26</sup> though standards of proof for withdrawing or withholding life-sustaining treatment vary by state and by medical context and some states restrict the circumstances under which advance directives can be used to withdraw certain types of care.<sup>27</sup>

Despite this heavy emphasis on the principle of autonomy, U.S. law also includes references to and consideration of, the principle of best interests. Many states' laws already acknowledge a place for best-interests analysis in making treatment decisions for incapacitated patients.<sup>28</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

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26. See Meisel, *supra* note 23, at 51–52.

27. See Stephen Arons, *Current Legal Issues in End-of-Life Care*, in *LIVING WITH DYING* 733–36 (Joan Berzoff & Phyllis R. Silverman, eds. 2004) (explaining, for example, that some state statutes restrict which treatments patients can forego via an advance directive or at the direction of a proxy, such as withdrawal of artificial nutrition and hydration, and some states do not include permanent unconsciousness as a condition which can trigger the provisions of an advance directive). About one-third of states exclude permanent unconsciousness as a condition for which advance directives can be used to withhold or withdraw care and at least three-quarters of states permit individual healthcare providers to refuse to carry out patient wishes, for reasons of conscience or for no reason at all. See *id.* at 730, 734.

28. For example, New York permits an appointed healthcare 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 the statute contains an express exception for artificial nutrition and hydration. Only if the patient has specifically spoken on this matter may the healthcare agent request the withdrawal of this type of life-sustaining medical technology. See N.Y. PUB. HEALTH LAW § 2982(4) (McKinney 2014). State law in Massachusetts instructs healthcare proxies to make decisions for incapacitated patients based on what the patient would choose but, if this is unknown, instructs the proxy to decide what is in the patient's best interests. See MASS. GEN. LAWS ch. 201D § 5 (1997) ("After consultation with healthcare providers, and after full consideration of acceptable medical alternatives regarding diagnosis, prognosis, treatments and their side effects, the agent shall make healthcare decisions: (i) in accordance with the agent's assessment of the principal's wishes, including the principal's religious and moral beliefs, or (ii) if the principal's wishes are unknown, in accordance with the agent's assessment of the principal's best interests.").

is virtually hopeless for any significant improvement in condition."<sup>29</sup> In one New York decision, the Superior Court refused to authorize life-prolonging treatment for an incapacitated adult who had suffered several strokes and had very little cognitive function, holding 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>30</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 type and amount of evidence of the patient's wishes that is available.<sup>31</sup>

Occasional references to best-interests analysis aside, U.S. law concerning end-of-life decision making favors, with little exception, continued life supportive measures when the patient's wishes are ambiguous or unknown. As the *Schiavo* litigation 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>32</sup>

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29. *Barber v. Superior Ct.*, 195 Cal. Rptr. 484 (Cal. Ct. App. 1983) (permitting withdrawal of treatment from a comatose patient).

30. *In re Beth Israel Med. Ctr. for Weinstein*, 136 Misc.2d 931, 934-35, 942 (N.Y. Sup. Ct. 1987).

31. *In re Conroy*, 98 N.J. 321, 324-26 (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 it is clear that the burdens of continued life with treatment outweigh the benefits, but 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).

32. *See, e.g., Conservatorship of Wendland*, 28 P.3d 151 (Cal. 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. PX-91-283 (Hennepin Cnty. Minn. Prob. Ct. 1989) (upholding the surrogate's request for continued treatment of the patient, who was in a persistent vegetative state and died of sepsis more than a year later); *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 281

*B. U.K. End-of-Life Law and Ethics*<sup>33</sup>

The legal system and its impact on medical practice in the United Kingdom differs significantly from that of the United States. 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). There is no formal legislation that exclusively regulates end-of-life care, although aspects of the Mental Capacity Act of 2005 (“MCA”) are relevant.<sup>34</sup>

In the United Kingdom, patients with decisional capacity are, of course, permitted to direct their care with guidance and input from treating physicians. Patients who do not complete an advance directive and who are either incapacitated or unconscious are generally treated in accordance with their best interests under the MCA.<sup>35</sup> Pursuant to current U.K. law, derived from the MCA, common law precedent, and guidance documents for physician practice, the physician retains the ultimate authority to make treatment decisions for incompetent

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(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.”). For information about the Schiavo litigation, see generally Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 *MIAMI L. REV.* 107 (2004) (describing the intervention of politicians and religious organizations in the dispute).

33. Much of this sub-section was derived and adapted from Noah, *supra* note 22, at 252–55.

34. See Mental Capacity Act, 2005, c. 9 (UK), available at [www.opsi.gov.uk/acts/acts2005](http://www.opsi.gov.uk/acts/acts2005). In 2008, the U.K. government also decided to adopt a systematic ten-year plan to improve the quality of end-of-life care. See Bradford H. Gray, *England’s Approach to Improving End-of-Life Care: A Strategy for Honoring Patients’ Choices*, COMMONWEALTH FUND, July 2011, at 2 (2011), available at <http://www.commonwealthfund.org/Publications/Issue-Briefs/2011/Jul/Englands-Approach-to-Improving-End-of-Life-Care.aspx>.

35. See SHAUN D. PATTINSON, *MEDICAL LAW AND ETHICS* 32 (3d ed., Sweet & Maxwell eds., 2011). Section 5 of the MCA authorizes physicians to act in the best interests of incapacitated patients. See Mental Capacity Act, c. 9 (UK), available at [www.opsi.gov.uk/acts/acts2005](http://www.opsi.gov.uk/acts/acts2005); see also DEP’T FOR CONSTITUTIONAL AFFAIRS, MENTAL CAPACITY ACT 2005: CODE OF PRACTICE 67 (2007), <http://www3.imperial.ac.uk/pls/portallive/docs/1/51771696.PDF> (explaining that the best-interests principle does not apply when someone has previously made an advance directive to refuse medical treatment).

adults rather than the next of kin.<sup>36</sup> The U.K. courts generally do not resolve end-of-life disputes except to pronounce on the lawfulness of the treatment that the physician proposes.<sup>37</sup>

The MCA specifically requires that the physician's authority is limited to acting in the best interests of incapacitated patients.<sup>38</sup> Both the MCA and courts have defined "best interests" to include not only medical interests but also the patient's own wishes, values, and preferences at the time they were competent.<sup>39</sup> Thus, the concept of "best interests" in the United Kingdom includes within it deference to patients' autonomous preferences. 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."<sup>40</sup>

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

37. *Id.* at 159.

38. See Mental Capacity Act, 2005, c. 4 (UK), available at [www.opsi.gov.uk/acts/acts2005](http://www.opsi.gov.uk/acts/acts2005). 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 has not made 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 progress 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 (2010), [http://www.gmc-uk.org/static/documents/content/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_-\\_English\\_0914.pdf](http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_0914.pdf) [hereinafter GMC].

39. DEP'T OF HEALTH, HSC 2001/023, GOOD PRACTICE IN CONSENT (2001); GEN. MED. COUNCIL, SEEKING PATIENTS' CONSENT: THE ETHICAL CONSIDERATIONS (1998).

40. See Bell, *supra* note 38, at 159. The General Medical Council's guidance also has specific recommendations for patients in permanent vegetative

The U.K. General Medical Council (“GMC”) published a guidance for doctors on *Treatment and Care Towards the End of Life* (“Guidance”),<sup>41</sup> which provides a very different picture of the approach in the United Kingdom to these treatment decisions compared with that of the United States. 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>42</sup> it has the effect of a series of regulatory statements. Doctors are informed that, in cases where the Guidance states “you must,” this creates an “overriding duty or principle” of practice.<sup>43</sup>

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states and other forms of unconsciousness. In situations where there is uncertainty about the continued care of patients who lack decisional capacity and who are in persistent vegetative state (“PVS”) or similar conditions, the 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 judgement, 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.” GMC, *supra* note 38. In England and Wales, it 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. *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.*

41. *Id.*

42. *Id.* at 6. In addition to the GMC’s Guidance, in 2007, the Department for Constitutional Affairs and the Lord Chancellor issued the *Mental Capacity Act Code of Practice* (“Code”). 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’ OF CONST. AFF., *supra* note 35, at 64–91 (2007). The Code informs physicians that the MCA does not impose a duty of compliance with the Code; “it should be viewed as guidance rather than instruction.” *Id.* at 1. 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.*

43. *Id.* at 7. By contrast, in the United States, 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, for example) and to discipline doctors who violate standards or mistreat or abuse patients. The state



Where there is disagreement about whether a particular treatment or intervention would be of overall benefit, either among 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.<sup>44</sup> Interestingly, the Guidance specifically addresses situations in which the proxy or decision maker requests treatment that the doctor believes would not be clinically appropriate or of overall benefit to the patient. In these circumstances, the Guidance instructs the doctor to explain the reasons for this opinion and discuss it with the decision maker. The doctor is not, however, obligated to provide such treatment.<sup>45</sup> Although it is also the case in the United States that physicians have no ethical or legal obligation to provide clinically inappropriate treatment,<sup>46</sup> the combined force of disa-

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boards of medicine do not, however, routinely promulgate general standards of practice for end-of-life care or any other area of medicine. The nearest equivalents in the United States are professional organizations such as the American Medical Association or the National Hospice and Palliative Care Organization. These private groups publish ethical standards, statements of practice, and principles of treatment, but they generally are not binding on physicians, even those who are members of the organizations.

44. The Guidance recommends various nonlegal 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. See GMC, *supra* note 38, at 30 (adding that in seeking consensus, physicians "should take into account the different decision making roles and authority of those [they] consult, and the legal framework for resolving disagreements"). If none of these steps effectively resolves the disagreement, the Guidance instructs doctors to seek legal advice and to apply to the appropriate statutory body for review (in Scotland) or an appropriate court for an independent ruling. See *id.* at 30. The Guidance adds that, in England, Wales, and Northern Ireland, the court will consider "whether treatment is in the patient's best interests—whereas in Scotland the courts will consider whether treatment is of benefit to the patient." *Id.* at 30, n.22 (internal quotations omitted).

