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# Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent

Barbara A. Noah\* and Neal R. Feigenson\*\*

“Life is pleasant. Death is peaceful. It’s the transition that’s  
troublesome.”<sup>1</sup>

—Isaac Asimov

## I. The Problem

Americans are reluctant to acknowledge their mortality,<sup>2</sup>

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1. This seemed like an appropriate epigraph to begin with, in part because it begs the question of when the transition starts. And the answer to this question is part of the problem that this article attempts to tackle—when is the right time to start thinking about preparing for death and therefore to consider ceasing medical efforts to prolong life? Part of the answer is that acknowledging the reality of death sooner rather than later in life probably makes it easier to accept when it arrives, but this is only a partial answer. At the end of life, modern technology often makes it difficult to know when death is imminent and when it is still a little way off. Expecting physicians to predict imminent death with enough precision and to know when to cease treatment or life support so that each patient dies neither a moment too soon nor a moment too late is expecting too much.

2. Craig Bowron, *Our Unrealistic Views of Death, Through a Doctor’s Eyes*, WASH. POST (Feb. 17, 2012), [https://www.washingtonpost.com/opinions/our-unrealistic-views-of-death-through-a-doctors-eyes/2012/01/31/gIQAeaHpJR\\_story.html](https://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.”); *see also* INSTITUTE OF MEDICINE, DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR

and this reluctance is closely correlated with the trend toward more medical treatment at the end of life. Recent research suggests that a growing number of Americans—nearly one-third—believe that physicians should do everything to keep patients alive under all circumstances.<sup>3</sup> Seriously ill patients and their physicians, not to mention healthy adults in general, often avoid discussing the inevitability of death and avoid planning for it. In the absence of such decisions, the default treatment model focuses on preservation of life, often resulting in overtreatment and avoidable suffering at the end of life.<sup>4</sup> Even worse, the treatment patients receive may not be consistent with what their informed preferences would have been if their physicians had acknowledged the patients' terminal prognoses, had appropriate discussions, and documented the patients' preferences in the medical record or via an advance directive.

There are various ways to assess whether, on the whole,

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THE END OF LIFE (Nat'l Acads, Press 2014) [hereinafter IOM, DYING IN AMERICA; see generally Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 ELDER L.J. 1-31 (2013) (discussing cultural, legal, and other reasons why patients and physicians avoid making end-of-life decisions); see also Institute of Medicine, *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*, available at < <http://iom.nationalacademies.org/Reports/2014/Dy>.

3. See *Views on End-of-Life Medical Treatments*, PEW RESEARCH CTR. (Nov. 21, 2013), <http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/> (noting that this belief is still the minority view—31% of those surveyed in 2013 favored doing everything compared with 15% of those surveyed in 1990). Some of this shift in favor of maximum treatment resulted from the fact that more of those surveyed were willing to express an opinion (versus choosing the option “don't know”) but the data clearly indicate less support for allowing patients to die in certain circumstances (73% supported this option in 1990 versus 66% in 2013). See *id.*

4. See DANIEL CALLAHAN, *SETTING LIMITS: MEDICAL GOALS IN AN AGING SOCIETY* 17 (Simon & Schuster 1987) (“Not only has health been transformed as a medical goal and social ideal, but the place of good health in individual lives . . . has moved from the sphere of the accidental and fortuitous—where death was once the companion of all age groups, beyond the help of medicine, politics, and economics—to the realms of high science and established psychological and political expectation. The technological imperatives that transformed the nature of medicine from caring to curing have no less profoundly affected our idea of health, moving it from a nebulous hope to a fundamental human and social requirement. What can be done medically ought to be done. What ought to be done ought to be available to all. What ought to be available to all becomes the moral responsibility of all.”).

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patients are receiving “the right amount” of therapy or life-prolonging technology. One approach is to ask whether the treatment improves physical outcomes objectively by prolonging life or improving quality of life. Another approach is to consider whether the cost of administering life-prolonging care at current levels is a wise expenditure of increasingly scarce health-care dollars. Finally, we can ask whether the treatment is consistent with the patient’s true wishes. This is a subjective measure in which the quality of the care is evaluated according to its consistency with the individual patient’s values and beliefs.

In the first part of this paper, we will explain that, by any of these measures, many dying patients are receiving too much therapy and life-prolonging care. We will also briefly discuss the many factors that contribute to this state of affairs: the culture of denial of death, physicians’ professional culture and attitudes toward treatment, physicians’ fear of liability, physician avoidance of discussions about prognosis, and the impact of payment incentives that encourage overutilization of medical technologies.

This paper’s primary focus, however, will be on considering how best to ensure that patients have the tools to make both informed and authentic choices about their care at the end of life. We will argue that truly informed decision making can help to reduce excessive end-of-life care by any measure. Most importantly for dying patients, better informed decisions can help reduce unnecessary suffering and result in care that aligns with their well-considered values and preferences.

In the second part of this paper, we will explain that, under the doctrine of informed consent, physicians have an ethical and legal obligation to provide patients with timely and accurate information that will enable patients to make informed decisions about end-of-life care. Yet compliance with informed consent law does not ensure that patients’ decisions are truly informed and, in practice, the norm is still to provide too much care. In the third part of the paper, we discuss several tools and techniques that are available to help physicians and patients achieve the goal of truly informed decision making, including training to promote the practice of shared decision making and the use of decision aids.

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Even with these improvements, however, decision making at the end of life may not result in the “right amount” of care. We therefore also explore the concept of *authentic* decision making: decisions regarding end-of-life care that are fully considered in light of a patient’s well-developed values, beliefs, and goals of care. The ideal of authenticity requires that the patient not only understand the nature of the treatment and its risks and benefits (as the doctrine of informed consent requires), but also have the emotional ability and the will to make the decision, as well as a functional value system that enables the patient to evaluate the appropriateness of the choice for him or herself. This is particularly challenging because of the uncertainty inherent in prognosis, treatment outcomes, and adverse effects. Although we do not argue that authenticity in this sense should or even can be legally required, we believe it is important to articulate it as an aspirational—and achievable—goal for decision making at the end of life.

A. *Overutilization of Care—The Evidence*

Patients say that they wish for a “good death,” but this idea surely must mean different things to different people. Nevertheless, most people’s idea of a “good death” likely have some elements in common, such as avoiding physical suffering.<sup>5</sup> As another example, most patients state that they would prefer to die at home.<sup>6</sup> Yet only about 30% of patients do

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5. 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 (home versus hospital), and cultural variables in different studied countries such as maintaining independence, control, self-determination, and entrusting decisions to others). *Id.* at 913. 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* (Vintage Books 1995).

6. See GEORGE H. GALLUP, JR., *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*

so.<sup>7</sup> Instead, we utilize significant amounts of hospital-based resources at the end of life,<sup>8</sup> often with little or no measurable benefit to dying patients. Many patients in the United States receive aggressive interventions such as cardiopulmonary resuscitation, ventilator support, or ICU care even when death is imminent.<sup>9</sup>

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*Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences*, 3 J. PALLIATIVE MED. 287, 287-300 (2000) (finding that despite the fact that the majority of patients in England suffering from serious illnesses wish to die at home, most die in either hospital or a long-term care facility).

7. 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 J. AM. MED. ASS'N 470 (2013) (concluding that, although only 24.6% of patients died in hospital in 2009 compared with 32.6% in 2000, percentages of deaths in long-term care facilities held steady at around 27% and deaths at home rose from 30.7% in 2000 to 33.5% in 2009); see also Yafu Zhao & William Encinosa, *The Costs of End-of-Life Hospitalizations, 2007*, HEALTHCARE COSTS & UTILIZATION PROJECT (Nov. 2009), <http://www.ncbi.nlm.nih.gov/books/NBK53605/> (describing data from 2007 indicating that one-third of Americans died in hospital); Jeanne Lenzer, *Unnecessary Care: Are Doctors in Denial and is Profit Driven Healthcare to Blame?*, 345 BRIT. MED. J. e6230 (2012) (referring to another estimate that 65% of deaths in the United States occur in hospitals). Yet another study found that 45% of U.S. deaths occur in hospitals and 22% in long term care facilities. See DIV. VITAL STATISTICS, NAT'L CTR. 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, 1999-2005 (2009), <http://www.cdc.gov/nchs/nvss/mortality/gmwk307.htm>.

8. 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 ARCHIVES 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, *supra* note 7, at 473 tbl. 2 (noting that, in 2009, 29.2% of patients who died had received care in an ICU in the previous 30 days); Donald M. Berwick & Andrew Hackbarth, *Eliminating Waste in U.S. Health Care*, 307 J. AM. MED. ASS'N 1513 (2012) (describing 6 categories of health care 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).

9. See Amresh Hanchate et al., *Racial and Ethnic Differences in End-of-Life Costs: Why Do Minorities Cost More than Whites?*, 169 ARCHIVES

These trends are worsening. The most recent data indicate that, in 2009, 28.4% of patients received hospice care for only three days or fewer before dying, an increase from 22.2% nine years earlier. Moreover, 29.2% of Medicare beneficiaries remained in an ICU during the final month of life compared with 24.3% in the earlier period.<sup>10</sup> This pattern of overutilization of care at end of life results in situations where dying patients continue to receive costly therapeutic care and life-prolonging treatment even when it is very likely that the benefits in terms of enhanced quality of life, increased survival time, or other measurable physical outcomes are limited or non-existent.<sup>11</sup> At the same time, we underutilize hospice and

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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 (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”).

10. See Teno, *supra* note 7, at 471-73 & tbl. 2 (also finding that 11.5% of patients had been hospitalized three or more times in the three months before death, up from 10.3% in the previous studied period).

11. 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% of patients in 5 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*, J. AM. MED. ASS’N INTERNAL MED. E1, E3-E4 and fig. 1 (Sept. 9, 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. See *id.* at E2. See also Robert D. Truog & Douglas B. White, *Futile Treatments in Intensive Care Units*, J. AM. MED. ASS’N INTERNAL MED. (Sept. 9, 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 over-treatment interferes with quality of life for these patients with little offsetting benefit).

palliative care.<sup>12</sup> The challenge is to identify those situations in which over-treatment is occurring (or is likely to occur) and to respond with treatment that is both clinically appropriate and consistent with the patient's wishes. Given that every patient is unique and end-of-life preferences and goals of care vary, this is not a simple process.

In the context of terminal illness, many people believe that more therapeutic care (such as tests, procedures, life-supportive measures and drug therapies) leads to longer life and improved physical well-being.<sup>13</sup> We have all heard grieving families assure others that "the doctors did everything they could." "Doing everything" may help to alleviate feelings of distress or helplessness on the part of families and physicians, but it is not necessarily in the patient's best interests.<sup>14</sup> In fact, a growing body of evidence demonstrates that an emphasis on palliative care,<sup>15</sup> in conjunction with

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12. See Teno, *supra* note 7, at 474 (noting that, although the use of hospice services has increased during the early 2000s, only 42.2% of Medicare beneficiaries with dementia and 59.5% of Medicare beneficiaries with cancer received hospice services at the time of death); Corita Grudzen & Deborah Grady, *Improving Care at the End of Life*, 171 ARCHIVES INTERNAL MED. 1202, 1202-04 (2011) (discussing over-use of therapeutic interventions 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 patients with stage IV lung cancer had had any discussion with their physicians about hospice in the two months prior to 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 349-78 (2012).

13. See Sean Palfrey, *Daring to Practice Low-Cost Medicine in a High-Tech Era*, NEW ENG. J. MED. (2011), <http://www.nejm.org/doi/pdf/10.1056/NEJMp1101392?source=hcrc.pdf>. (commenting on the mistaken belief that "'doing everything' is the best practice and the way to prevent harm"); Grudzen, *supra* note 12 (discussing comparative outcomes in the end of life care for three patients).

14. See Bowron, *supra* note 2.

15. "Palliative care" refers to medical care intended to alleviate symptoms associated with illness, whatever the patient's prognosis. Such care may address pain, shortness of breath, insomnia, depression, nausea and lack of appetite, among other symptoms. See Lise M. Stevens, *Palliative Care*, 296 J. AM. MED. ASS'N 1428 (2006). Palliative care is often appropriate even while the patient is receiving therapeutic care; the two are not mutually exclusive. Once therapeutic care is discontinued, palliative care continues in



carefully considered therapeutic care, can improve patients' quality of life and even prolong survival.<sup>16</sup>

An example helps to illustrate the seriousness of the problem and how easily the care of dying patients can go awry. A 73-year-old man was admitted via the emergency room complaining of progressive weakness on his left side.<sup>17</sup> A CT indicated lung cancer with metastasis in the brain. The patient refused further invasive tests, including biopsy of the lung tumor, explaining that he had watched his wife die of lung cancer and did not want tests or life-prolonging treatment. Various physicians again pressed the patient to undergo lung biopsy and he then agreed. The biopsy confirmed lung cancer. The patient refused surgery to resect the cancer in the lung and brain and was discharged after 21 days in the hospital with full-time home care.<sup>18</sup> The patient was readmitted to the hospital three months later after suffering three grand mal seizures. A CT scan indicated that the brain mass had worsened; the patient continued to suffer seizures, could not talk, and was lethargic. The patient's son requested a DNR

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order to manage symptoms.

16. See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 736-38 (2010) (finding that patients recently diagnosed with lung cancer who began receiving palliative care immediately lived an average of three months longer than patients who received standard therapeutic treatment only); Matthijs Kox & Peter Pickkers, "Less Is More" in *Critically Ill Patients Not Too Intensive*, 173 J. AM. MED. ASS'N INTERNAL MED. 1369 (2013) (concluding, based on a meta-analysis of multiple clinical trials, that many common treatments for critically ill patients pose a high risk of iatrogenic harm compared with their potential benefit and ought to be used more cautiously).

17. See Morrison, *supra* note 11 (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 over-treatment interferes with quality of life for these patients with little offsetting benefit).

18. One of the commentators on the case observed that, at that point, "He wants to return home as soon as possible and lead as normal a life as he can for as long as he can. With such a large brain lesion and lung mass, it is unlikely that he could be cured, and he should have been told this. He should also have been told that . . . the survival is generally longer after surgical resection than with no therapy or radiation therapy alone. However, we must remember that it is his choice." *Id.* at 1756. Of course, the patient's "choice" is only meaningful if he has received the additional information. Failing to provide this information makes "his choice" a bit hollow in retrospect.

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order based on his father's prior wishes. The neurology team again recommended surgery to resect the tumor in the brain but the family declined. Over the next three weeks the patient received oxygen, various fluids and drugs via an IV, multiple blood tests and additional CT scans, and was fed via a nasogastric tube. Although he was minimally responsive, he managed to remove the NG tube multiple times. He was then placed in restraints and, after 24 days of hospitalization, the family was persuaded to consent to a gastrostomy tube for feeding. The tube was surgically inserted on the 29<sup>th</sup> day of hospitalization. The patient had a cardiopulmonary arrest and died the following day.<sup>19</sup>

This example illustrates several of the measures of overutilization of care described above. The patient clearly suffered unnecessarily and also very likely incurred additional health care costs. Most importantly, the care he received was inconsistent with his expressed wishes. The patient was quite clear about his refusal of life-prolonging care. He went home and skipped all follow-up appointments. Nevertheless, he spent his final month of life in the hospital, attached to various tubes and restrained to prevent him from removing them. His family appears to have wavered between respecting his wishes and being persuaded to do more. As one physician put it, "We want our loved ones to live as long as possible, but our culture has come to view death as a medical failure rather than life's natural conclusion . . . When their loved one does die, family members can tell themselves, 'We did everything we could for Mom' In my experiences, this is a stronger inclination than the equally valid (and perhaps more honest) admission that 'we sure put Dad through the wringer.'"<sup>20</sup>

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19. *Id.* at 1757. For another similar example of physician resistance and family ambivalence to withholding treatment, see Kathleen Bartholomew, "Saving" Bonnie, 174 J. AM. MED. ASS'N INTERNAL MED. 13 (2014) (describing a dying 88 year old woman who, as a Christian Scientist had no regular medical care from physicians, and the refusal of an emergency room physician to write a DNR order at the request of the patient and her daughter-in-law (the author) because he didn't "feel comfortable").

20. See Bowron, *supra* note 2.

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B. *Causes of Overutilization of Care at the End of Life*

How and why does this sort of excessive end-of-life care come about so routinely? Broadly speaking, our medical system operates within a culture of denial of death. A combination of trends provides evidence of denial. Longer average lifespans, together with the promise of new therapies, encourages individuals to avoid confronting mortality. Some researchers now talk of doubling the human life span, even of a “cure for death,” and of aging as a “disease” that should be “treated.”<sup>21</sup> Although commentators have criticized this mindset,<sup>22</sup> research into lifespan extension continues with little regard for the consequences of the distorted message it sends.<sup>23</sup> This quest for a fountain of youth denies the reality of mortality, and ignores the fact that more days or years of life do not necessarily guarantee more quality of life or more happiness. In addition, cultural portrayals of older people create more ambivalence about aging. We hear phrases like “fifty is the new thirty” and see advertisements for “adult communities” depicting vigorous, tanned septuagenarians playing golf and tennis. At the same time, unlike other animals, we are conscious of our own mortality, which creates, at least for some, unsettling feelings of ambivalence. The

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21. *Closing in on the Cure for Death*, FIGHT AGING (Sept. 2, 2003), <https://www.fightingaging.org/archives/2003/09/closing-in-on-the-cure-for-death.php>; see also Penni Crabtree, *Fountain of Youth with Just a Shot in the Arm?*, SAN DIEGO UNION TRIB., July 25, 2004, at A1 (describing the Institute's claims and explaining that mainstream science has debunked anti-aging claims as “hucksterism” that offers little or no benefit but poses potentially serious health risks).

