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# Denying Death

Teneille R. Brown

*S.J. Quinney College of Law, University of Utah*, [teneille.brown@law.utah.edu](mailto:teneille.brown@law.utah.edu)

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# DENYING DEATH

Teneille R. Brown\*

*Terminal cancer patients are being kept in the dark about the purpose of their care. Several studies show that these patients undergo expensive and painful interventions because they are holding out hope for a cure, even when their physicians know that a cure is very unlikely. The current Medicare reimbursement system encourages this false hope by incentivizing physicians to medicate and operate on patients, rather than to talk about whether or why to do these things. Our culture also encourages this false hope by treating cancer as a war that must be won. As a result, patients are admitted to the ICU, infused with toxic chemotherapy, and operated upon within the last few days of their lives. They pursue risky, painful, and expensive treatments that they might not otherwise undergo if they knew they were gaining weeks instead of months, or not gaining any time at all. Whatever their wishes for their death, a substantial number of patients are not given a chance to articulate them because nobody asks. This situation is a disaster on many levels. In this Article, I explore the reasons for this complex phenomenon—scouring the medical, psychological, and legal literature. I then conclude with ten legal mechanisms that could be used to cut against this current state of affairs.*

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\* Professor of Law at the University of Utah, S.J. Quinney College of Law and Adjunct Professor of Internal Medicine at the University of Utah School of Medicine. Professor Brown is also a member of the Division of Medical Ethics and Humanities and has served on various hospital ethics committees. This research was made possible in part through generous support from the Albert and Elaine Borchard Fund for Faculty Excellence.

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## INTRODUCTION

### *A. Our Cultural Denial of Death*

From the moment each of us is born we must balance the exhilaration of new beginnings with the absolute certainty of death. And even though we are superficially aware of our mortality, most do not want to be reminded of it. Our reluctance to acknowledge death is perhaps due to a superstitious belief that “if we do not talk about something, it does not exist.”<sup>1</sup> This is as true for advanced cancer patients as it is for those of us who are healthy.

Death is an inevitable part of life, yet we Americans put off talking about it until we cannot talk anymore. And then—in a flash—a sudden health crisis strikes and decisions are made without much reflection. We miss the chance to explain our final wishes.<sup>2</sup> We crash. Chest compressions begin.<sup>3</sup> We are rushed to the emergency room and a ventilator is placed down our throats, which helps us breathe, but takes away our ability to speak. We are admitted to an intensive care unit (“ICU”). The window for communication closes. We now must place our lives in the unenviable custody of others. They will struggle to speak for us and will try to imagine whether they would be letting us down by letting us go. So instead, they tell the physicians to “do everything.” This means that an alarming number of us in America will die in hospitals with plastic tubes in our noses, mouths, necks, chests, and bladders, feeding our stomachs, oxygenating our lungs, or dialyzing

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1. Instead of confronting our mortality head on, we shroud it in cartoons where the villains are “shot with rifles, crushed by gigantic boulders, blown to pieces by dynamite . . . only to jump to their feet (after the laughter stops) to be ‘killed’ again.” RICHARD DUMONT & DENNIS FOSS, *THE AMERICAN VIEW OF DEATH: ACCEPTANCE OR DENIAL?* 36 (1972). We also use elaborate euphemisms around our death rituals, hide morgues, and consider people who talk about death to have poor manners.

2. Many patients with cancer do not discuss the benefits and risks of intensive care with their clinicians before it is needed, and their code status (whether they wish to receive CPR) is often unknown or undocumented. Christopher G. Slatore et al., *Reply to F. Vincent et al and S.M.H. Alibhai*, 30 *J. CLINICAL ONCOLOGY* 3652–53 (2012) (citing Cristina A. Reichner et al., *Outcome and Code Status of Lung Cancer Patients Admitted to the Medical ICU*, 130 *CHEST* 719 (2006)).

3. Alexi A. Wright et al., *Associations Between End-of-Life Discussions, Patient Mental Health, Medical Care Near Death, and Caregiver Bereavement Adjustment*, 300 *JAMA* 1665, 1665 (2008). In this study, end-of-life discussions were associated with lower rates of ventilation, cardiopulmonary resuscitation, ICU admission, and earlier hospice enrollment. This means that if patients are asked, they are likely to say that they do not want these intensive interventions.

our kidneys.<sup>4</sup> We compel the broad use of technologies that were developed for narrower purposes, and we mistake artificial mechanics for the presence of life.<sup>5</sup>

But not all of us will die like this. Many of us will have long, drawn-out, negotiated deaths due to terminal illnesses like cancer. And even in these nonemergency cases when our death is less imminent, we often still miss the opportunity for deep, personal end-of-life (“EOL”) conversations about where we would like to die, with whom, and how.<sup>6</sup> This is why, for many Americans, the modern dying experience is “deplorable and in need of full reconstitution,” as well as “painful, lonely and invasive.”<sup>7</sup>

Of course it was not always this way. Before the twentieth century, our friends and neighbors died earlier, sensitizing us to death’s inevitable return.<sup>8</sup> Women died in childbirth, babies died before their first birthdays, risky blood-letting procedures actually made our conditions worse, and wounds became too infected to treat. Fewer of us died of old age. We died at home with our families gathered by our bedside. We tried to practice the good or “holy” death, where we gracefully accepted the will of God, welcomed the chance to atone for our sins, and did not treat illness as a war to be won.<sup>9</sup>

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4. Nearly 40% of all deaths nationwide occur in the acute care setting and 20% involve the use of intensive care services. See Derek C. Angus et al., *Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study*, 32 CRITICAL CARE MED. 638, 639–41 (2004). Twenty percent of elderly Americans die in intensive-care services and of these patients, about half undergo mechanical ventilation and a quarter undergo CPR in the days before death. However, the intensity of EOL care varies substantially based upon the facility where patients receive care. See Alvin C. Kwok et al., *The Intensity and Variation of Surgical Care at the End of Life: A Retrospective Cohort Study*, 378 LANCET 1408, 1408 (2011).

5. Murray Enkin, Alejandro R. Jadad & Richard Smith, *Death Can Be Our Friend: Embracing the Inevitable Would Reduce Both Unnecessary Suffering and Costs*, 343 BRIT. MED. J. 1277, 1277 (2011) (“Too many people are dying undignified graceless deaths in hospital wards or intensive care units, with doctors battling against death way past the point that is humane.”).

6. The impetus for this Article came from a close friend who worked in a cancer hospital and lamented the fact that terminal cancer patients who were dying in the ICU had never had an oncologist or nurse talk to them about their EOL goals of care. She was the first person to ask them how they would like to die, despite the fact that they had been seen dozens of times by physicians at that facility.

7. Sean O’Mahony et al., *A Review of Barriers to Utilization of the Medicare Hospice Benefits in Urban Populations and Strategies for Enhanced Access*, 85 J. URB. HEALTH 281, 281–83 (2008).

8. SAMUEL MORRIS BROWN, IN HEAVEN AS IT IS ON EARTH: JOSEPH SMITH AND THE EARLY MORMON CONQUEST OF DEATH 20 (2012).

9. DREW GILPIN FAUST, THIS REPUBLIC OF SUFFERING: DEATH AND THE AMERICAN CIVIL WAR 6 (2008) (“The concept of the Good Death was central to mid-nineteenth-century America, as it had long been at the core of Christian practice. Dying was an art, and the tradition of *ars moriendi* had provided rules for conduct for the moribund and their attendants since at least the fifteenth century: how to give up one’s soul ‘gladly and wilfully’; how to meet the devil’s temptations of unbelief, despair, impatience, and worldly attachment . . .”).

Sociologists and historians tell us that the way we practice death is intensely cultural. As our culture has changed, so too has the way we die. Due mostly to public health measures and expanded insurance coverage of the elderly, the average American life expectancy has nearly doubled from 47 years in 1900 to 78 in 2008.<sup>10</sup> This is a remarkable human achievement in such a short time. The development of sanitary water supplies, antiseptics, and antibiotics means that we do not die as frequently of acute infections.<sup>11</sup> Instead, death comes later and more often from chronic diseases like congestive heart failure, diabetes, or cancer—the gifts of progress.

Not only are common causes of death affecting us later in life, we are also more methodical in our management of them. Where Americans used to rely on experimental “treatments,” we now have drugs and devices that are assessed, albeit imperfectly, by the Food and Drug Administration (“FDA”) to determine their safety and effectiveness. The substantial investment in clinical research has paid off. We can cure many diseases and have proved the efficacy of treatments through clinical trials.

This medical innovation is a huge success when the drugs or devices are used appropriately. But the expanded use of medical treatments can cause mayhem when clinical goals are poorly defined. In many instances where no one has discussed the patient’s EOL preferences with them, the “treatments” that are offered may not be treating anything at all. Instead, the next clinical arrow in the quiver just provides another means of avoiding the tricky conversation about a patient’s death.

### ***B. Cancer Exceptionalism Fosters Our Cultural Denial of Death***

We had no difficulty explaining the specific dangers of various treatment options, but we never really touched on the reality of his disease. His oncologists, radiation therapists, surgeons, and other doctors had all seen him through months of treatments for a problem that they knew could not be cured. We could never bring ourselves to discuss the larger truth about his condition or the ultimate limits of our capabilities, let alone what might matter most to him as he neared the end of his life. If he was pursuing a delusion, so were we.<sup>12</sup>

The quote above is from Dr. Atul Gawande’s insightful 2014 book, *Being Mortal*. In it, Dr. Gawande describes with moving detail how physicians and

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10. See U.S. CENSUS BUREAU, STATISTICAL ABSTRACT OF THE UNITED STATES: 2012, at 77 tbl.104 (2012), <http://www.census.gov/prod/2011pubs/12statab/vitstat.pdf>; see also Muriel R. Gillick, *How Medicare Shapes the Way We Die*, 8 J. HEALTH & BIOMED. L. 27, 33 (2012).

11. There are some data to suggest that our life expectancies continued to rise in the latter part of the twentieth century and was correlated with passage of the Medicare Act. However, other countries saw an increase in their life expectancies around the same time, so it is not clear whether the correlation is in fact causal. See Gillick, *supra* note 10, at 33.

12. ATUL GAWANDE, *BEING MORTAL: MEDICINE AND WHAT MATTERS IN THE END* 5–6 (2014).

patients collaborate to deny death. While Dr. Gawande takes on this phenomenon generally, he uses compelling patient narratives from his terminal cancer patients to illustrate this point. The problem that he identifies—that our healthcare system perpetuates death denial—is particularly acute when seen through the lens of cancer patients.

In many ways, cancer is different. Cancer hijacks our bodies' natural production systems and makes them go haywire. Cancer cells sinisterly take refuge in hidden corners of our bodies and then cleverly mutate to evade new drug treatments. The “C-word” used to be so feared that physicians did not utter its name in the presence of patients.<sup>13</sup> Cancer is cruel. It strikes innocent people without warning, people who do not seem to have done anything to deserve its wrath. In many ways, cancer is not treated as a disease at all. It is personified. It is a thing with intention: to destroy us. As far as chronic diseases go, cancer is not wholly unique in these ways. Still, there is something about our cultural response to it that renders the biography of cancer inimitable.

As Siddhartha Mukherjee describes in *The Emperor of All Maladies: A Biography of Cancer*, cancer possesses uniquely modern and seductive metaphors.<sup>14</sup> Cancer is a fierce, territorial, desperate, malevolent, and evolving colonizer of our bodies. It demands a worthy combatant, and we are called upon to wage a war on the group of diseases cast as the monolith of “cancer.”<sup>15</sup> Patients are expected to be hopeful, to fight the war against their evil enemy, and to win. There is no war on diabetes—no war on heart attacks.

At Utah's distinguished Huntsman Cancer Institute (located on a cul-de-sac called the “Circle of Hope”), a patient has the encouraging message of “hope” presented to her on a mural in the lobby, on a large plaque in the elevator bank, and in selected inspirational quotes throughout the gift shop and building. The website for the hospital also highlights three institutional goals at the top of the homepage: (1) hope through research; (2) hope through education; and (3) hope through patient care.<sup>16</sup> Noticeably, there are no such merchants of hope for diabetes patients or patients with chronic obstructive pulmonary disease (“COPD”)—two diseases that regularly cause premature death.

The purpose of this Article will be to investigate the significant role cancer plays in our cultural denial of death. I will also analyze the legal structures,

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13. See Gregory W. Ruhnke et al., *Ethical Decision Making and Patient Autonomy: A Comparison of Physicians and Patients in Japan and the United States*, 118 CHEST 1172, 1173 (2000) (“Disclosure of a cancer diagnosis to the patient, for example, is a relatively recent phenomenon. Of US doctors surveyed in 1961, 88% generally did not inform their cancer patients of the diagnosis; by 1979, 98% generally did so. Physician-patient communication in the United States is now characterized by an emphasis on patient autonomy, which has become institutionalized by legally mandated informed consent procedures and the ideal of information disclosure.”).

14. SIDDARTHA MUKHERJEE, *THE EMPEROR OF ALL MALADIES: A BIOGRAPHY OF CANCER* 39 (2010).

15. *Id.* at 172–73.

16. See HUNTSMAN CANCER INST., <http://www.healthcare.utah.edu/huntsmancancerinstitute/> (last visited Oct. 2, 2015).

such as Medicare reimbursement policies, that perpetuate this death denial. These legal mechanisms often operate by encouraging unrealistic hope and aggressive care at the end of cancer patients' lives.

### I. A PREVALENT PROBLEM: INCURABLE CANCER PATIENTS THINK THEY CAN BE CURED

Death by cancer is becoming much more common. Roughly one in three women and one in two men will be diagnosed with cancer in their lifetime.<sup>17</sup> Nearly one-quarter of all deaths in the United States are from cancer.<sup>18</sup> Of those Americans who will die of cancer, the majority will be taken by one diagnosis: lung cancer. This Article will focus mostly on the data surrounding the treatment of lung cancer by the U.S. healthcare system.