45. *Id.* at 18–19 (providing that, at this point, the decision maker or proxy can request a second opinion or seek review from the appropriate statutory body in Scotland or an appropriate court in the rest of the United Kingdom).

46. See AM. MED. ASS'N, COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, *Opinion 2.035, Futile Care*, available at <https://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2035.page> (last visited Aug. 13, 2014) ("Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients. Patients should not be given treatments simply because they demand them. Denial of treatment should be justified by reliance on openly stated ethical principles

greement 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, the doctor in the United States is more likely to take the path of least resistance.

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 who are permanently unconscious or who otherwise lack decisional capacity.<sup>47</sup> 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.<sup>48</sup> 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.<sup>49</sup> Overall, the Guidance suggests that physicians have significant authority and even the obligation to decide that artificial nutrition and hydration are not of overall benefit for particular patients. In the United States, by contrast, the physician can discuss the matter with the patient's family or proxy but rarely

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and acceptable standards of care . . . not on the concept of 'futility,' which cannot be meaningfully defined.”)

47. See generally GMC, *supra* note 38, at 112–27 (discussing the provision of clinically assisted nutrition and hydration generally to patients who have capacity, adults who lack capacity with varying prognoses, and 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. *Id.* at 57 (“The 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).

48. *Id.* at 57.

49. *Id.* at 57–58.

possesses the legal authority to make a decision to withdraw artificial nutrition and hydration over the family's objections.<sup>50</sup>

### C. System-wide Differences

#### 1. Fragmented U.S. System of Health Care Delivery

Health care delivery in the United States, including end-of-life care, suffers from the effects of our fragmented health care delivery system, lack of insurance coverage or of consistency in coverage, and a multi-payer private/public system. There are wide variations in health insurance coverage among the states, which have a significant impact on those patients who are too young to be eligible for Medicare. For example, Massachusetts has approximately 97 percent of its citizens covered through employer coverage, compulsory purchase rules and subsidies for low-income individuals to assist the purchase.<sup>51</sup> By contrast, 30 percent of Texas citizens lack health insurance of any kind—that is 5.8 million Texas citizens including 1.5 million children. Only 47 percent of Texans have employer-based coverage.<sup>52</sup> The latest Census data confirm that Florida and Texas have the lowest rates of insurance coverage in the nation.<sup>53</sup>

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50. Texas's Advance Directives Act is a rare example of a statute that allows healthcare facilities to discontinue life-sustaining medical treatment in cases where the treating physicians believe that continuing such care is medically or ethically inappropriate. See TEX. HEALTH & SAFETY CODE ANN. § 166.046(e) (West 2003). Three other state medical associations also have expressed support for similar legislation. See Douglas B. White & Thaddeus M. Pope, *The Courts, Futility, and the Ends of Medicine*, 307 JAMA 151, 151 (2012).

51. See COMMW. MASS., CTR. FOR HEALTH INFO. & ANALYSIS, ANNUAL REPORT ON THE MASSACHUSETTS HEALTH CARE MARKET 4 (2013), <http://www.mass.gov/chia/docs/r/pubs/13/ar-ma-health-care-market-2013.pdf>.

52. See TEXAS MEDICAL ASSOCIATION, [www.texmed.org](http://www.texmed.org) (last visited Aug. 8, 2014). To compound this dubious distinction further, Texas is now the largest state in population to refuse to participate in the Medicaid expansion under the Affordable Care Act, thereby denying approximately one million of its citizens insurance coverage with a generous federal subsidy from the federal government. See Jackie Calmes & Jonathan Weisman, *Despite Fumbles, Obama Defends Health Care Law*, N.Y. TIMES, Nov. 7, 2013, at A24, 31.

53. See U.S. CENSUS BUREAU, *Small Area Health Insurance Estimates*, CENSUS, <http://www.census.gov/did/www/sahie/data/interactive> (last visited Aug. 5, 2014). Note that the ACA was not in effect at the time of the last census.

The Patient Protection and Affordable Care Act (“ACA”) aims to minimize these state-by-state differences through a combination of strategies including the individual mandate<sup>54</sup> but, even after the ACA is fully implemented, many individuals will continue to experience the effects of inadequate access to health care for years into the future in the form of the long-term effects of previously unmanaged chronic health conditions. Variations in rates of insurance are at least partly to blame for enormous variations in health care spending and quality of care in different parts of the United States.<sup>55</sup> Although increasing insurance coverage to a near-universal level will surely improve overall health status in the United States, universal coverage alone is unlikely to have much impact on the problems discussed here.

## 2. The National Health Service

The British National Health Service (“NHS”) was created in 1948 to provide health care for all people who need it.<sup>56</sup> It is funded through a combination of general taxation and contributions to the National Insurance Program.<sup>57</sup> The National Health Service in the United Kingdom was traditionally a single-payer system, but now sections of the NHS are increasingly privatized and there is a political battle in the United Kingdom over the system’s future.<sup>58</sup> Some recently enacted reforms allow hospitals to earn up to half of their incomes from private pay-

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54. See *Summary of the Affordable Care Act*, KAISER FAMILY FOUNDATION (Apr. 25, 2013), <http://kff.org/health-reform/fact-sheet/summary-of-new-health-reform-law/> (describing the ACA and providing a timeline for implementation of the Act’s various provisions).

55. The Dartmouth Atlas of Health Care documents these differences across a wide variety of spending topics, such as hospitalization in the final month of life and care of chronic illness in the last two years of life. See generally *Understanding of the Efficiency and Effectiveness of the Health Care System*, DARTMOUTH ATLAS OF HEALTH CARE, <http://www.dartmouthatlas.org/> (last visited Aug. 13, 2014).

56. See FRANCIS LYALL, *AN INTRODUCTION TO BRITISH LAW* 114 (1994).

57. *Id.* at 114–15 (explaining that the NHS, once implemented, operated mostly hospital property, which had been transferred to the Ministry of Health via the implementing act, and that physicians and other specialists such as pharmacists and dentists entered into contractual relationships with the NHS).

58. See Ingrid Torjesen, *Labour Will Halt Sell Off of NHS to Private Sector if Elected*, *Burnham Says*, 345 *BRIT. MED. J.* 6718 (2012).

ing patients, though the Labour Party has promised a return to previous policies if it regains control of the government.<sup>59</sup>

With NHS's unified delivery system and single payer structure, it is not surprising that its critics express concern that budget limitations exert pressure on physicians to engage in covert rationing. In the United Kingdom, these resource limitations are enforced within a system in which the general practitioner physicians serve as gatekeepers to specialized and expensive medical care, basing their decisions about referrals to specialists on clinical need rather than patient demand.<sup>60</sup> Thus, the U.K. system functions based on an agreement by the government and the medical profession that allows physicians to retain their professional autonomy in how they allocate resources, as long as they remain within the budgetary limitations set by the government.<sup>61</sup>

In a single payer system, it is also likely true that pragmatic concerns about how to utilize a finite pool of resources will lead to consideration of the economic impact of continuing life-supportive care where a patient will surely not recover.<sup>62</sup> In fact, much of the furor occasioned by the LCP in its last two years stemmed from the revelation that hospices and hospital trusts received financial rewards for meeting implementation targets for the care pathway.<sup>63</sup> By contrast, in the United

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59. *See id.*

60. *See* George J. Annas & Frances H. Miller, *The Empire of Death: How Culture and Economics Affect Informed Consent in the U.S., the U.K., and Japan*, 20 AM. J. L. & MED. 357, 363 (1994).

61. *See* Carolyn Hughes Tuohy, *Dynamics of a Changing Health Sphere: The United States, Britain, and Canada*, 18 HEALTH AFFAIRS 114, 118 (May–June 1999).

62. For example, one opinion in *Bland* noted that the NHS's limited resources necessitated allocation and rationing choices. *See* *Airedale NHS Trust v. Bland* [1993] AC 789 (HL) 833 (UK) (“No one is under a moral duty to do more than he can, or to assist one patient at the cost of neglecting another. The resources of the National Health Service are not limitless and choices have to be made. . . . [We have been] invited to decide the case on the assumption that . . . resources were unlimited and we have done so. But one is bound to observe that the cost of keeping a patient like Anthony Bland alive is very considerable and that in another case the health authority might conclude that its resources were better devoted to other patients.”).

63. *See* Jacqueline Laing, *A Lethal Power?*, 162 NEW L.J. 1444 (2012), available at [http://www.newLawjournal.co.uk/nlj/content/lethal-power](http://www.newlawjournal.co.uk/nlj/content/lethal-power) (discussing the rollout of the LCP after it was recommended by the U.K.'s Department of Health and expressing concern that some hospitals had set tar-

States, considerations of cost of care for individual patients are often ignored, especially when the patient is insured.<sup>64</sup> At some level, however, the cost of ongoing care is beside the point—those who find discussions of economics distasteful might nevertheless adopt the position that providing therapeutic interventions or life-prolonging care for an individual in the last days of life is not always ethically necessary or appropriate.

Finally, much of the difference between the two systems is a matter of differing societal attitudes toward physicians and the health care system. In the American system, patients tend to operate as consumers of medical services (with doctors as service providers) and want the best quality and the most care for their money.<sup>65</sup> By contrast, in the United Kingdom patients view physicians in a more authoritarian role when they seek advice and treatment. Moreover, U.K. physicians, working under the unifying umbrella of the NHS, have more of a common sense of identity that comes with the unified approach to care delivery and therefore less fear of discord (or liability) when withholding or withdrawing care for dying patients.<sup>66</sup>

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gets of between a third and two thirds of all the deaths to be Pathway deaths).

64. See Robert Steinbrook, *The End of Fee-for-Service Medicine? Proposals for Payment Reform in Massachusetts*, 361 *NEW ENG. J. MED.* 1036 (2009) (discussing the incentives for overutilization of medical services created by a fee-for-service payment system).