22. See Daniel Callahan, *Death and the Research Imperative*, 342 NEW ENG. J. MED. 654, 654-55 (2000) (quoting William Haseltine, then CEO of Human Genome Sciences as saying that “[d]eath is a series of preventable diseases” and arguing that research “should not, even implicitly, have eradication of death as its goal” because it supplants emphasis on the importance of relieving suffering at the end of life and it “promotes the idea among the public and physicians that death represents a failure of medicine.”).

23. Recent news stories document the efforts of tech billionaires to fund research into lifespan extension. See, e.g., Ariana Eunjung Cha, *Tech Titans’ Latest Project: Defy Death*, WASH. POST (Apr. 4, 2015), <http://www.washingtonpost.com/sf/national/2015/04/04/tech-titans-latest-project-defy-death/>.

philosopher Ernst Becker captured the paradox eloquently: “Man is literally split in two: he has an awareness of his own splendid uniqueness . . . and yet he goes back into the ground in order blindly and dumbly to rot . . . .”<sup>24</sup> These cultural influences have played a significant role in transforming the natural process of dying into a technologically-driven and, often, illogically overzealous prolongation of the lives of terminally ill patients. It is also no surprise that, in this culture of denial, many people avoid planning for the end of life until the matter becomes urgent, and may try to avoid it even then.

Physicians’ professional culture also appears to contribute to the problem. Physicians themselves sometimes exhibit a striking reluctance to cease curative care for their patients, acknowledge their dying, and focus on symptom management instead of continuing to treat the illness aggressively. Commentators have noted that physicians’ attitudes towards these issues can vary according to their specialty.<sup>25</sup> Surgeons, for example, have difficulty relinquishing control over post-surgical patients because they fear retrospective censure about the appropriateness of the decision to perform the surgery, or because of guilt or “ego alienation” if the patient is faring poorly.<sup>26</sup> One physician tells a story of an oncologist who was upset about his patient’s decision to stop chemotherapy and enroll in a hospice program. The oncologist confronted the hospice physician and said, “We might as well just be walking away, and we might just as well shoot [the patient] now.”<sup>27</sup> Interestingly, physicians themselves, when facing death, frequently refuse invasive treatment, including CPR, preferring instead to accept the prognosis and spend their

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24. ERNEST BECKER, *THE DENIAL OF DEATH* 26 (The Free Press 1973).

25. See Soumitra R. Eachempati et al., *The Surgical Intensivist as Mediator of End-of-Life Issues in the Care of Critically Ill Patients*, 197 J. AM. COLL. SURGEONS. 847, 849-51 (2003).

26. See *id.* at 850 (adding that surgeons may also wish to avoid appearing to lack confidence in themselves or may worry that losing a surgical patient will ruin their statistical success numbers).

27. See Kevin B. O’Reilly, *End-of-Life Care: Pain Control Carries Risk of Being Called a Killer*, AM. MED. NEWS (Apr. 16, 2012), <http://www.amednews.com/article/20120416/profession/304169955/2/> (relating an anecdote from a physician who directs a hospice program).

remaining time feeling as well as possible.<sup>28</sup>

Another cause of overutilization of medical tests and interventions is the fear of making a medical error or being accused of hastening death, with the accompanying prospect of malpractice litigation.<sup>29</sup> Fear of liability, together with a reluctance to deprive patients of hope, has created a culture in which physicians may hesitate even to raise the question of withdrawal or withholding of therapeutic or life-sustaining medical care unless the patient or family initiates the conversation. And physicians are justified in this concern: The data suggest that a significant number of physicians in the United States have been accused of, investigated for, and occasionally prosecuted for murder and euthanasia in circumstances in which they discontinued life-supportive measures, provided drugs for pain control, or sedated patients

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28. See Teresa A. Hillier et al., *Physicians as Patients: Choices Regarding Their Own Resuscitation*, 155 ARCHIVES INTERNAL MED. 1289, 1289-92 (1995) (describing a study in which physicians were asked whether they would want cardiopulmonary resuscitation if diagnosed with Alzheimer's Disease, or various other advanced chronic diseases at various ages and finding that at all projected ages, most physicians would not want CPR, particularly with advancing age); Gregory P. Gramelspacher et al., *Preferences of Physicians and Their Patients for End-of-Life Care*, 12 J. GEN. INTERNAL MED. 346, 349-50 (1997) (finding that physicians preferred significantly less care at end of life than patients usually receive); cf. Garrett M. Chinn et al., *Physicians' Preferences for Hospice if They Were Terminally Ill and the Timing of Hospice Discussions With Their Patients*, 174 J. AM. MED. ASS'N INTERNAL MED. 466 at E1, E1-E2 (finding that physicians who preferred hospice for themselves were more likely to discuss hospice with terminally ill cancer patients); Ken Murray, *How Doctors Die: It's Not Like the Rest of Us, But it Should Be*, ZOCALO PUB. SQUARE (Nov. 30, 2011), <http://zocalopublicsquare.org/thepublicsquare/2011/11/30/how-doctors-die/read/nexus>.

29. See Alan Meisel et al., *Seven Legal Barriers to End-of-Life Care: Myths, Realities, and Grains of Truth*, 284 J. AM. MED. ASS'N 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); Palfrey, *supra* note 13, at e(21)(1) ("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).

whose suffering they were unable to alleviate in other ways.<sup>30</sup> Yet continuing inappropriate or “aggressive” care also poses risks of iatrogenic harm and additional pain or discomfort, often with no discernable offsetting medical benefit. As commentators have recognized, sometimes less is more; there is a real risk of harm “in an environment that values treatment over care.”<sup>31</sup>

It is difficult to say precisely how much unnecessary care at the end of life results from patient and family requests for such care and how much is the result of physicians’ unwillingness to be candid about the likely ineffectiveness of the care in prolonging life or improving quality of life. Nevertheless, there is clearly a causal connection between overtreatment at the end of life and poor communication between physicians and patients. Research suggests that physicians avoid or delay disclosing details about patients’ prognoses or spontaneously initiating discussions about ending therapeutic care and making the transition to hospice.<sup>32</sup> With respect to patients with likely incurable cancers, research demonstrates that, while two-thirds of physicians tell their patients at the initial visit that they have an incurable form of cancer, only one-third ever state the prognosis at any point in

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30. See Nathan E. Goldstein et al., *Prevalence of Formal Accusations of Murder and Euthanasia Against Physicians*, 15 J. PALLIATIVE MED. 334 (2012) (finding, based on survey data, that over half of respondents had been accused of euthanasia or murder by a patient or patient’s family member within the previous five years and 4% of those surveyed had been formally investigated for hastening a patient’s death); 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).

31. See, e.g., Grudzen & Grady, *supra* note 12, at 1202.

32. See, e.g., Nancy L. Keating et al., *Physician Factors Associated With Discussions About End-of-Life Care*, 116 CANCER, 998 (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 RESEARCH (2011) (discussing the distinctions between and intersection of palliative care and end of life care and recommending better training of health care providers to understand that “end of life” is not a “well-demarcated period of time before death.”).

the relationship.<sup>33</sup> Physicians also tend to overestimate the remaining life spans of seriously ill patients and to convey prognoses in overly optimistic terms.<sup>34</sup> Even worse, a surprising number of physicians acknowledge deliberately deceiving patients when discussing prognoses. In a recent survey of physicians, one in ten physicians admitted to lying to a patient within the previous year, and over half acknowledged that they had been unreasonably optimistic about a patient's prognosis.<sup>35</sup> Moreover, physicians report that even when

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33. See Belinda E. Kiely et al., *Thinking and Talking About Life Expectancy in Incurable Cancer*, 38 SEMINARS IN ONCOLOGY 380, 380-81 (2011).

34. See Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients*, 320 BRIT. MED. J. 469, 470-71 (2000) (finding that, in predicting patients' remaining life expectancies, physicians were correct only 20 percent of the time and were over-optimistic 63 percent of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions); Elizabeth B. Lamont & Nicholas A. Christakis, *Prognostic Disclosure to Patients with Cancer Near the End of Life*, 134 ANNALS INTERNAL MED. 1096 (2001) (finding that, in communicating expected survival times to patients with terminal cancer, physicians were frank with patients only 37% of the time, provided deliberately inaccurate survival estimates 40.3% of the time and preferred to offer no estimate for 22.7% of the patients studied). The authors concluded that "for all of these patients, physicians were able and willing to formulate objective prognoses, whether accurate or not, but had difficulty communicating them, even to insistent patients."; cf. Elisa J. Gordon & Christopher K. Daugherty, *'Hitting You Over the Head:' Oncologists' Disclosure of Prognosis to Advanced Cancer Patients*, 17 BIOETHICS 142, 142-68 (2003) (describing the results of a small focus group discussion with physicians in which many expressed reluctance to convey statistical details about prognosis because they felt that the information would seem too abrupt and would interfere with patients' hope).

35. See Lisa I. Lezzoni, et al., *Survey Shows That at Least Some Physicians Are Not Always Open or Honest with Patients*, 31 HEALTH AFFAIRS 383, 383-88 (2012); Sandeep Jauhar, *The Lies That Doctors and Patients Tell*, N.Y. TIMES (Feb. 20, 2014, 10:21 AM), [http://well.blogs.nytimes.com/2014/02/20/the-lies-that-doctors-and-patients-tell/?\\_r=0](http://well.blogs.nytimes.com/2014/02/20/the-lies-that-doctors-and-patients-tell/?_r=0) (explaining, with reference to his over-treatment of a very elderly and dying patient, that "[a]t their core, my actions were a kind of deception—convincing myself, despite all the evidence, that I could save her, stay the inexorable course of her disease. Perhaps I was afraid of failure, or embarrassed by my impotence. Those last few days of her life she almost ceased to be a person for me. She became an experiment, a puzzle—one that I desperately wanted to solve."); cf. *Arato v. Avedon*, 858 P.2d 598 (Cal. 1993) (involving a claim by a deceased patient's family that the physicians' failure to disclose specific information about survival rates and times with pancreatic cancer impaired the patient's ability to get his financial and

cancer patients specifically request prognostic estimates, they would withhold their opinion or provide a willfully inaccurate figure in almost two-thirds of cases.<sup>36</sup> This increases the risk that patients will pursue aggressive and debilitating treatments in the hope of prolonging life without fully understanding the implications of this choice.<sup>37</sup>

Even when patients and families are generally well informed about medical matters, avoiding end-of-life decisions appears common. In a recent article in the *Hastings Center Report*, one of the authors (a doctoral candidate in a well-regarded medical humanities program) describes her mother's struggle with advanced ovarian cancer and her attempts to protect her mother from hearing the truth of her prognosis.<sup>38</sup> After a brief remission following "countless rounds of aggressive chemotherapy," the cancer had metastasized to the patient's brain, yet no physician ever stated that the cancer was no longer curable or mentioned dying. Just one day after the patient's oncologist came by to discuss his recommendation of a new chemotherapy (which would have been the patient's fifth), a palliative care physician explained that they should talk about the mother's "options" because "things didn't look good" on recent scans. The patient decided to start hospice care, explaining that she felt "incredibly relieved" not to have to fight any more. She died the next day.<sup>39</sup>

This story illustrates a couple of common and problematic issues. First, physicians will avoid having "the conversation," especially if the patient and family also carefully avoid raising

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business affairs in order). Of course, if the patient's preference is to avoid receiving explicit information about prognosis, this is a different matter. See *infra* notes 66 - 76, and accompanying text.

36. See E.B. Lamont & N.A. Christakis, *Prognostic Disclosure to Patients with Cancer Near the End of Life*, 134 ANNALS INTERNAL MED. 1096, 1096-98 (2001) (concluding that physicians would provide a honest estimate only 37% of the time and would provide no estimate, or a deliberate overestimate or underestimate 63 % of the time).

37. See *supra* notes 32- 36 and accompanying text (discussing physicians' and patients' over-optimism with respect to therapeutic benefits of treatment).

38. See Nicole M. Piemonte & Laura Hermer, *Avoiding a "Death Panel" Redux*, 43 HASTINGS CTR. REP. 20-21 (2013).

39. See *id.* (The daughter added that "I could not believe that the conversation I had dreaded most, the words that I thought would destroy my mother, had given her such a deep and profound sense of peace.").



questions about prognosis. Second, the current system creates an artificial dichotomy between curative and palliative care. Physicians who practice in the “curative” role tend to focus on clinical problem solving, will continue to advocate for therapy even when the prognosis is grim, and may often view death as a failure. Physicians who practice in the “palliative care” role focus on the patient as a whole person rather than as a disease diagnosis and will view unnecessary suffering at the end of life as a failure. When, however, care for a seriously ill patient *integrates* curative goals (for as long as they are clinically appropriate) with palliative goals, the patient, the family, and the physicians are better off. There is no reason to keep these goals separate or to provide these two types of care only sequentially.<sup>40</sup>

All of these problems are made worse by the fact that the system of reimbursement for health care in the United States often deforms the goals of care by paying physicians who provide more treatments and tests while failing to reimburse physicians for the more time-consuming and emotionally onerous task of discussing with patients the option of doing less. The Medicare program reimburses physicians and hospitals on a fee-for-service basis. Simply put, this means that the more treatments, tests, and procedures the patient receives, the more reimbursement the physician and/or hospital will receive.<sup>41</sup> Even not-for-profit hospitals need to

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40. There is much more to be said on the integration of curative and palliative care, but this is outside the scope of this article. For an excellent treatment of this topic, see Laura P. Gelfman & Diane E. Meier, *Making the Case for Palliative Care: An Opportunity for Health Care Reform*, 8 J. HEALTH & BIOMEDICAL L. 57 (2012); Marie Bakitas, et al., *Oncologists' Perspectives on Concurrent Palliative Care in an NCI-designated Comprehensive Cancer Center*, 11 PALLIATIVE SUPPORT CARE 415 (2013).

41. See, e.g., Stephen F. Jencks et al., *Rehospitalizations Among Patients in the Medicare Fee-for-Service Program*, 360 NEW ENG. J. MED. 1418, 1419 (2009) (discussing the Medicare fee-for-service reimbursement system in the context of rates of rehospitalization for Medicare beneficiaries); Robert Steinbrook, *The End of Fee-for-Service Medicine? Proposals for Payment Reform in Massachusetts*, 361 NEW ENG. J. MED. 1036, 1036 (2009) (discussing the incentives for overutilization of medical services created by a fee-for-service payment system). There is some promising news on this front. The U.S. recently passed a bill that will attempt to remedy the worst effects of fee-for-service medicine in the Medicare Program. The revamped reimbursement system will pay physicians based on the quality of the care

keep their “patient census” high—their beds full—in order to avoid a deficit. 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 problem.<sup>42</sup>

Until very recently, attempts by the Obama administration to enact a provision to compensate physicians for discussing end-of-life planning with patients in the Medicare program have been derailed by “death panel” accusations.<sup>43</sup> Despite repeated corrections of false statements regarding the content and intent of these regulatory proposals, recent polls showed that 41% of those surveyed continue to believe that reforms in the Affordable Care Act include panels that will opine on patients’ fitness to receive health care or will promote euthanasia.<sup>44</sup> Nevertheless, in July, 2015, the Centers for

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they deliver rather than the quantity of care. See Carol W. Cassella, *Keep Patients Healthy, and Doctors Sane*, N.Y. TIMES (Apr. 15, 2015), [http://www.nytimes.com/2015/04/16/opinion/keep-patients-healthy-and-doctors-sane.html?\\_r=0](http://www.nytimes.com/2015/04/16/opinion/keep-patients-healthy-and-doctors-sane.html?_r=0); see also Siobhan Hughes, *House Passes Medicare ‘Doc Fix’ Bill*, WALL ST. J. (Mar. 26, 2015, 7:03 PM), <http://www.wsj.com/articles/house-passes-medicare-doc-fix-bill-1427386278>.

42. See, e.g., Christine K. Cassel & James A. Guest, *Choosing Wisely: Helping Physicians and Patients Make Smart Decisions About Their Care*, 307 J. AM. MED. ASS’N 1801, 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).

43. See Earl Blumenauer, *My Near Death Panel Experience*, N.Y. TIMES, Nov. 15, 2009, at WK12 (describing U.S. Rep. Blumenauer’s efforts to implement Medicare reimbursement for this service and political uproar that followed, including a series of blatant falsehoods about the proposal offered up by its opponents); Robert Pear, *Medicare Rule Urges Planning for End of Life*, BOSTON GLOBE, Dec. 26, 2010, at A13 (discussing the initial Medicare regulation and the provision in the Affordable Care Act); Kevin B. O’Reilly, *76% of Patients Neglect End-of-Life Care Planning*, AM. MED. NEWS (Feb. 27, 2012), <http://www.amednews.com/article/20120227/profession/302279943/6/>; cf. Benjamin Anastas, *The Foul Reign of Emerson’s ‘Self-Reliance’*, N.Y. TIMES MAG., Dec. 2, 2011 at MM58 (discussing, as a modern result of Ralph Waldo Emerson’s “Self-Reliance,” “the American affliction of ignoring volumes of evidence in favor of the flashes that meet the eye, the hunches that seize the gut”).