The prognoses for most lung, brain, pancreatic, liver, and ovarian cancers are incredibly grim and have only improved modestly over the last 30 years. This is in part because screening tools are ineffective, and advanced symptoms, like persistent coughing, may be confused with bronchitis. As a result, the most common deadly cancer, lung cancer, is typically not diagnosed until after the tumors have spread, or metastasized, to other areas of the body. There are four stages of lung cancer, which represent how large the tumor is and how much the tumor has metastasized through the body. Doctors stage lung cancer through the use of blood tests, tissue biopsies, and radiological scans of the chest. In stage I, the tumor is confined to the lung, in stages II and III the tumor may reach the lymph nodes. In stage IV, the tumor has spread outside of the lung to other parts of the body. Almost 70% of lung cancer patients have progressed to stage III or IV by the time of diagnosis. In stage IV, where the five-year survival rate is less than 1%,<sup>19</sup> the oncology team's efforts are aimed at treating the side effects of the disease, not the disease itself. Similarly, by the time most ovarian, pancreatic, brain, and mesothelioma tumors are detected, the focus is on treating side effects rather than curing the underlying disease.

To put it bluntly, from the moment patients find out they have these common cancers, there is usually *zero* possibility for a cure.<sup>20</sup> Visits to the hospital's ICU then—to drain fluid, give pain medications, or remove a tumor that is making them uncomfortable—are generally *palliative*, not *therapeutic*.<sup>21</sup> The

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17. MUKHERJEE, *supra* note 14, at ix.

18. *Id.* Cancer is slowly edging out heart disease as the number one killer in America. *Id.*

19. NAT'L CANCER INST., SEER STAT FACT SHEETS: LUNG AND BRONCHUS CANCER, <http://www.seer.cancer.gov/statfacts/html/lungb.html> (last visited Oct. 2, 2015). This survival rate is based on people who were diagnosed with nonsmall-cell lung cancer between 1998 and 2000. *Id.*

20. See Jane C. Weeks et al., *Patients' Expectations About Effects of Chemotherapy for Advanced Cancer*, 367 NEW ENG. J. MED. 1616, 1617 (2012).

21. In addition to describing a type of intervention, there is also an entire medical specialty called palliative care. Palliative care physicians focus on pain management and physical comfort. While the service used to be associated with hospice almost exclusively, it has become much more integrated into inpatient and outpatient cancer care. Like hospice, early referral to palliative care results in fewer emergency room visits,



distinction, between improving the quality of life and treating the underlying disease, has been shown to be quite significant to nurses and physicians when making clinical decisions.<sup>22</sup> However, the dichotomy between the goals of palliative and therapeutic care is all too often obscured in the minds of terminal cancer patients.

#### *A. What Terminal Cancer Patients Say They Want to Be Told*

We have quite a bit of data as to what terminal cancer patients say they want to be told. Despite important individual differences, nearly all patients asked in the last 20 years have said that they want “full disclosure” about their prognosis, treatment options, and their expected survival outcomes.<sup>23</sup> Though the Institute of Medicine issued a report 15 years ago that called for this, most patients still do not have frank and ongoing conversations with their oncologists about their EOL goals of care.<sup>24</sup> Of course, sometimes a gap exists between what patients *report* that they would like to know (everything), and what they may *actually want to know* when confronted with the reality of terminal cancer (only the hopeful stuff). In one small study of terminal patients receiving palliative care, all patients desired their doctor to be “honest,” yet only 70% wanted to know the likelihood of a cure, and only 60% wanted to know their life expectancy.<sup>25</sup> Having stopped therapeutic measures,

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hospitalizations, and hospital deaths in the last 30 days of life. In a multivariate analysis, outpatient palliative-care referral was independently associated with less aggressive EOL care. See David Hui et al., *Impact of Timing and Setting of Palliative Care Referral on Quality of End-of-Life Care in Cancer Patients*, 120 *CANCER* 1743, 1746 (2014); Raymond W. Jang et al., *Palliative Care and the Aggressiveness of End-of-Life Care in Patients with Advanced Pancreatic Cancer*, 107 *J. NAT'L CANCER INST.* 1, 3–4 (2015).

22. See Hilde M. Buiting et al., *Understanding Provision of Chemotherapy to Patients with End Stage Cancer: Qualitative Interview Study*, 342 *BRIT. MED. J.* 1, 9 (2011). One general hospital physician from the interview study agreed:

Yes, I think the distinction [between a palliative and therapeutic approach] is always extremely important. I think it is important for the patient to know that, but it also has a tremendous impact on the way you administer the course of treatment. . . . In the case of palliative treatment, a holiday awkwardly planned in the middle of that treatment suddenly becomes nevertheless very important so that you have to adapt the treatment schedule accordingly.

*Id.* at 3.

23. Robin Matsuyama et al., *Why Do Patients Choose Chemotherapy near the End of Life? A Review of the Perspective of Those Facing Death from Cancer*, 24 *J. CLINICAL ONCOLOGY* 3490, 3494 (2006); see also Tracy M. Robinson et al., *Patient-Oncologist Communication in Advanced Cancer: Predictors of Patient Perception of Prognosis*, 16 *SUPPORT CARE CANCER* 1049, 1050 (2008) (“Many patients desire that their physicians provide detailed prognostic information in a direct and honest manner.”).

24. Matsuyama et al., *supra* note 23, at 3494; see also MARILYN J. FIELD & CHRISTINE K. CASSEL, *APPROACHING DEATH: IMPROVING CARE AT THE END OF LIFE* 61–64 (1997).

25. See K.C. Kadakia et al., *Palliative Communications: Addressing Chemotherapy in Patients with Advanced Cancer*, 23 *ANNALS OF ONCOLOGY* iii29, iii29 (2012) (citing Jean S. Kutner et al., *Information Needs in Terminal Illness*, 48 *SOC. SCI. & MED.* 1341, 1341–52 (1999)).

this willful ignorance may be because the patients knew that the number would be small.

There are many reasons why patients are not receiving full disclosure about their treatment options and survival outcomes. One reason is that physicians “pass the buck” and assume that someone else will have the difficult conversation with the patient. Intensive care doctors cannot assume that the oncologist has discussed EOL care, and oncologists cannot make the reverse assumption. Physicians cannot wash their hands of any EOL conversations, hoping that someone else will take care of them. Depending on the context, patients might be more willing to open up to particular doctors over others. For example, while most patients do not want to be kept in the dark regarding their prognosis, it seems that some would prefer to discuss their EOL plans with the physician that admits them into the ICU rather than their regular oncologist.<sup>26</sup> In other words, some patients would prefer to bring up their desires for hospice or withdrawal of care with someone that they have *only just met*, rather than someone with whom they have an extensive clinical history. This may seem counter-intuitive, but data suggest that patients might be afraid to raise the possibility of transitioning to palliative care with their oncologists because they worry that their oncologist will perceive them as giving up on the fight. Ironically, they do not want to let their oncologists—who have become their co-pilots in the battle against cancer—down. An ICU doctor, therefore, may present the outside perspective that the patient needs to voice her true desires. This again speaks to the cultural denial of death in most oncology practices; patients feel the need to distance themselves from their oncologists in order to feel free to discuss the reality of their death.

Another reason patients are not receiving the full disclosure they desire is that physicians seek to maintain hope for the patient’s loved ones. Physicians assume that surrogate decision-makers prefer hope over the truth when discussing prognoses, in order to not become too overwhelmed by the gravity of their loved ones’ situations. Once again, data suggest that this assumption does not hold. In face-to-face interviews with 179 surrogate decision-makers, 93% of the surrogates considered avoidance of prognosis discussions to be an “unacceptable way of maintaining hope.”<sup>27</sup> The main explanation that surrogates gave for this response was that a “timely discussion of prognosis is essential to allow family members to prepare emotionally and logistically for the possibility of a patient’s death.”<sup>28</sup>

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26. Nancy L. Keating et al., *Physician Factors Associated with Discussions About End-of-Life Care*, 116 *CANCER* 998, 1003 (2010) (“A small study of hospitalized cancer patients found that only 9% had discussed advance care preferences with their outpatient oncologist and only 23% of the remaining patients reported wanting to do so, although 58% of patients supported policies requiring housestaff to discuss advance care preferences at hospital admission.”) (citing Elizabeth B. Lamont & Mark Siegler, *Paradoxes in Cancer Patients’ Advance Care Planning*, 3 *J. PALLIATIVE MED.* 27, 27–35 (2000)).

27. Latifat Apatira et al., *Hope, Truth, and Preparing for Death: Perspectives of Surrogate Decision-Makers*, 149 *ANN. INTERNAL MED.* 861, 861 (2008).

28. *Id.* at 861–62. One limitation of the Apatira study is that the researchers did not assess the psychological outcomes of family members who did and who did not receive the prognostic information they say that they wanted.

Surrogate decision-makers also felt that without accurate prognosis information, they could not fulfill their role of supporting the patient's preferences and emotional needs.<sup>29</sup> In sum, those surrounding the patient do not appreciate when clinicians obscure the truth about the prognosis, even if clinicians only do so in order to maintain hope.

Again, counter-intuitively, even when the hard truth is shared with patients, researchers have found that patients remain hopeful. In fact, advanced cancer patients maintain hope about their future even after they are given a poor prognosis, told there is a low likelihood of response to treatment, and told there is *no chance* for a cure.<sup>30</sup> It is thought that receipt of honest prognostic information is an important component of hope because it empowers patients in their decision-making about medical care.<sup>31</sup> Even surrogates, who understood that the physician regarded the patient's prognosis as grim tended to remain hopeful in the face of this. Surrogates could recount the physician's estimate for survival, but personally believed that the patient was *twice as likely* to survive the cancer.<sup>32</sup>

Further complicating the idea that avoiding EOL discussions encourages hope, another study found that the parents of children with cancer were *more* hopeful, rather than less, when they received increased prognosis disclosure.<sup>33</sup> This held true even when the likelihood for a cure was low.<sup>34</sup> While this data may not extrapolate to larger groups, it does provide a basis for challenging the common assumption that providing prognostic information, even when it is incredibly grim, will devastate our capacity for hope. Many patients will find it empowering to have this prognostic information and to participate in treatment decision-making.<sup>35</sup> Remarkably, many will still find a way to remain hopeful in the face of near certain death.

To respond to a patient's unique disclosure preferences, any EOL discussion should begin with the physician asking the patient what she would like to be told and how much she would like to participate in decisions regarding her

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29. *Id.* at 865.

30. Jennifer W. Mack & Thomas J. Smith, *Reasons Why Physicians Do Not Have Discussions About Poor Prognosis, Why it Matters, and What Can Be Improved*, 30 J. CLINICAL ONCOLOGY 2715, 2715 (2012).

31. *Id.*

32. Susan J. Lee Char et al., *A Randomized Trial of Two Methods to Disclose Prognosis to Surrogate Decision Makers in Intensive Care Units*, 182 AM. J. RESPIRATORY CRITICAL CARE MED. 905, 907 (2010) (observing that surrogates were not far off when responding to questions about the physician's estimate for prognosis, but they thought the physicians were wrong; when asked what they themselves thought their loved one's prognosis was, they were much more optimistic).

33. The respondents were mostly white, married, well-educated women. It is not clear whether these results would extrapolate to other parent groups. Jennifer W. Mack et al., *Hope and Prognostic Disclosure*, 25 J. CLINICAL ONCOLOGY 5636, 5638 (2007).

34. *Id.*

35. Natasha Leighl et al., *Discussing Adjuvant Cancer Therapy*, 19 J. CLINICAL ONCOLOGY 1768, 1768 (2001) ("Among cancer patients, those who are offered choices in their treatment show better psychologic adjustment, and those who feel they have little control over their disease and treatment have a poorer psychosocial outcome.").

care. When a patient states that she does *not* want to participate in her EOL decision-making, physicians must explore the reasons for this to correct any factual misconceptions about the disease or its potential treatment. Although asking patients what they already know about the disease progression and the EOL decision-making process may be unpleasant, it can ensure that patients are making an informed choice. Regardless of the patient's answer, their disclosure preferences should be respected so long as it is autonomous and informed.<sup>36</sup>

***B. Empirical Data Confirm Terminal Cancer Patients Are Being Kept in the Dark***

Studies have shown that roughly one-third of all terminal lung cancer patients believe their cancer can be cured,<sup>37</sup> and if the question is asked in terms of the likelihood of being cured, *roughly 70% of lung cancer patients and 80% of colorectal cancer patients do not realize that a cure is "not at all likely."*<sup>38</sup> Of course, the progression of some breast, skin, and prostate cancers may be successfully halted, making the pursuit of a cure a realistic goal. However, other common cancers, such as mesothelioma, small-cell lung, or pancreatic cancer have median survival periods of about six to eight months after diagnosis—and fewer than 10% make it to five years.<sup>39</sup> For stage IV lung cancer, less than 1% of patients survive to five years.<sup>40</sup> *Less than one percent.* The fact that about 70% of these patients do not realize that a cure is highly unlikely indicates that a significant information gap exists between the physician and patient in terms of expected prognosis.

To be fair to physicians, they may not share the grim reality of the patient's prognosis out of a belief that they are helping. Physicians may worry about burdening their patients with excessively pessimistic information when their patients already have so much on their plate. This may be why physicians present fewer facts to patients regarding disease prognosis and EOL care compared with other types of clinical information.<sup>41</sup> Their reluctance to provide survival estimates has been demonstrated time and time again, and is ironic, given that if the physicians were terminally ill, they report wanting this information for themselves.<sup>42</sup> In addition to worrying about encouraging pessimism among

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36. Kadakia et al., *supra* note 25, at iii29.

37. Jennifer S. Temel et al., *Longitudinal Perceptions of Prognosis and Goals of Therapy in Patients with Metastatic Non-Small-Cell Lung Cancer: Results of a Randomized Study of Early Palliative Care*, 29 J. CLINICAL ONCOLOGY 2319, 2321 (2011).

38. Weeks et al., *supra* note 20, at 1617.

39. NAT'L CANCER INST., SEER CANCER STATISTICS. REVIEW 1975–2009, at 1–2 (2009), [http://www.seer.cancer.gov/csr/1975\\_2009\\_pops09/results\\_merged/topic\\_survival.pdf](http://www.seer.cancer.gov/csr/1975_2009_pops09/results_merged/topic_survival.pdf).

40. *Id.*

41. Karen Hancock et al., *Truth-Telling in Discussing Prognosis in Advanced Life-Limiting Illnesses: A Systematic Review*, 21 PALLIATIVE MED. 507, 507 (2007) (“Reasons [for why health professionals avoid discussing prognosis] include . . . fear of negative impact on the patient . . .”).