65. The ACA creates a 'Physician Compare' website that allows consumers to evaluate information on physician quality. See Patient Protection and Affordable Care Act § 10331(a)(1) (2010). Commentators disagree about whether patients really act as consumers looking for the best quality and value when choosing physicians. See, e.g., Kristin Madison, *Patients as Regulators? Patients' Evolving Influence Over Health Care Delivery*, 3 *J. LEGAL MED.* 9, 13 (2010) (describing the new consumerism in healthcare); Mark A. Hall & Carl E. Schneider, *Patients as Consumers: Courts, Contracts, and the New Medical Marketplace*, 106 *MICH. L. REV.* 643, 659 (2008) (questioning whether patients are likely to act as discerning consumers of healthcare quality when they are very ill).

66. See *infra* notes 111–112 and accompanying text (discussing varying rates of malpractice litigation between the United States and the United Kingdom).

### III. THE LIVERPOOL CARE PATHWAY FOR THE DYING PATIENT: A CASE STUDY

#### A. Description and Goals

In general, “care pathways” are defined as “a complex intervention for the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period.”<sup>67</sup> The Liverpool Care Pathway for the Dying Patient was originally developed by physicians at the Marie Curie Hospice in Liverpool, England to care for cancer patients at the end of life.<sup>68</sup> It is an attempt to establish best practices with respect to end-of-life care for hospitals based on the standard of care provided in hospices. Because approximately 58 percent of patients in the United Kingdom die in the hospital,<sup>69</sup> the goal of the LCP is to describe and replicate hospice practices in the hospital setting and for patients receiving care at home,<sup>70</sup> and thus to improve the quality of care for dying patients in the last days and hours of their lives. Over the years since its inception, the LCP has been adopted and implemented on a widespread basis by hospitals throughout the United Kingdom and has been endorsed by the NHS and various professional organizations.<sup>71</sup>

The LCP is intended to support physicians in making clinical decisions about end-of-life care but it does not replace clinical

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67. See *What is the LCP?*, *supra* note 14, at 2 (elaborating on the five key elements of care pathways, including explicit statements of goals, coordination of care, and monitoring and evaluation of outcomes).

68. See Chinthapalli, *supra* note 16, at 4669.

69. See TIM BURR, NATIONAL AUDIT OFFICE, END OF LIFE CARE (2008), <http://www.nao.org.uk/wp-content/uploads/2008/11/07081043.pdf>.

70. See JULIA NEUBERGER ET AL., MORE CARE, LESS PATHWAY: A REVIEW OF THE LIVERPOOL CARE PATHWAY 3, 5 (2013), available at [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/212450/Liverpool\\_Care\\_Pathway.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/212450/Liverpool_Care_Pathway.pdf) [hereinafter LCP REVIEW].

71. See *What Is the LCP?*, *supra* note 14 (explaining that the LCP was recognized in 2001 as a model of best practice by the National Health Service (“NHS”) and was later incorporated into the Cancer Services Collaborative Project and National End of Life Care Programme). The LCP has been amended numerous times since its inception to reflect experience and changing circumstances based on regular audits of its use. As of now, it is in its twelfth version. *Id.*; see also Katherine E. Sleeman & Emily Collis, *The Liverpool Care Pathway: A Cautionary Tale*, 347 BRIT. MED. J. 4779 (2013) (explaining that the rapid rollout of the LCP across England was part of the National End of Life Care Programme and the End of Life Care Strategy).

judgment. As the explanatory documents note, the “LCP is only as good as the teams using it and must be underpinned by a robust ongoing education and training programme.”<sup>72</sup> It is not intended to hasten or postpone death, and it neither recommends the routine use of continuous sedation nor prohibits the use of artificial nutrition and hydration.<sup>73</sup> It also requires decision making by a multi-disciplinary team including a doctor, a nurse, and other appropriate professionals in order to conclude that the patient is likely to die within two to three days.<sup>74</sup> The assessment of the patient prior to making any clinical decisions includes required inquiries into potentially reversible causes of the patient’s condition, such as medication toxicity, kidney failure, and infection. Once a patient is determined to be imminently dying, the physician must explain the diagnosis to the patient and family members or caregivers.<sup>75</sup> The latest formal audit of the LCP, published in 2012, found that patients on the pathway were receiving a high quality of care, with most patients reporting that they were comfortable even in the last hours of life.<sup>76</sup>

The LCP was one of a variety of integrated treatment approaches for patients who are actively dying. By no means are all patients’ situations suited for the LCP.<sup>77</sup> Implementation of the LCP for a particular patient involves a series of decisions, beginning with a determination that the patient is imminently dying. Once a patient is placed on the care pathway, additional decisions arise, including questions about whether to continue artificial nutrition and hydration, whether sedation or cardiopulmonary resuscitation is appropriate, and how to manage pain and other symptoms.<sup>78</sup> It also requires that the team reconsider the necessity of continuing with or initiating new tests and treatments.<sup>79</sup> The LCP also explicitly requires physicians and others on the team to communicate with relatives and the

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72. See *What is the LCP?*, *supra* note 14, at 3.

73. See *id.* at 1–2.

74. See LCP REVIEW, *supra* note 70, para. 1.2.

75. See *id.* at 6.

76. See MARIE CURIE PALLIATIVE CARE INST. & ROYAL C. PHYSICIANS, NATIONAL CARE OF THE DYING AUDIT OF HOSPITALS: ROUND 3, at 5 (2011–2012), [http://www.rcplondon.ac.uk/sites/default/files/national\\_care\\_of\\_the\\_dying\\_audit\\_-\\_hospitals\\_exec\\_summary.pdf](http://www.rcplondon.ac.uk/sites/default/files/national_care_of_the_dying_audit_-_hospitals_exec_summary.pdf).

77. See LCP REVIEW, *supra* note 70, para. 1.12.

78. See *id.* at 7–8.

79. See *id.* para. 1.3.



patient, where appropriate, about these decisions, and to obtain consent from the patient if the patient retains decisional capacity.<sup>80</sup> The overall goal of the care pathway is to support and guide physicians and other health care professionals caring for the dying patient to provide care that keeps the patient comfortable and maintains the patient's dignity, while also supplying information and emotional support to the family.<sup>81</sup>

Part of the goal of the LCP was to address a perceived need to correct physician attitudes toward the acceptance of dying:

A major cultural shift is required if the needs of dying people are to be met and the workforce are to be empowered to take a leading role in this process. Dying patients are an integral part of the population. Their death must not be considered a failure; the only failure is if a person's death is not as restful and dignified as possible.<sup>82</sup>

Even in the U.K. system, which charges physicians with the authority and responsibility to make health care decisions for their patients who lack decisional capacity and to consider the patients' best interests as well as their individual preferences, the LCP was thought necessary to address difficulties with communication about end-of-life care, particularly about withholding or withdrawing therapeutic and life-supportive care. The adoption of a care pathway acknowledges and formalizes the idea that it is ethically acceptable and in fact "good care" to cease therapeutic and life-supportive measures in certain circumstances. Even critics of the LCP do not recommend returning to a system of care that treats dying patients as if they are curable.

### *B. The Demise of the LCP*

The LCP may be viewed as handing too much authority to physicians, potentially at the expense of the well-being of patients. Certainly, it is understandable that grieving families could misunderstand the implementation of the LCP in the care of a loved one, particularly if the goals and reasons for the implementation were not well-explained. In response to anec-

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80. *See id.* at 7.

81. *See id.* para. 1.3.

82. *See What is the LCP?*, *supra* note 14, at 9.

dotal reports in the press of frightening abuses,<sup>83</sup> the Minister of State for Care Support, a member of Parliament, commissioned an independent panel to review the evidence of the care pathway's implementation.<sup>84</sup> As the review panel concluded, "when the LCP is used properly, patients die a peaceful and dignified death."<sup>85</sup> Other commentators<sup>86</sup> and many clinicians praised the LCP and have indicated that they would choose it for themselves.<sup>87</sup> Nevertheless, a cluster of troubling implementation and administration issues illustrate that the LCP requires substantial revision and clarification if it is to be re-implemented in future end-of-life practice.

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83. See, e.g., Sophie Arie, *Inquiry Launched into Newspaper Story About Babies on "Death Pathway"*, 346 BRIT. MED. J. 1273 (2013) (describing false allegations in a DAILY MAIL article alleging that babies were routinely "starved" and that parents were coerced into consenting); John Bingham, *Nurse Accuses Top Hospital over Liverpool Care Pathway*, TELEGRAPH, Mar. 7, 2013, <http://www.telegraph.co.uk/health/healthnews/9913472/Nurse-accuses-top-hospital-over-Liverpool-Care-Pathway.html> (describing a patient who spent six days "on the pathway" and describing the patient's care as "barbaric"). Some alleged abuses were confirmed upon investigation of the LCP, including examples of patients who were placed on the pathway prematurely or who suffered thirst because oral hydration was withheld while they were conscious. See *infra* note 84 and accompanying text.

84. See LCP REVIEW, *supra* note 70, at 5. For a detailed chronology of the events leading up to the request for independent review, see David Brooks & Bee Wee, *The Liverpool Care Pathway: What is the Furore in the Press About?*, 74 BRIT. J. HOSP. MED. 4, 4–5 (2013).

85. See LCP REVIEW, *supra* note 70, para. 1.8.

86. See, e.g., Bill Keller, *How to Die*, N.Y. TIMES, Oct. 7, 2012, at A23 (describing how his father-in-law, who had terminal and inoperable cancer, was placed on the LCP, which entailed unplugging him from medications and artificial nutrition and hydration and providing an intravenous drip to relieve pain and nausea, and how he intermittently regained consciousness to reminisce with his family and to receive Catholic rites, finally dying peacefully several days later).

87. See Krishna Chinthapalli, *Nine Out of Ten Palliative Care Experts Would Choose Liverpool Care Pathway for Themselves*, 346 BRIT. MED. J. 1303 (2013) (describing the results of a survey of U.K. palliative medicine physicians); Krishna Chinthapalli, *The Liverpool Care Pathway: What Do Specialists Think?*, 346 BRIT. MED. J. 184 (2013) [hereinafter *What do Specialists Think?*]; Zosia Kmiotowicz, *Doctors, Leaders, Charities, and Hospices Back Liverpool Care Pathway*, 345 BRIT. MED. J. 6654 (2012) (describing a consensus statement issued by a group of twenty healthcare organizations in support of the LCP).