44. See ASSOCIATED PRESS, THE ASSOCIATED PRESS-GfK POLL: HEALTH CARE REFORM (Sept. 25, 2012), [http://surveys.ap.org/data%5CGfK%5CHealthReform\\_2012\\_Topline\\_1st%20release.pdf](http://surveys.ap.org/data%5CGfK%5CHealthReform_2012_Topline_1st%20release.pdf); *Kaiser Health Tracking Poll – July 2010*, KAISER FAMILY FOUND. (July 29, 2010), <http://kff.org/health-reform/poll-finding/kaiser-health->

Medicare and Medicaid Services (CMMS) issued a proposed rule that would reimburse physicians and other qualified health professionals such as nurse practitioners for having one or more discussions with Medicare patients and families about advance care planning.<sup>45</sup> There now appears to be sufficient political support for these provisions to enable them to become final, though there remains a risk of obstruction from organizations such as the National Right to Life Committee, which argues that payment for advance care planning creates a bias against life-prolonging treatment and could exert pressure on some people to forego medical treatment in order to reduce costs.<sup>46</sup>

Finally, all of this extra medical spending at the end of life does not appear to improve quality of care. Recent studies have concluded that dramatic spending differences on end of life care among different counties in the United States have very little measurable effect on quality of care.<sup>47</sup> To be clear,

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tracking-poll-july-2010/\_ (finding that 36% of senior citizens still believe that the health reform law will allow government panels to make end of life decisions for Medicare beneficiaries).

45. See Medicare Program; Revisions to Payment Policies Under the Physician Fee Schedule and Other Revisions to Part B for CY 2016, 80 Fed. Reg. 41,686, 41,773 (July 15, 2015) (to be codified at 42 C.F.R. pts. 405, 410, 411, 414) (providing two new payment codes for advance care planning including the explanation and discussion of advance directives such as standard forms (with completion of such forms, when performed), by the physician or other qualified health professional—one code for the first 30 minutes, face-to-face with the patient, family member(s) and/or surrogate and an second payment code for each additional 30 minutes of discussion and advance directive completion).

46. See Pam Belluck, *Medicare Plans to Pay Doctors for Counseling on End of Life*, N.Y. TIMES, July 8, 2015, at A1.

47. See Janice Hopkins Tanne, *High Quality, Low Cost Healthcare Can Be Provided in U.S., Experts Say*, 344 BRIT. MED. J. e1190 (2012) (explaining that “[t]he programme showed that some U.S. counties spend \$17,000 (10,800 pounds; 13,000 euros) per person annually on healthcare for people over 65 years, whereas others provide equally good care for just \$6000.”). Elliott Fisher, professor of medicine at Dartmouth University, New Hampshire, said: “We could cover everybody without spending more,” adding that excess spending in the U.S. goes on hospitalization rather than outpatient care, specialist visits rather than care by primary physicians, and unnecessary tests and procedures. “If all hospitals adopted the practices of the lower spending regions, health care costs would go down by 30%, saving \$700bn to \$800bn per year.” *Id.*; see also THE DARTMOUTH ATLAS OF HEALTH CARE, <http://www.dartmouthatlas.org/data/region/> (last visited Feb. 1, 2016) (providing state by state data on various aspects of end of life care).

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the focus of this paper is on improving communication and quality of care at the end of life, not on cost reduction.<sup>48</sup> Although the issue is complex and the data inadequate to support any predictions, cost savings would be a fortunate side effect of achieving the central goal of providing patients with relevant information about their choices and encouraging them to think about and articulate to their health care providers their authentic end-of-life choices.<sup>49</sup>

### C. *Calibrating Care Based on Patients' Informed Wishes*

These systemic problems, together with the general reluctance to confront end-of-life decision making until the question becomes unavoidable, means that many end of life discussions happen too late or not at all. While we will argue that improved and timely communication between physicians and patients and families at the end of life may result in improved quality of life, reduced overutilization of care, and

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48. 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 over-treatment will generate controversy (to put it mildly). In the U.S. cultural climate, 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.

49. See Steven J. Katz & Sarah Hawley, *The Value of Sharing Treatment Decision Making With Patients: Expecting Too Much?*, 310 J. AM. MED. ASS'N 1559, 1560 (2013) (questioning the design of studies suggesting that shared decision making reduces health care spending in general and noting that "there is no evidence that patient preferences would inherently favor less extensive treatments than recommendations made by their physicians"); cf. Abigail Zuger, *Testing the Limits of 'Terminal,'* N.Y. TIMES, Oct. 14, 2013, at D6 (describing the case of an acutely ill patient who was deemed "terminal" and thus denied ICU care and, arguing that ICU care would have been appropriate for this patient: "What are health care dollars, really, but bitcoins to feed time's meter till mind, brain and body are all in the same place?").

reduced risk of physician malpractice liability, the primary focus of this paper is on a different but related measure of quality of care at the end of life: whether the care that a patient receives comports with his or her preferences and goals for care.<sup>50</sup> On this measure, “good medical care” can include the entire range of options from minimal treatment and emphasis on comfort care to providing all life-prolonging care in cases where the patient’s goal is maximal life-extension. The autonomy principle that undergirds end of life decisions protects each individual patient’s goals of care, whatever they may be.<sup>51</sup> In order to evaluate whether quality of care is consistent with that principle, we must focus on the patient’s level of understanding about the medical interventions he or she accepts (or rejects) rather than the medical outcomes of those decisions.

The law of informed consent, as explained in the next part of this paper, provides some protection for patients in this regard. It requires that patients receive information about risks, benefits, and alternatives to treatment and that health care providers and institutions document that consent.<sup>52</sup> Informed consent alone should not, however, constitute the ultimate goal for this measure of quality of care. As other

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50. See Jaime S. King et al., *Toward the ‘Tipping Point’: Decision Aids and Informed Patient Choice*, 26 HEALTH AFFAIRS 716, 716 (2007) (distinguishing between “effective” treatments and “preference-sensitive” treatments for which the best choice is measured according to how patients rate benefits versus harms).

51. Physicians and health care institutions of course retain the right and responsibility not to provide medically futile care—care that cannot as a scientific matter reasonably achieve the medical goals sought. Futility questions arise in two categories—questions of subjective value of the proposed medical intervention and questions about the probability of whether the medical intervention will be successful. See Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561 (1992). When it is clear that a proposed medical intervention simply will not accomplish its intended goal, physicians have no ethical or legal obligation to provide this care. Commentators now recommend that the term futile should be replaced with “potentially inappropriate” to refer to medical care that has some chance of clinical success but that, for ethical reasons, clinicians feel should not be provided. See Gabriel T. Bosslet et al., *An Official ATS/AACN/ACCP/ESICM/SCCM Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units*, 191 AM. J. RESPIRATORY & CRITICAL CARE MED. 1318, 1319 (2015).

52. See *infra* notes 53 to 90 and accompanying text.

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commentators have observed, informed consent law fails to guarantee that patients actually comprehend their end-of-life care options. To increase the chances that patients will be able to give (or withhold) truly informed consent to life-prolonging therapies and technologies, physicians, bioethicists, and others have promoted the practice of *shared decision making* and the use of *decision aids*, among other methods. In the next parts of the paper, we will comment on these techniques in the context of how doctors and patients interact with each other and within our health care system.

As we will explain in the last section of the paper, informed consent law, shared decision making, and decision aids can help to improve the quality of end-of-life decisions by any measure, but they do not guarantee the *authenticity* of end-of-life choices.<sup>53</sup> Authenticity is an ideal that goes beyond informed consent. Authentic end-of-life choices are not just informed in the sense of being based on accurate understanding of risks and benefits of treatment; they also reflect the individual's willingness to acknowledge his or her approaching death and to consider treatment and life-prolonging measures in the broader context of his or her life and values. In this respect, authentic decision making most fully promotes the ethical value of individual autonomy at the time in life when it matters most.

## II. End of Life Decision Making: The Limits of Informed Consent

This section will provide a brief overview of end-of-life law in the United States, beginning with some background on patient decision making, surrogate decision making, and the ethical values of autonomy and best interests. It will then

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53. See, e.g., Insoo Hyun, *Waiver of Informed Consent, Cultural Sensitivity, and the Problem of Unjust Families and Traditions*, 32 HASTINGS CTR. REP. 14, 15 (2002) (describing the role of authentic values in the ideal of personal autonomy and arguing that informed consent or the waiver of consent must rest on patient values that are "free of coercive formative influences."); see also Daniel Brudney, *Choosing for Another: Beyond Autonomy and Best Interests*, 39 HASTINGS CTR. REP. 31, 31-32 (2009) (describing authenticity as "the capacity to be a particular self, a distinctive individual . . .").

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describe the legal doctrine of informed consent and its limited effectiveness in achieving its goals, due in part to patients' limited ability to understand and process complex and inherently incomplete medical information. Finally, the section will introduce the concept of shared decision making and the role of decision aids in promoting patient understanding and informed decisions about end-of-life care. These techniques can help to ameliorate, but cannot by themselves entirely solve, the problem of overutilization of care at the end of life.

A. *Patient and Surrogate Decision Making*<sup>54</sup>

In the United States, according to both law and ethical principles, medical care should accord with the individual patient's wishes. *Patient autonomy* (also sometimes referred to as the principle of self-determination), as implemented in law via the doctrines of informed consent and substituted judgment, is the primary principle that governs medical decisions, including those made on behalf of patients who have lost decisional capacity.<sup>55</sup> In ideal circumstances, patients can express their preferences directly to their physicians at the appropriate time. When a patient retains decisional capacity, the patient's choice may be irrational, unreasonable, or unwise, but the doctrine of autonomy, with limited exceptions, protects these choices. If, however, the patient has lost decisional capacity, physicians must attempt to ascertain the patient's

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54. Much of this background discussion on U.S. end of life law is derived from Barbara A. Noah, *A Better Death in Britain?*, 40 BROOK. J. INT'L L. 868, 870-915 (2015).

55. See Alan Meisel, *End-of-Life Care*, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS 51, 51-52 (Mary Crowley ed., 2008) ("Autonomy is paramount for patients who possess decision making capacity, but it is also a major consideration for patients who lack this capacity. Their wishes must be respected by the relatives or other health care proxies who make decisions on their behalf."). The American Medical Association (AMA) has acknowledged that patients have a right of self-determination that includes the right to refuse unwanted medical treatment, and that this right is not lost when a patient loses decisional capacity. See Council on Ethical and Judicial Affairs, AMA, *Decisions Near the End of Life*, 267 J. AM. MED. ASS'N 2229, 2229-33 (1992).

preferences through a process known as substituted judgment, using information from advance directives, conversations with family members or proxy decision makers, and the context of the patient's values to guide patient care. Under this approach of patient-directed care supplemented with substituted judgment, the goal is to preserve the patient's autonomy even when he or she can no longer articulate a preference.

For patients who lose decisional capacity, an autonomy-based model of medical decision making does not work well unless the patients were previously willing to discuss their preferences in advance and, ideally, to document them in some form of advance directive. Unfortunately, this does not happen as often as it should. A recent survey conducted in California indicated that, while 80 percent of those surveyed believed that it was important to record their end-of-life wishes in an advance directive, less than a quarter of them had actually done so.<sup>56</sup> Only 42 percent of those surveyed indicated that they had talked with a loved one about their end-of-life wishes, and only seven percent had discussed their wishes with their physicians.<sup>57</sup> More recent sources indicate similarly low rates of advance directive completion.<sup>58</sup>

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56. See CALIFORNIA HEALTHCARE FOUNDATION, FINAL CHAPTER: CALIFORNIANS' ATTITUDES AND EXPERIENCES WITH DEATH AND DYING (Feb. 2012), <http://www.chcf.org/~media/MEDIA%20LIBRARY%20Files/PDF/PDF%20F/PDF%20FinalChapterDeathDying.pdf> (surveying 1700 adults in California).

57. See *id.*

58. See U.S. GOV'T ACCOUNTABILITY OFF., GAO-95-135, PATIENT SELF-DETERMINATION ACT: PROVIDERS OFFER INFO. ON ADVANCE DIRECTIVES BUT EFFECTIVENESS UNCERTAIN 2 (1995) (concluding that "advance directives have been advocated more than they have been used" and that "in general, only 10 to 25 percent of Americans have documented their end-of-life choices or appointed a health care agent"); 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 having living wills and that studies also suggest that living wills rarely influence the level of medical care—in fact at least a quarter of patients with living wills receive care that is inconsistent with their instructions). The most recent data suggest a slight uptick in the percentage of Americans who have completed advance directives. See Jaya K. Rao et al., *Completion of Advance Directives Among U.S. Consumers*, 46 AM. J. PREV. MED. 65, 65-67 (2014) (finding, based on survey data from 2009-2010, that 26.3% of respondents had completed an advance directive and that older age, higher income, and higher educational attainment were correlated with a higher likelihood of having an advance



The law governing medical treatment and decision making, including end-of-life decision making, is mostly left to the states.<sup>59</sup> Each of the 50 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>60</sup> Thus, while all 50 states have incorporated the autonomy principle into their individual laws by acknowledging the authority of advance directives and formally appointed health care proxies,<sup>61</sup> 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 or withhold some types of care.<sup>62</sup>

directive).

59. 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., GAO-95-135, PATIENT SELF-DETERMINATION ACT: PROVIDERS OFFER INFO. ON ADVANCE DIRECTIVES BUT EFFECTIVENESS UNCERTAIN 1 (1995); see also Fagerlin & Schneider, *supra* note 58, at 30, 32 (commenting on the empirical studies that demonstrate the PSDA's lack of effectiveness).

60. For more detailed discussion on the United States end of life law, see generally ALAN MEISEL & KATHY L. CERMINARA, THE RIGHT TO DIE: THE LAW OF END-OF-LIFE DECISIONMAKING (3d., Aspen Publishers 2004); Noah, *supra* note 2, 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).

61. See Alan Meisel, *End-of-Life Care*, in FROM BIRTH TO DEATH AND BENCH TO CLINIC: THE HASTINGS CENTER BIOETHICS BRIEFING BOOK FOR JOURNALISTS, POLICYMAKERS, AND CAMPAIGNS 51, 51-52 (Mary Crowley ed., 2008).

62. See Stephen Arons, *Current Legal Issues in End-of-Life Care in LIVING WITH DYING: A HANDBOOK FOR END-OF-LIFE HEALTHCARE PRACTITIONERS* 730, 733-36 (Phyllis R. Silverman & Joan Berzoff eds., 2004) (explaining, for example, that some state statutes restrict which treatments one 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 health care providers to refuse to carry out patient wishes, for reasons of conscience or for no reason at all. See *id.* at 730, 734. Many of the state statutes that restrict the use of advance directives to particular types of medical situations potentially raise constitutional questions and might be challenged on this basis.

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Despite this heavy emphasis on the principle of autonomy, American law also includes references to, and consideration of, the principle of the patient's best interests. In some cases, an analysis based on the patient's best interests can lead to the rejection of life-prolonging treatment that might otherwise be continued, on the basis that the treatment in question does not confer a benefit to the patient by improving quality of life. Many states' laws already acknowledge a place for best interests analysis in making treatment decisions for incapacitated patients.<sup>63</sup> For example, courts have recognized the concept of "proportionate treatment," and have suggested that "a treatment course which is only minimally painful or intrusive may nonetheless be considered disproportionate to the potential benefits if the prognosis is virtually hopeless for any significant improvement in condition."<sup>64</sup> In one New York decision, the court refused to authorize life-prolonging treatment for an incapacitated adult who had suffered several strokes and had very little cognitive ability, 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>65</sup> And in a well-regarded New Jersey decision, the New Jersey Supreme Court envisioned a sliding

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63. For example, New York permits an appointed health care agent to make a decision, in the absence of information about the patient's wishes, to withdraw care in accordance with the patient's best interests, but it contains an express exception for artificial nutrition and hydration. Only if the patient has specifically spoken on this matter may the health care agent request the withdrawal of this type of life-sustaining medical technology. See N.Y. PUB. HEALTH LAW art. 29-C § 2982(4) (McKinney 2014). State law in Massachusetts instructs health care 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 health care providers, and after full consideration of acceptable medical alternatives regarding diagnosis, prognosis, treatments and their side effects, the agent shall make health care 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.").

64. *Barber v. Superior Ct.*, 195 Cal. Rptr. 484, 491 (Ct. App. 1983) (permitting withdrawal of treatment from a comatose patient).