42. See Christopher K. Daugherty & Fay J. Hlubocky, *What Are Terminally Ill Cancer Patients Told About Their Expected Deaths? A Study of Cancer Physicians' Self-Reports of Prognosis Disclosure*, 26 J. CLINICAL ONCOLOGY 5988, 5992 (2008).

patients, physicians may also worry that they could thwart the patient's recovery if the healer is seen to be giving up. The problem is, of course, that while the physicians are waiting for the patients to signal their interest in an EOL conversation, the patients are similarly waiting for the physicians to raise these matters.<sup>43</sup> With no party wanting to take the lead, EOL discussions become an awkward dance of sorts, where each side expects the other to introduce the topic.<sup>44</sup> Consequently, meaningful EOL conversations rarely take place. It is understandable that everyone involved wants to encourage hope, but they incorrectly believe that denial is the best way to do so.

We know quite a bit about patients' understanding of their cancer prognoses and the care they are receiving. While the context varies, studies have repeatedly demonstrated that patients are *not* having necessary conversations about their EOL goals of care.<sup>45</sup> In addition, patients are often mistaken about what their process of dying will be like, what the rough survival estimates are, and whether there is a possibility of being cured.<sup>46</sup>

In 2001, researchers from the Netherlands conducted an observational study of small-cell lung cancer patients and noticed a recurring phenomenon in patients that they labeled "false optimism."<sup>47</sup> This term was used to describe patients who were significantly more hopeful about their prognosis than their healthcare providers were, at least when the providers were asked privately. The team found that false optimism typically developed during the first course of chemotherapy, and was most common when the cancer could no longer be seen on X-ray films.<sup>48</sup> When the tumor reappeared, optimism waned a bit, but it never fully went away; it would often reappear to a lesser degree during the later courses of chemotherapy.<sup>49</sup>

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43. See Mack & Smith, *supra* note 30, at 2715 ("Because many patients relied on physicians to initiate discussions, however, fears for the worst threatened hope when discussions did not take place."); see also Keating et al., *supra* note 26, at 1006.

44. Mary M. Step & Eileen Berlin Ray, *Patient Perceptions of Oncologist-Patient Communication About Prognosis: Changes from Initial Diagnosis to Cancer Recurrence*, 26 HEALTH COMM. 48, 54 (2011) ("It's a dance; and she'll tell me if I ask her, but I don't really ask her. I did ask her once and I didn't like the answer, so I don't ask her anymore [laughter].").

45. Rachele E. Bernacki & Susan Block, *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174 J. AM. MED. ASS'N INTERNAL MED. 1994, 1995 (2014).

46. Approximately one-third of the patients with terminal cancer incorrectly thought that the treatment would cure them. See Richard N. Eidinger & David V. Schapira, *Cancer Patients' Insight into Their Treatment, Prognosis, and Unconventional Therapies*, 53 CANCER 2736, 2738 (1984) ("These patients with advanced cancer were optimistic when asked the goal of their treatment program, with 37% of patients thinking it would cure them . . ."); see also WJ Mackillop et al., *Cancer Patients' Perceptions of Their Disease and Its Treatment*, 58 BRIT. J. OF CANCER. 355, 355 (1988) ("Sixteen of the 48 patients being treated palliatively believed that they were being treated with curative intent.").

47. Anne-Mei The et al., *Collusion in Doctor-Patient Communication About Imminent Death: An Ethnographic Study*, 321 BRIT. MED. J. 1376, 1376-77 (2001).

48. *Id.* at 1378.

49. *Id.*

This early study was intriguing. It described how patients could know on some level that they had cancer, but could still largely ignore their approaching deaths and remain optimistic. As the patients physically deteriorated and conversed in waiting rooms with other cancer patients, they learned that they were dying.<sup>50</sup> But because physicians were so active and aggressive in their treatment suggestions—and patients complied so enthusiastically with the “recovery plot”—the patients could “avoid acknowledging explicitly what they should and could know.”<sup>51</sup> Although patients recognized that they were dying, they did not want to hear their physicians say so. And physicians, trained to heal, did not want to explain this to their patients.<sup>52</sup>

A few other studies around this same time demonstrated that terminal patients were utterly confused about the purpose of their care. One study showed that 35% of cancer patients believed incorrectly that their purely palliative radiation was being done to cure their disease.<sup>53</sup> Another study showed that one third of metastatic lung cancer patients mistakenly thought that their palliative therapy had curative intent.<sup>54</sup> This last finding was replicated in a 2011 study of patients with metastatic nonsmall-cell lung cancer, where one third reported that their incurable cancer was curable, and a majority suggested that their clinical goal was “getting rid of all of the cancer.”<sup>55</sup> To recap, in four different studies, a *third* of terminally ill cancer patients did not understand why they were being given noxious and potentially debilitating treatments. While the patients thought these treatments might cure them, the medical team entertained no such hope. Instead, they pursued these courses to give their patients a few more weeks to live, or to make them more comfortable.

The false optimism that was shown over a decade ago can still be seen in cancer patients today. Perhaps they are in denial of their impending deaths, as the studies above indicate, because physicians are sending them mixed messages that lure them into thinking they can be cured. By aggressively pursuing new chemotherapies, devices, and surgeries, physicians and their teams may be inadvertently sending a message to cancer patients that they can beat the odds. And

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50. *Id.* (“Gradually patients would find out the facts about their prognosis, partly because of physical deterioration and partly through contact with fellow patients who were in a more advanced stage of the illness and were dying.”).

51. *Id.* at 1380. (“Initially patients and relatives colluded with doctors in maintaining a ‘recovery plot’: yesterday the patient was healthy, today he is ill, but tomorrow he will be better again, thanks to the efforts of the doctor and the patient, with support of carers. Although all parties individually would have occasional doubts about the validity of this plot, they would not acknowledge this publicly so as not to be seen as undermining the others’ trust in future recovery.”).

52. *See* Robinson et al., *supra* note 23, at 1056 (“Oncologists made statements of optimism twice as often as statements of pessimism in the recorded visits, although they were talking with patients that they would not be surprised if they died within a year.”).

53. *See* Edward Chow et al., *Patients with Advanced Cancer: A Survey of the Understanding of Their Illness and Expectations from Palliative Radiotherapy for Symptomatic Metastases*, 13 *CLINICAL ONCOLOGY* 204, 205 (2001).

54. Mackillop et al., *supra* note 46, at 356.

55. Temel et al., *supra* note 37, at 2319.

while obviously some of them can and will, it is nonsensical to say that all patients can be at the far right-end tail of the bell curve.

Unfortunately, the most recent and thorough study finds the same patient ignorance regarding prognosis that the older studies found. In a 2012 study of 1,193 advanced cancer patients published in the *New England Journal of Medicine*, 69% of those with lung cancer and 81% of patients with colorectal cancer misunderstood the purpose of their care. Specifically, when each group was asked how likely they thought chemotherapy was to cure their cancer, the patients did not understand that the chemotherapy was “not at all likely” to result in a cure.<sup>56</sup> Interestingly, patients were more likely to understand the purpose of the palliative chemotherapy if they received their care in an integrated network, or if they rated their physicians as having poor communication skills.<sup>57</sup> This suggests that physicians who are better at communicating an accurate, though dire, prognosis may be considered by patients to be “too negative” or “too pessimistic” in their communication style.<sup>58</sup> The implications for this last finding will be discussed later.<sup>59</sup>

When patients do not understand the purpose of their care, they are more likely to enter phase I clinical trials.<sup>60</sup> While recruiting enough phase I trial subjects is important to the commercialization of all drugs, cancer patients should be aware of what they are likely to receive by enrolling. The only purpose of a phase I trial is to test for toxicity in the drug; the patient is not likely to receive *any* clinical benefit.<sup>61</sup> Given that phase I trials are meant to gauge the safety of a drug and not benefit individual subjects it may seem surprising that patients are more likely to enroll in phase I clinical trials when they are optimistic about their outcome. Perhaps the reason is that they still see a small window, a chance of beating the cancer, and the clinical trial provides a means for exploiting this chance. Many patients confuse clinical trials with clinical care, and assume that they will receive some therapeutic benefit. This misunderstanding is called the “therapeutic misconception,” and occurs frequently when a patient signs up to be a

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56. Weeks et al., *supra* note 20, at 1616–19.

57. *Id.* at 1622.

58. *Id.* at 1619 (“Patients were less likely to provide inaccurate responses if they received their care in an integrated network (odds ratio, 0.70; 95% CI, 0.52 to 0.94; P = 0.02) or if they reported lower scores for physician communication, including a score of 80 to 99 versus a score of less than 80 (odds ratio, 1.37; 95% CI, 0.93 to 2.02) and a perfect score of 100 versus a score of less than 80 (odds ratio, 1.90; 95% CI, 1.33 to 2.72; P = 0.002 for the overall comparison).”).

59. *See infra* Part V.

60. *See* Robinson et al., *supra* note 23, at 1050.

61. U.S. FOOD & DRUG ADMIN., THE DRUG DEVELOPMENT PROCESS: CLINICAL RESEARCH, <http://www.fda.gov/ForPatients/Approvals/Drugs/ucm405622.htm> (last updated June 24, 2015) (“Phase I studies are closely monitored and gather information about how a drug interacts with the human body. Researchers adjust dosing schemes based on animal data to find out how much of a drug the body can tolerate and what its acute side effects are.”).

subject in a trial, confusing their status as patient and subject, and confusing the role of clinician and researcher.<sup>62</sup>

They incorrectly assume that the drug has some efficacy, even when the efficacy has not been demonstrated, and the trial is just gauging the toxicity of the compound. They might also misunderstand randomization, and assume that their “doctor” is always wearing his clinical hat, and would never assign them to the arm of the research where they merely receive placebo. In addition to the therapeutic misconception, optimistic cancer patients might be more likely to enroll in phase I clinical trials because they altruistically wanted to give back to the cancer community. Either way, signing up to test the toxicity of new drugs without receiving any personal clinical benefit is not a trivial thing. Advanced cancer patients should be aware that their cancer is incurable before they agree to suffer the side effects of new, and possibly ineffective, drugs.

Adding to the contours of this portrait, it is not as if oncologists are telling patients nothing at all. Multiple studies have shown that oncologists usually *do* talk to patients about their disease prognoses, and may mention that a particular cancer, like non-small-cell lung cancer, is not curable.<sup>63</sup> Relatedly, at some point in the patient’s disease progression, virtually all oncologists report that they do inform their patients that “they will die of their disease.”<sup>64</sup> How then, is there an information gap?

Even when physicians tell patients that their cancer will kill them, they usually do so ambiguously or in ways that leave the patients misunderstanding essential facts.<sup>65</sup> If the patient’s chart merely says that the disclosure of

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62. Gail E. Henderson et al., *Clinical Trials and Medical Care: Defining the Therapeutic Misconception*, 4 PUB. LIBR. SCI. MED. 1735, 1735 (2007) (“[M]any trial participants [are] unaware of study design implications, especially random assignment to a control or comparison group, often believing that they were assigned a medication based on what was best for them, personally.”).

63. The et al., *supra* note 47, at 1378; *see also* Melina Gattellari et al., *When the Treatment Goal Is Not Cure: Are Cancer Patients Equipped to Make Informed Decisions?*, 20 J. CLINICAL ONCOLOGY 503, 507 (2002) (“The majority of patients were told how treatment would act on the tumor (85.6%), the aim of treatment (84.7%), and that their disease was incurable (74.6%).”).

64. Elizabeth B. Lamont & Nicholas A. Christakis, *Prognostic Disclosure to Patients with Cancer near the End of Life*, 134 ANNALS OF INTERNAL MED. 1096, 1096 (2001) (“For 300 of 311 evaluable patients (96.5%), physicians were able to formulate prognoses. Physicians reported that they would not communicate any survival estimate 22.7% (95% CI, 17.9% to 27.4%) of the time. Of the discrepant survival estimates, most (70.2%) were optimistically discrepant. Multivariate analysis revealed that older patients were more likely to receive frank survival estimates, that the most experienced physicians and the physicians who were least confident about their prognoses were more likely to favor no disclosure over frank disclosure, and that female physicians were less likely to favor frank disclosure over pessimistically discrepant disclosure.”).

65. Anthony L. Back et al., *Communication About Cancer near the End of Life*, 113 CANCER 1897, 1900 (2008) (“Although physicians generally self-assess their communication about disclosure favorably, studies of patients show gaps in what physicians think they convey and what patients actually perceive. In a Canadian study, 98% of physicians thought they had accurately described the extent of disease to their patients, but



“incurability” was made on a given date, it does not mean that the patient fully understood. Our denial of death and optimism bias are both so strong that we may need to hear this information more than once, and not sandwiched in between the physician’s optimism regarding the patient’s short-term success with palliative treatments. If the message is ever mixed, patients will likely choose to remember the good news rather than the bad.

More to the point for this Article, patients who have overly optimistic perceptions of their prognosis are also more likely to pursue aggressive surgeries, chest compressions, tracheotomies, mechanical ventilation, and palliative chemotherapy.<sup>66</sup> In addition to causing nausea, fatigue, and pain, aggressive therapies significantly drive up the cost of coverage for both Medicare patients and the privately insured.<sup>67</sup> These treatments also make it much more likely that the patient will die in the hospital, unable to speak, and connected to multiple machines. Of course, many would still elect to do everything, even if they completely understood what these interventions could actually do for them. They might find it much more reassuring to die from the removal of a ventilator. The choice of how to proceed at the end of life is undoubtedly a spiritual and personal one, and must be based on full information about disease prognosis, reasonable clinical options, and the patient’s values.

### ***C. The Gap Between Physician and Patient Understanding of Prognosis Impairs EOL Decision-Making***

It has been well-documented for over 15 years that a significant gap exists between what healthcare providers know and what terminal cancer patients understand about their prognosis and the purpose of their care.<sup>68</sup> I will refer to this

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almost [one-]third of patients with metastases thought their disease was localized. Similarly, although 90% of physicians reported telling the patient the intent of therapy, almost [one-]third of patients being treated palliatively thought that their therapy was curative.”)

66. Matsuyama et al., *supra* note 23, at 3491 (“Patients who thought they were going to live for 6 months were 2.6 times as likely to choose aggressive anticancer therapy instead of palliative care. These patients who received so-called aggressive antineoplastic treatment had the same survival as those who received other types of care, but were more likely to have a hospital readmission, undergo attempted resuscitation, or die while receiving ventilator support.”); *see also* Temel et al., *supra* note 37, at 2319 (“Patients with advanced cancer who have poor illness understanding and overestimate their prognosis are more likely to choose aggressive medical care at the end of life.”).