The cumulative impact of these implementation problems doomed the LCP, and appropriately so, as its implementation was occasionally seriously flawed. The review panel's report, entitled *More Care, Less Pathway*, provides a very thorough, thoughtful, and balanced review of the LCP's content and implementation, along with recommendations for improvement. Many of the implementation problems appear to spring from lack of physician and other health care provider training, resulting in poor or absent communication with patients and families and faulty understanding of the LCP's goals and principles.<sup>88</sup> There is little in the literature on the LCP to suggest that its principles or goals are flawed—it was only flawed in implementation.

Much of the criticism of the LCP in practice arises from cases in which patients were mistakenly diagnosed as dying, and then went on to survive for some time. The report acknowledges the difficulty of diagnosing when a patient is imminently dying.<sup>89</sup> As the LCP is designed for patients in the last hours or days of life, prematurely withdrawing life supportive measures can deprive patients of days of life.<sup>90</sup> As the report reminds its audience,

Dying is not only a physical event—it is the conclusion of a life defined in its nature, content and connections within a society . . . that are every bit as important as the mechanism of how dying happens. Patients, their relatives . . . see them-

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88. See LCP REVIEW, *supra* note 70, paras. 1.39–1.41 (explaining that the multidisciplinary team approach to decisions about placing a patient on the LCP contains some uncertainties about who is ultimately responsible for initiating the discussion and conducting ongoing patient assessments and describing lack of warning to or discussion with family members about the decision to place patients on the pathway).

89. See *id.* at 6, paras. 1.25–1.26, 1.35–1.36 (acknowledging the difficulty in predicting when a patient will die and recommending research into the biology of dying and the experience of dying in order to provide an evidence base on which to improve quality of care and communication).

90. See *id.* para. 1.34 (“Families expect that, because a patient is placed on the LCP, they must be in the last hours or days of life; but the Review panel knows from the evidence . . . that some patients then remain on the pathway for several days or longer. Relatives naturally become distressed, and this is heightened if pain relief is not effective and ‘normal’ drugs, nutrition and, particularly, hydration are discontinued.”).

selves as people, not as biological specimens in the laboratory.<sup>91</sup>

The authors of the report thus emphasized the need for doctors and nurses to be more honest about the uncertainties of diagnosing imminent dying.<sup>92</sup>

Other problems leading to the backlash against the LCP arose from misunderstanding on the part of the public, patients, and families of some of the terminology and goals of the LCP. For example, the report notes that the term “end of life” is quite vague and can mean vastly different things to different people. To some, it might mean the last year of life for a person with chronic or progressive disease whereas, in the context of the LCP, “end of life” means the last days or hours of life.<sup>93</sup> These differences in context and meaning can lead to misunderstandings about whether and when the LCP is appropriate, both on the part of clinicians and family members.<sup>94</sup>

Similarly, the term “pathway” became negatively charged, primarily as a result of journalistic hype. The *Daily Mail* has repeatedly referred to the LCP as the “death pathway.”<sup>95</sup> As commentators have explained, the media campaign against the LCP caused the term “pathway” to be misunderstood as a form of “euthanasia by the back door” when it is in fact a “complex clinical medical process being reported very hysterically.”<sup>96</sup> One

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91. See *id.* para. 1.25.

92. See *id.* para. 1.34.

93. See LCP REVIEW, *supra* note 70, paras. 1.9–1.11.

94. See *id.* (explaining that a doctor’s statement that a patient is at the end of life might be misinterpreted and the LCP commenced prematurely and recommending that the NHS publish clear definitions of time frames relevant to decision making at the end of life that are consistent with those in use in current policies and protocols).

95. See, e.g., Sue Reid & Simon Caldwell, *Now Sick Babies Go on Death Pathway*, DAILY MAIL, Nov. 28, 2012 (“Until now, end of life regime the Liverpool Care Pathway was thought to have involved only elderly and terminally-ill adults. But the Mail can reveal the practice of withdrawing food and fluid by tube is being used on young patients as well as severely disabled newborn babies.”). The United States has “death panels,” the United Kingdom has “death pathways.”

96. See Arie, *supra* note 83 (quoting Louise Shepherd, director of the children’s hospital being accused); LCP REVIEW, *supra* note 70, paras. 1.14–1.21 (explaining that physicians and other health professionals who use the pathway have misunderstood it as a set of instructions and prescriptions (a protocol) rather than as a guideline to making better clinical decisions for dying

of the results of the press coverage, according to clinicians involved in end-of-life care, was "scaremongering" which made patients and relatives more likely to refuse the LCP and made clinical staff fear complaints.<sup>97</sup> The negative publicity also apparently made physicians more hesitant even to raise the possibility of implementing the LCP with some patients and families, potentially depriving some patients of an important option concerning their care.<sup>98</sup>

More generally, the report criticized failures of communication, citing cases in which relatives were not informed that their family member was being placed on the pathway or why.<sup>99</sup> U.K. law creates some complexities regarding informed consent. As explained above, U.K. law requires consent for treatment from patients who retain decisional capacity and asks the physician to act in the patient's best interests if the patient lacks capacity. The decision to implement the LCP for a particular patient raises issues of consent and communication. Because the LCP is not a simple, individual medical procedure, physicians technically need not seek consent from the patient before it is begun.<sup>100</sup> However, with respect to particular medical treatment decisions, such as use of powerful pain relief or stopping artificial nutrition and hydration, discussion with and consent from the patient is required if the patient is able to engage in these discussions. Otherwise, physicians must also make these medical decisions based on the patient's best interests, in consultation with the patient's family.<sup>101</sup> Because the LCP documents do not clearly address issues of treatment and consent, the review panel urged improved communication

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patients and recommending that the term "pathway" be abandoned and replaced with 'end of life care plan').

97. See *What Do Specialists Think?*, *supra* note 87 (explaining that 57 percent of doctors overall and 74 percent of palliative medicine physicians felt that the negative press coverage had lowered utilization rates of the LCP).

98. See *id.* (quoting one surveyed physician who said that the negative press "has caused additional distress for relatives at an already distressing time . . . [and] a dilemma in judging if discussing the LCP will cause more distress than the benefit of being on the LCP for coordination of care in the dying phase").

99. See LCP REVIEW, *supra* note 70, para. 1.29.

100. See *id.* para. 1.45.

101. See *id.* para. 1.46.

about consent, and more generally about the LCP's purpose and appropriate use.<sup>102</sup>

In addition to reports of abuses in implementation, press reports that various hospitals were receiving payments from the U.K. Department of Health in exchange for placing patients on the LCP prompted a torrent of criticism.<sup>103</sup> The Department of Health responded that, under its "Commissioning for Quality and Innovation" program, local NHS commissioners were acting under this program which permits rewarding hospital trusts for meeting targets for excellence in health care, including end-of-life care.<sup>104</sup> When surveyed on the question of whether the LCP was a cost-containment measure in disguise, 98 percent of physicians responding did not believe that resource pressures had influenced decisions to utilize the LCP, though many of the respondents did not support the use of financial incentives to encourage pathway use.<sup>105</sup>

The panel report recommends abandoning the LCP in favor of developing guidelines on the principles of good palliative care specific to different disease groups. It also recommended that each dying patient have an individualized end-of-life care

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102. *See id.* paras. 1.47–1.50 (recommending that the "clinician should explain their thinking, ensure it is understood, and offer referral for another opinion if appropriate" and condemning instances of "brutal or callous language" being used with family members). *See also id.* paras. 2.40–2.42 (emphasizing the need for effective communication with patients and families to inspire trust and adding that "[g]ood communication is about the depth, and not the length, of an encounter").

103. *See, e.g.,* John Bingham, *NHS Millions for Controversial Care Pathway*, TELEGRAPH, Oct. 31, 2012, <http://www.telegraph.co.uk/health/healthnews/9644287/NHS-millions-for-controversial-care-pathway.html> (finding, based on a FOIA request, that 85 percent of hospital trusts had adopted the LCP and the approximately 60 percent of these had received payments for placing patients on the pathway).

104. *See id.* (explaining that, because quality of care goals are set locally, they can vary from one region to another, resulting in different levels of reward payments or none at all, and that, while some hospital trusts set goals to place a specific percentage of patients onto the LCP, others did not); *see also* Zosia Kmietowicz, *Health Professionals Defend the Liverpool Care Pathway*, 345 BRIT. MED. J. 7511 (2012) (quoting an NHS physician who said, on the topic of payments to hospitals, "[t]hat some hospitals have been 'paid' for putting people on this pathway, as reported, sounds grotesque, but the payment is recognition of what clinical consensus deems best practice. It is also simply a product of the commodified health-care system that now exists, in which every procedure is given a price.>").

105. *See* Chinthapalli, *supra* note 87, at 1303.

plan.<sup>106</sup> In addition to emphasizing the need for research into the biology and experience of dying, the report recommended that the National Institute for Health Research fund and conduct rigorously designed research into communication about end-of-life issues from the perspective of patients and families.<sup>107</sup> It is unclear what guidance will take the place of the LCP,<sup>108</sup> but the experiences with it, both ill and good, have already generated a substantive national conversation about what constitutes high quality end-of-life care.

#### IV. LESSONS FROM THE LIVERPOOL CARE PATHWAY

Although the United States and the United Kingdom operate under very different health care finance and delivery systems, both countries have struggled to improve quality of care at the end of life. The United Kingdom possesses some significant structural advantages over the United States when it comes to delivering high quality, compassionate end-of-life care. The United Kingdom has universal health care coverage; health policy is developed under the unifying influence of the NHS (rather than as a fragmented fifty state plus federal system as in the United States); and U.K. law and policy requires physicians in the United Kingdom to respect patients' autonomous wishes but also to consider their best interests, particularly when their wishes are unknown or unclear. The survey data say that the United Kingdom has succeeded in delivering the best end-of-life care in the world,<sup>109</sup> yet the report on the implementation failings of the LCP suggests that, even under these apparently superior circumstances, it is very difficult to get end-of-life care right all of the time.