65. *In re Beth Israel Med. Ctr. for Weinstein*, 519 N.Y.S.2d 511, 513-14, 18 (Super. Ct. 1987).

scale from pure autonomy-based decision making to pure best interests-based decision making, depending on the quality and quantity of available evidence of the patient's wishes.<sup>66</sup>

Often, however, when a patient loses decisional capacity, insufficient evidence of the patient's wishes 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 and the possibility of some recovery of function in the case of severe brain injury add to the complexity of decisions about withdrawing treatment or life-supportive measures. Occasional references to best interests analysis aside, American law generally favors continued life supportive measures when the patient's wishes are in dispute or unknown. As the *Schiavo* litigation and other cases of its type illustrate, many individuals, with the backing of courts, take the position that end-of-life laws should default to continued treatment whenever a patient's choice or best interests are in dispute, without regard to any assessment of the patient's quality of life.<sup>67</sup>

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66. *In re Conroy*, 486 A.2d 1209, 1232-33 (N.J. 1985) (explaining that under a "limited-objective test," life-sustaining treatments may be withdrawn or withheld when there is some reliable evidence that the patient would wish it and when it is clear that the burdens of continued life with treatment outweigh the benefits and that under a "pure-objective test," treatment similarly may be withdrawn or withheld in cases where the "net burdens of the patient's life with the treatment . . . clearly and markedly outweigh the benefits that the patient derives from life" even where there is no evidence of the patient's preferences).

67. *See, e.g.*, *Cruzan v. Dir., Missouri Dep't. of Health*, 497 U.S. 261, 281 (1990) ("[A] state may properly decline to make judgments about the 'quality' of life that a particular person may enjoy and simply assert an unqualified interest in the preservation of human life to be weighed against the constitutionally protected interests of the individual."); *Conservatorship of Wendland*, 28 P.3d 151, 174 (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 Wanglie*, No. PX-91-283 (Prob. Ct. Hennepin Co., Minn., June 28, 1991) (upholding the surrogate's request for continued treatment of the patient, who was in a persistent vegetative state and who died more than a year later of sepsis).

*B. Informed Consent Law and Its Role in End-of-Life Decisions*

Ideally, patients' decisions would always reflect the principle of autonomy because they are governed by the law of informed consent. Informed consent is ethically and legally required for all medical procedures and treatment relationships. As explained in the Nuremberg Code, ethically valid consent requires adequate information, freedom of choice, and the capacity to make the decision in question.<sup>68</sup> As to the information disclosed, in general, informed consent requires a discussion of the risks,<sup>69</sup> benefits, and alternatives to the proposed medical intervention, including the option of doing nothing, or withholding or withdrawing care.<sup>70</sup> The protection of the autonomy principle that informed consent law provides

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68. See *The Nuremberg Code*, HHS (Nov. 7, 2005), <http://www.hhs.gov/ohrp/archive/nurcode.html> (describing "voluntary consent" as meaning that "that the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved, as to enable him to make an understanding and enlightened decision."). For a careful analysis of decisional capacity and its elements see Eike-Henner W. Kluge, *Competence, Capacity, and Informed Consent: Beyond the Cognitive-Competence Model*, 24 CAN. J. ON AGING 295, 297 (2005) (distinguishing between competence and capacity in the context of informed consent and suggesting that valid consent requires more than simply the cognitive ability to process the relevant information); see also Paul S. Appelbaum, *Assessment of Patients' Competence to Consent to Treatment*, 357 NEW ENG. J. MED. 1834, 1834-35 (2007) (describing the requirement of decisional capacity (or competence) for valid informed consent to treatment).

69. As commentators on medical consent have explained, "The magnitude of the risks and their frequency should receive special emphasis. Also considered are alternative treatments and their benefits, risks, and measured utility, the likely results of no treatment; and the probability of a good outcome with the proposed strategy." See Timothy J. Paterick et al., *Medical Informed Consent: General Considerations for Physicians*, 83 MAYO CLINIC PROC. 313, 316 (2008).

70. See generally BARRY R. FURROW ET AL., HEALTH LAW § 3-11 (3d ed. 2015) (explaining that factors to be disclosed include diagnosis, nature and purpose of treatment, risks of treatment and, in some circumstances comparative data on the treating physician's skills, alternatives to the proposed treatment, prognosis with and without the treatment, and conflicts of interest).

is, however, only as good as the quality and accuracy of the information on which the consent is based and the individual decision maker's ability to comprehend and process that information. The scope of required disclosure varies by jurisdiction, but typically follows one of two models, with states about evenly divided between the two.<sup>71</sup> In states that have adopted the *professional* standard of disclosure, physicians must disclose all information that a reasonable physician would disclose under the circumstances.<sup>72</sup> In jurisdictions that follow the *patient-oriented* standard, the physician must disclose what a reasonable patient would want to know under the circumstances.<sup>73</sup>

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71. See BARRY R. FURROW ET AL., LAW AND HEALTH CARE QUALITY, PATIENT SAFETY, AND MEDICAL LIABILITY 195 (7th ed. 2013).

72. See, e.g., Tashman v. Gibbs, 556 S.E.2d 772, 777 (Va. 2002) (explaining that “[a] physician has a duty in the exercise of ordinary care to inform a patient of the dangers of, possible negative consequences of, and alternatives to a proposed medical treatment or procedure. To recover against a physician for failure to provide such information, the patient generally is required to establish by expert testimony whether and to what extent any information should have been disclosed.”); see also FURROW ET AL., *supra* note 70, at § 3-10(a) (describing the physician-based standard of disclosure).

73. See, e.g., Canterbury v. Spence, 464 F.2d 772, 787 (D.C. Cir. 1972); Cobbs v. Grant, 502 P.2d 1 (Cal. 1972); see also FURROW ET AL., *supra* note 70, at § 3-10(b) (describing the reasonable patient standard of disclosure). As the *Canterbury* opinion explains, disclosure should include a number of elements:

The cases demonstrate that the physician is under an obligation to communicate specific information to the patient when the exigencies of reasonable care call for it. Due care may require a physician perceiving symptoms of bodily abnormality to alert the patient to the condition. It may call upon the physician confronting an ailment that does not respond to his ministrations to inform the patient thereof. It may command the physician to instruct the patient as to any limitations to be presently observed for his own welfare, and as to any precautionary therapy he should seek in the future. It may oblige the physician to advise the patient of the need for or desirability of any alternative treatment promising greater benefit than that being pursued. Just as plainly, due care normally demands that the physician warn the patient of any risks to his well-being which contemplated therapy may involve.

*Canterbury*, 464 F.2d at 789. Although the two standards have varying effects on the plaintiff's burden of proof, these effects are not relevant for purposes of this discussion. It is also worth noting that documentation of

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When a patient is asked to make an informed decision to consent to, say, a surgical procedure to remove his gall bladder, the physician will describe the purpose of the surgery, its risks and benefits, and alternatives to the procedure, if any, and the patient then will sign a consent form indicating a willingness to undergo the surgery. In the context of decisions about whether to provide life-prolonging care to a dying patient, however, the consent process becomes more complicated. When a dying patient has not expressed any preferences about life-prolonging technology and has lost decisional capacity, the decision defaults to a proxy or family member who may, for various reasons, hesitate to refuse proffered life-prolonging care.<sup>74</sup> In these cases, the proxy or surrogate decision maker may agree to, for example, intubation or artificial nutrition and hydration, and may sign a consent form after receiving information about the purpose, risks, and benefits of these interventions—not because the surrogate believes that this is what the patient would want, but rather because feelings of grief, guilt, or other emotions make it more difficult to refuse life-prolonging treatment on behalf of a loved one than to consent to it. The surrogate thus provides legally valid consent, but based on a potentially misplaced understanding of what is in the patient's best interests rather than on what the patient, if able, would choose.<sup>75</sup> Thus, the operation of the usual consent process

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informed consent via the patient's or surrogate's signature on a form simply memorializes the prior consent discussion between physician and patient—the signed form itself does not constitute “informed consent.” *Id.* at 780 n. 15.

74. It is important to note that the role of surrogate and proxy decision makers is not limited to making decisions for dying patients. Proxies and surrogates are asked to make medical decisions in any context (including non-terminal situations) in which the patient has lost decisional capacity.

75. There are also good arguments for considering the potential motivations of legally appointed health care proxies differently from the motivations of surrogates who assume the role because they are the first available person in the hierarchy of decision-making. In the case of proxies who have been duly appointed by the now-incapacitated patient, there is arguably more cause for confidence that the proxy will decide based on the patient's wishes, particularly if the patient has instructed the proxy as to his wishes. The very fact of the appointment suggests that the patient has placed his trust in the proxy. In contrast, we might be less inclined to trust the instructions of a person who serves as a surrogate based on a state statutory hierarchy of surrogate decision-making to reflect a decision based on the patient's choice rather than on the surrogate's assessment of the patient's best interests. In any event, recent evidence suggests that, even

means that, for patients who do not clearly opt *out* of life-prolonging treatment before losing decisional capacity, the path of least resistance can lead to decisions in favor of initiating or continuing life-prolonging care. As explained above, courts have endorsed this default path by ruling in favor of continuing life-prolonging care in cases of uncertainty about the patient's preference.<sup>76</sup> Physicians can, of course, simply decline to discuss and proffer life-prolonging options for dying patients where they think it clinically inappropriate, but, as the discussion in Part I illustrates, the current reality of end-of-life care makes this challenging.

The law sends conflicting signals to physicians regarding the management of patient care at the end of life. On the one hand, physicians *do* have an ethical and legal obligation to avoid providing treatments that are harmful to patients or are inconsistent with their wishes. Courts have recognized this obligation and have awarded damages against physicians and institutions for providing treatment contrary to patients' wishes.<sup>77</sup> Conversely, many state statutes insulate physicians from liability for patient deaths that result from withdrawal of life-sustaining treatment as requested by a patient's advance directive.<sup>78</sup> On the other hand, despite this apparent protection

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when patients appoint a health care proxy, there is little change in the utilization of end-of-life treatment. See Amol K. Narang et al., *Trends in Advance Care Planning in Patients With Cancer: Results from a National Longitudinal Survey*, 1 J. AM. MED. ASS'N E5-E6 (2015) (finding that assignment of proxies or durable powers of attorney for health care was not associated with decisions to limit aggressive care at the end of life).

76. See *supra* note 35 and accompanying text.

77. See, e.g., *Estate of Leach v. Shapiro*, 469 N.E.2d 1047 (Ohio Ct. App. 1984) (recognizing a civil cause of action for wrongful continuation of life supportive measures); *but see Anderson v. St. Francis-St. George Hosp., Inc.*, 671 N.E.2d 225 (Ohio 1996) (rejecting a "wrongful living" claim based on hospital's resuscitation of patient after he had requested a succeeded in having a "no code blue" order placed in his chart and holding that "continued living" is not a compensable injury); see also *Allore v. Flower Hosp.*, 699 N.E.2d 560 (Ohio Ct. App. 1997) (refusing to recognize a battery claim for intubation and ventilation of a dying patient contrary to his advance directive and the statements of his health care proxy and citing *Anderson* with approval and critiquing the court's decision in *Leach*).

78. See, e.g., FLA. STAT. § 765.109 (2015) ("A health care facility, provider, or other person who acts under the direction of a health care facility or provider is not subject to criminal prosecution or civil liability, and will not be deemed to have engaged in unprofessional conduct, as a result of carrying

of patient autonomy when the patient has expressed a preference, many states have enacted conscience clause legislation, which allows a physician to transfer the care of a patient when compliance with that person's advance directive would conflict with the physician's conscience.<sup>79</sup> In addition, case law suggests that many states adopt a position of erring on the side of continued treatment in cases of uncertainty or disagreement about the patient's choice.<sup>80</sup>

This state of affairs which, as we have seen, often results in overutilization of care at the end of life, may seem to follow from the autonomy principle, but in fact it results from a stunted or overly mechanistic view of the physician's role in guiding end-of-life decision making. Physicians are rarely called upon to make the actual decision about whether to withdraw life-sustaining medical treatment, and even if the patient or surrogate requests that the physician decide, the physician has an ethical obligation to do so based on an understanding of the particular patient's values and goals of

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out a health care decision made in accordance with the provisions of this chapter."); N.H. REV. STAT. ANN. § 137-J:12(II)(a) (2015) ("No health care provider . . . shall be subjected to civil or criminal liability or be deemed to have engaged in unprofessional conduct for . . . [a]ny act or intentional failure to act, if . . . done pursuant to the dictates of an advance directive . . .").

79. See A.B.A. *Myths and Facts About Health Care Advance Directives*, [http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths\\_fact\\_act\\_hc\\_ad.authcheckdam.pdf](http://www.americanbar.org/content/dam/aba/migrated/Commissions/myths_fact_act_hc_ad.authcheckdam.pdf) (last visited March 28, 2016); N.H. REV. STAT. ANN. § 137-J:7(I)(D) ("If a physician . . . because of his or her personal beliefs or conscience, is unable to comply with the terms of the advance directive or surrogate's decision, he or she shall immediately inform the qualified patient, the qualified patient's family, or the qualified patient's agent. The qualified patient, or the qualified patient's agent or family, may then request that the case be referred to another physician . . ."); see also FURROW ET AL., *supra* note 70, at § 16-21 (discussing statutory protections from liability for compliance with advance directives and statutory inclusion of conscience clauses). Nevertheless, some commentators have advocated for the legal enforcement of these documents. See generally Andrew J. Broder, *She Don't Want No Life Support: A Summary of Osgood and Other Developments in Michigan Since Martin*, 75 U. DET. MERCY L. REV. 595-605 (1998); NORMAN L. CANTOR, *ADVANCE DIRECTIVES AND THE PURSUIT OF DEATH WITH DIGNITY* 130-34 (Indiana University Press 1993); Adam A. Milani, *Better Off Dead than Disabled?: Should Courts Recognize a "Wrongful Living" Cause of Action When Doctors Fail to Honor Patients' Advance Directives?*, 54 WASH. & LEE L. REV. 149 (1997).

80. See *supra* note 67 and accompanying text.



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care.<sup>81</sup> Physicians instead usually are asked to implement decisions made by patients (directly or via advance directives) or their proxies. Because the autonomy principle focuses on the patient's preferences, the physician can, if he or she chooses, avoid the more complex discussion of whether continuing treatment serves the patient's best interests as a medical matter, even if the patient consents to that treatment. As commentators have observed:

Responsibility for medical care has landed on the shoulders of patients with a resounding thud. Patients have the choice of telling physicians what to do in relation to health care decisions. The tone of medical practice has shifted from paternalistic to consultative, in which the physician lays the possibilities before the patient, with the potential pluses and minuses of each, and the patient makes a choice.<sup>82</sup>

Under most circumstances, if a patient or surrogate requests continued treatment or life-prolonging interventions, the physician can simply acquiesce (assuming the requested intervention is not futile as a scientific matter). But where the requested intervention is arguably not in the patient's best interests, mere acquiescence debases the physician's role. Because the physician is responsible for the patient's well-being, the physician has an ethical and legal obligation to help the patient or surrogate decision maker understand the risks, potential outcomes, and alternatives associated with the requested intervention, not just its purpose. In some

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81. For an interesting case study of a situation in which the patient delegated the decision about whether to have CABG surgery to his physician, see Alan W. Cross & Larry R. Churchill, *Ethical and Cultural Dimensions of Informed Consent: A Case Study and Analysis*, 96 ANNALS INTERNAL MED. 110, 110-12 (1982) (explaining that in this "paternalism with permission" situation, consent is not invalidated but rather requires the physician to "gain as complete an understanding as possible for the patient's values, culture, and life-style . . . [to] appreciate the larger significance for the treatment choice for the patient.").

82. See Paterick et al., *supra* note 69, at 318 (adding that "[w]hen it comes to medical treatment, patients see choice as a burden and a blessing.").

circumstances physicians, while acknowledging that the decision remains the patient's, will have an ethical obligation to opine as to what is in the patient's best medical interests and to discuss this opinion in the context of the patient's expressed wishes.<sup>83</sup> Ideally, the goal is to help the patient or surrogate make a decision that is consistent with the patient's goals of care as well as the patient's broader values, preferences, and beliefs, so that the decision is truly informed, as both the law and the ethical principle of autonomy require.

This is no easy task. To start, these discussions often occur at the point of decision rather than in advance, leaving little time for reflection. The presence of relatives may heighten emotions or tensions, particularly if the relatives disagree with the patient's or surrogate's choices. In addition to being emotionally challenging, decisions about whether and when to cease curative care and whether to begin or to withdraw life-prolonging technology are inherently complex as a scientific matter. Physicians and patients want to make the "best" choices about medical care for terminal illness but obviously lack the omniscience needed to calculate future possibilities without error. The ability of physicians and patients to make rational calculations about the comparative desirability of various options is limited not only by the imperfections of predictive data on therapeutic response, adverse effects, and prognosis, among other things, but also by their limited abilities to process the available information rationally.<sup>84</sup> Although it is impossible to eliminate uncertainty about treatment decisions, physicians can provide more guidance and more accurate information about the relative merits of various options for individual patients than they

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83. The ethical principle of beneficence, which operates alongside the primary principle of autonomy, requires that physicians which requires that physicians provide that care which is in their patients' best medical interests. See JOHN C. FLETCHER ET AL., *INTRODUCTION TO CLINICAL ETHICS* 12 (2d ed. 1997) (describing beneficence as the "obligation to benefit patients . . . and to further their welfare and interests").