67. *See* Patricia Bomba, *Landmark Legislation in New York Affirms Benefits of a Two-Step Approach to Advance Care Planning Including MOLST: A Model of Shared, Informed Medical Decision-Making and Honoring Patient Preferences for Care at the End of Life*, 17 WIDENER L. REV. 475, 485 (2011).

68. Jane Weeks et al., *Relationship Between Cancer Patients' Predictions of Prognosis and Their Treatment Preferences*, 279 JAMA 1709, 1712 (1998) (“Specifically, patients who believed that they would survive for at least 6 months favored life-extending therapy over comfort care at more than double the rate of those who believed that there was at least a small chance (as little as 10%) that they would not live 6 months. This association was most marked in patients who were optimistic about their probability of surviving 6 months despite physician estimates to the contrary. In addition, we found that patients greatly overestimated their chances of surviving 6 months, while physician-prognostic

information asymmetry simply as the “information gap.”<sup>69</sup> This information gap represents fundamental flaws in our current model of informed consent, which focuses on capturing a patient’s signature as opposed to understanding the patient’s evolving preferences.

The existence of the information gap is important for three reasons. First, patients cannot fully participate in their treatment decisions if there is an information gap. Specifically, patients cannot provide meaningful consent to particular drugs, procedures, or hospital admissions if they assume that the goal of these treatments is to cure the cancer when in reality a cure is nearly impossible and the treatments will only reduce the side effects of the disease. Expecting a cure skews the benefits of intervention; patients are much more willing to experience pain, removal from their homes, disability, fatigue, and financial cost if they think they are waging a war on cancer that they could win.

The second, and related problem with the information gap is that patients are robbed of the opportunity to get their personal and financial affairs in order. If they think that they have more time left than they do, patients may avoid the administrative tasks related to death, including estate planning. When a patient does pass, their loved ones are left in an incredible bind—where they must simultaneously grieve, plan a funeral, and divide assets. This burden could be eased if patients took the initiative and conducted some financial planning before they got too sick to do so. But of course, patients may need to realize that the end is near before they will be motivated to engage in this sort of personal and financial planning.

The third problem with the information gap is perhaps the most psychologically troubling. When patients misunderstand the goals of their care and the likelihood of being cured, it suggests that no one has spoken with them frankly about their impending death. And if this is the case, then the clinical team cannot possibly know the patients’ desires regarding the dying process itself. Without this knowledge, the final wishes of the patient will likely not be honored. If the providers wait until the very end to engage in EOL conversations, the discussions may be rushed or stressful, or the emotions of the very near death may impair patients’ ability to engage.

In the event the patient does suddenly crash, this can also put an unbelievable burden on the surrogate decision-makers, who may be left speculating what the patient would have wanted done to her body. Should the feeding tube be inserted? Would she want that? What sorts of risks would she be willing to endure to potentially gain a few more months? Would she rather be at home? Does she just want to make it to see the birth of her granddaughter? If there is no discussion of the dying process, the best that surrogates can do is guess.

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estimates were more accurate. Finally, we found that patients who expressed a preference for life-extending therapy were more likely to undergo aggressive treatment, but controlling for known prognostic factors, their 6-month survival was no better.”).

69. More will be said about the empirical support for this phenomenon. *See infra* Part III.

To some readers, it might be shocking that there really is an information gap. *How could advanced cancer patients not know that they are dying?* We are all dying; death is unavoidable. But for terminally ill patients, death can be so drawn-out and negotiated that they are coaxed into thinking they can halt it by trying just one more drug, or undergoing just one more surgery. Thus, despite knowing on some level that they have cancer, and perhaps even understanding that this will significantly shorten their lives, advanced cancer patients are quite frequently holding out hope for a cure. The development and use of so many different cancer drugs only fuels this fire, as clinicians experiment to see if their particular type of cancer mutation responds to novel treatments. There is frequently another option that just *might* work in this case. This narrative is reinforced by the messages of hope that are so pervasive in the promotion of cancer hospitals and clinics.

Emboldened with faith in modern medicine, patients pursue risky, painful, and expensive treatments that they might not pursue if they knew they were gaining weeks instead of months, or not gaining any time at all. Whatever their wishes for their death, a substantial number of patients are not given a chance to articulate them because nobody asks. Instead, metastatic cancer patients are exposed to third-line experimental chemotherapy treatments, even when the first and second efforts were unsuccessful.<sup>70</sup> They are operated on within the last days of life and are placed on ventilators, compelling difficult decisions by family about whether to “pull the plug.” Not only can these interventions actually hasten death, but they can also lead to deaths that are more psychologically stressful for patients and their caretakers, especially if they involve interventions that the patient did not understand or want.<sup>71</sup>

Some patients would still wish to “do everything” if they fully appreciated their prognosis, and when possible, this request should be respected. However, other patients would choose differently. Instead of receiving painful and expensive treatments, many patients would likely transition to hospice care.<sup>72</sup> Hospice is a philosophy of care that focuses on the symptoms of one’s disease, and on prioritizing comfort, compassion, quality of life, and the patient’s autonomy.<sup>73</sup> Hospice treatment often involves administering things like antibiotics, placing feeding tubes, removing fluids, managing wounds, or giving pain medications. It

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70. Third-line therapy is the use of chemotherapy for a third time, often with the third treatment being considered less effective than the “first-line” or “second-line” options. See Nick Thatcher et al., *Gefitinib Plus Best Supportive Care in Previously Treated Patients with Refractory Advanced Non-Small-Cell Lung Cancer: Results from a Randomised, Placebo-Controlled, Multicentre Study (Iressa Survival Evaluation in Lung Cancer)*, 366 LANCET 1527, 1533 (2005).

71. Buiting et al., *supra* note 22, at 4; Maarten Hofman et al., *Cancer Patients’ Expectations of Experiencing Treatment-Related Side Effects: A University of Rochester Cancer Center—Community Clinical Oncology Program Study of 938 Patients from Community Practices*, 101 CANCER 851, 851–57 (2004).

72. See Ziad Obermeyer et al., *Association Between the Medicare Hospice Benefit and Health Care Utilization and Costs for Patients with Poor-Prognosis Cancer*, 312 JAMA 1888, 1889 (2014).

73. *What Is Hospice?* HOSPICE FOUND. OF AM., <http://hospicefoundation.org/End-of-Life-Support-and-Resources/Coping-with-Terminal-Illness/Hospice-Services> (last visited Oct. 30, 2015) [hereinafter *What Is Hospice?*].

usually does not involve intensive procedures such as chemotherapy, cardio resuscitation (“CPR”), or mechanical ventilation. Hospice represents an alternative to the invasive and heroic measures of research hospitals and ICUs. In its many forms, hospice can also provide assistance to the patients’ caregivers and families to help them cope with their loved one’s death, and to provide nursing support if the patient wants to remain at home.

Regrettably, due to many misconceptions about hospice care, hospice suffers from an unjustified stigma. Many people think that hospice care accelerates death, because patients are “giving up.” With hospice, there are usually no ICU visits or hospital interventions,<sup>74</sup> and patients are given powerful narcotics to combat pain. But astonishingly, hospice does not actually hasten death for cancer patients. A study of roughly 4,500 Medicare patients found that for some conditions, hospice care seemed to extend survival.<sup>75</sup> Patients with pancreatic cancer gained an average of three weeks, those with lung cancer gained six weeks, and those with congestive heart failure gained three months. According to Atul Gawande’s take on this research: “The lesson seems almost zen—you live longer only when you stop trying to live longer.”<sup>76</sup>

The use of hospice has increased in the United States in the last two decades, but still remains relatively low, and the average length of hospice stays has decreased.<sup>77</sup> More terminally ill patients would choose hospice if they were given a forthright account of the progress of their disease.<sup>78</sup> This would allow some to say goodbye to loved ones on their own terms. More patients would be able to die at home, which is where the large majority of Americans say that they would prefer to die.<sup>79</sup>

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74. In July of 2015, the Centers for Medicare & Medicaid Services (“CMS”) announced that a select number of pilot hospices would be able to introduce the new “Medicare Care Choices Model.” This model provides Medicare beneficiaries who qualify for the Medicare hospice benefit and *dually eligible beneficiaries who qualify for the Medicaid hospice benefit* the option of receiving palliative care as well as some curative services. See Press Release, U.S. Dep’t of Health & Human Servs., CMS Announces Medicare Care Choices Model Awards (July 20, 2015), <http://www.hhs.gov/news/press/2015pres/07/20150720a.html>.

75. Stephen R. Connor et al., *Comparing Hospice and Nonhospice Patient Survival Among Patients Who Die within a Three-Year Window*, 33 J. PAIN & SYMPTOM MGMT. 238, 242–43 (2007).

76. GAWANDE, *supra* note 12, at 178–79.

77. Obermeyer et al., *supra* note 72, at 1889.

78. *Id.* at 1895 (“[T]hose receiving hospice care, compared with matched control patients not receiving hospice care, had significantly lower rates of hospitalization, intensive care unit admission, and invasive procedures at the end of life, along with significantly lower health care expenditures during the last year of life.”).

79. I.J. Higginson & G.J.A. Sen-Gupta, *Place of Care in Advanced Cancer: A Qualitative Systematic Literature Review of Patient Preferences*, 3 J. PALLIATIVE MED. 287, 297 (2000); see also Nancy E. Morden et al., *End-of-Life Care for Medicare Beneficiaries with Cancer Is Highly Intensive Overall and Varies Widely*, 31 HEALTH AFF. 786, 786 (2012) (“When confronted with such poor survival chances [dying in one year] in the face of cancer and other illness, the average patient prefers to spend as much time as possible in a home-like setting with good control of pain and other symptoms.”).

To be abundantly clear, hope is not the enemy. Hope energizes us and it reminds us why we live. The mere presence of optimism or hope in terminal cancer care is not the concern of this Article. This Article also makes no claim about how individuals *ought* to value an incremental extension of their life at the end of life.<sup>80</sup> Rather, this Article is concerned with the unique way the legal system encourages the *denial of death* in terminally ill cancer patients—a pursuit that is expensive and psychologically harmful.<sup>81</sup>

#### ***D. Why Physicians Do Not Initiate Prognosis-Related EOL Conversations***

Several studies have been conducted regarding physicians' communication with terminally ill lung cancer patients. In one study, 20% of respondents (n=276) reported that their physicians communicated “not at all” or “a little bit” about symptoms, spiritual concerns, practical needs, proxy appointment, living will preparation, prognosis, care goals, and potential complications of treatment.<sup>82</sup> Disclosing a poor prognosis may conflict with the clinician's sense of obligation to communicate in a way that leaves room for hope.<sup>83</sup> In this way, physicians and nurses may be withholding prognostic information with the paternalistic belief that they are actually helping. This explains why nearly half of patients report that their physician communication *always* made them feel hopeful.<sup>84</sup>

##### *1. Executing a Living Will Is the Beginning of the Conversation, Not the End*

Regardless of whether the reason is charitable, in 2015 it is unethical for a physician to fail to examine how much a patient wants to know, and if the patient seeks to be fully informed, it is similarly unethical to fail to discuss the patient's disease and treatment prognosis with her—no matter how grim. There are many avenues for introducing the topic of EOL care. One way is to suggest that the patient complete an advance directive (otherwise known as a “living will”). An advance directive can take the form of appointing a surrogate decision-maker to make certain healthcare decisions in the event one loses medical decision-making

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80. A recent article detailed the various psychological factors that might explain how terminally ill people value life at the end of life. Paul T. Menzel, *The Value of Life at the End of Life: A Critical Assessment of Hope and Other Factors*, 39 J. L. MED. & ETHICS 215 (2011). This article does not suggest that there is one subjectively or normatively correct way to value life. Rather, it encourages the patient to work this out in a way that is concordant with her values, but with the requirement that this evaluation be fully informed and not the result of confusion or ignorance. *See id.* at 217.

81. While some have argued “it would be inaccurate to describe hope as ‘false’ when the available evidence suggests that it consistently contributes to greater productivity and well-being in various life arenas,” in this Article I argue that encouraging false hope is always unduly harmful if it rests on the patient's ignorance to her disease prognosis. *See C.R. Snyder et al., “False” Hope*, 58 J. CLINICAL PSYCHOL. 1017 (2002).

82. Judith E. Nelson et al., *Patients Rate Physician Communication About Lung Cancer*, 117 CANCER 5212, 5214–15 (2011).

83. Mack et al., *supra* note 33, at 5636.

84. *See id.* at 5640 (“[T]he relationship between hope and disclosure could be explained by the disclosure of overly optimistic prognoses to parents.”).

capacity. Alternatively, an advance directive can also instruct physicians as to specific types of care that a patient may or may not want.

Federal law requires healthcare institutions to provide adult patients with information about how to complete an advance directive when patients are admitted to the facility.<sup>85</sup> Each state, however, has different legal requirements for enforcing advance directives, making them confusing for patients to complete. In addition, the terms of an advance directive are not easy to interpret once a patient lacks medical decision-making capacity. In many cases, patients are given a form to sign, and no one consults with the patient after completing the form to make sure their selections make sense. For example, patients may select the box saying that should they crash, they want to be “DNR” (do not resuscitate). But patients may also elect to be ventilated and receive tube feedings—two procedures that are typically not indicated when a patient prefers not to be resuscitated. Furthermore, the form itself may not wind up in the patient’s medical record, or in the emergency department when there is a crisis. Finally, many patients are reluctant to complete the form out of a fear that it may set their present intentions in stone, or out of a general fear of death.<sup>86</sup> This reluctance may be overcome when patients hear “personal stories of others who have had to make EOL decisions for a loved one without any guidance, [as] the desire to save their family from these painful experiences can become a prime motivator for putting their own wishes in writing.”<sup>87</sup> Despite the shortcomings of relying on advance directives exclusively, requiring patients to complete an advance directive can initiate conversations about patient preferences at the end of life. This is an important first step that should be the beginning of the conversation, not the end.