Although physicians in the United Kingdom have significantly more decisional responsibility than those in the United States, it is unsurprising that more physician authority alone has failed to prompt consistent use of best practices in end-of-life care. Even with the assistance of guidelines that have been implemented on a widespread basis like the LCP, other inher-

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106. See LCP REVIEW, *supra* note 70, at 10.

107. See *id.* para. 1.26.

108. See Christian Duffin, *End of Pathway Leaves Questions About What Will Take Its Place*, 27 NURSING STANDARD 12, 12–13 (2013) (expressing concern about the “vacuum” in guidance for palliative care practices that is left behind with the recommendation that the LCP be abandoned).

109. See *supra* notes 17 – 18 and accompanying text.

ent challenges involving communication and training pose barriers to improvement. Despite all of the differences between the two systems, both labor under the same primary obstacle to good care: systemic problems with communication about end-of-life choices among physicians, patients, and families. The panel report's recommendations for improvement in the United Kingdom strongly emphasize improved communication, along with more evidence-based guidance to physicians. As the report explained, guidelines for best practices in end-of-life care are only as good as the professionals who apply them in daily practice. In the United States, similar efforts are needed. However, the United States faces additional barriers to quality care at the end of life that are less prevalent or have less impact in the United Kingdom. Some of these are, at least in theory, susceptible to change while others are probably too deeply entrenched for change to be realistically achievable.<sup>110</sup> All of these phenomena, however, have an immediate chilling or distorting impact on the achievement of open and complete communication among physicians, dying patients, and their families.

#### *A. Barriers to Quality Improvement in the United States*

##### 1. Fear of liability for withholding or withdrawing life-supportive measures.

Although physicians in the United Kingdom may fear censure from patients, families, or the licensing authority, there is significantly less concern about potential legal liability for the withdrawal of life-supportive measures.<sup>111</sup> By contrast, in the United States, physicians fear liability and will often practice defensive medicine, including deliberate overtreatment at the end of life, in order to avoid litigation.<sup>112</sup> Physicians also may

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110. Many of these obstacles to improvement also exist in the United Kingdom, despite its very different finance and delivery system, but detailed discussion of how these obstacles play out in the United Kingdom is outside the scope of this article.

111. Rates of malpractice lawsuits in the United Kingdom are significantly lower than in the United States. See Gerard F. Anderson et al., *Health Care Spending in the United States and the Rest of the Industrialized World*, 24 HEALTH AFFAIRS 903 tbl.3 (2005) (citing data that the United States “had 50 percent more malpractice claims filed per 1,000 population filed than the United Kingdom and Australia, and 350 percent more than Canada”).

112. See Jeanne Lenzer, *Unnecessary Care: Are Doctors in Denial and is Profit Driven Healthcare to Blame?*, 345 BRIT. MED. J. 6230 (2012) (describing



hesitate even to initiate conversations about ceasing therapy or withdrawing life-supportive care because these conversations risk generating conflict, publicity, or litigation.<sup>113</sup> A surprising number of physicians in the United States have been accused of, investigated for, and occasionally prosecuted for murder and euthanasia in circumstances where they discontinued life-supportive measures, provided drugs for pain control, or sedated patients whose suffering they were unable to alleviate in other ways.<sup>114</sup> One practice in particular, palliative sedation,

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a meeting of one hundred thirty physicians from the United States, United Kingdom, and Canada to discuss the causes of overutilization of healthcare technologies and procedures and the group's conclusion that malpractice liability fears constitute a major cause); Alan Meisel et al., *Seven Legal Barriers to End-of-Life Care*, 284 JAMA 2495, 2495 (2000) (explaining that physicians overestimate the risk of malpractice lawsuits and that poor communication by physicians about end of life issues increased the risk of litigation); Sean Palfrey, *Daring to Practice Low-Cost Medicine in a High-Tech Era*, 364 NEW ENG. J. MED. 21, e(21)(1) (2011), available at <http://www.nejm.org/doi/pdf/10.1056/NEJMp1101392?source=hrc> ("Most doctors are intensely risk-averse. We don't tolerate uncertainty. Not wanting anything bad to happen, we reflexively overtest and overtreat in order to protect our patients and ourselves."); Phillip Wickenden Bale, *Honoring Patients' Wishes for Less Health Care*, 171 ARCHIVES INTERNAL MED. 1200 (2011) (describing the repeated hospitalization of a very elderly patient in a long term care facility in contravention of surrogate decision makers' request to provide only comfort care in apparent reaction to a government fine of the facility due to the accidental death of another patient).

113. As the *Schiavo* litigation demonstrated, once a particular case comes to the public's attention, the discussion can devolve into a larger debate about the sanctity of life while losing sight entirely of the patient's interests and values. See generally Barbara A. Noah, *Politicizing the End of Life: Lessons from the Schiavo Controversy*, 59 MIAMI L. REV. 107 (2004) (describing the intervention of politicians and religious organizations in the dispute); Barbara A. Noah, *The Role of Religion in the Schiavo Controversy*, 6 HOUS. J. HEALTH L. & POL'Y 319 (2006) (elaborating on the intervention of the Catholic Church in the controversy). Moreover, conflict about end-of-life care in the United States contains the additional dimension of disagreement over whether decisions about withdrawal of life-support should be left to the family or regulated or even decided by the government or the courts. See Lawrence O. Gostin, *Ethics, the Constitution, and the Dying Process: The Case of Theresa Marie Schiavo*, 293 JAMA 2403, 2403 (2005). Leaving it to the family in Theresa Schiavo's case created a schism between her husband and her parents. Allowing the government to interfere led to a political circus.

114. See Nathan E. Goldstein et al., *Prevalence of Formal Accusations of Murder and Euthanasia Against Physicians*, 15 J. PALLIATIVE MED. 334 (2012) (finding that over half of survey respondents had been accused of euthanasia or murder by a patient or patient's family member within the previ-

uses high doses of sedatives and narcotics to induce unconsciousness in patients whose suffering cannot be relieved in other ways.<sup>115</sup> In combination with the withdrawal of artificial nutrition and hydration, the practice certainly can hasten death.<sup>116</sup> Although palliative sedation is not an explicit requirement of the LCP, it is one option available to physicians in the United Kingdom to manage otherwise intractable symptoms at the end of life, as it is here in the United States.<sup>117</sup> In cases where palliative sedation seems appropriate to relieve pain or suffering, it appears that it is sometimes not offered out of concern about potential liability for hastening death.<sup>118</sup>

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ous five years and 4 percent of those surveyed had been formally investigated for hastening a patient's death); *see also* Lewis Cohen et al., *Accusations of Murder and Euthanasia in End-of-Life Care*, 8 J. PALLIATIVE MED. 1096, 1096–97, 1101 (2005) (describing examples of such accusations along with occasional prosecutions and providing data for rates of prosecution in end-of-life care cases).

115. *See* Cohen et al., *supra* note 114, at 1099–1100 & tbl.1 (discussing the legality of palliative sedation when it is used as a last resort to relieve the effects of pain, dyspnea, and agitated delirium).

116. *See* Bernard Lo & Gordon Rubinfeld, *Palliative Sedation in Dying Patients*, 294 JAMA 1810, 1812 (2005).

117. Some case law suggests that the practice, which consists of sedation of the patient to unconsciousness (or whatever level that relieves suffering) and withholding life-sustaining treatment including nutrition and hydration, is not only legally permissible but required if no other options relieve the patient's suffering. *See* Meisel, *supra* note 112, at 2499 (adding that, as long as the physician's intention is to relieve suffering rather than to cause death, the practice is ethically and legally acceptable even if it hastens death); *see also* State v. McAfee, 385 S.E.2d 651 (Ga. 1989) (requiring physicians to provide sedation to a ventilator-dependent adult quadriplegic patient who requested his ventilator to be shut off); McKay v. Bergstedt, 801 P.2d 617 (Nev. 1990) (same); AM. MED. ASS'N, CODE OF MEDICAL ETHICS, *Opinion 2.201, Sedation to Unconsciousness in End-of-Life Care* ("Palliative sedation . . . is an intervention of last resort to reduce severe, refractory pain or other distressing clinical symptoms that do not respond to aggressive symptom-specific palliation. It is an accepted and appropriate component of end-of-life care under specific, relatively rare circumstances.").

118. Anecdotally, stories suggest that, even in hospice, providers misunderstand the ethical status of palliative sedation. *See* Janice Lynch Schuster, *Progress Needed on End-of-Life Care*, WASH. POST, Apr. 18, 2011, [http://articles.washingtonpost.com/2011-04-18/national/35262334\\_1\\_palliative-care-palliative-care-patients-hospice-care](http://articles.washingtonpost.com/2011-04-18/national/35262334_1_palliative-care-palliative-care-patients-hospice-care) (describing a case in which a friend "died gasping for air and begging her husband for help; she died with a hospice nurse asserting that it was not the hospice's philosophy to hasten death").

Although physicians overestimate the risk of liability (in fact, many valid claims for injuries due to medical negligence are never litigated),<sup>119</sup> open discussion about end-of-life choices and transparency in decision making can only reduce this risk. Given the relatively high rate of malpractice litigation in the United States compared with other countries, it will be difficult to assuage physicians' concerns about potential liability in situations where there is disagreement among physicians and patients or families about care at the end of life. Nevertheless, there is good evidence that open and honest communication about these matters reduces conflict in many cases and, along with it, the risk of litigation.<sup>120</sup>

## 2. Disagreement about the ethical status of artificial nutrition and hydration.

While most medical ethicists and physicians agree that artificial nutrition and hydration is no different from other technological life-supportive measures and, as such, can be withheld or withdrawn, even from permanently unconscious patients under appropriate circumstances,<sup>121</sup> some commentators, par-

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119. See Meisel, *supra* note 112, at 2495 (explaining that physicians overestimate the risk of malpractice lawsuits and that poor communication by physicians about end-of-life issues increases the risk of litigation); Palfrey, *supra* note 112 ("Most doctors are intensely risk-averse. We don't tolerate uncertainty. Not wanting anything bad to happen, we reflexively overtest and overtreat in order to protect our patients and ourselves."); cf. A. Russell Localio et al., *Relation Between Malpractice Claims and Adverse Events Due to Negligence*, 325 NEW ENG. J. MED. 245, 249 (1991) (finding that, of patients with serious, disabling injuries that were clearly due to negligence, 5400 of the studied cases did not file malpractice claims and only 3570 did file such claims).