84. Cf. Herbert A. Simon, *A Behavioral Model of Rational Choice*, 69 Q. J. ECON. 99-118 (1955) (describing the limitations of individuals to process information due to limited data and limitations of intellectual calculative abilities as "bounded rationality"); see generally JEROME GROOPMAN, *HOW DOCTORS THINK* (Houghton Mifflin Comp. 2007) (discussing clinical uncertainty in diagnosis and treatment recommendations).

typically do now. And, as explained above, what constitutes “best” for a patient will vary depending on whether the patient evaluates quality based on the likely effectiveness of the care in achieving its medical goals or on how the care comports with the patient’s own values.

It is important to avoid shortcuts in these conversations. For example, statistical life expectancy values based on past experience with similar populations provide a snapshot of population trends, but it is difficult to assess their relevance to any particular patient’s situation. There is often no way to predict whether a particular patient will, on the one hand, outlive the statistical projection for life expectancy or, on the other hand, die much sooner than the average.<sup>85</sup> Similarly, prognosis for meaningful recovery in many medical circumstances, such as for stroke patients, requires a discussion between physician and patient of complex variables such as the likelihood that the patient will regain various degrees of physical function.<sup>86</sup>

And these conversations are not simply about prognosis. Physicians also must recognize that patients frequently fail to understand the likely curative value of certain invasive treatments, either because this information is not included in the discussion or because it is impossible to predict with any

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85. See George A. Diamond, *Future Imperfect: The Limitations of Clinical Prediction Models and the Limits of Clinical Prediction*, 14 J. AM. COLL. OF CARDIOLOGY A12, A12-22 (1989) (describing different ways in which statistical regressive models to predict clinical outcomes can go awry). Courts also have recognized the limitations of statistical prognoses in the context of defining boundaries of informed consent. See, e.g., *Arato v. Avedon*, 858 P.2d 598 (Cal. 1993) (“[S]tatistical life expectancy data had little predictive value when applied to a particular patient with individualized symptoms, medical history, character traits, and other variables.”).

86. A meta-analysis of data from multiple studies on the recovery of stroke patients who were receiving mechanical ventilation found that prognosis was generally poor, with 58% of these patients dying within 30 days, but that a minority of patients survived without severe disability. See Robert G. Holloway et al., *Prognosis and Decision Making in Severe Stroke*, 294 J. AM. MED. ASS’N 725, 727-28 & tbl. 1 (2005). The authors of this study caution that physicians can be unrealistically optimistic or pessimistic in various circumstances and that physicians should think carefully about how they convey prognostic evidence. See *id.* at 729 & tbl. 3 (offering the example of a surgical intervention giving a person “a 50% chance at a better outcome” versus that same intervention increasing the person’s chance “of improved outcome from 5% to 7.5%”).

accuracy the effects of the treatment on a particular patient. With respect to chemotherapy for metastatic cancer, one study found that 69% of patients with lung cancer and 81% of patients with colorectal cancer mistakenly believed that the chemotherapy they were receiving was likely to cure their disease.<sup>87</sup> The problem with this unrealistic expectation of cure is that patients will be more likely to consent to treatment that, while it may palliate symptoms or even extend life, is also likely to cause significant toxic effects that will impair quality of life. Patients who understand that chemotherapy under these circumstances cannot cure their illness and will at best have a palliative effect on it may weigh the value of this treatment differently and may be more likely to decline it. The conversation between physician and patient that is needed to evaluate the patient's level of understanding in these circumstances is likely to be as challenging as any conversation about poor prognosis.

Simply presenting patients with statistics about likely prognoses and side effects of various treatment options is a poor substitute for the broader responsibility to the patient to discuss the reality of the patient's particular situation (as far as it can be known) and the available options. The challenge for physicians is to present information that will allow patients and families to make informed decisions and to guide those decisions with the physician's expert judgment about the best course of action without overwhelming patients with unwanted or confusing data.<sup>88</sup> Of course, some physicians will resist such conversations, either because of their personal moral or religious views or because they find this sort of communication too difficult.

In sum, the process and substance that constitutes

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87. See Jane C. Weeks et al., *Patients' Expectations About Effects of Chemotherapy for Advanced Cancer*, 367 NEW ENG. J. MED. 1616, 1619 (2012) (noting that, "[p]aradoxically, patients who reported higher scores for physician communication were also at higher risk for inaccurate expectations" regarding the curative potential of chemotherapy).

88. See C. Alifrangis et al., *The Experiences of Cancer Patients*, 104 Q. J. MED. 1075, 1079-80 (2011) (emphasizing the need for physicians to take the lead and ask what individual patients would like to know before providing detailed information about prognosis, efficacy of proposed therapy and related matters).

“informed consent” satisfies physicians’ and health care institutions’ legal obligations: If the patient receives comprehensible information about the relevant decision through an appropriate process and then makes a choice, the physician and institution are insulated from liability for providing (or withholding) continued therapy or life-prolonging medical treatment. But mere compliance with legal informed consent requirements does not ensure that patients’ end of life choices are *truly* informed; as a consequence, many patients continue to receive care in excess of what they would have chosen had they fully understood their options and more thoroughly considered, together with their physicians and family members, how those options comport with their values.

Two relatively recent developments in the clinical decision making process seek to address some of the limitations of relying solely on the mechanics of informed consent doctrine. The first is *shared decision making* (SDM).<sup>89</sup> The SDM model recognizes and respects patient autonomy while simultaneously acknowledging the physician’s responsibility for the patient’s well-being.<sup>90</sup> It represents an effort to include the patient more actively in the process of making complex medical choices, including choices about end-of-life care.<sup>91</sup> Rather than viewing informed consent as a rigid two-step process in which the physician provides information and the patient then makes a decision—a burdensome model for many

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89. See, e.g., Institute of Medicine, *Crossing the Quality Chasm: A New Health System for the 21st Century* (2001), <https://www.iom.edu/~media/Files/Report%20Files/2001/Crossing-the-Quality-Chasm/Quality%20Chasm%202001%20%20report%20brief.pdf> (advocating shared decision-making in the form of emphasis on the patient’s values and beliefs and encouraging the open exchange of information between physician and patient); see also Cathy Charles et al., *Shared Decision-Making in the Medical Encounter: What Does It Mean? (or It takes at Least Two to Tango)*, 44 SOC. SCI. MED. 681 (1997) (advocating improved clarity as to what is meant by the term “shared decision making”); Jaime Staples King & Benjamin Moulton, *Rethinking Informed Consent: The Case for Shared Medical Decision-Making*, 32 AM. J. L. & MED. 429 (2006).

90. Alan Meisel & Mark Kuczewski, *Legal and Ethical Myths About Informed Consent*, 156 ARCHIVES INTERNAL MED. 2521, 2522 (1996).

91. See Chuck Alston, et al., *Shared Decision-Making Strategies for Best Care: Patient Decision Aids* NAT’L ACAD. OF MED. (2014), <http://nam.edu/perspectives-2014-shared-decision-making-strategies-for-best-care-patient-decision-aids/>.

patients, as suggested above—SDM “does not restrict the physician to providing the facts and insist[] that the patient supply all the values. The physician and the patient each have access to interrelated facts and values.”<sup>92</sup>

As part of or in addition to SDM, *decision aids* can play an important role in helping patients comprehend complex medical information more easily.<sup>93</sup> Decision aids come in multiple forms, including videos and interactive computer programs.<sup>94</sup> Decision aids have been around for some time, but appear to be proliferating as information technology advances and becomes more widely accessible. They have multiple goals, including explaining patients’ options and the risks and benefits of various choices in accessible, jargon-free language, helping patients to articulate the goals or outcomes that are most important to them, and guiding patients through the steps to making choices consistent with their values.<sup>95</sup> Decision aids are particularly useful in assisting patients to make decisions about “preference-sensitive” medical care—care for medical situations in which multiple reasonable options exist<sup>96</sup> and the goal is to help patients make a choice that

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92. See Meisel & Kuczewski, *supra* note 90, at 2522; see also Michael J. Barry & Susan Edgman-Levitan, *Shared Decision Making—The Pinnacle of Patient-Centered Care*, 366 NEW ENG. J. MED. 780, 781 (2012) (explaining that, in shared decision making, “both parties share information: the clinician offers options and describes their risks and benefits, and the patient expresses his or her preferences and values. Each participant is thus armed with a better understanding of the relevant factors and shares responsibility in the decision about how to proceed.”).

93. See Annette M. O’Connor et al., *Toward the ‘Tipping Point’: Decision Aids and Informed Patient Choice*, 26 HEALTH AFFAIRS 716, 717-18 (2007); See also Jonathan Rauch, *How Not to Die*, THE ATLANTIC, May 2013, at 64-66 (profiling the efforts of Dr. Angelo Volandes, a professor at Harvard Medical School, who makes brief but graphic informational videos to educate patients about the rigors of interventions such as cardiopulmonary resuscitation and mechanical ventilation).

94. For a selection of decision aids, see *Decision Aids*, DARTMOUTH-HITCHCOCK, [http://www.dartmouth-hitchcock.org/medical-information/decision\\_aids.html](http://www.dartmouth-hitchcock.org/medical-information/decision_aids.html).

95. See O’Connor, *supra* note 93, at 717.

96. See Barry & Edgman-Levitan, *supra* note 92, at 780 (explaining that, for some medical conditions, “there is one clearly superior path, and patient preferences play little or no role . . . For most medical decisions, however, more than one reasonable path forward exists (including the option of doing nothing, when appropriate), and different paths entail different combinations . . . effects . . . . In such cases, patient involvement in decision making adds

comports with the patient's own ideas of benefits and harms.<sup>97</sup> For these reasons, decision aids appear well suited to assist patients and surrogates with complex end-of-life decisions.

Both SDM and decision aids can help advance end-of-life decision making beyond the bare requirements of informed consent law, reducing excess treatment and leading to care that more often comports with patients' truly informed wishes. Both SDM and decision aids add an extra dimension to the decision making process and, if used properly, require additional interaction between physician and patient. In this respect, both developments can improve on the unfortunately common practice of having only minimal discussions about end-of-life planning or avoiding those discussions altogether. In the next part of this paper, we pursue further how these techniques can contribute to improved physician-patient communication.

### III. Improving Communication Between Physicians and Patients

Informed consent is and will remain the legal standard for medical decision making, including decisions at the end of life. But the physician-patient relationship obviously consists of more than the delivery of tests and treatments with the patient's "informed consent." Unfortunately, physicians often lack training "in recognizing and accepting the process of dying, managing pain and other symptoms adequately, and attending to the emotional needs of the dying and their families."<sup>98</sup> Moving beyond this treatment-focused model to a

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substantial value."); Simon N. Whitney et al., *A Typology of Shared Decision Making, Informed Consent, and Simple Consent*, 140 ANNALS INTERNAL MED. 54, 55-56 (2004) (observing that shared decision making makes the most sense "only when real choice exists and the physician involves the patient in the decision" and suggesting categories of consent and decision making and zones of overlap between the two concepts).

97. See O'Connor et al., *supra* note 93, at 716; see also John E. Wennberg & Philip G. Peters, *Unwanted Variations in the Quality of Health Care: Can the Law Help Medicine Provide a Remedy/Remedies?*, 37 WAKE FOREST L. REV. 925, 930-35 (2002).

98. See James R. Patterson & Marion O. Hodges, *Letter to the Editor*, 338 NEW ENG. J. MED. 1389 (1998) (adding that "[i]t is sad that our care of the dying has lagged behind other forms of medical care, justifying the fear of

genuine relationship involving trust, truthfulness, and caring for the patient as a person (rather than as a diagnosis) requires that all parties be willing to talk openly about the dying process and to share the burden of making decisions in a context rife with ambivalence and emotion. Given the complexity of the information involved, informed consent in the end-of-life context should be an ongoing conversation that evolves as the situation progresses and gives the patient or surrogate an opportunity to discuss care preferences as the need arises. Although the current pattern of overutilization of care at the end of life suggests that these conversations happen less often and in less detail than they should, there are some ways to encourage this sort of SDM process between physicians and patients.

Before seeking informed consent for life-prolonging care, physicians must first consider whether the proposed care is potentially inappropriate or “futile.”<sup>99</sup> Subjective futility questions may lead to disagreement among health care providers and patients and families about the appropriate point to discontinue or withhold therapeutic or life-supportive interventions.<sup>100</sup> There is, however, unsettling evidence that physicians knowingly provide treatments that they conclusively believe to be futile for the patient.<sup>101</sup> At least in

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many persons that they will not be able to die with dignity and comfort. Our emphasis must be on providing the necessary training.”).

99. For more detailed discussion of futility questions, see generally Robert D. Truog et al., *The Problem with Futility*, 326 NEW ENG. J. MED. 1560, 1561 (1992); Robert D. Truog, *Medical Futility*, 25 GA. ST. U. L. REV. 985 (2009); Lawrence J. Schneiderman, *Defining Medical Futility and Improving Medical Care*, 8 J. BIOETHICAL INQUIRY 123, 123-31 (2011).

100. See *supra* notes 99 – 102 and accompanying text (discussing cases in which futility disputes required judicial resolution).

101. See Huynh, *supra* note 11, at E3-E6 (finding, in a survey of clinicians caring for critically ill patients, that while 80% of the patients were not thought to be receiving futile treatment, 8.6% were perceived as receiving probably futile treatment and 11% were thought to be receiving treatment that was definitely futile). Not only did the authors conclude that the costs of this probably or definitely futile care were substantial, they also acknowledged that “the burdens to patients, families, and clinicians also deserve attention.” *Id.* at E7. The term “futile” has been much criticized in recent years. Commentators now recommend using the term “potentially inappropriate care” or “inappropriate care” in order better to capture the idea of treatments that may have some chance of success but for which clinicians worry that “the treatment is highly unlikely to be successful, is extremely



these cases, the physician could choose to discuss the matter with the patient or surrogate decision maker in order to explain why the treatment is arguably medically inappropriate, rather than simply providing the treatment and avoiding the discussion and the possibility of conflict.<sup>102</sup> In the case of genuine disagreement over the appropriateness of a particular treatment, the physician is placed in an even more difficult situation.<sup>103</sup> Without guidance about an individual patient's beliefs regarding continued life-supportive measures, it is difficult to know when to cease providing support to a person whose condition will not improve.

Conversations about end-of-life care feature yet another layer of complexity. Although most patients want to know whether their disease is curable and, if not, how long they can expect to live,<sup>104</sup> the autonomy principle and the law of informed consent recognize the right of patients *not* to participate in their medical decisions.<sup>105</sup> While physicians have

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expensive, or is intended to achieve a goal of controversial value." See Bosslet et al., *supra* note 51, at 1319, 1322-33.

102. We do not address here the separate question of whether physicians should override patient and surrogate decisions in cases where the physician believes continued treatment to be futile but the patient or surrogate demands continued treatment. Other commentators have ably addressed these issues. See, e.g., Eric Gampel, *Does Professional Autonomy Protect Medical Futility Judgments?*, 20 *BIOETHICS* 92, 92-104 (2006). Instead, we focus on the question of what physicians can and should do in response to requests for medically inappropriate treatment.

103. For a detailed set of suggestions aimed at preventing and/or resolving treatment conflicts via "proactive communication," see Bosslet et al., *supra* note 51, at 1320-24 (recommending a series of steps to resolve disputes with surrogate decision makers including the use of experts in mediation and negotiation, seeking a second medical opinion, seeking review by a hospital ethics committee, offering the option of transferring the patient to another institution, and informing surrogates of the possibility of judicial review).

104. See, e.g., Alifrangis, *supra* note 88, at 1077-79 (concluding, based on survey data, that only 66% of patients in the U.K. wanted to be given a prognosis and 12% said that they would not want to be told that they had a short time to live); Rebecca C. Hagerty et al., *Communicating with Realism and Hope: Incurable Cancer Patients' Views on the Disclosure of Prognosis*, 23 *J. CLINICAL ONCOLOGY* 1278 (2005) (finding that 98% of Australian patients surveyed preferred to receive realistic information about prognosis); Belinda E. Kiely et al., *Thinking and Talking About Life Expectancy in Incurable Cancer*, 38 *SEMINARS IN ONCOLOGY* 380 (2011).

105. The U.S. law of informed consent and the ethical principle of self-determination on which it is based allow patients to reject information as

no ethical or legal obligation to *force* patients to engage in these discussions, this does not provide an excuse to sidestep the conversation altogether. In situations where the patient has not specifically declined to discuss his or her medical situation, the physician must be more proactive in initiating discussions about end of life care.

Better training in communication with patients and families can help physicians become more skilled in initiating and having these very challenging discussions. Institutional or organizational guidelines can help to promote best practices, including SDM. In addition, the use of decision aids can provide a basis for patients and physicians to discuss the advisability of particular interventions and can improve patients' comprehension of and active participation in complex medical decisions. The POLST paradigm, also described below, offers another promising framework for discussion between physicians and terminally ill patients. There are limitations to all of these interventions, but all can improve the quality of medical decision making, whether gauged objectively in terms of outcomes, or subjectively, in terms of patient preferences.