## 2. *The Timing of EOL Conversations Is Often Inopportune*

In addition to the formal process of completing an advance directive, providers must take the time to discuss EOL goals of care with their patients. Once physicians have determined that a patient is terminal, this conversation should take place multiple times throughout the course of the patient’s subsequent treatment. Alas, telling a patient that she is near death, and then offering to discuss her EOL care, is easier said than done. There are multiple reasons why thorough EOL conversations rarely take place. A major reason is that physicians are busy. Given everything that they are expected to accomplish in the short amount of time that they have with patients, it may be impractical to ask them to spend more time discussing EOL care. The current fee-for-service reimbursement climate makes this even more improbable. Physicians get paid to *do* things to patients, not to *talk*

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85. The Patient Self-Determination Act (“PSDA”) was passed by Congress in 1990 as an amendment to the Omnibus Budget Reconciliation Act of 1990. Pub. L. No. 101-508, 104 Stat. 1388 (1990) (codified in scattered sections of 42 U.S.C.).

86. See INST. OF MED., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCE NEAR THE END OF LIFE 117–18 (2015) (observing that patients who have a greater fear of death are significantly less likely to complete a form).

87. *Id.* at 126 (citing S.D. Halpern, *Shaping End-of-Life Care: Behavioral Economics and Advance Directives*, 33 SEMINARS IN RESPIRATORY AND CRITICAL CARE MED. 393 (2012); K.E. Steinhauer et al., *Factors Considered Important at the End of Life by Patients, Families, Physicians, and Other Care Providers*, 284 JAMA 2476 (2000)).

about why or whether to do these things. More will be said about this important factor later.<sup>88</sup>

To highlight how short the initial conversations about prognosis typically are, a 2010 study of 437 patients found that nearly half (44%) remember being given their cancer diagnosis during a conversation that lasted no longer than ten minutes, with 8% saying that the initial discussion of diagnosis lasted less than one minute.<sup>89</sup> Moreover, almost a fifth of the patients (18%) were told about their diagnosis over the phone.<sup>90</sup> Of course, an EOL conversation should be thought of as an ongoing dialogue, and not a one-time event that occurs at diagnosis. Indeed, it may be better for physicians to discuss prognosis during a later conversation, after the patient has had some time to reflect on their new reality. Even so, a critical opportunity for discussing typical disease trajectories is missed if the initial conversation is impersonal or rushed.<sup>91</sup> And a brief or impersonal initial conversation about diagnosis might set the wrong tone for the future doctor–patient relationship, one in which the patient assumes that the role of the doctor will be to provide information, and the role of the patient will be to listen.

Even after diagnosis, patients are not being told enough about their EOL options. This means that, while some oncologists may be doing all that they can to ensure their patients die the way they want to die, most are not doing nearly enough. Prognosis disclosures range from the simple oral communication of a diagnosis, to a description of anticipated symptoms, to a written time estimate of disease or symptom progression.<sup>92</sup> The timing of this disclosure also varies, often coming too late.<sup>93</sup> In one study, only about two-thirds of physicians discussed disease prognosis on the first visit, when the cancer diagnosis was made.<sup>94</sup> Fifteen percent of physicians reported that they would have an EOL discussion only if the

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88. See *infra* Section I.D.7.

89. William D. Figg et al., *Disclosing a Diagnosis of Cancer: Where and How Does It Occur?*, 28 J. CLINICAL ONCOLOGY 3630, 3632 (2010). Their memories might over- or underestimate the actual time that was spent. This study has been criticized because the researchers did not provide the actual questionnaire in the appendix.

90. *Id.* at 3633.

91. In this first encounter, the physician should make sure the room is private and comfortable, the diagnosis is delivered in person and with competence, and the patient has adequate time to ask questions. See Francesca C. Dwamena et al., *Breaking Bad News: A Patient-Centered Approach to Delivering an Unexpected Cancer Diagnosis*, 11 SEMINARS IN MED. PRAC. 11, 14 (2008); see also Patricia A. Parker et al., *Breaking Bad News About Cancer: Patients' Preferences for Communication*, 19 J. CLINICAL ONCOLOGY 2049, 2054 (2001).

92. Kadakia et al., *supra* note 25, at iii29.

93. See Jennifer W. Mack et al., *Associations Between End-of-Life Discussion Characteristics and Care Received near Death: A Prospective Cohort Study*, 30 J. CLINICAL ONCOLOGY 4387, 4394 (2012) (“One path is characterized by early discussion about EOL care, greater use of hospice care including early hospice initiation, and less use of aggressive care. The alternative path features EOL discussions that start in the last 30 days of life (or never take place), accompanied by aggressive care in the last month and less and later hospice initiation.”).

94. Keating et al., *supra* note 26, at 1000 (“Overall, 65% of physicians would discuss prognosis [when the victim is first diagnosed].”).

patient or her family initiated it.<sup>95</sup> In this same study, about one-quarter of physicians said they would wait until they have *exhausted all treatment options* before discussing the patient's code status<sup>96</sup> with them.<sup>97</sup> This defers the EOL discussion until it is woefully too late, and can create a very desperate and pessimistic tone when it finally does take place.<sup>98</sup> It would be much better to discuss the patient's values and EOL goals of care periodically and in light of new clinical information, rather than waiting until the doctor has decided that there is nothing more that can be done.

### 3. Physicians Are Uncomfortable Prognosticating

At this point, any healthcare provider reading this will say that there is an explanation for their uneasiness in delivering direct EOL prognoses. Their defense goes like this: Disease survival estimates are notoriously incorrect. Physicians, knowing this from their own humbled experience of being wrong, resist giving patients overly objective estimates.<sup>99</sup>

To be fair, the data show that physicians *are* often wrong in their survival estimates. A meta-review of eight different studies showed that physicians' predictions were "poor."<sup>100</sup> However, this was not because physicians' life expectancy estimates were all over the map. Instead, it was because the estimates were usually *too optimistic*, with physicians overestimating survival time in roughly 80% of cases.<sup>101</sup> Still, in this meta-review, while the estimates were usually rosy, the predictions were still not *that* far off. Physicians predicted a median survival of 42 days and the median actual survival was 29 days.<sup>102</sup> Unfortunately, this does not appear to be remedied by getting to know patients personally, as the doctors who knew their patients better were *even more likely* to overestimate survival time.<sup>103</sup> This suggests that as the physicians became more personally invested in seeing their patient survive, physicians themselves were more likely to experience a false sense of hope.

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95. *Id.*

96. Code status refers to whether the patient would want to be resuscitated should she go into cardiac arrest. *See id.* at 1001.

97. Keating et al., *supra* note 26, at 1003.

98. *See* Wentlandt et al., *Preparation for the End of Life in Patients with Advanced Cancer and Association with Communication with Professional Caregivers*, 21 *PSYCHO-ONCOLOGY* 868, 874 (2011).

99. *See* Hancock et al., *supra* note 41, at 511.

100. Marija Trajkovic-Vidakovic et al., *Symptoms Tell It All: A Systematic Review of the Value of Symptom Assessment to Predict Survival in Advanced Cancer Patients*, 84 *CRITICAL REVIEWS IN ONCOLOGY/HEMATOLOGY* 130, 137 (2012).

101. *See* Elizabeth B. Lamont & Nicholas A. Christakis, *Complexities in Prognostication in Advanced Cancer: "To Help Them Live Their Lives the Way They Want to,"* 290 *JAMA* 98, 99 (2003) ("[I]n this vignette, Dr D substantially underestimated Ms M's survival, an event which has been shown to occur in less than 20% of patients.").

102. Paul Glare et al., *A Systematic Review of Physicians' Survival Predictions in Terminally Ill Cancer Patients*, 327 *BRIT. MED. J.* 195, 196 (2003).

103. GAWANDE, *supra* note 12, at 167.



Even when patients press their physicians to give them specific survival estimates, many physicians resist doing so. As Atul Gawande notes:

More than 40 percent of oncologists admit to offering treatments that they believe are unlikely to work. In an era in which the relationship between patient and doctor is increasingly miscast in retail terms—‘the customer is always right’—doctors are especially hesitant to trample on a patient’s expectations. You worry far more about being overly pessimistic than you do about being overly optimistic.<sup>104</sup>

Stunningly, it has also been shown that the youngest patients with the poorest prognoses are the *least* likely to get an honest prognosis.<sup>105</sup> Physicians “give the least honest figures to those with the worst prognoses (and perhaps most in need of information to make decisions).”<sup>106</sup> One study found that when patients who were referred to hospice explicitly asked about their prognosis, physicians provided an honest estimate only 37% of the time.<sup>107</sup> Typically, they would provide no estimate or a conscious overestimate of survival time to these terminal patients.<sup>108</sup> Another study showed that physicians could mitigate this information gap if they removed overly positive qualitative statements from their conversations with patients or gave one negative fact about the patient’s prognosis.<sup>109</sup>

To improve disease prognosis, physicians and nurses need more communication training in how to convey bad news. In one study, 58% percent of surveyed physicians said that they had *no formal education* in delivering negative prognoses or discussing EOL options.<sup>110</sup> Given how tight their time is with patients, their insecurity in delivering bad news, and perhaps their own fear of mortality, it is no wonder physicians do not prioritize communicating unpleasant prognoses.

One way of signaling that the goals of care are palliative rather than therapeutic is to say, “[t]he goal is for you to do as well as possible for as long as possible.”<sup>111</sup> Experts recognize that this statement may be difficult to comprehend, so they recommend separating it into more digestible goals. The physician may therefore say that her treatment goals are to have: “(1) the fewest side effects as possible from the cancer, (2) the fewest side effects as possible from the treatment, (3) the best quality of life, and (4) the longest life. These simpler concepts are more understandable.”<sup>112</sup>

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104. *Id.* at 167–68.

105. Keating et al., *supra* note 26, at 998–1006.

106. Mack & Smith, *supra* note 30, at 2716.

107. *Id.* (citing Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctor’s Prognoses in Terminally Ill Patients: Prospective Cohort Study*, 320 BRIT. MED. J. 469 (2000)).

108. *Id.* (citing Robinson et al., *supra* note 23, at 1049–57).

109. *Id.* (citing Robinson et al., *supra* note 23, at 1049–57).

110. Daugherty & Hlubocky, *supra* note 42, at 5990.

111. Kadakia et al., *supra* note 25, at iii29.

112. *Id.* at iii30.

At present, providers are not well prepared psychologically to answer the tough question: “Doctor, how long do I have?”<sup>113</sup> Providers resist putting a fixed number on the predicted survival time, or having an EOL discussion generally, because they not only want to encourage hope but also lack training in responding to a patient’s emotions or fears. In two studies, “stress” was cited as a major factor inhibiting a physician’s full prognostic disclosure.<sup>114</sup> A majority of doctors from various countries reported “it was stressful to deal with their patients’ families, respond to their patients’ emotions, to be honest without depressing their patients and to handle their own negative feelings . . . .”<sup>115</sup>

Prognostic models exist to aid physicians along the way—though many clinicians find them to be cumbersome and inaccurate.<sup>116</sup> While some models are more accurate than others, predictions of life expectancy are more accurate—and less misleading to patients—when expressed in probabilistic terms, rather than absolute values.<sup>117</sup> And even though probabilities may be more accurate, making an inference from group data—e.g., lung cancer patients (generally) to the individual (this patient)—can be tricky.

To aid in providing inferences from groups to individuals, researchers and clinicians must collect and publish more precise population data regarding predicted versus actual survival times. These studies must stratify patients by factors such as age, the potential genetic contributions to their cancer, their individual symptoms, tumor burden, or immune function. This will assist physicians in contextualizing disease prognoses by tailoring the group information to account for individual differences. It will also go a long way to help patients comprehend the probabilistic figures, a task at which we humans are notoriously weak.<sup>118</sup> Some of these studies have already been done.<sup>119</sup>

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113. Paul A. Glare & Christian T. Sinclair, *Palliative Medicine Review: Prognostication*, 11 J. OF PALLIATIVE MED. 84, 84 (2008) (“Despite this crucial role, expertise in the art and science of prognostication diminished during the twentieth century, due largely to the ascendancy of accurate diagnostic tests and effective therapies. Consequently, ‘[d]octor, how long do I have?’ is a question most physicians find unprepared to answer effectively. As we focus on palliative care in the twenty-first century, prognostication will need to be restored as a core clinical proficiency.”).

114. Hancock et al., *supra* note 41, at 510 (citing Walter F. Baile et al., *Oncologists’ Attitudes Toward and Practices in Giving Bad News: An Exploratory Study*, 20 J. CLINICAL ONCOLOGY 2189 (2002); Nicholas A. Christakis & Theodore J. Iwashyna, *Attitude and Self-Reported Practice Regarding Prognostication in a National Sample of Internists*, 158 ARCHIVES INTERNAL MED. 2389 (1998)).

115. Hancock et al., *supra* note 41, at 510.

116. David Hui et al., *The Accuracy of Probabilistic Versus Temporal Clinician Prediction of Survival for Patients with Advanced Cancer: A Preliminary Report*, 16 ONCOLOGIST 1642, 1643 (2011).

117. Physicians were more accurate in estimating life expectancy when their answers took the form of “the approximate probability that this patient will be alive . . . in [x] hours, days, weeks, months is [y] %” rather than when they attempted to give an approximate number for the survival time for this particular patient. *See id.* at 1646–47.

118. Adrian Edwards et al., *Explaining Risks: Turning Numerical Data into Meaningful Pictures*, 324 BRIT. MED. J. 827, 827 (2002) (“Terms such as probable, unlikely, rare, and so on have been shown to convey ‘elastic’ concepts. One person’s understanding

In the meantime, even if a physician does not have specific and accurate predictors of probable disease prognosis, she can better serve patients by telling them whether it is likely they will fall into the “worst case,” “normal,” or “best case” survival estimates. These classifications for some types of cancer can be determined based on deriving multiples of an overall survival curve’s median, with estimates of “worst-case” being one quarter of the median survival time, “typical” being half to double the median, and “best-case” life expectancy being triple the median.<sup>120</sup> While still far from perfect, classifying patients into these probabilistic groups can, at the very least, help patients determine whether to start chemotherapy or pursue risky and expensive interventions.

The general belief that physicians are poor prognosticators offers a plausible cover. Under this cover, physicians can, and do, refuse to offer specific estimates of survival time. Instead of being seen as paternalistic, their withholding is somehow justified by their humble ineptitude and lack of data. It can also be justified on the basis that patients will struggle to understand the probabilistic data. However, we should not let the perfect prediction be the enemy of the good that comes from open discussion, given all that is riding on these estimates. Even if some patients misunderstand or deny the facts that are given to them, it does not mean that physicians should stop providing *everyone* with reasonable estimates. Compassion, or imperfect reception, should not translate into the withholding of critical information. Rather, the information must be qualified as an estimate, a likelihood, but not the product of a perfect crystal ball.