120. See F. Daniel Duffy, *Dialogue: The Core Clinical Skill*, 128 ANNALS INTERNAL MED. 139, 140-41 (1998) (discussing evidence suggesting that physician traits such as empathy and listening improve the patient treatment encounter); Wendy Levinson et al., *Physician-Patient Communication: The Relationship With Malpractice Claims Among Primary Care Physicians and Surgeons*, 277 JAMA 553, 554-59 (1997) (finding that physicians who had no malpractice claims also had different communication styles, including encouraging patients to talk, asking patients' opinions, and ensuring patients' understanding, compared with physicians with malpractice claims).

121. See George J. Annas, *Nancy Cruzan and the Right to Die*, 323 NEW ENG. J. MED. 670, 670-71 (1990); Lo & Rubenfeld, *supra* note 116, at 1811-12 (describing the process of palliative sedation and the patients for whom it may be indicated and recommending talking points to assist physicians in

ticularly those arguing from religious perspectives, have likened withdrawal of nutrition and hydration to “starving a patient to death.”<sup>122</sup> Guidance documents, such as the GMC Guidance, in the United Kingdom specifically address questions about withdrawal of artificial nutrition and hydration. This specific attention, together with the fact that withdrawal of this treatment was one of the more controversial issues when it occurred as part of care for a patient on the LCP, suggests that physicians, patients, and families in the United Kingdom also think about artificial nutrition and hydration differently than about other types of life-supportive care. Despite attempts in both countries to define artificial nutrition and hydration as life-supportive technology like a ventilator or dialysis, the fact remains that many families experience visceral reactions to discussions about withdrawing this form of care. This suggests that physicians will need to employ both empathy and precision in discussing the withholding or withdrawal of artificial nutrition and hydration in cases where families initially misunderstand this as “starving the patient.”

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discussing the option with patients and surrogates); Robert D. Truog & Thomas I. Cochrane, *Refusal of Hydration and Nutrition: The Irrelevance of the “Artificial” versus “Natural” Distinction*, 165 ARCHIVES INTERNAL MED. 2574, 2574 (2005) (adding that all nutrition and hydration, including hand-feeding, can also be withheld or withdrawn under the same principles of autonomy and self-determination and on a patient’s behalf by a surrogate decision maker); Meisel, *supra* note 112, at 2497 (explaining that, when the appropriate standard of proof is met, withholding or withdrawing artificial nutrition and hydration is legally and ethically permissible and the patient’s death results from the underlying condition). *But see* COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS, AMA, *Decisions Near the End of Life*, 267 JAMA 2229–33 (1992).

122. See *Congregation for the Doctrine of the Faith: Doctrinal Commentary on the Concluding Formula of the Professio Fidei*, VATICAN, [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cf\\_aith\\_doc\\_20070801\\_nota-commento\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cf_aith_doc_20070801_nota-commento_en.html) (last visited May 22, 2015) (“Patients in a ‘vegetative state’ breathe spontaneously, digest food naturally, carry on other metabolic functions, and are in a stable situation. But they are not able to feed themselves. If they are not provided artificially with food and liquids, they will die, and the cause of their death will be neither an illness nor the ‘vegetative state’ itself, but solely starvation and dehydration. At the same time, the artificial administration of water and food generally does not impose a heavy burden either on the patient or on his or her relatives.”).

### 3. Broader fear of “death panel” criticism.

U.S. culture is heavily divided on the most challenging issues in end-of-life care. Physicians, bioethics experts, and other stakeholders involved in health policy discussions acknowledge that protocols or guidelines relating to end-of-life decision making run the risk of provoking the pro-life elements of our politically and religiously polarized society.<sup>123</sup> In recent years, the United States has seen political and religious conservatives intentionally undermine meaningful discussion about end-of-life care in favor of appealing to their support base with superficial or false and misleading characterizations of issues.<sup>124</sup> These sorts of deliberately deceptive statements frustrate any reasonable attempts to engage in careful discussion and necessary debate about ethically complex end-of-life issues.<sup>125</sup> As the

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123. See, e.g., Keller, *supra* note 86, at A25 (explaining that, when well-respected bioethicist Dr. Ezekiel Emanuel was asked whether a program such as the LCP could be implemented in the United States, he replied that the chances were “zero” and that “[a]nything that looks like an official protocol, or guideline you’re going to get death-paneled”).

124. Sarah Palin’s fear-mongering rhetoric about government-sponsored “death panels” provides a memorable example. See Sarah Palin, *Statement on the Current Health Care Debate*, FACEBOOK (Aug. 7, 2009, 4:26 PM), [http://www.facebook.com/note.php?note\\_id=113851103434](http://www.facebook.com/note.php?note_id=113851103434) (“The America I know and love is not one in which my parents or my baby with Down Syndrome will have to stand in front of Obama’s ‘death panel’ so his bureaucrats can decide, based on a subjective judgment of their ‘level of productivity in society,’ whether they are worthy of healthcare.”). Palin’s statement actually referred to a proposal in President Obama’s healthcare reform legislation to provide Medicare beneficiaries with *optional* and free counseling on end-of-life decision making, including the *option* of making an advance directive to announce the individual’s preferences about life-supportive care. See Michelle Andrews, *Rather Than Creating “Death Panels,” New Law Adds to End-of-Life Options*, WASH. POST, Sept. 7, 2010, at HE5 (explaining that, in the wake of the outcry, legislators abandoned the provision). The damage created by these lies was significant.

125. See, e.g., Jim Rutenberg & Jackie Calmes, *False “Death Panel” Rumor Has Some Familiar Roots*, N.Y. TIMES, Aug. 14, 2009, at A1 (describing the false statements as attempts by those who are ideologically opposed to the president to weaken his authority, not as genuine efforts to engage in a debate about the merits of the actual proposal). In addition to Ms. Palin’s outrageous distortions, a newspaper editorial compared the proposal to reimburse physicians for end-of-life discussions with the Nazi Germany program to execute children and adults with disabilities, and a newspaper columnist described it as euthanasia to control costs. See *id.* at A2; cf. Rudy Ruiz, *Open Your Minds, America*, CNN (Sept. 3, 2009), <http://articles.cnn.com/2009-09->

events leading up to the LCP's abandonment illustrate, hype of this kind, particularly in our instant information age, can have a profoundly negative influence on health policy, to everyone's detriment.<sup>126</sup> The law provides some help in creating consensus by codifying fundamental rights of individual decision making, but attempts to systematize end-of-life care via care pathways or similar practice guidelines are likely to result in "death panel" accusations or limiting legislation.<sup>127</sup>

In spite of all of this, there are a number of guidelines and standards applicable to end-of-life care in the United States that have been published and adopted by various professional organizations. The American Medical Association (AMA), for example, has adopted a number of position statements dealing with end-of-life issues.<sup>128</sup> Similarly, the National Hospice and

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03/politics/ruiz.closed.minds\_1\_health-care-listening-labels?\_s=PM:POLITICS (suggesting that, with the healthcare debate, we should be listening to differing opinions and acknowledge that changing one's mind in the face of new information is not a character flaw).

126. See Chinthapalli, *supra* note 16, at 4669 ("More insidiously, the decision to phase out the pathway shows how sensationalist journalism can dictate health policy and gives implicit credence to some of the more outlandish claims.").

127. For an example of the type of backlash that can be expected, consider a bill drafted by the National Right to Life Committee, the "Model Starvation and Dehydration of Persons with Disabilities Prevention Act." This legislation, if enacted, would forbid any proxy decision maker or court from discontinuing artificial nutrition and hydration for any incapacitated patient unless that person has a valid advance directive specifically directing the withdrawal of such care. See MODEL STARVATION & DEHYDRATION OF PERSONS WITH DISABILITIES ACT (Nat'l Right to Life Comm. 2006), <http://www.nrlc.org/uploads/medethics/MODELN&HStateLaw.pdf>. This legislation would have the effect of creating a presumption in favor of continued life support for the vast majority of Americans who do not have an advance directive. See Stephen Arons, *Palliative Care in the U.S. Healthcare System: Constitutional Right or Criminal Act?*, 29 W. NEW ENG. L. REV. 309, 339–40 (2007) (discussing this and similar legislation and suggesting that, were it to survive constitutional scrutiny, it would invite further legislation to limit the removal of other types of life-supportive technology).

128. See, e.g., AM. MED. ASS'N, *supra* note 46 ("Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefitting their patients. Patients should not be given treatments simply because they demand them."); AM. MED. ASS'N, CODE OF MEDICAL ETHICS, *Opinion 2.037, Medical Futility in End-of-Life Care*, available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2037.page?> (last visited June 23, 2015) ("When further intervention to prolong the life of a patient becomes futile,

Palliative Care Organization recently released clinical practice guidelines designed to improve the quality of palliative care.<sup>129</sup> Nevertheless, none of these guidelines to improving care at the end of life has been systematically implemented across hospitals, still the site of most deaths around the country, and there is no enforcement mechanism or requirement of compliance by physicians. This is not surprising—the U.S. system, as described above, is much more fragmented than that in the United Kingdom and is not regulated via a single National Health Service and General Medical Council but rather by fifty state medical boards and state legislatures.<sup>130</sup> Moreover, any state whose politics are influenced by conservative political and religious groups might very well prevent the implementation of any specific guideline for end-of-life care.<sup>131</sup>

#### 4. Debate about what is meant by “the sanctity of life.”

The public *melée* over the care of Theresa Schiavo illustrates that many Americans hold the view that all human life is sacred and must be preserved, even if the person in question is permanently and irretrievably unconscious or imminently dying. While there are certainly British citizens who share this view, British courts have taken the position that “a view that life must be preserved at all costs does not sanctify life.”<sup>132</sup> A related concern involves the risk of pressure on the seriously disabled to refuse treatment or on surrogate decision makers to

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physicians have an obligation to shift the intent of care toward comfort and closure. However, there are necessary value judgments involved in coming to the assessment of futility. These judgments must give consideration to patient or proxy assessments of worthwhile outcome.”).