#### A. *Physician Training to Improve Communication*

Better physician training regarding communication about prognosis, treatment options, withdrawal and withholding of life-sustaining care, and palliative and hospice care is sorely needed.<sup>106</sup> In order to change the habits and practices of

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well as to receive it. *See, e.g.,* *Canterbury v. Spence*, 464 F.2d 772, 789 (D.C. Cir. 1972) (describing an exception to the rule of informed consent in circumstances where “risk-disclosure poses such a threat of detriment to the patient as to become unfeasible or contraindicated from a medical point of view”). This “therapeutic privilege” not to disclose certainly would provide support to a physician who chooses not to discuss prognosis and end of life choices with a patient who declines to have the discussion; *see also* Meisel & Kuczewski, *supra* note 90, at 2525 (“Withholding information from patients when they request that it not be given respects their autonomy as much as providing information to patients who want it . . . . Withholding information from patients at their request is a legally recognized exception to informed consent referred to as a waiver.”).

106. *See* Neil J. Farber et al., *Physicians' Decisions to Withhold and Withdraw Life-Sustaining Treatment*, 166 ARCHIVES INTERNAL MED. 560, 563 (2006) (noting that lack of training about the ethical and legal issues may

physicians, education should begin in medical school. Young physicians in training are frequently eager to discuss ethical challenges and are open to debate about best practices.<sup>107</sup> Identification and directed discussion of problems in end of life care during clinical training, along with instructors who model good communication with patients, can achieve incremental change. And, of course, continuing medical education that trains practicing physicians regarding best practices and the need for frank communication with patients and families about end-of-life choices can provide physicians with the tools to initiate and conduct these conversations under challenging circumstances.

For many physicians, these conversations feel daunting. A number of excellent publications suggest specific approaches to discussing end of life treatment, particularly topics such as ceasing active therapy, the transition to hospice, and withdrawing or withholding life-sustaining treatments.<sup>108</sup>

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lead to dissent among physicians when patients request that care be withheld or withdrawn).

107. We base this claim on one author's own multi-year experience as part of a team teaching "Ethical and Legal Issues in the Practice of Medicine" at a large medical school. The course was offered in the first semester of the second year and consisted of weekly one-hour lectures followed by one or more hours of small group discussion, led by faculty, centering around how to resolve a clinical ethics dispute in the context of law, ethics, and feasible medical options. The students in these small groups debated the issues avidly and often left the room continuing the discussion. They also were frequently incredulous about the law's limitations in dealing with complex ethical dilemmas in health care.

108. There is a wealth of literature that proposes and discusses such frameworks for these conversations. See, e.g., NANCY BERLINGER, ET AL., THE HASTINGS CENTER GUIDELINES FOR DECISIONS ON LIFE-SUSTAINING TREATMENT AND CARE NEAR THE END OF LIFE (2d ed. 2013); KATY BUTLER, KNOCKING ON HEAVEN'S DOOR: THE PATH TO A BETTER WAY OF DEATH (2013); Jim deMaine & Joi Murotani Dennett, *Communicating with Patients and Families About Difficult End of Life Decisions: A Guide for Medical Providers*, 36 HAMLINE L. REV. 299 (2013); R. M. Epstein et al., *Communicating Evidence for Participatory Decision Making*, 291 J. AM. MED. ASS'N 2359, 2362 (2004) (reviewing the literature to identify research that guides physicians in communicating with their patients about end of life choices and recommending five communication tasks to facilitate good discussion between physician and patient); Dale G. Larson & Daniel R. Tobin, *End-of-Life Conversations: Evolving Practice and Theory*, 284 J. AM. MED. ASS'N 1573, 1576-77 (2000) (urging that end of life conversations become a routine part of health care and that advance care planning function as a key aspect of these discussions); Quyen Ngo-Metzger et al., *End-of-Life Care: Guidelines for*

Many guidelines for end-of-life conversation recommend that physicians begin by asking the patient what he or she would like to know about the illness and prognosis.<sup>109</sup> For example, the American Society of Clinical Oncology has published a “best practices” model that recommends a series of conversations with patients with terminal cancer diagnoses, with content to reflect the patient’s evolving medical condition.<sup>110</sup> One large facility that implemented this best practices model found that it doubled the length of patient participation in hospice care and decreased total costs while maintaining survival rates.<sup>111</sup>

Curricula designed to teach physicians skills for conversation with patients also are available. The American Academy on Communication in Healthcare and the Association for Behavioral Sciences in Medical Education are among

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*Patient-Centered Communication*, 77 AM. FAM. PHYSICIAN 167 (2008); Timothy E. Quill, *Initiating End-of-Life Discussions With Seriously Ill Patients: Addressing the “Elephant in the Room”*, 284 J. AM. MED. ASS’N 2502, 2503-04 (2000) (providing a list of clinical indications for discussing end of life care, including imminent death, talk about wanting to die, inquiries about hospice, recent hospitalization for severe progressive illness, severe suffering, questions about prognosis, discussing treatment with low probability of success, discussing hopes and fears, and in cases where the physician would not be surprised if the patient died within 6-12 months).

109. For example, one commentator advises that physicians ask what the patient wants to know and then tell the truth in an understandable and clear way about the time that the patient may have left and what he or she can expect. See Thomas J. Smith & Dan L. Longo, *Talking with Patients About Dying*, 367 NEW ENG. J. MED. 1651 (2012). Another commentator proposed a five step sequential approach to communication with dying patients and their families, beginning with consent for an initial trial of treatment, and addressing topics such as treatment failure, stopping treatment, and requests for arguably futile treatment. See Stephen Workman, *A Communication Model for Encouraging Optimal Care at the End of Life for Hospitalized Patients*, 100 Q. J. MED. 791, 792-94 (2007).

110. See Thomas J. Smith et al., *American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care*, 20 J. CLINICAL ONCOLOGY 880, 880 (2012) (“While a survival benefit from early involvement of palliative care has not yet been demonstrated in other oncology settings, substantial evidence demonstrates that palliative care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include improvement in symptoms, QOL, and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care.”).

111. *Id.* at 881-82.

several organizations that have developed evidence-based clinical teaching exercises designed to improve the physician-patient encounter.<sup>112</sup> Physicians and medical students who complete these sorts of courses can learn to incorporate empathy and listening skills into their relationships with patients.<sup>113</sup> These efforts should also reach beyond physicians to other non-physician health care providers, as well as social workers and related professionals. Again, some of this is happening already, but making this type of training routine (or even mandating it for certain specialties) may help to accelerate change. And, if multiple members of a team or department incorporate these values into their interactions with patients and families, it will reinforce best practices and model them for any providers who remain reluctant.

“How to” articles, guidelines, and courses provide a useful tool for training, but still do not bridge the gap between theory and practice. Physicians still may hesitate to take the lead. Yet they have an ethical and clinical obligation to initiate these discussions, even though the ultimate decision making authority lies with the patient or surrogate decision maker. Physicians may worry that discussing these matters with patients will generate anxiety or may give the patient or family the idea that the physician is abandoning care of the patient,<sup>114</sup>

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112. See AM. ACAD. ON COMM’N IN HEALTHCARE, <http://www.aachonline.org> (last visited Mar. 28, 2016); ASS’N FOR THE BEHAVIORAL SCIS. & MED. ED., <http://www.absame.org/About-ABSAME> (last visited Mar. 28, 2016) (providing information and resources for medical school and continuing medical education curricula).

113. See Daniel F. Duffy, *Dialogue: The Core Clinical Skill*, 128 ANNALS INTERNAL MED. 139, 140 (1998) (discussing evidence suggesting that physician traits such as empathy and listening improve the patient treatment encounter).

114. Cf. Steven Z. Pantilat, *Communicating With Seriously Ill Patients: Better Words to Say*, 301 J. AM. MED. ASS’N 1279, 1279 (2009) (explaining that recent research on physician-patient communication emphasizes the value of a model that involves multiple conversations over time and that offers the prospect of continued care, even if active therapy to cure the disease no longer makes sense); Quill, *supra* note 108, at 2503 (“Timely, sensitive discussions with seriously ill patients regarding medical, psychosocial, and spiritual needs at the end of life are both an obligation of and privilege for every physician.”); Larson & Tobin, *supra* note 108, at 1575 (“[D]iscussing palliative care issues while disease-remitting treatments are continued without creating a perception of abandonment requires the utmost empathy and skill.”).

but they need to recognize the importance of these conversations and to proceed, gently. Recent studies demonstrate that surrogate decision makers also frequently experience stress and anxiety during and well after the process of making treatment decisions for a family member.<sup>115</sup> Some physicians have acknowledged this concern and are willing to take on this responsibility in appropriate situations.<sup>116</sup>

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115. See, e.g., Ellen Iverson et al., *Factors Affecting Stress Experienced by Surrogate Decision-Makers for Critically Ill Patients: Implications for Nursing Practice*, 30 INTENSIVE CRITICAL CARE NURSING 77, 77-85 (2014); D. Wendler & Anette Rid, *Systematic Review: The Effect on Surrogates of Making Treatment Decisions for Others*, 154 ANNALS INTERNAL. MED. 336, 336-46 (2011) (concluding that at least one-third of surrogate decision-makers experience lasting negative emotional symptoms from making health care decisions for a loved one).

116. See, e.g., Opinion, April R. Dworetz, *End of Life, At Birth*, N.Y. TIMES (Aug. 4, 2013), [http://www.nytimes.com/2013/08/05/opinion/end-of-life-at-birth.html?\\_r=0](http://www.nytimes.com/2013/08/05/opinion/end-of-life-at-birth.html?_r=0) (describing difficult decisions to cease treatment of extremely premature infants and arguing that “[u]ltimately, parents have the right to decide, but we physicians must help them make informed decisions” and adding that she occasionally offers to make the decision for the parents. “If they agree, they are essentially making the decision, but are shifting the burden to me. It’s harder for parents to say, ‘I unplugged my baby,’ than to let the doctor do it.”); Schneiderman, *supra* note 99, at 131 (describing a clinical case in which a dying patient’s family requested all life-supportive measures and the decision of the physicians to withdraw care from the patient after notifying the family and giving them an opportunity to transfer the patient or seek judicial intervention and observing that, after the patient died peacefully, the family “seemed relieved in the end that the physicians had assumed responsibility for this difficult decision”). Commentators also have argued persuasively that the costs of the autonomy-based system are too frequently ignored and should be considered in making end of life decisions in limited classes of cases. Alexander M. Smith, *Beyond Autonomy*, 14 J. CONTEMP. HEALTH L. & POL’Y 23, 25-27 (1997) (“[M]edical law . . . [embodies] in the form of legal rules, the prevailing rejection of paternalism and the widely-held belief that people should be allowed to determine the shape of their own lives . . . . What is perhaps less obvious, however, is just how autonomy has crowded out other values and how uncritically it is used.”); see also Harry R. Moody, *From Informed Consent to Negotiated Consent*, 28 GERONTOLOGIST 64, 64-65 (1988) (arguing that autonomy and paternalism are not, in fact, opposite concepts and suggesting that, in the context of long term care facility residents, it is ethically appropriate to use concepts of paternalism to enhance patient autonomy); Hilary Young, *Why Withdrawing Life-Sustaining Treatment Should Not Require “Rasouli Consent”*, 6 MCGILL J. L. & HEALTH 54-104 (2012) (“[W]hen consent is applied to create de facto entitlements to medical treatment, . . . interests other than those of the patient become relevant, such as physicians’ interest in not having to provide nonbeneficial treatment and the public interest in not having to fund treatment of little or no medical value. Yet the law of

Although physician concerns about patient and family anxiety are well-founded, these conversations are integral to helping patients and families make good choices about end-of-life care. Avoiding discussions about the patient's situation may in fact perpetuate anxiety by prolonging the process of accepting the illness and deciding about future care.<sup>117</sup>

In this regard, two commentators have proposed a concept of "informed *assent*" to reduce the burden on surrogate decision makers who must make choices about withholding or withdrawing life-sustaining treatment.<sup>118</sup> Research suggests that family members in these circumstances welcome physicians' explicit recommendations.<sup>119</sup> The authors describe informed assent as inviting the patient or family "to defer to the clinicians' judgment in favor of withholding or withdrawing life-sustaining therapy."<sup>120</sup> The idea behind informed assent is to convey to families as surrogate decision makers "the information that the clinicians are prepared to relieve them of unwanted burdens of making life-or-death decisions."<sup>121</sup> This proposal for a process of informed assent, while unlikely to be widely adopted, further emphasizes the importance of physicians' initiating and leading conversations that the patient and family may otherwise have little appetite to

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informed consent is exclusively patient-centered and does not allow these factors to be considered . . . ." and adding that, although she does not advocate that physicians have a unilateral right to withhold or withdraw treatment, future policy in this area should consider interests beyond patient autonomy-based entitlements to care.)

117. See Rachele E. Bernacki et al., *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, J. AM. MED. ASS'N, E1, E2 (Oct. 20, 2014).

118. See J. Randall Curtis & Robert A. Burt, *Point: The Ethics of Unilateral "Do Not Resuscitate" Orders: The Role of "Informed Assent"*, 132 CHEST 748, 748-50 (2007) [hereinafter Curtis & Burt, *The Role of "Informed Assent"*].

119. See Renee D. Stapleton et al., *Clinician Statements and Family Satisfaction with Family Conferences in the Intensive Care Unit*, 43 CRITICAL CARE MED. 1679, 1679-84 (2006).

120. See Curtis & Burt, *The Role of "Informed Assent"*, *supra* note 118, at 748 (arguing that informed assent is sometimes an appropriate, ethical alternative to informed consent).

121. See *id.* at 749 (providing also a discussion of three categories of withholding or withdrawing life-supportive measures and suggesting circumstances under which physicians could unilaterally decide not to offer particular types of care).

undertake.<sup>122</sup>

Policies to encourage quality care at the end of life should be specific enough to encourage timely discussions and informed decision making but sufficiently flexible to incorporate the preferences of individual patients. While some patients may prefer to remain in a state of ignorance, which is their right, there is surely another group of patients who will prefer the truth, and it is the physician's obligation in these cases to provide it. Determining in which group a particular patient places herself is simple—the physician need only ask, "What would you like to know about your prognoses and treatment options?" (Even this question may prove difficult to ask, however, because it posits that there *is* something to know, and therefore tips the physician's hand). Nevertheless, the onus is on the physician to initiate the conversation, even if the patient then chooses to end it.

The development and publication of guidelines for excellence in physician-patient communication may, by itself, fail to bring about widespread changes in physician practice for another set of reasons. In addition to an understandable reluctance to have difficult conversations with dying patients, many physicians still value the exercise of individual clinical judgment above compliance with even the best of guidelines,<sup>123</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>124</sup> There is also some suspicion that practice

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122. In any event, the idea of replacing informed consent with assent raises serious ethical concerns, since physicians' prognostication skills are necessarily imperfect and a patient's silence in response to a medical recommendation may not necessarily reflect comprehension of the recommendation, let alone agreement based on understanding. See Constantine A. Manthous, *Counterpoint: Is It Ethical to Order "Do Not Resuscitate" Without Patient Consent?*, 132 CHEST 751, 751-54 (2007) (rejecting as unethical the option of entering a DNR order for a patient without the patient's consent and suggesting that even informed assent risks arbitrary outcomes because it relies exclusively on the physician's non-omniscient judgment that CPR is medically inappropriate in a particular patient's case).

123. See Stefan Timmermans, *From Autonomy to Accountability: The Role of Clinical Practice Guidelines in Professional Power*, 48 PERSPECTS IN BIOLOGY & MED. 490, 494 (2005).

124. See Dimitri A. Christakis & Frederick P. Rivara, *Pediatricians'*



guidelines seek to reduce cost as much as to improve clinical practice,<sup>125</sup> a concern that, in the case of end-of-life care practices, could be fatal to the implementation of the guidelines if it provokes sufficient opposition from pro-life groups.

Ideally, health care providers, institutions, and policy analysts should reach consensus on how to approach the discussion of end-of-life issues, including an explicit statement of problems and goals, and an elaboration of clear, evidence-based standards for best practices. This would improve transparency and thus help allay at least some physicians' concerns about adopting best practices guidelines. The challenge is to implement these consensus-based practices consistently, beginning with the earliest steps of medical education, so that the culture of care at the end of life changes from one of denial and avoidance to one of open communication and cooperative decision making. The process will take time and consistent effort but may, eventually, reach a tipping point where timely and informative conversations will become the norm.

Recent developments promise improvement. For those patients who are willing and able to engage in advance care planning, there is evidence of real progress 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>126</sup> Unlike other advance directives that patients complete with attorneys or on their own, the POLST document

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*Awareness of and Attitudes About Four Clinical Practice Guidelines*, 101 PEDIATRICS 825, 825-830 (1998) (surveying pediatricians about their awareness of four pediatric practice guidelines and finding a range of awareness that varied from 16% to 64%).

125. See Timmermans, *supra* note 123, at 496 ("The 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.").

126. See Editorial, *Care at the End of Life*, N.Y. TIMES, Nov. 24, 2012, at SR10, <http://www.nytimes.com/2012/11/25/opinion/sunday/end-of-life-health-care.html> (noting that 15 states have enacted laws authorizing the use of POLST forms and nearly 30 other states are considering such legislation); see also POLST, <http://www.polst.org> (last visited Mar. 28, 2016) (providing detailed information about these forms, their legal status and implementation).

requires the participation of the treating physician, who reviews the various options with the patient, signs the form along with the patient, and includes it in the patient's medical chart. The POLST paradigm has spread rapidly in the last decade and is now in some stage of development or implementation in approximately 45 states.<sup>127</sup> In states that choose to mandate the utilization of POLST forms for seriously ill patients, the paradigm will have the effect of routinizing end-of-life discussions with patients and surrogates. While this process hardly guarantees the substance and quality of these discussions, it at least requires physicians to have the conversation.