While physicians are uncomfortable telling patients how much time they have left, they are often much more comfortable estimating *treatment* prognosis. Compared to disease prognosis, which assesses the overall goals of care for the disease, treatment prognosis involves the physician providing information on the outcome of particular treatments, such as a chemotherapy drug, a tumor resection,

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of ‘likely’ may be a chance of 1 in 10, whereas another may think that it means a chance of 1 in 2 . . . . Interpretation of numerical information is problematic. For example, [one research team] found that death rates of 1,286 out of 10,000 were rated as more risky than rates of 24.14 out of 100. In addition, the interpretation of the probabilistic elements of risk cannot be divorced from the importance of the harm, which includes the meaning of the harm and its implications for lifestyle and health (such as the threat of cancer).”); *see also* Lisa G. Aspinwall, *Persuasion for the Purpose of Cancer Risk Reduction: Understanding Responses to Risk Communications*, 1999 J. NAT’L CANCER INST. MONOGRAPHS 88, 88 (“A pressing need exists to understand how people process risk information over time and how such processing may differ as a function of risk status, individual differences, social context, and other factors.”).

119. Rachel Ballard-Barbash et al., *Physical Activity, Biomarkers, and Disease Outcomes in Cancer Survivors: A Systematic Review*, 104 J. NAT’L CANCER INST. 815 (2012); *see also* Patricia González-Arriaga et al., *Genetic Polymorphisms in MMP 2, 9 and 3 Genes Modify Lung Cancer Risk and Survival*, 12 BMC CANCER 121 (2012); Ya-Hsuan Chang et al., *Pathway-Based Gene Signatures Predicting Clinical Outcome of Lung Adenocarcinoma*, 5 SCI. REPS. 1 (2015).

120. Barry E. Kiely et al., *Estimating Typical, Best-Case and Worst-Case Life Expectancy Scenarios for Patients Starting Chemotherapy for Advanced Non-Small-Cell Lung Cancer: A Systematic Review of Contemporary Randomized Trials*, 77 LUNG CANCER 537, 537–38 (2012).

or a series of radiation.<sup>121</sup> These predictions usually involve a shorter time span and are easier to estimate. As Gawande put it in his book, *Being Mortal*, “[w]ords like ‘respond’ and ‘long-term’ provide a reassuring gloss on a dire reality.”<sup>122</sup> If the physician does not feel confident asserting the likely benefits of a particular chemotherapy regimen, then the treatment should not be offered in the first place. Most cancer treatments come with a nontrivial amount of risk, and when conducting a cost-benefit analysis, an unknown on the benefit side will likely be overpowered by the risk. The American Society of Clinical Oncology strongly recommends that treatments have a definable benefit before they are suggested to patients.<sup>123</sup> If possible, physicians should provide the mean response time or mean improvement in stabilizing the disease (not in curing, but in slowing down cancer progression) as part of the informed consent process to treatment.

In many cases, the treatment will offer some short-term benefit by reducing the tumor load, improving the airway and breathing, or reducing discomfort. By switching from a focus on the overall disease prognosis to a focus on the prognosis of an isolated treatment, physicians are capable of dodging the EOL discussion and instead offering a glimmer of hope. Individual treatments might be successful without having any positive impact on life expectancy. Unfortunately, because physicians are more likely to share treatment information when it is optimistic, patients can confuse treatment prognosis with disease prognosis.<sup>124</sup> This can lead patients to focus on the positive results from palliative therapy, ignoring the fact that the underlying disease prognosis is still incredibly grim, and the survival estimate has not changed. Because of this, physicians should make it clear when they are providing treatment prognosis to patients, as compared to underlying disease prognosis.

#### 4. EOL Conversations Are Increasingly Just About “Consenting” Patients

Engaging in effective EOL discussions is difficult, but not impossible. It takes time, patience, and, importantly, training. According to Susan Block, a renowned palliative care physician, physicians err when they dismiss EOL conversations as requiring less thought or training than surgical procedures. As she puts it, “a family meeting is a procedure, and it requires no less skill than performing an operation.”<sup>125</sup>

In my experience on hospital ethics committees and attending resident conferences, physicians often treat EOL conversations as an opportunity to have patients “consent” to being classified as DNR. The family meeting is successful if the team comes away with an order that they can place in the patient’s chart, stating that the patient would not want chest compressions or resuscitation. If the

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121. See, e.g., Weeks et al., *supra* note 20 (showing that many patients receiving chemotherapy for incurable cancers did not understand that chemotherapy would not be curative for their conditions and concluding that physicians could provide patients with more accurate information regarding the treatment efficacy—at the cost of the patients’ satisfaction rating).

122. GAWANDE, *supra* note 12, at 151.

123. Kadakia et al., *supra* note 25, at iii30.

124. Matsuyama et al., *supra* note 23, at 3490.

125. GAWANDE, *supra* note 12, at 181.

patient crashes, they will be treated only with comfort care and no heroic interventions will be performed. If the aims of the family meeting are not actually this sinister, then they still seem focused on determining whether a patient wants a particular procedure. When physicians focus only on the risks and benefits of particular procedures, and on the goal of “consenting” patients, they ignore their role as *interpreters* of the risk/benefit data. While the law still requires physicians to let patients decide whether to consent to care, patients often want physicians to put the data into context, to let them know what *the physician would* do, what *the physician’s* concerns are, and how this relates to the patient’s individual case.

Susan Block believes that a critical component of EOL conversations is:

[H]elping people negotiate the overwhelming anxiety—*anxiety about death, anxiety about suffering, anxiety about loved ones, anxiety about finances . . . [and] no one conversation can address them all. Arriving at an acceptance of one’s mortality and a clear understanding of the limits and the possibilities of medicine is a process, not an epiphany.*<sup>126</sup>

Adopting this perspective is crucial for physicians to realize that EOL conversations evolve, and cannot be reduced to a legalistic form. These conversations must begin with clinicians asking patients open-ended questions about what they want their death to be like, what they value, and then revisiting how their values impact their treatment preferences as the disease takes its course.

For example, in some parts of East Asia, it still remains common to keep the diagnosis of cancer from the patient.<sup>127</sup> The word—“cancer”—is considered taboo, and so it is seldom uttered in a patient’s presence.<sup>128</sup> While the patient may understand that she is sick, there is plausible deniability as to the cause of the illness. In the United States and most of the Western world, however, this is not the case. It is no longer a legal or ethical question of *whether* to tell competent patients about the fact that they have cancer but *how* best to do so.<sup>129</sup>

All state tort laws are interpreted in ways that require the patient to participate and consent to her care, either personally, or through the channeling of her choices through a surrogate.<sup>130</sup> If medical intervention is not consented to, the

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126. *Id.* at 181–82.

127. See Mitsuru Seo et al., *Telling the Diagnosis to Cancer Patients in Japan: Attitude and Perception of Patients, Physicians and Nurses*, 14 PALLIATIVE MED. 105 (2000); Angel Lee & H.Y. Wu, *Diagnosis Disclosure in Cancer Patients—When the Family Says “No!”*, 43 SING. MED. J. 533 (2002); see also Ruhnke et al., *supra* note 13 (observing that in Japan, 80% of physicians and 65% of patients believed that the patient’s family should be told of a cancer diagnosis first, and then they should decide whether to tell the patient).

128. Seo et al., *supra* note 127; Lee & Wu, *supra* note 127.

129. William Figg et al., *Disclosing a Diagnosis of Cancer: Where and How Does It Occur?* 28 J. CLINICAL ONCOLOGY 3630, 3630 (2010); see also Rebecca Hagerty et al., *Communicating with Realism and Hope: Incurable Cancer Patients Views on the Disclosure of Prognosis*, 23 J. CLINICAL ONCOLOGY 1278, 1278 (2005).

130. “A patient must consent before a physician renders medical treatment of any kind.” 61 AM. JUR. 2D *Physicians, Surgeons, Etc.* § 148 (2015).

clinician has committed a form of negligence, which is a breach of the medical standard of care.<sup>131</sup> In order to fulfill her legal duties, the physician must therefore disclose *both* the diagnosis and its prognosis to the patient. While legal norms for sharing disease *diagnosis* have coalesced around patient autonomy and full disclosure in the United States, the methods of disclosing *prognosis* have often stagnated in the world of “doctor knows best.”

Treating informed consent as a legal document that must be signed, rather than a process of understanding patient preferences, has led to physicians ignoring the enormous skill that is required in these conversations. Rather than seeing informed consent as a purely legal requirement, physicians need to be made aware of the ethical importance of discussing both clinical risks and benefits as well as patient values. The problems of obtaining meaningful informed consent are only compounded in the context of EOL conversations, where physicians have additional reasons for avoiding frank conversations about patient values.

#### *5. Informed Consent Does Not Incentivize Physicians to Have Meaningful EOL Conversations*

Unfortunately, we cannot expect the common law of informed consent to solve this matter for us. The tort model of informed consent typically focuses not on the patient in front of the physician, but on what a “prudent patient” would want to know.<sup>132</sup> A physician can only be held to have breached his legal duty if the undisclosed information is of a type that would be *material ex ante* to the objective *prudent patient*.<sup>133</sup> This legal standard is pretty helpful at countering the paternalistic 1950s model of “doctor knows best.”<sup>134</sup> It works well when the patient is basically healthy and is contemplating an isolated treatment. However, when we are discussing something as idiosyncratic and spiritual as how one chooses to die, it seems vulgar to impose a “prudent patient” standard on this necessarily highly subjective decision.

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131. Laurent B. Frantz, Annotation, *Modern Status of Views as to General Measure of Physician's Duty to Inform Patient of Risks of Proposed Treatment*, 88 A.L.R. 3d 1008 (2015).

132. In a majority of jurisdictions, to establish a cause of action to recover damages for malpractice based on lack of informed consent, a plaintiff must prove that a reasonably prudent patient in the same position would not have undergone the treatment if she had been fully informed. See Beth Holliday, Annotation, *Cause of Action Against Physician for Failure to Obtain Patient's Informed Consent*, 49 Causes of Action 2d 573, § 22 (2015). In a few jurisdictions, the court is allowed to look subjectively at whether this particular patient would have consented. *Id.* at § 23.

133. See *Canterbury v. Spence*, 464 F.2d 772, 786–87 (D.C. Cir. 1972) (discussing the “prudent person in the patient’s position” standard).

134. See Nathan A. Kottkamp, *Finding Clarity in a Gray Opinion: A Critique of Pennsylvania's Informed Consent Doctrine*, 61 U. PITT. L. REV. 241, 278–79 (1999) (citing Lynne Heckert, Comment, *Informed Consent in Pennsylvania—the Need for a Negligence Standard*, 28 VILL. L. REV. 149, 158 (1982–1983)) (“[The] ancient conceit of the medical profession [was] that ‘the doctor knows best’ and that patients are people of low intelligence, who cannot possibly understand the complexities involved in medical decision making, and ought not to be given a say about treatment even when it involves the patient’s own body.”).

A particularly striking example of the failure of the law's informed consent model to address EOL care comes from the 1993 California case *Arato v. Avendon*.<sup>135</sup> In *Arato*, the patient died of pancreatic cancer, but only after he had consented to and underwent a painful and experimental chemotherapy treatment that proved ineffective. His family filed an informed consent claim, and argued that the physicians should have disclosed his grim life expectancy to him; they say he would have rejected the chemotherapy treatment, and instead spent time with his family and ordered his financial affairs. In declining to hold that, as a matter of law, physicians owe a duty to disclose life expectancy data, the court bungled the informed consent doctrine.<sup>136</sup>

First, the court dismissed the importance of probabilistic life expectancy data, but its reasoning proves too much.<sup>137</sup> The opinion states that “statistical morbidity values derived from the experience of population groups are inherently unreliable and offer little assurance regarding the fate of the individual patient.”<sup>138</sup> While it is certainly true that drawing inferences from group data to individual cases is imprecise, this is true of *all risk data*. All data—for instance, mortality risk, risk of infection, risk of losing a limb, and risk of blindness—are probabilistic. We cannot know with any positive predictive value whether a particular patient will experience these side effects. If we truly felt that group risk data are “too unreliable” to be material to an individual prudent patient, then we are gutting the entire basis of informed consent doctrine, and might as well do away with it entirely.

Second, the court argued that there could be no duty for physicians to disclose information that is relevant to a patient's nonmedical interests, such as her desire to plan her finances.<sup>139</sup> This is also an obfuscation of informed consent doctrine. A patient might want to know about the risk of losing her arm in a surgery because she is a concert pianist or painter, or because the out-of-pocket costs of the procedure might be too high to justify that risk to her body. Any of these reasons for her decision are protected by the doctrine of informed consent. The law would not be protecting autonomy if it held that patients had to use the material clinical information in specified, pre-determined ways.

Importantly, the *Arato* court did not say that life-expectancy statistics are *never* material to a patient's decision. Rather, the court correctly argued that it should be up to the jury to decide what information is material in any patient's case, given the context.<sup>140</sup> Unfortunately, the very nature of after-the-fact tort litigation means that the violation of the patient's autonomy has already occurred. The remedy is imperfect and cannot change the way the individual died. There is

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135. 858 P.2d 598, 605–07 (Cal. 1993).

136. *Id.* at 599–600.

137. *Id.* at 607.

138. *Id.*

139. *Id.* at 609.

140. *Id.* at 607.

also considerable literature demonstrating how ineffective tort law is at deterring proscribed behavior.<sup>141</sup>

Together, these points illustrate why we cannot rely on informed consent doctrine to solve our dilemma. The reliance on objective standards of care and what a “prudent patient” would find material conflicts with the idea that patients need not be prudent, reasonable, or overly cognitive about their EOL decisions. There must be room for emotions, spirituality, and idiosyncratic values; therefore, tort law will not prompt meaningful EOL conversations.