129. See NAT'L HOSPICE & PALLIATIVE CARE ORG., CLINICAL PRACTICE GUIDELINES FOR QUALITY PALLIATIVE CARE (3d. ed., 2013), [http://www.nationalconsensusproject.org/NCP\\_Clinical\\_Practice\\_Guidelines\\_3rd\\_Edition.pdf](http://www.nationalconsensusproject.org/NCP_Clinical_Practice_Guidelines_3rd_Edition.pdf).

130. Federal insurance programs such as Medicare and, to a lesser extent, Medicaid, have the opportunity to make a nationwide impact, but the glare of conservative scrutiny has prevented much action as of now.

131. See *supra* note 27 and accompanying text (discussing state legislative limitations on what treatments can be foregone via advance directives and surrogate decision makers).

132. In the Matter of a Ward of the Court, [1995] 2 ILRM 401 (SC) (Ir.) (“[S]anctity of life was not a principle on which legal structures should be based since it depended on a religious outlook that not everyone shared.”).

refuse treatment on their behalf.<sup>133</sup> In the *Bland* case, Lord Justice Hoffmann wrote,

[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>134</sup>

Certainly, many in the United States, including some respected jurists,<sup>135</sup> agree with this position, but it is difficult to implement a policy that carefully considers this more nuanced concept of the sanctity of life in the face of vocal opposition from social and religious conservatives.<sup>136</sup>

##### 5. Focusing on cost reduction may derail efforts at improvement

Many commentators have recognized the general problem of overutilization of health care resources and have recommended the implementation of various programs designed to target this

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133. For an excellent discussion of the effect of these “subtle pressures” from a person living with a serious disability, see Ben Mattlin, *Suicide By Choice? Not So Fast*, N.Y. TIMES, Oct. 31, 2012, at A31.

134. See *Airedale NHS Trust v. Bland* [1993] AC 789 (HL) 833 (UK).

135. See *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 281 (1990) (Stevens, J., dissenting) (“[I]t is an effort to define life, rather than to protect it, that is at the heart of Missouri’s policy . . . Life, particularly human life, is not commonly thought of as merely physiological condition or function. Its sanctity is often thought to derive from the impossibility of any such reduction.”).

136. Cf. *Planned Parenthood v. Casey*, 505 U.S. 833, 851 (1992) (“These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one’s own concept of existence, of meaning, of the universe, and of the mystery of human life.”). In fact, the pro-life movement in the United States has little to do with protecting life in its broadest sense and much to do with imposing a narrow worldview on those who do not share it by maximizing opportunities to wield secular political power. Cf. Thomas L. Friedman, *Why I Am Pro-Life*, N.Y. TIMES, Oct. 28, 2012, at SR13 (questioning how individuals who label themselves “pro-life” can consistently oppose reasonable gun control laws, environmental protection, and programs which provide nutrition and early education for children living in poverty, and adding that “[r]espect for the sanctity of life, if you believe that it begins at conception, cannot end at birth.”).



problem.<sup>137</sup> Nevertheless, there is little evidence that guidelines for end-of-life care reduce costs, and at the same time there is a great deal of risk that discussing cost reduction in the same conversation with ideas about improving end-of-life care by reducing overtreatment will generate controversy. In both the United States and the United Kingdom, discussion of cost savings in conjunction with discussions about minimizing inappropriate treatment or life-supportive measures, leads to public outcry while reducing opportunities for clear-headed conversation about how to improve care at the end of life. And, because high-quality palliative and hospice care also costs money, it is unclear how much savings would accrue if we were able to achieve a substantial system-wide reduction in ICU care and hospitalization at the end of life in favor of emphasis on palliative and hospice care. Therefore, it is probably better to keep these issues separate and trust that cost savings may prove to be a positive side effect of improved end-of-life care. In any event, as this Article explains, there are other, better reasons for making these changes.

*B. Lessons from the Liverpool Care Pathway—Implementing Best Practices*

So, what can physicians and policy makers in the United States learn from the United Kingdom's experience with the LCP? Care pathways or guidelines can improve quality of care and reduce unnecessary care. At the same time, uncritical or ill-informed implementation of such guidelines risks automating care in a way that ignores the importance of meaningful communication about patients' and families' preferences, beliefs, and fears. It also risks serious error, that is, hastening a patient's death inappropriately. Communication problems constitute the biggest shared obstacle in the United States and the United Kingdom to excellent end-of-life care.

It is unlikely that a guideline like the LCP, which actually describes a decision tree of steps for implementing quality care in the last hours and days of life, will ever gain widespread

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137. See, e.g., Christine K. Cassel & James A. Guest, *Choosing Wisely: Helping Physicians and Patients Make Smart Decisions About Their Care*, 307 JAMA 1801 (2012) (describing various programs such as Choosing Wisely, Less is More, and the Good Stewardship Working Group that aim to educate physicians about commonly over-utilized tests and procedures).

traction in the United States, for all of the reasons described above. More realistically, health care providers and other stakeholders in the United States should focus on guidelines to facilitate communication between individual physicians and individual patients about how to address end of life matters such as ceasing active therapy, the introduction of palliative care, transition to hospice, and the withdrawal or withholding of life-prolonging measures. Truthful, substantive conversations centered around these topics can lead to the development of individualized plans of care like those recommended by the critics of the LCP. Additionally, for those patients who are willing and able to engage in advance care planning, there is evidence of real progress in advance planning with the proliferation of Physician Orders for Life Sustaining Treatment ("POLST"), which allow patients and surrogates to make and document detailed, situation-specific medical orders for end-of-life care.<sup>138</sup> POLSTs and similar documents provide something akin to the individualized plan of care recommended by the authors of the LCP Review.

The U.S. law's emphasis on autonomy and patient decision making is unlikely to change in any dramatic way (though, as suggested above, there is nothing to prevent physicians supplementing it with information that will help the patient or her surrogate evaluate what is in the patient's best interests). The influence of the pro-life culture also will persist and is unlikely to change at anything more than glacial speed. Furthermore, it is not possible to change the structure of how the practice of medicine is regulated in the United States. In other words, a top down solution is not available as it would be via the NHS in the United Kingdom. Any regulatory approaches to change will likely rest with the fifty states, since any federal effort to promulgate guidelines, let alone requirements, for how end-of-life decisions get made likely would be death-paneled. There is a similar risk in many of the states and a patchwork solution to this complex problem will bring its own challenges, as has al-

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138. See *Care at the End of Life*, N.Y. TIMES, Nov. 24, 2012, at SR10 (noting that fifteen states have enacted laws authorizing the use of POLST forms and nearly thirty other states are considering such legislation); see also *About the National POLST Paradigm Program*, NATIONAL POLST, <http://www.polst.org/about-the-national-polst-paradigm/> (last visited Apr. 9, 2015) (providing detailed information about these forms, their legal status, and implementation).

ready been demonstrated with widely varying state approaches to major health care issues such as abortion, stem cell research, and medically assisted dying.

Despite these challenges, there has been some movement at the state level to address these issues. At least two states, California and New York, have enacted legislation to require physicians to provide patients and families with information about end-of-life choices. California's Right to Know End of Life Options Act only requires physicians to provide information upon request of the patient or surrogate,<sup>139</sup> which was required anyway under existing informed consent law. New York's Palliative Care Patient Information Act requires physicians to provide information about prognosis, risks and benefits of various treatment options, and rights to pain and symptom management to terminally ill patients or their surrogates.<sup>140</sup> Both laws generated controversy prior to enactment, and physicians in New York State have criticized the statute for vagueness<sup>141</sup> and a "heavy-handed intrusion into the doctor-patient relationship."<sup>142</sup> The critics argue that a better approach to the problem is to "focus on obstacles to respectful conversation about the limits of medical efforts to extend life and about the alternatives to disease-directed treatments."<sup>143</sup> Although these objections have merit, it is unsurprising that a state legislature became impatient with the slow progress toward the goal of timely and appropriate conversation and decided to move the process along. It is too soon to say whether the New York law will have much effect on the overutilization of care at the end of life.

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139. See CAL. HEALTH & SAFETY CODE § 442–442.7 (West 2009).

140. Violations of the statute are punishable by fines of up to \$5000 for repeated offenses and physicians face up to a year in jail for intentional violations. See N.Y. PUB. HEALTH LAW § 2997-c (McKinney 2010).

141. See Alan B. Astrow & Beth Popp, *The Palliative Care Information Act in Real Life*, 364 NEW ENG. J. MED. 1885, 1885 (2011) (explaining that, while survival prognoses for cancer patients are relatively well defined, it is difficult to estimate life expectancy for the 75 percent of people who die from other diseases).

142. See *id.* at 1885–86 ("New York is attempting to prescribe legislatively what should be a subtle, intimate conversation between doctor and patient that often happens over time . . . . Admittedly, physicians have too often left patients with advanced incurable illness unaware of the reality of their condition.").

143. *Id.* at 1886.

In addition to these limited legislative interventions, there are some strategies to implement best practices for end-of-life care in the United States that are consistent with U.S. law and that are realistic in the context of U.S. culture and politics. Apart from physicians, patients, and families, there are a number of other stakeholders that can participate in the move toward best practices, including hospitals, medical schools, and public and private insurers. Influencing physicians and these stakeholders represents the only realistic avenue for influencing behavior and improving quality of care at the end of life.