Autonomy is meaningful only when it is exercised within a collaborative relationship between physician and patient, with the physician acting as an advisor as well as a source of information. Focused physician training to improve communication and encourage shared decision making will lead to improvement over the basic model of informed consent. SDM provides opportunities for the physician to evaluate the patient's understanding of his or her medical situation and encourages physicians to offer their own values (such as opinions about whether a particular medical technology is in the patient's best interests) rather than simply providing patients with information and asking for a decision. Shared decision making, when the patient and physician are willing and able to participate meaningfully, has the potential to ameliorate the problem of overutilization of care at the end of life. As such, this model of decision making should constitute an important part of medical training and practice.

#### B. *The Important Role of Decision Aids*

Decision aids appear to have a significant impact on patient decision making in many medical contexts and will no doubt continue to play an important role in improving communication between physicians and patients or

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127. See POLST, *supra* note 126. POLST received tremendous support from the Institute of Medicine in its 2014 report. See IOM, DYING IN AMERICA, *supra* note 2, at 17, 173-81

surrogates.<sup>128</sup> Videos have been used as patient decision aids since the 1990s in a variety of clinical settings, including treatment for ischemic heart disease<sup>129</sup> and PSA screening.<sup>130</sup> More recently, video decision aids have been proposed as a way to help patients and their surrogates make better-informed decisions regarding end of life care. These aids are a promising development that can improve the possibilities for truly informed decision making. To the extent that they deliberately or inadvertently manipulate the patient's perceptions of the best choice, however, they may disserve that goal.

A leading figure in the field is Dr. Angelo Volandes, an internal medicine physician at Massachusetts General Hospital and faculty member at the Harvard Medical School. Together with his colleagues (the VIDEO Consortium), Volandes has created video decision aids for advance care planning and conducted an extensive program of studies to test their efficacy.<sup>131</sup> One video tested in these studies depicts the daily

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128. See Chuck Alston et al., *Shared Decision-Making Strategies for Best Care: Patient Decision Aids*, NAT'L A.C.A. OF MED. (Sept. 2014), <http://nam.edu/wp-content/uploads/2015/06/SDMforBestCare2.pdf>; Glyn Elwyn et al., *Shared Decision Making: Developing the OPTION Scale for Measuring Patient Involvement*, 12 QUALITY SAFETY HEALTH CARE 93 (2003) (describing the development and testing of a measurement tool to evaluate patient involvement and satisfaction in medical decision making); E.A.G. Joosten et al., *Systematic Review of the Effects of Shared Decision-Making on Patient Satisfaction, Treatment Adherence and Health Status*, 77 PSYCHOTHERAPY & PSYCHOSOMATICS 219 (2008) (reviewing research evaluating shared decision making approaches in the context of a variety of health conditions and concluding that shared decision making is helpful in reaching treatment agreements); Annette M. O'Connor et al., *Modifying Unwarranted Variations in Health Care: Shared Decision Making Using Patient Decision Aids*, HEALTH AFFAIRS (Oct. 7, 2004), <http://content.healthaffairs.org/content/early/2004/10/07/hlthaff.var.63.full.pdf> (reviewing the evidence in support of using decision aids and recommending strategies to increase utilization and ensure quality of decision aids).

129. See Matthew W. Morgan et al., *Randomized, Controlled Trial of an Interactive Videodisc Decision Aid for Patients with Ischemic Heart Disease*, 15 J. OF GEN. INTERNAL MED. 685, 685-86 (2000).

130. Dominick L. Frosch et al., *A Randomized Controlled Trial Comparing Internet and Video to Facilitate Patient Education for Men Considering the Prostate Specific Antigen Test*, 18 J. OF GEN. INTERNAL MED. 781, 781-82 (2003).

131. ANGELO E. VOLANDES, *THE CONVERSATION: A REVOLUTIONARY PLAN FOR END-OF-LIFE CARE* (2015) [hereinafter VOLANDES, *THE CONVERSATION*]; see also ADVANCE CARE PLANNING (ACP) DECISIONS, <http://www.acpdecisions.org> (last visited Mar. 29, 2016).

routine of an elderly woman with advanced dementia. The other explains three goals-of-care options: life-prolonging care, including images of simulated CPR and intubation and an image of a patient on a mechanical ventilator; limited or basic care, including images of a patient getting antibiotics via a peripheral intravenous catheter; and comfort care, including images of a patient on home hospice care receiving medications. Doctors or other health care professionals may invite patients to watch either or both videos as appropriate, depending on the patient and the situation. The videos are intended to supplement, not replace, doctors' verbal explanation of dementia and care options.<sup>132</sup>

The motivating idea behind these video aids is that, by improving patients' understanding of the benefits and risks of different levels of end-of-life care, the videos can help them make better-informed decisions about the kind of care they would prefer – and ideally, to express those preferences in advance directives, increasing the likelihood that unwanted care will in be avoided. Volandes and his colleagues have published approximately 15 peer-reviewed studies to date on the impact of seeing these videos on different patient groups' preferences regarding end-of-life care, their knowledge of relevant care options, and other variables.<sup>133</sup> Almost all of

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132. See VOLANDES, *THE CONVERSATION*, *supra* note 131, at 112-15. For a systemic overview of decision aids generally and their relationship to shared decision making, see Glyn Elwyn et al., *Investing in Deliberation: A Definition and Classification of Decision Support Interventions for People Facing Difficult Health Decisions*, 30 *MED. DECISION MAKING* 701 (2010).

133. Kristy S. Deep et al., *'It Helps Me See With My Heart': How Video Informs Patients' Rationale for Decisions About Future Care in Advanced Dementia*, 81 *PATIENT EDUC. & COUNSELING* 229 (2010); Andrew S. Epstein et al., *A Randomized Controlled Trial of a Cardiopulmonary Resuscitation Video in Advance Care Planning for Progressive Pancreas and Hepatobiliary Cancer Patients*, 16 *J. OF PALLIATIVE MED.* 623 (2013); Andrew S. Epstein et al., *"We Have to Discuss It": Cancer Patients' Advance Care Planning Impressions Following Educational Information About Cardiopulmonary Resuscitation*, *PSYCHOONCOLOGY* (2015); Areej El-Jawahri et al., *A Randomized Controlled Trial of a CPR and Intubation Video Decision Support Tool for Hospitalized Patients*, 30 *J. OF GEN. INTERNAL MED.* (2015) [hereinafter El-Jawahri et al., *A Randomized Controlled Trial of a CPR and Intubation Video Decision Support Tool*]; Areej El-Jawahri et al., *Use of Video to Facilitate End-of-Life Discussions With Patients With Cancer: A Randomized Controlled Trial*, 28 *J. CLINICAL ONCOLOGY* 305 (2010) [hereinafter El-Jawahri et al., *Use of Video to Facilitate End-of-Life*

these studies have found that participants who watch a video decision aid are significantly more likely to prefer comfort care to other end-of-life care options<sup>134</sup> and to prefer not to be resuscitated via CPR, intubated, or put on mechanical ventilation.<sup>135</sup> These findings have been observed for many

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*Discussions*]; Jessica B. McCannon et al., *Augmenting Communication and Decision Making in the Intensive Care Unit with a Cardiopulmonary Resuscitation Video Decision Support Tool: A Temporal Intervention Study*, 15 J. OF PALLIATIVE MED. 1382 (2012); Angelo E. Volandes et al., *A Randomized Controlled Trial of a Goals-of-Care Video for Elderly Patients Admitted to Skilled Nursing Facilities*, 15 J. OF PALLIATIVE MED. 805 (2012); Angelo E. Volandes et al., *Assessing End-of-Life Preferences for Advanced Dementia in Rural Patients Using an Educational Video: A Randomized Controlled Trial*, 14 J. OF PALLIATIVE MED. 169 (2011) [hereinafter Volandes et al., *Assessing End-of-Life Preferences for Advanced Dementia in Rural Patients*]; Angelo E. Volandes et al., *Augmenting Advance Care Planning in Poor Prognosis Cancer with a Video Decision Aid: A Pre-Post Study*, 118 CANCER 4331 (2012) [hereinafter Volandes et al., *Augmenting Advance Care Planning*]; Angelo E. Volandes et al., *Health Literacy Not Race Predicts End-of-Life Care Preferences*, 11 J. OF PALLIATIVE MED. 754 (2008); Angelo E. Volandes et al., *Improving Decision Making at the End of Life With Video Images*, 30 MED. DECISION MAKING 29 (2009) [hereinafter Volandes et al., *Improving Decision Making at the End of Life With Video Images*]; Angelo E. Volandes et al., *Overcoming Educational Barriers for Advance Care Planning in Latinos with Video Images*, 11 J. OF PALLIATIVE MED. 700 (2008); Angelo E. Volandes et al., *Randomized Controlled Trial of a Video Decision Support Tool for Cardiopulmonary Resuscitation Decision Making in Advanced Cancer*, 31 J. CLINICAL ONCOLOGY 380 (2013) [hereinafter Volandes et al., *Cardiopulmonary Resuscitation Decision Making*]; Angelo E. Volandes et al., *Using Video Images of Dementia in Advance Care Planning*, 167 ARCHIVES OF INTERNAL MED. 828 (2007); Angelo E. Volandes et al., *Using Video Images to Improve the Accuracy of Surrogate Decision-Making: A Randomized Controlled Trial*, 10 J. AM. MED. DIRECTORS ASS'N 575 (2009); Angelo E. Volandes et al., *Video Decision Support Tool for Advance Care Planning in Dementia: Randomised Controlled Trial*, 338 BRITISH MED. J. b1964 (2009) [hereinafter Volandes et al., *Video Decision Support Tool for Advance Care Planning in Dementia*].

134. 10 of 11 studies measuring goals of care preferences found that those who saw videos were likelier to prefer comfort care than those who did not.

135. Six of seven studies measuring one or more of these specific interventions found that those who saw videos were less likely to choose these forms of life-prolonging care than those who did not. Note that these results are consistent with those from studies of video decision aids in other, non-end-of-life clinical settings, which also tended to show that participants who watch videos are less likely to opt for more aggressive treatments. *E.g.*, David Arterburn et al., *Introducing Decision Aids At Group Health Was Linked To Sharply Lower Hip And Knee Surgery Rates And Costs*, 31 HEALTH AFFAIRS 2094 (2012); Frosch et al., *supra* note 130; Morgan et al., *supra* note

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different types of patients: seniors in doctors' offices and rural health clinics, for whom end-of-life care is not imminent; elderly persons at skilled nursing facilities following acute hospital care, for whom it may well be a more pressing concern; patients suffering from advanced gliomas or gastrointestinal cancers with poor prognoses, for whom end-of-life issues are urgent; and persons of various races/ethnicities, religions, education levels, and health literacy levels.

Insofar as a greater preference for comfort or palliative care is desirable for the reasons discussed earlier, the research suggests that video decision aids can increase the likelihood of outcomes that are both medically and economically beneficial. More importantly for this paper's central theme, the research also indicates that video decision aids may improve the *process* of end-of-life decision making in several ways, including: (1) by making patients better informed about their options; (2) by making them more likely to have "the conversation" with their doctors and more likely to memorialize their end-of-life care preferences in an advance directive; and (3) by helping them to feel better about this difficult decision.

First, the research indicates that patients who use video decision aids are better informed about their end-of-life choices. Generally speaking, using video decision aids can ensure not only that each patient receives a certain minimum of information relevant to their end-of-life decisions – thus addressing the problem created when either the patient or the physician is reluctant to broach the subject at all – but also that each patient receives the *same* basic information, in a clearly structured format (which of course may be augmented by additional communication by the physician).<sup>136</sup> More specifically, in six of seven of the studies in which Volandes and his group have compared what participants who watched the videos knew about relevant end-of-life facts (advanced dementia or the likely outcomes from life-prolonging care) to what those who didn't watch knew, participants demonstrated that they were more accurately informed about the prospects for the end of life after watching the video.<sup>137</sup>

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136. VOLANDES, *THE CONVERSATION*, *supra* note 131, at 112.

137. Significant effects for the video decision aids on knowledge of the

Second, one recent study indicates that video decision aids also facilitate doctor-patient communication and that patients who watch videos are more likely to translate their preferences into advance directives that guide their subsequent treatment when they are no longer able to express their wishes. Participants were 150 inpatients who were suffering from various advanced diseases and had poor prognoses – less than one year to live. Those who watched a video depicting CPR and intubation were significantly more likely than those who did not to have a discussion about these interventions with their inpatient doctors before being discharged from the hospital. And while the proportion of patients in each group with documented advance orders to withhold treatment was about the same before the study began, those who watched the video were significantly more likely to have such orders in their records as of the date of discharge.<sup>138</sup>

Third, video decision aids may help patients to feel better about the decision making process. One therapeutic benefit is that video decision aids appear to reduce the uncertainty that people feel in making end-of-life care decisions. In one study, the researchers specifically compared participants' level of uncertainty regarding their choices for care in case of advanced dementia before and after watching the dementia video, and found that watching the video led them to be more certain about their preferences. In several other studies, fewer participants asked to choose a level of care option selected "uncertain" after watching a video than they did before. To the

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depicted condition and/or intervention were found in: El-Jawahri et al., *A Randomized Controlled Trial of a CPR and Intubation Video Decision Support Tool*, *supra* note 133 (video vs. no video); El-Jawahri et al., *Use of Video to Facilitate End-of-Life Discussions*, *supra* note 133 (video plus verbal vs. verbal only); McCannon et al., *Augmenting Communication and Decision Making in the Intensive Care Unit*, *supra* note 133 (video vs. no video); Volandes et al., *Augmenting Advance Care Planning*, *supra* note 133 (video vs. no video); Volandes et al., *Cardiopulmonary Resuscitation Decision Making*, *supra* note 133 (video plus verbal vs. verbal only); Volandes et al., *Video Decision Support Tool for Advance Care Planning in Dementia*, *supra* note 133 (video plus verbal vs. verbal only). The only study in which significant effects were not found was Epstein et al., *A Randomized Controlled Trial of a Cardiopulmonary Resuscitation Video*, *supra* note 133 (video vs. verbal only).

138. El-Jawahri et al., *A Randomized Controlled Trial of a CPR and Intubation Video Decision Support Tool*, *supra* note 133.

extent that being certain feels better than being uncertain – that is, being confident is good hedonically<sup>139</sup> – video aids have therapeutic value. And to the extent that patients who are more certain about their care preferences are less passive about their own health care-related choices,<sup>140</sup> video aids may have therapeutic value in that respect as well.

It is important, however, to point out two basic limitations of the empirical research supporting the claimed benefits of video decision aids. First, in all but one of the studies comparing the preferences and/or knowledge of participants who saw a video about dementia and/or goals of end-of-life care to those who only heard a verbal presentation of that information, participants in the video group *also* heard the verbal presentation first. None of those studies, therefore, allow us to determine whether the reported effects of the video on goals of care preferences or knowledge were due to the video itself as opposed to the mere *repetition* of the relevant information, first in verbal form and then in the video. The potentially confounding effect of the repetition of the information would seem to be especially problematic with regard to the measurement of knowledge effects immediately after the experimental manipulation.<sup>141</sup> Indeed, in the one study that appears to have controlled for this potential confound,<sup>142</sup> the researchers found *no difference* in the increase in knowledge about CPR and mechanical ventilation produced by exposure to a verbal account versus the video. Second, assuming for sake of argument that video decision aids both increase patients' knowledge about their end-of-life options and

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139. See, e.g., Hart Blanton et al., *Overconfidence as Dissonance Reduction*, 37 J. OF EXPERIMENTAL SOC. PSYCHOL. 373, (2001).

140. See Volandes et al., *Improving Decision Making at the End of Life with Video Images*, *supra* note 133, at 33.

141. "Repetition is one of the most powerful variables affecting memory . . . [T]he fact that repetition improves retention . . . seems beyond dispute." Douglas Hintzman, *Repetition and Memory*, 10 PSYCHOL. OF LEARNING AND MOTIVATION 47, 47 (1976). The knowledge measures in the Volandes et al. studies are essentially measures of recall, and should thus be subject to this general principle.