*6. Physicians Mistakenly Believe that Medical Malpractice Is Just About the Failure to Provide Care*

While unlikely to be a conscious factor, physicians also collude in the denial of death because they prefer not to be sued.<sup>142</sup> To avoid litigation, they could justify performing unnecessary or futile care at the end of life out of an unjustified fear that a dissatisfied patient may file a medical malpractice claim. However, as the Institute of Medicine’s 2014 report *Dying in America* pointed out,

Family lawsuits against physicians who honored a patient’s preference for less aggressive care are virtually nonexistent . . . and to the contrary, are most likely to occur when a patient or family does not feel respected or heard by a physician.<sup>143</sup>

Physicians often assume that patients desire more care at the end of life than they actually do.<sup>144</sup> The practice of “defensive medicine” is a real cost-driver, albeit more modest than once thought.<sup>145</sup> A general fear of being sued might explain aggressive care at the end of life, which in turn encourages false hope and our denial of death. Ironically, if patients are not sufficiently informed of the goals

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141. Gary T. Schwartz, *Reality in the Economic Analysis of Tort Law: Does Tort Law Really Deter?*, 42 UCLA L. REV. 377, 378 (1994) (“[E]conomic analysis has provoked a large number of critics who claim that tort law does not really influence behavior in the way that the economists suggest. These critics identify a number of ‘realistic’ factors that, in their view, prevent tort law from achieving deterrence. None of those who engage in the economic analysis has done an adequate job in responding to the realists’ critique.”).

142. Therese M. Mulvey, *Cancer Care Is Costly*, 4 J. ONCOLOGY PRAC. 77, 77 (2008) (“Although oncologists are infrequently sued, much of what an oncologist does in the course of the work day is spent indirectly practicing defensive medicine. The added time, technology overuse, testing, and treatments near the end of life that a patient with cancer is subjected to are often primarily born out of a defensive medicine strategy.”).

143. COMM. ON APPROACHING DEATH, INST. OF MED., *DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE* 323 (2014) (citation omitted).

144. Lois Downey et al., *Life-Sustaining-Treatment Preferences: Matches and Mismatches Between Patients’ Preferences and Clinicians’ Perceptions*, 46 J. PAIN SYMPTOM MGMT. 9, 13 (2013).

145. See Michelle Mello et al., *National Costs of the Medical Liability System*, 29 HEALTH AFF. 1569, 1569 (2010) (“Overall annual medical liability system costs, including defensive medicine, are estimated to be \$55.6 billion in 2008 dollars, or 2.4 percent of total health care spending.”).



of care so they can meaningfully consent, physicians may be committing malpractice *by providing*, rather than *withholding*, care.

7. *Physician Reimbursement Systems Discourage Meaningful EOL Conversations*

Finally, the system of physician reimbursement encourages death denial. If physicians rely on the cultural denial of death and allow patients to believe that they may be cured, they can then justify billing insurance for expensive chemotherapy, ICU visits, and procedures. This is not meant to cast physicians in an unduly negative light, and their financial incentives may not be consciously driving their actions. However, if the fee-for-service system rewards those who *do* rather than those who *discuss*, then rational actors will do more. In early 2015, the American Medical Association gained traction for providing reimbursement codes for EOL counseling, and by July 2015 the Centers for Medicare and Medicaid (“CMS”) announced plans to reimburse EOL conversations.<sup>146</sup> This would be a fantastic way to incentivize physicians to take the time to discuss EOL care with their dying patients.

Any of the factors discussed above could alone encourage cancer exceptionalism and false hope. Together, they reinforce the American healthcare system’s rampant denial of death. Unlike many social problems, here we have massive datasets with overlapping conclusions: The denial of death in cancer patients is real, and it imposes significant psychological and financial costs on our country’s already budget-crippling healthcare system. While the law cannot solve this stunning sociological problem, at the very least legal measures should not exacerbate it. Many Medicare regulations and federal statutes unfortunately do just that.<sup>147</sup>

## II. PHYSICIANS SHOULD NOT REINFORCE THE PSYCHOLOGICAL BIAS TOWARD HEARING AND REMEMBERING OPTIMISTIC NEWS

Psychological research bridging three decades has found that human judgment is influenced by unrealistic optimism (or “optimism bias”).<sup>148</sup> Even if aspects of the optimism bias may be particularly pronounced in American culture, some form of it is found across cultures and age groups.<sup>149</sup> This bias represents the propensity to underestimate the likelihood of negative events and overestimate the likelihood of positive events.<sup>150</sup> Studies have shown that this happens as we

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

147. See *infra* Sections III.B.2.b–e; see also Obermeyer et al., *supra* note 72, at 1888 (discussing the ways medicare incentivizes costlier care).

148. David Eil & Justin Rao, *The Good News-Bad News Effect: Asymmetric Processing of Objective Information About Yourself*, 3 AM. ECON. J. MICROECONOMICS 114, 116 (2011) (observing that participants in a study involving process and acquisition of information tended to attach more weight to favorable news and incorporate it into their belief system, perhaps a little unrealistically, while also discounting unfavorable news).

149. Tali Sharot et al., *How Dopamine Enhances an Optimism Bias in Humans*, 22 CURRENT BIOLOGY 1477, 1477 (2012).

150. Neil D. Weinstein, *Unrealistic Optimism About Future Life Events*, 39 J. PERSONALITY & SOCIAL PSYCHOL. 806, 818 (1980); see also Neil Weinstein, *Unrealistic*

selectively update our incorrect risk appraisals only when we are being too pessimistic as opposed to being too optimistic. Put another way, when we are wrong about the risk of something happening, we correct upward to the correct and rosier reality, but not downward to the correct and darker reality.<sup>151</sup> The ubiquity of the optimism bias means that even when physicians *do* disclose a grim prognosis and discuss the patient's need to develop EOL goals of care, the patient may come away from that conversation focusing on the positive bits, and ignoring the reality of the grim prognosis.<sup>152</sup>

This selective updating occurs in part because Americans perceive themselves as having greater self-control than they actually have. While perception of self-control is critical to a healthy self-esteem, it appears we actually have inflated and unrealistic beliefs about our ability to control environmental events.<sup>153</sup> In a series of studies, researchers have shown that even when a situation is determined purely by chance, individuals will behave as if the situation is determined by skill and self-control.<sup>154</sup> For example, take rolling a dice; people suppose that they have greater control over the outcome if they personally throw the dice than if someone else does it for them.<sup>155</sup> The only subjects that seem less susceptible to the illusion of self-control are the mildly and severely depressed.<sup>156</sup>

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*Optimism About Susceptibility to Health Problems: Conclusions from a Community-Wide Sample*, 10 J. BEHAV. MED. 481, 456 (1987) (observing that college students were unrealistically optimistic about experiencing health problems and generally thought that their own chances of experiencing health problems were less than their peers).

151. Tali Sharot et al., *How Unrealistic Optimism Is Maintained in the Face of Reality*, 14 NATURE NEUROSCIENCE 1475, 1477–78 (2011); see also Punit Shah, *Toward a Neurobiology of Unrealistic Optimism*, 3 FRONTIERS IN PSYCHOL. 344, 344 (2012) (describing Sharot's study).

152. Researchers found that the bias toward changing our estimates more in the face of positive shifts in information than negative shifts in information is the result of a bias in the way we predict cognitive errors, and assign salience to these errors in order to learn from them. See Sharot et al., *supra* note 151, at 1478. The strength of the learning signal depends on whether the updated information is positive or negative. *Id.* Neuroscientists have found that selective updating is mediated by regions of the frontal cortex, which track errors in estimation when a shift in information calls for a positive update, but show a relative failure to code for information that might induce a negative update. See *id.* at 1477.

153. Shelley Taylor & Jonathan Brown, *Illusion and Well-Being: A Social Psychological Perspective on Mental Health*, 103 PSYCHOL. BULL. 193, 196 (1988).

154. *Id.*

155. *Id.* (citing John H. Fleming & John M. Darley, *The Purposeful Action Sequence and the Illusion of Control: The Effects of Foreknowledge and Target Involvement on Observers' Judgments of Others' Control over Random Events*, 16 J. PERSONALITY SOC. PSYCHOL. BULL. 346, 351 (1990); Ellen J. Langer, *The Illusion of Control*, 32 J. PERSONALITY SOC. PSYCHOL. 311, 312 (1975)).

156. See Lyn Y. Abramson et al., *Depression, Nondepression, and Cognitive Illusions: Reply to Schwartz*, 110 J. EXPERIMENTAL PSYCHOL. 436 (1981) (discussing the effect that optimism has on perceptions of future outcomes); see also Sanford Golin et al., *The Illusion of Control Among Depressed Patients*, 88 J. ABNORMAL PSYCHOL. 454, 454 (1979)).

This illusion of self-control leads us to believe that we can influence chance events in ways that will make us healthier, stronger, and better than others.

A second component of the optimism bias is our obsession with the future, our insistence that the present is better than the past, and our belief that the future will be even better than today.<sup>157</sup> This aspect of optimism bias may be a uniquely American phenomenon. When asked about the future, the majority of Americans are confident that things can only get better.<sup>158</sup> Together with our excessive sense of self-control, this translates into thinking that even if we have been plagued by bad luck in the past, we will be luckier tomorrow.

A third reason why we may be biased toward optimism is that we tend to have a sense of individual exceptionalism. As compared to our peers, we think it is more likely that *we* will experience a variety of positive life events, such as liking our first job, receiving a good salary, or having a gifted child.<sup>159</sup> This persists even when we have incentives to be accurate in our predictions of the future.<sup>160</sup> Conversely, when we are asked our chances of experiencing a variety of negative life events, such as being in a car accident, a crime victim, having trouble finding a job, or becoming ill, most of us believe that we are *less* likely than our peers to encounter these events. As one researcher put it, “most people seem to be saying, ‘The future will be great, especially for me.’”<sup>161</sup> Statistically, of course, not everyone can have a future that is rosier than her peers. This suggests that for most of us, the unwavering optimism that we exhibit is indeed illusory.<sup>162</sup>

Given the above information, patients, when confronted with negative prognosis information, likely assume three things. First, they may assume that they have greater control over the course of their cancer than they actually have, and perhaps just by willing the cancer to go away, it will. Second, they will assume that simply because the present diagnosis seems bleak, things can, and will, improve in the future. Finally, they will assume that the dismal prognosis statistics apply to others, but not to themselves. All of these phenomena are present in terminal cancer patients.<sup>163</sup>

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157. See Philip Brickman et al., *Lottery Winners and Accident Victims: Is Happiness Relative?*, 36 J. PERSONALITY SOC. PSYCHOL. 917, 921 (1978) (observing that an individual's ratings of happiness predictions are higher in the future than in the past or present).

158. See LLOYD A. FREE & HADLEY CANTRIL, *THE POLITICAL BELIEFS OF AMERICANS: A STUDY OF PUBLIC OPINION* 101–07 (1967) (observing that people generally rated their expectation for future quality of life higher than their current quality-of-life rating).

159. Taylor & Brown, *supra* note 153, at 197 (citing Weinstein, *supra* note 150).

160. See Joseph Simmons & Cade Massey, *Is Optimism Real?*, 141 J. EXPERIMENTAL PSYCHOL.: GEN. 630, 630 (2012) (observing that even when participants were incentivized to pick winners of a football game, many participants ignored the incentives and chose their favorite teams).

161. Taylor & Brown, *supra* note 153, at 198.

162. *Id.*

163. However illusory, individual exceptionalism is pervasive among terminal cancer patients. Mary Step & Eileen Berlin Ray, *Patient Perceptions of Oncologist-Patient Communication About Prognosis: Changes from Initial Diagnosis to Cancer Recurrence*,

As previously mentioned, the optimism bias exists even in the face of random, uncontrollable events. Even so, it can be particularly acute in the domain of cancer, where individuals have some modest influence over the course of their disease. Thus a patient may feel she will be healthier and longer-living because she will have a better attitude, stronger religious beliefs, and superior self-control. While healthy behaviors definitely impact the occurrence of some types of cancer, once diagnosed, many types of cancer develop regardless of one's healthy lifestyle or positive attitude. Indeed, some researchers argue that "claims that positive thinking or stress reduction will cure disease," can place a significant burden on patients: "[P]retending to be positive, denying negative emotions, denying stress and distress, etc., are counterproductive to both physical and psychological health."<sup>164</sup> In many cases, patients feel that society expects them to feel hopeful and to be a fighter. The inspirational cancer patient is a frequent trope in popular media and many patients feel pressure to emulate that narrative. If they do not take on these optimistic roles, they feel they are not being "good" cancer patients.

The idea that we will be statistically-optimistic outliers seems to hold for life expectancy estimates by third parties as well. Surrogates who were given prognostic information and then later asked to interpret this information were much more accurate when the risk of death was low.<sup>165</sup> However, when the risk of death was communicated as being high, surrogates were less accurate in interpreting these grim prognoses.<sup>166</sup> Surrogates were also much more likely to believe that unique patient attributes unknown to the physician would lead their loved one to attain better-than-predicted outcomes.<sup>167</sup> Because the optimism bias is so pervasive, even in the face of discussions of how short a cancer patient's life expectancy is, physicians will need to do more than disclose a grim prognosis with the patient. Physicians should disclose information but also ask questions about what the patient understands about her prognosis and ability to be cured. They should keep asking the patient about her own desires and goals of care. Communication researchers will need to educate providers as to how to deliver prognosis information that is emotionally sensitive, but factually blunt.

### III. EVIDENCE OF THE EFFECTS OF THE INFORMATION GAP

The status quo is that many patients are receiving lots of aggressive care at the end of life, and some percentage of these patients are not fully consenting to this care. The sheer volume of aggressive care would be less ethically upsetting if

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26 HEALTH COMM. 48, 54 (2011). Even when they are actually aware of the gloomy survival statistics, they maintain hope by believing that they will be statistical outliers. *Id.*

164. Lisa Aspinwall & Richard Tedeschi, *Of Babies and Bathwater: A Reply to Coyne and Tennen's Views on Positive Psychology and Health*, 39 ANNALS BEHAV. MED. 27, 28 (2010).

165. Lucas Zier, *Surrogate Decision Makers' Interpretation of Prognostic Information: A Mixed-Methods Study*, 156 ANNALS INTERNAL MED. 360, 363 (2012).

166. *Id.*

167. *Id.* at 363–64 (observing that two themes address the trend toward overly optimistic interpretation of grim prognostic statements, including (1) surrogates' need to register optimism when patients are at a high risk for death, and (2) surrogates' belief that positive patient attributes lead them to outperform physicians' grim prognostications).

the patients were experiencing a meaningful benefit from the treatments, if the patients understood the purpose of their care, or if ignorance over the purpose of the care was not driving up the cost of Medicare and health insurance generally. But each of these conditions has been proven *not* to be met. The result is that the care being given is ethically (and legally) unsound.