The LCP experience demonstrates that guidelines alone cannot promote best practices without physicians and other health care providers who understand and support the guidelines and are willing to invest the time and energy to implement them with care. Physicians struggle with time pressures and the growing physician shortage will exacerbate this problem.<sup>144</sup> Coupled with patients who are reluctant to confront death and prepare for it until it is absolutely unavoidable, and distressed family members who understandably hesitate to make decisions to withdraw or withhold care, the problem seems almost insurmountable.

The LCP experience and its demise shines a spotlight on the underlying problems of communication in both the United Kingdom and the United States. Physicians, of course, are on the front line. The United States will never adopt the U.K.'s position that end-of-life decisions ultimately should rest with the physician, nor should it. Nevertheless, physicians in the United States can learn to initiate discussions with the patient and family, to clearly explain the facts of the patient's situation as well as they can be determined, and to discuss with the patient and family the options available at this point, including the patient's prognosis with and without treatment or life-supportive measures and the benefits and burdens of continued treatment and life support.

It also seems clear that the development and publication of guidelines for excellence in physician-patient conversation will not, alone, bring about system-wide changes in physician prac-

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144. See ASS'N OF AM. MED. COLLEGES, *GME Funding: How to Fix the Doctor Shortage*, AAMC, [https://www.aamc.org/advocacy/campaigns\\_and\\_coalitions/fixdocshortage/](https://www.aamc.org/advocacy/campaigns_and_coalitions/fixdocshortage/) (last visited Feb. 21, 2014) (predicting a shortage of 91,500 physicians by 2020 and 130,600 by 2025).

tice. In addition to an ingrained reluctance to have emotionally challenging conversations with dying patients, many physicians still value individual clinical autonomy above compliance with even the best of guidelines,<sup>145</sup> and may therefore decline to follow them. Moreover, physicians often remain unaware of guidelines, even those developed and published by organizations in their field of specialty.<sup>146</sup> Finally, there is understandable suspicion that practice guidelines actually seek to reduce cost as much as to improve clinical practice,<sup>147</sup> a suspicion that, in the case of end-of-life practices, could undermine the effectiveness of the guideline in practice.

Nevertheless, insurers, managed-care organizations, and employers often rely on practice guidelines to define and limit the scope of health benefits.<sup>148</sup> If insurers condition payment on compliance with guidelines, this may encourage and accelerate the implementation of best practices.<sup>149</sup> Enforcement mechanisms may help to influence physician behavior but, realistically, it may take a generation of doctors training or re-training toward these goals before these conversations become sufficiently ingrained in medical practice at the end of life. There is a tipping point, as with all cultural shifts, but reaching this point collectively in the medical profession will take some time.

At a system-wide level, many organizations already are working on consensus-building through meetings of patient organi-

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145. See Stefan Timmermans, *From Autonomy to Accountability: The Role of Clinical Practice Guidelines in Professional Power*, 48 PERSP. BIOLOGY & MED. 490, 494 (2005); see also *supra* notes 139–143 and accompanying text (discussing physicians' reactions to New York's Palliative Care Information Act).

146. See Dimitri A. Christakis & Frederick P. Rivara, *Pediatricians' Awareness of and Attitudes About Four Clinical Practice Guidelines*, 101 PEDIATRICS 825, 825–30 (1998) (surveying pediatricians about their awareness of four pediatric practice guidelines and finding a range of awareness that varied from 16 to 64 percent).

147. See Timmermans, *supra* note 145, at 496 (explaining that “[t]he path of professional development is treacherous because the line between adopting and enforcing is easily blurred” and that “clinical practice guidelines are strongly associated with quality improvement and cost-control initiatives”).

148. *Id.*

149. See Wally R. Smith, *Evidence for the Effectiveness of Techniques to Change Physician Behavior*, 118 CHEST 8S, 8S–17S (2000) (concluding that there is no single effective method for changing physician behavior and that multiple concurrent approaches are likely to work better than a single strategy).

zations and professional organizations, both as to methods of communication and the substantive decisions that are required at the end of life.<sup>150</sup> As the experience with the LCP demonstrated, guidelines for end-of-life care must be carefully stated and evidence-based. The ACA mandates research on best practices in medicine to be conducted and disseminated. The ACA requires the Secretary of Health and Human Services to “identify, develop, evaluate, disseminate, and provide training in innovative methodologies and strategies for quality improvement practices in the delivery of health services that represent best practices in health care quality, safety, and value.”<sup>151</sup> Based on this best practices research, the ACA then instructs the Secretary to work to develop and identify new and existing clinical practice guidelines.<sup>152</sup> The federal mandate for this work may have the added benefit of changing the culture over time to one in which physicians in hospital settings (not just in hospice) routinely consider and discuss topics such as transition to hospice with their patients early enough in the dying process to improve the “quality of death.”

There have already been some successful system-wide initiatives to improve end-of-life care. The Department of Veterans Affairs (“VA”) implemented policies designed to ensure access to palliative care and hospice for veterans with terminal illness.<sup>153</sup> In 2002, deaths of veterans were at an all-time high

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150. The Conversation Project provides an example of a patient education program designed to develop consensus and to educate patients. The program seeks to “transform our culture so we shift from not talking about dying to talking about it . . . [and] communicate about the kind of care we want and don’t want for ourselves.” See CONVERSATION PROJECT, <http://theconversationproject.org/about/> (last visited Oct. 20, 2013); see also *End-of-Life Issues*, AM. C. PHYSICIANS, [https://www.acponline.org/patients\\_families/end\\_of\\_life\\_issues/](https://www.acponline.org/patients_families/end_of_life_issues/) (last visited Sept. 28, 2015) (describing initiatives to develop guidelines and educational materials to promote conversations with patients about their end-of-life options); *supra* notes 128–129 and accompanying text (describing organizations that promulgate guidelines that reflect consensus about best practices in end-of-life care).

151. See Affordable Care Act § 10331 (2010).

152. See *id.* (requiring the Center for Quality Improvement and Patient Safety to “facilitate the adoption of best practices that improve the quality, safety, and efficiency of healthcare delivery services”).

153. See Thomas Edes et al., *Increasing Access and Quality in Department of Veterans Affairs Care at the End of Life: A Lesson in Change*, 55 J. AM.

and few VA hospitals had inpatient palliative care services. At the same time, there was little access to home hospice care. The VA identified the barriers to access to quality end-of-life care and then established palliative care teams at each VA facility. It also partnered with community hospice care organizations.<sup>154</sup> The results were immediate and impressive: within three years of implementation, the number of veterans receiving hospice care at home had tripled, all VA facilities had a well-trained palliative care staff and a formal palliative care program, and 42 percent of veterans who died during that period had palliative care consultations.<sup>155</sup> Those who developed the plan noted that “a change of this magnitude requires a coordinated and synchronous change at many levels and in many aspects of the organization.”<sup>156</sup>

Of course, access to palliative care and hospice programs does not guarantee their use—utilization will still depend on the initiative of either the physician or the patient to have the conversation that will move the patient in that direction. Moreover, the VA is in many ways like the NHS, a closed system funded and regulated by government and staffed by government employees. System-wide changes like those at the VA in hospitals public or private hospitals with multiple sources of funding, staffed by a combination of employees and independent contractors, and regulated by laws in fifty different states will prove more challenging.

## V. NOT THE END

As is frequently the case in matters of medical care, the law is an inadequate and unwieldy tool for improvement. Similarly, guidelines for end-of-life care are helpful in setting out best practices but they are insufficient. The U.K. experience with a well-intentioned effort to systematize best practices ultimately failed, despite its many successes. We in the United States would do well to realize the magnitude of the problem that we face and to tackle it systematically and aggressively.

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GERIATRIC SOC'Y 1645, 1645–49 (describing the creation and implementation of a program to increase access to home hospice care for veterans).

154. *See id.*

155. *See id.* at 1647–48 (describing the results of the program).

156. *See id.* at 1648.

The good news is that in the United States the medical community and other interested groups have begun serious work into methods to improve the quality of communication and care at the end of life. The topic of frank communication with patients has received more attention within and outside of the medical literature recently<sup>157</sup> and, if the public discussion of communication and truth-telling at end of life continues, it may help over time to reduce the reluctance of individual physicians and patients to speak plainly and make plans for care. There is also growing interest in the integration of the modifying influence of palliative care into the care and culture of the ICU.<sup>158</sup>

The bad news is that we are a long way from understanding how best to bridge the gap between theory and practice across a vast and diffuse health care system. In end-of-life care, many patients and families will require guidance, information, and emotional support from physicians in order to make sound medical decisions. Physicians must more willingly take on the responsibility of initiating these emotionally challenging conversations in order to provide candid information and advice about appropriate end-of-life choices. Sometimes, this will require the physician to inform the patient that additional treatment is unlikely to ameliorate their condition or extend their life and that it may, in fact, increase suffering with no offsetting benefit. Continuing to provide treatment under these circumstances on the basis that it is “what the patient or family wants” deprives the patient of the best opportunity for a good death and does a disservice to the patient, his family, and the health care system more broadly. In the last days of life, the physician’s obligation is not to work miracles but to use his or her skills to “alleviate suffering, enhance well-being, and support the dignity of the patient.”<sup>159</sup> These are the last acts of medical care, and they are never futile.

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157. See, e.g., MAGGIE CALLANAN & PATRICIA KELLEY, *FINAL GIFTS: UNDERSTANDING THE SPECIAL AWARENESS, NEEDS, AND COMMUNICATIONS OF THE DYING* (2012) (describing the philosophy and workings of hospice care and sharing narratives of dying patients who have found comfort in their beliefs and in working to address unresolved issues in their lives).

158. The IPAL-ICU project seeks to improve palliative care in the ICU by providing a central repository for exchanging evidence, expertise, and information. See CTR. TO ADVANCE PALLIATIVE CARE, *Improving Palliative Care in the ICU*, IPAL-ICU, <http://www.capc.org/ipal-icu/> (last visited Mar. 4, 2014).

159. See Lawrence J. Schneiderman, *Defining Medical Futility and Improving Medical Care*, 8 *BIOETHICAL INQUIRY* 123, 128 (2011).