142. Andrew S. Epstein et al., *A Randomized Controlled Trial of a Cardiopulmonary Resuscitation Video in Advance Care Planning for Progressive Pancreas and Hepatobiliary Cancer Patients*, 16 J. OF PALLIATIVE MED. (2013).



incline them to prefer comfort care, none of the published studies strongly support the inference that (as some might suppose) the two outcomes are *causally connected*—that people who watch video decision aids are more likely to choose comfort care *because* they understand their end-of-life options better.<sup>143</sup>

Still, the consistent finding that watching video decision aids makes people more likely to choose comfort care is provocative and demands further investigation. Do the videos have this effect because they *improve* end-of-life decision making or, on the contrary, because they *impair* it by biasing patients' choices? Although the research does not yet permit a definitive answer, there is some evidence for both.<sup>144</sup>

On the one hand, video decision tools can influence judgment processes about end-of-life choices in a positive way. First, the use of video may increase patients' attention to the information being presented, making the information likelier to be noticed, remembered, and used in subsequent decision

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143. This inference could be indicated, for instance, by a basic mediational analysis. Specifically, a traditional mediational analysis would support the inference that watching a video decision aid makes people more likely to prefer comfort care *because* it makes them more knowledgeable about end-of-life outcomes if it showed that (a) watching video makes participants significantly likelier to prefer comfort care; (b) when increased knowledge is added to the model as a potential mediator of that main effect, watching video significantly predicts increased knowledge and increased knowledge significantly predicts a greater preference for comfort care, but (c) the direct path from watching video to the degree of preference for comfort care is no longer statistically significant. See Reuben M. Barron & David A. Kenny, *The Moderator-Mediator Variable Distinction in Social Psychological Research: Conceptual, Strategic, & Statistical Considerations*, 51 J. OF PERSONALITY & SOC. PSYCHOL. 1173, 1179-81 (1986). None of the studies, however, report any form of this statistical test.

144. The following discussion applies to video aids for end-of-life decision making generally. Although we have Volandes and his colleagues' videos in mind, we have been unable to obtain access to the actual videos used in their studies. Links in their published studies are no longer active and other attempts to access the material have been unsuccessful. We rely, therefore, on the descriptions of the videos in peer-reviewed publications, as well as what we infer to be still images or brief clips taken from those videos that appear in other, publicly available material and correspond to the published descriptions. Talks at Google, *Angelo Volandes: "The Conversation"*—Talks at Google, YOUTUBE (Mar. 24, 2015), [https://www.youtube.com/watch?v=fAOq1\\_qIstg&noredirect=1](https://www.youtube.com/watch?v=fAOq1_qIstg&noredirect=1) (showing CPR on a mannequin at 34:53-35:05).

making.<sup>145</sup> Second, considerable research on multimedia learning attests to the benefits of well-designed visual instruction.<sup>146</sup> *Dual coding theory*<sup>147</sup> posits that people think both visually and verbally. By offering visual stimuli, video decision aids should appeal more directly to the visual processing channel, and may be especially effective for people whose learning style inclines toward the visual.<sup>148</sup> Third, and perhaps most importantly, a video depicting a person with advanced dementia or a patient undergoing CPR or mechanical ventilation is likely to induce stronger, more confident understanding than a verbal description of those things. Seeing the video provides patients with a vicarious form of *experiential* knowledge, and a person who has had the experience of *x* can imagine and remember *x* in ways that someone lacking that experience cannot.<sup>149</sup> Volandes and colleagues have often remarked that watching these videos enables patients to “imagine the unimaginable” and begin to understand what it might be like to be in the depicted person’s position<sup>150</sup> – surely a component of truly informed decision making.

On the other hand, video decision tools may also bias end-of-life choices. One concern is that video decision aids may prompt overly emotional decision making.<sup>151</sup> Volandes and colleagues acknowledge this risk,<sup>152</sup> and their descriptions of

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145. See e.g., Brad E. Bell & Elizabeth F. Loftus, *Vivid Persuasion in the Courtroom*, 49 J. OF PERSONALITY ASSESSMENT 659, 661-63 (1985).

146. See e.g., RICHARD E. MAYER, *MULTIMEDIA LEARNING* (2d ed. 2001).

147. ALLAN PAIVIO, *IMAGERY AND VERBAL PROCESSES* (1971); ALLAN PAIVIO, *MENTAL REPRESENTATIONS: A DUAL CODING APPROACH* (1990).

148. RITA DUNN, *Capitalizing on College Students’ Learning Styles: Theory, Practice, and Research*, in PRACTICAL APPROACHES TO USING LEARNING STYLES IN HIGHER EDUCATION 1, 3-18 (2000).

149. David Lewis, *What Experience Teaches*, in THE NATURE OF CONSCIOUSNESS: PHILOSOPHICAL DEBATES 579, 579-95 (1997).

150. Angelo E. Volandes et al., *The Psychology of Using and Creating Video Decision Aids for Advance Care Planning*, PSYCHOL. OF DECISION MAKING IN MED. AND HEALTH CARE, 190, 190 (2007) [hereinafter Volandes et al., *The Psychology of Using and Creating Video Decision Aids for Advance Care Planning*].

151. See *id.*

152. See e.g., Volandes et al., *The Psychology of Using and Creating Video Decision Aids for Advance Care Planning*, *supra* note 150, at 193; Volandes et al., *Assessing End-of-Life Preferences for Advanced Dementia in*

their videos and the production process indicate that they have taken some pains to avoid overly emotion-provoking content.<sup>153</sup> Nevertheless, the fact that even Volandes' most in-depth discussions of his filmmaking strategies and goals make only the most passing reference to viewers' emotional responses<sup>154</sup> indicates that the research may not have adequately accounted for potential emotional bias. Whether and to what extent emotional responses to video decision aids should be considered as impairing or enhancing good judgment is itself a highly debatable matter. Some emotions (for instance, moderate sadness and/or sympathy) may facilitate good decision making about end-of-life care, whereas others (e.g., disgust) may not. None of the studies by Volandes and colleagues have measured specific emotional responses to the videos, however, so we simply do not know how strong those effects may be or whether they played any role in participants' end-of-life care preferences.

Second, video decision aids may *frame* the information on which a decision is to be based in such a way as to bias the decision. Generally speaking, people are more willing to incur risks or costs to avoid a loss than to obtain or preserve the equivalent gain (*prospect theory* or *loss aversion*).<sup>155</sup> If the end-of-life scenario is framed so as to characterize or make salient the patient's death, that would likely be perceived as a loss relative to the status quo (living patient), and the decision maker would be more inclined to incur costs – here, the pain and risk of life-prolonging treatment – to avoid that loss. If, in contrast, the same scenario is framed to make salient the patient's continuing diminished existence, that would likely be

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*Rural Patients Using an Educational Video: A Randomized Controlled Trial*, *supra* note 133, at 174.

153. See e.g., VOLANDES, *THE CONVERSATION*, *supra* note 131, at 104-06.

154. Angelo Volandes et al., *Audio-Video Decision Support for Patients: The Documentary Genre as a Basis for Decision Aids*, 16 HEALTH EXPECTATIONS: AN INT'L J. OF PUB. PARTICIPATION IN HEALTH CARE AND HEALTH POL'Y 80 (2011) (not mentioned); Volandes et al., *The Psychology of Using and Creating Video Decision Aids for Advance Care Planning*, *supra* note 150, at 193 (mentioned in passing); Volandes et al., *Assessing End-of-Life Preferences for Advanced Dementia in Rural Patients*, *supra* note 133, at 174 (mentioned in passing).

155. Amos Tversky & Daniel Kahneman, *The Framing of Decisions and the Psychology of Choice*, 211 SCI. 453, 453-58 (1981).

perceived as a (minimal) gain relative to the status quo, and the decision maker would be less inclined to incur the same costs to preserve the gain. A video decision aid showing a patient with advanced dementia, for instance, makes salient the patient's diminished life rather than the patient's death as a loss of life, and hence would be predicted to incline decision makers against life-prolonging treatment.

Third, watching the videos may trigger patients' use of the *affect heuristic*,<sup>156</sup> which could impair end-of-life decision making both by oversimplifying it and by biasing its outcome. Most activities involve both risks and benefits, which tend to be positively correlated (if correlated at all). "Activities that bring great benefits may be high or low in risk but activities that are low in benefit are unlikely to be high in risk (if they were, they would be proscribed)."<sup>157</sup> According to the affect heuristic, however, people tend to perceive risks and benefits as inversely correlated.<sup>158</sup> "If [people] like an activity, they are moved to judge the risks as low and the benefits as high; if they dislike it, they tend to judge the opposite – high risk and low benefit."<sup>159</sup> Thus, a person's affective response converts what should be a complex decision – such as whether to use life-prolonging treatment in cases of advanced dementia – into a simpler, less conflicted judgment by aligning the pros and cons. The video decision aids, although apparently eschewing dramatic emotional appeal, still show distasteful images, whether of advanced dementia or sternum-breaking CPR, and the limited data available indicates that viewers respond aversively to these images.<sup>160</sup> If their affective response to the video is one of dislike, viewers may intuitively regard life-prolonging treatment as high cost and low benefit and thus to be avoided, rather than considering more thoughtfully the pros and cons of what might reasonably be described as a high cost and (depending on the value placed on continued life) a high benefit activity.

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156. Paul Slovic et al., *The Affect Heuristic*, 177 EUR. J. OF OPERATIONAL RES. 1333, 1338-39 (2007).

157. *Id.* at 1343.

158. *Id.* at 1342-43.

159. *Id.* at 1343.

160. *See generally* Deep et al., *supra* note 133.

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It is important to put the critiques in perspective. Video decision aids may well improve end-of-life decision making to the extent that their strengths and even their potential biases help to counteract the judgmental biases likely to exist when patients or their surrogates make these decisions *without* the videos. The relevant question, that is, is not whether video decision aids lead to *optimal* decision making, but rather whether they are likely to lead to *better* decision making. For instance, we observed earlier that videos may induce a framing bias that makes the risks and costs of life-prolonging treatment more salient relative to its benefits. It's very possible, however, that without the videos, patients, especially healthy patients, would tend to underestimate how bad things are likely to be toward end of their lives if they should then be suffering from advanced dementia or terminal cancer. People are generally poor at *affective forecasting*, that is, predicting how they will feel in the future after various life changes, and they are prone to *optimism bias*, tending to believe that they will be able to avoid the bad events that befall others.<sup>161</sup> In light of these default biases, even the biasing effects of video decision aids could provide a helpful corrective, making it likelier that the level of care that people receive at the end of life accords with what they would prefer to receive, even if they are unable to express those preferences when the end approaches. Moreover, given the pervasive denial of death in American culture mentioned earlier, and (relatedly) the “magical thinking” that leads many patients to “believe that however unlikely a procedure is to be effective, it will work when applied to their particular case,”<sup>162</sup> decision aids that give patients and their families a more realistic and a deeper, more experiential understanding of the actual benefits and costs of life-prolonging treatment would seem, on balance, to be worthwhile.

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161. On affective forecasting errors, see, e.g., DANIEL GILBERT, *STUMBLING ON HAPPINESS* (2006). On optimism bias, see, e.g., Neil D. Weinstein, *Unrealistic Optimism About Future Life Events*, 39 *J. OF PERSONALITY & SOC. PSYCHOL.* 806 (1980); Neil D. Weinstein, *Unrealistic Optimism About Susceptibility to Health Problems: Conclusions from a Community-Wide Sample*, 10 *J. OF BEHAV. MED.* 481 (1987).

162. Volandes et al., *The Psychology of Using and Creating Video Decision Aids for Advance Care Planning*, *supra* note 150, at 195.

C. *Beyond Informed Consent: Achieving the Goal of Authentic Choice*

Shared decision making and the appropriate use of decision aids promise much progress beyond the minimum required by informed consent law towards the goal of truly informed consent. Nevertheless, even these measures do not guarantee the *authenticity* of end-of-life choices.<sup>163</sup> The ideal of authenticity requires that the patient not only understand intellectually the nature of the treatment and its risks and benefits, but also have the emotional ability to make these decisions and a functional value system through which to evaluate the appropriateness of the choice for him or herself.<sup>164</sup>

In order to make authentic medical decisions, patients must be willing to acknowledge that they are dying (which requires honest information about terminal status and prognosis from the physician) and to think about and then articulate to the physician their goals of care—such as prolongation of life, reduction of suffering, or maintenance of dignity and independence. The broader goal, then, is to create an environment and a process that maximizes the opportunity for patients to make end-of-life decisions using accurate, comprehensible information and while reflecting on how they have lived their lives and what they value at the end.

It is difficult to assess how often patient decisions reflect this sort of authenticity, but it is probably relatively rare

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163. See, e.g., Insoo Hyun, *Waiver of Informed Consent, Cultural Sensitivity, and the Problem of Unjust Families and Traditions*, 32 HASTINGS CTR. REP. 14, 15 (2002) (describing the role of authentic values in the ideal of personal autonomy and arguing that informed consent or the waiver of consent must rest on patient values that are “free of coercive formative influences.”); see also Daniel Brudney, *Choosing for Another: Beyond Autonomy and Best Interests*, 39 HASTINGS CTR. REP. 31, 31-32 (2009) (describing authenticity as “the capacity to be a particular self, a distinctive individual . . .”).

164. One commentator, in discussing decision-making competence, captures the elements of an authentic decision: “Logically and conceptually, decision-making competence can be broken down into three distinct rubrics. They are, respectively, cognitive, emotional, and valuational competence.” See Kluge, *supra* note 68, at 297.

because so many barriers exist. Patients do not know what questions to ask. Even when patients have questions, fear and denial of illness or deference to physicians may inhibit them from asking. The ability to talk openly requires that both patients and physicians acknowledge what they are feeling and undertake these conversations despite their inherent emotional challenges.<sup>165</sup> There is no way to mandate this level of emotional engagement between any individual physician and patient; it will, if it occurs, depend entirely on the character and inclinations of the individuals in question. From the physician's perspective, authenticity requires physicians to be emotionally self-aware enough to recognize when they are avoiding difficult conversations with patients and families and to correct for this avoidance. Physicians must also have sufficient emotional intelligence to manage these conversations with patients and families whose own part in the conversation is very likely hampered by fear, regret, or grief. Many physicians very capably engage in these conversations, but because people vary so much in temperament and their ability to acknowledge and discuss difficult emotions, it would be unrealistic to expect all physicians (or patients) to behave this way. Nevertheless, given the complexity and importance of end-of-life decisions, striving for authenticity is worth the effort.

#### IV. Conclusion

As the baby boomer population continues to age, the problems surrounding end-of-life care will become both more prevalent and more complex. Recognizing the acute need to address the lives and deaths of an aging population, health policy experts, legislatures, and the medical community are seeking ways to improve the quality of both communication

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165. See Duffy, *supra* note 113, at 140 (noting that good communication, in the form of allowing the patient to talk, responding to patients' emotions, and building rapport "are not trivial skills. They are the crux of competent medical care, particularly from the patient's and the public's point of view."); Diane E. Meier et al., *The Inner Life of Physicians and Care of the Seriously Ill*, 286 J. AM. MED. ASS'N 3007, 3007-08 (2001) (encouraging physicians to be self-aware, to acknowledge their emotions as they care for dying patients in order to improve quality of care and to guard the physician's own well-being).

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and care at the end of life. Part of the solution is to remove the dividing line between therapeutic and palliative care and to focus instead on training physicians to integrate the two.<sup>166</sup> But that alone will not improve care as desired unless physicians and patients communicate better about their choices and the implications of these choices.

Informed consent law, the SDM model, and video decision aids all can play an important part in trying to reorient physicians and patients toward truly informed (and perhaps even authentic) choice, but no legal reform can require that patients confront their own mortality or that physicians help them to do so. In end-of-life care, relying on the patient's exercise of his autonomous choice is often insufficient to promote sound medical decision making and, in particular, to avoid care that is excessive, whether measured by its physical benefits or its consistency with the patient's own true values and preferences. Fear, denial of death, deference to physician authority, lack of trust, or simple ignorance often makes patients and families reluctant to initiate discussions about the uncertain future. Physicians must be more willing to step outside the comfortable confines of the traditional model of informed consent, which sometimes allows them to evade responsibility for the well-being of patients, and initiate conversations that provide honest information and advice about end-of-life choices. The process of shared decision making, if well implemented, represents a significant step forward, but it requires willingness on the part of individual physicians and patients to undertake it, which is something that education or reform can encourage but not compel.

Fully informed and authentic decision-making represents the gold standard for end-of-life choices. When achieved, this gold standard means that the patient's decisions truly satisfy the goal of autonomy, whether the decision is to receive or forego all life-prolonging care, or to request something along

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166. There is a growing interest in the integration of the modifying influence of palliative care into the care and culture of the ICU. The IPAL-ICU project seeks to improve palliative care in the ICU by providing a central repository for exchanging evidence, expertise, and information. See *Improving Palliative Care in the ICU*, CAPC.ORG, <https://www.capc.org/ipal/ipal-icu/> (last visited Feb. 18, 2016); see also [add cross-reference to forthcoming article with Kathy Cerminara].



the continuum of care options. Meaningful communication between physician and patient is what makes the realization of autonomy possible. Similarly, where the patient's wishes are unknown or in dispute, good care requires meaningful communication with the patient's family or appointed proxy about discontinuing medically inappropriate treatments while avoiding misunderstandings with the family about the goals of care. It is important for both physicians and patients to recognize that ceasing therapeutic care or life-prolonging measures when they are no longer beneficial is not a failure of care. In fact, the opposite is true. The conversations needed to yield this kind of communication, and the emotions that inhere in those conversations, ask much of physicians because providing comfort to dying patients and their families requires physicians to move beyond the idea of cure to a broader notion of medical care. That broader notion of care, however, can reduce unwanted suffering and better comport with patients' true preferences, both of which are surely desirable outcomes at the end of life.