*A. Patients Receive a Great Deal of Aggressive Care at the End of Life*

In the United States, over-aggressive care is the norm in cancer treatment,<sup>168</sup> and this phenomenon appears in other cultures as well.<sup>169</sup> Aggressive care includes the provision of chemotherapy, admissions to the ICU, the receipt of surgery within the last few weeks of life, and late referral to hospice.<sup>170</sup> These interventions are considered aggressive because they are painful, alienating, expensive, and not at all likely to extend life or improve its quality. The same interventions may be justified earlier in the course of care; however, their benefits are likely outweighed by their risks and harms when the patient is so near death. While some patients might still opt for these invasive measures, it is crucial that they do so with a clear view of their prognosis.

Late referral to hospice (defined as within three days of death) is an indicator of overly aggressive care because patients receive little palliative benefit when it is initiated at this late stage.<sup>171</sup> Such late referrals have been described as “using hospice to manage death rather than palliate disease.”<sup>172</sup> This practice defeats the chief purpose of hospice care, which is to help patients remain comfortable and be prepared for their death, not merely to outsource the location of the death.<sup>173</sup> While hospice use increased from 2005 to 2009, nearly 30% of those decedents were in hospice for three days or less, with a large chunk

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168. Craig Earle et al., *Aggressiveness of Cancer Care near the End of Life: Is It a Quality-of-Care Issue?*, 26 J. CLINICAL ONCOLOGY 3860, 3860–61 (2008); see also Joan Teno et al., *Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009*, 309 JAMA 470, 476–77 (2013) (observing, in studying ICU visits and transition services, that there is not a trend towards less aggressive care).

169. In a study of Taiwanese cancer patients, “[u]p to 81% of the cancer deaths presented at least one indicator of aggressive EOL care.” See Chun-Ming Chang et al., *Low Socioeconomic Status Is Associated with More Aggressive End-of-Life Care for Working-Age Terminal Cancer Patients*, 19 ONCOLOGIST 1241, 1247 (2014).

170. Earle et al., *supra* note 168, at 3860–61.

171. Nina R. O’Connor et al., *Hospice Admissions for Cancer in the Final Days of Life: Independent Predictors and Implications for Quality Measures*, 32 J. CLINICAL ONCOLOGY 3184, 3187 (2014).

172. Morden et al., *supra* note 79, at 787.

173. While more of the Medicare population is dying at home, many are transferred to their homes just a few days before they die. Teno et al., *supra* note 162, at 476. Thus, using the location of death as a benchmark for the level of care at the end of life may be deceptive. For cancer patients specifically, 15.5% were transitioned to a different facility in the last three days of life. See *id.* at 472. This suggests that hospice enrollment, or location of death, will not tell the full story, and the care that patients receive in the weeks leading up to their death may paint a clearer picture.

(approximately one-third) of these patients coming to hospice directly from the ICU.<sup>174</sup>

In the United States, chemotherapy is used more often in the final stages of cancer than in any other country, with tens of thousands of American patients projected to be receiving chemotherapy just days before they die.<sup>175</sup> The American Society of Clinical Oncology has sought to reduce this over-aggressive use of chemotherapy, citing cessation in the last two weeks of life as a benchmark for improving clinical practice.<sup>176</sup> The percentage of patients who really *should* receive chemotherapy in the last 14 days of life is less than 10%, but in the United States, administration is closer to 20%.<sup>177</sup>

It is not a surprise that there has been a long-standing concern that precious healthcare resources are being wasted on unnecessary ICU care.<sup>178</sup> In the last decade, the rate of ICU use in the last month of life has increased for all types of patients,<sup>179</sup> and nearly 40% of Medicare decedents are admitted to an ICU during the final months of their illness. Using hospital discharge data from 1999, one study found that one-in-five Americans died using ICU services, and this ratio is only likely to increase given that the number of persons over the age of 65 will double by the year 2030.<sup>180</sup> Admissions to the ICU are both more common and more resource-intensive because prior to being admitted, dying patients do not have informed discussions about palliative and EOL care.<sup>181</sup> In one study, over 70% of those who died during an ICU admission were found to have received aggressive therapy, including mechanical ventilation, despite the fact that their short-term survival from a critical illness was not considered probable.<sup>182</sup> Multiple studies confirm these findings in terminal cancer patients.<sup>183</sup>

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174. *Id.* at 474.

175. Matsuyama et al., *supra* note 23, at 3490; *see also* Craig Earle et al., *Trends in the Aggressiveness of Cancer Care near the End of Life*, 22 J. CLINICAL ONCOLOGY 315, 317 (2004) (observing that approximately 15% of the 8,000 patients who received chemotherapy were still receiving treatment within two weeks of life).

176. *See* Steven Kao et al., *Use of Chemotherapy at End of Life in Oncology Patients*, 20 ANNALS ONCOLOGY 1555, 1557–59 (2009).

177. *See* Craig Earle et al., *Identifying Potential Indicators of the Quality of End-of-Life Cancer Care from Administrative Data*, 21 J. CLINICAL ONCOLOGY 1133 (2008).

178. Daniel J. Cher & Leslie A. Lenert, *Method of Medicare Reimbursement and the Rate of Potentially Ineffective Care of Critically Ill Patients*, 278 JAMA 1001, 1002 (1997).

179. Teno et al., *supra* note 162, at 473–74 (observing that nearly 30% of Medicare patients in 2009 visited the ICU in the last months of life, up from 26% in 2005 and 24% in 2000).

180. Derek Angus et al., *Use of Intensive Care at the End of Life in the United States: An Epidemiologic Study*, 32 CRITICAL CARE MED. 638, 641 (2004).

181. Mohamed Y. Rady & Daniel J. Johnson, *Admission to Intensive Care Unit at the End-of-Life: Is It an Informed Decision?*, 18 PALLIATIVE MED. 705, 708–10 (2004).

182. *Id.* at 708.

183. *See* Marya D. Zilberberg & Andrew F. Shorr, *Economics at the End of Life: Hospital and ICU Perspectives*, 33 SEMINARS RESPIRATORY CRITICAL CARE MED. 362, 363–64 (2012); *but cf.* Marcio Soares et al., *Characteristics and Outcomes of Patients with Cancer Requiring Admission to Intensive Care Units: A Prospective Multicenter Study*, 38

Specifically, a study of Medicare patients who died with poor-prognosis cancer found that over-aggressive care was the norm rather than the exception.<sup>184</sup> Using a cohort of 237,098 now-deceased Medicare beneficiaries who were deemed likely to die within a year of when the study commenced, the research team examined the association between hospital characteristics—e.g., for-profit status and size—and 11 EOL care measures, such as hospice use and ICU hospitalization.<sup>185</sup> The study defined *over-aggressive care* as care that did little to improve short- or long-term prognosis, but came with significant risk of reduced quality of life.<sup>186</sup> The team evaluated measures such as late referral to hospice, ICU admissions in the last month of life, receipt of chemotherapy in the last two weeks of life, and receipt of uncomfortable procedures soon before dying (feeding tubes, breathing machines, and CPR).<sup>187</sup> In this exhaustive study, overall referral to hospice was low (54%) for all hospitals, regardless of size, setting, or for-profit status.<sup>188</sup> The use of over-aggressive care was high.<sup>189</sup> The research team determined that “no hospital group excelled”—on any of the indicators—at providing quality, patient-centered EOL care. The study concluded by saying the “results indicate a need for a broad reexamination of EOL cancer care and whether it meets the needs and wants of patients.”<sup>190</sup> The obvious question is: Do patients truly desire over-aggressive care, or do they not realize that it *is* over-aggressive?

This same Medicare study showed that there was great variation in what care patients received, which could not be accounted for by their needs or preferences. Because data on EOL care are not publicly available, patients could not select clinics based on these differences in the provision of EOL care.<sup>191</sup> While the team noted trends in the types of hospitals that are more likely to provide over-aggressive care, these differences were “dwarfed by the variation *within* hospital groups defined by common features such as hospital type, size, or for-profit

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CRITICAL CARE MED. 9, 11–14 (2010) (finding ICU mortality more closely tied to organ failure, performance status, or the need for mechanical ventilation rather than characteristics of individuals’ cancers).

184. Morden et al., *supra* note 79, at 791–92 (“Our study of Medicare patients dying with poor-prognosis cancer revealed a relatively high intensity of care in the last weeks of life. Some experts, including oncologists, have labeled this pattern of care aggressive or overaggressive.”).

185. *Id.* at 793.

186. *Id.*

187. *Id.* at 788.

188. *Id.* at 792.

189. *Id.* (“Our study of Medicare patients dying with poor-prognosis cancer revealed a relatively high intensity of care in the last weeks of life. Some experts, including oncologists, have labeled this pattern of care aggressive or overaggressive.”).

190. *Id.*

191. *Id.* at 790–92 (“Generally, more than a twofold variation was noted within the hospital groups with common features . . . [this does] not support the possibility that the observed wide variation in aggressiveness of care could be explained by patients with distinctive preferences selecting specific care settings. Such an explanation would require that patients know in advance the intensity of care common at each hospital and choose their care setting based on that knowledge. There is no hospital-specific, publicly available information about end of life care intensity to guide patients’ hospital selection.”).

status.”<sup>192</sup> A different study likewise found that the only variable predicting the aggressive use of chemotherapy in the last month of life was the treating oncologist.<sup>193</sup> Given that similarly situated patients are receiving very different levels of care, it is likely that physician preference or financial incentives are driving the difference, and not the needs of the patient.<sup>194</sup>

Many studies have demonstrated that poor people and people of color are less likely to receive cancer care than their wealthier or whiter counterparts.<sup>195</sup> This holds true for some forms of new and expensive chemotherapy; however, in the EOL context, this disparity is largely turned on its head.<sup>196</sup> An analysis of Medicare claims data indicated that costs for EOL care for racial minorities were 18% *higher* in the last year of life but 25% *less* in the three years prior to death.<sup>197</sup> Lung cancer patients who identify as racial minorities had more ICU days, ER visits, and inpatient days than non-Hispanic whites.<sup>198</sup> The same is true for patients living in urban areas or those with lower socioeconomic status.<sup>199</sup>

The receipt of aggressive care is also correlated with low-hospice use. Unsurprisingly, race plays a role here as well. Fewer racial minorities are enrolled in or take advantage of the Medicare hospice benefit.<sup>200</sup> The same holds true for very poor lung cancer patients, as they are less likely to “ever use hospice or be enrolled in hospice care in the last [three] days of life.”<sup>201</sup>

***B. Patients Are Not Experiencing Significant Clinical or Quality-of-Life Benefit to Justify the Aggressive Care***

The technological advances that medicine has witnessed in the last few decades are no more apparent than in the ICU. Yet when

192. *Id.* at 791–92 (emphasis added).

193. Kao et al., *supra* note 176, at 1557.

194. For a study that found that oncologists are susceptible to financial incentives when choosing drugs, see Andrew J. Epstein & Scott J. Johnson, *Physician Response to Financial Incentives When Choosing Drugs to Treat Breast Cancer*, 12 INT’L. J. HEALTH CARE FIN. & ECON. 285, 287 (2012).

195. Cary Gross et al., *Racial Disparities in Cancer Therapy*, 112 CANCER 900, 900 (2008) (“Racial disparities have been demonstrated at each step of the cancer-care continuum, ranging from the unequal distribution of cancer risk factors to inequities in prompt diagnosis and appropriate therapy.”).

196. Xianglin L. Du et al., *Racial and Geographic Disparities in the Patterns of Care and Costs at the End of Life for Patients with Lung Cancer in 2007–2010 After the 2006 Introduction of Bevacizumab*, LUNG CANCER (forthcoming 2015).

197. O’Mahony et al., *supra* note 7, at 281–83.

198. Preethy Nayar et al., *Disparities in End of Life Care for Elderly Lung Cancer Patients*, 39 J. COMMUNITY HEALTH 1012, 1017 (2014).

199. *Id.* at 1014.

200. O’Mahony et al., *supra* note 7, at 283 (“The Urban Institute analysis of 1995–1998 Medicare Current Beneficiary Survey Cost and Use Files demonstrated that 11% of nonwhite decedents used hospice in comparison with 17% of white decedents. Fourteen percent of decedents who had incomes less than 100% of the [f]ederal [p]overty level had hospice use in comparison with 20% of decedents with reported incomes 300% or greater than the federal poverty level.”).

201. *Id.*



used inappropriately, this technology may not save lives nor improve the quality of a life, but rather transform death into a prolonged, miserable, and undignified process. Life support technology is intended to provide temporary support for patients with potentially reversible organ failure and not a measure to conquer death.<sup>202</sup>

Researchers have also attempted to study the relative value of providing over-aggressive cancer care. These studies are fraught with problematic qualifiers, such as “benefit,” which is obviously a subjective measure. Even so, they provide a means for describing and quantifying the negative impact on patients of false optimism and the decision to “avoid death at any cost.”<sup>203</sup> Unfortunately, this form of death-denial attitude is associated with patients receiving poor clinical care,<sup>204</sup> dying sooner, and being more depressed just before they die.<sup>205</sup>

Many cost-benefit studies focus on the crude metric of mortality rather than a brief but significant improvement in the patient’s quality of life.<sup>206</sup> This is unfortunate. To move from what most rational people *ought* to want to the clinical standard of what this person *actually* wants—if given the full picture—studies must incorporate the patient’s assessment of value. The few studies that have looked at this issue have found that over-aggressive EOL cancer care has been associated with poor quality of life, poor quality of death, impaired caregiver’s bereavement,<sup>207</sup> as well as increased patient pain and discomfort.<sup>208</sup> In addition to

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202. Kelly Wood & Paul Marik, *ICU Care at the End of Life*, 126 CHEST 1403, 1403 (2004).

203. Matsuyama et al., *supra* note 23, at 3495.

204. Earle et al., *supra* note 168, at 3860.

205. The study of pancreatic cancer patients was mentioned in the Introduction, where it was demonstrated that less aggressive care resulted in patients actually living longer. See Connor et al., *supra* note 75. Another three-year study observing patients with metastatic non-small-cell lung cancer found similar results. See Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 739–41 (2010). Metastatic non-small-cell lung cancer was randomly assigned at the time of diagnosis to either palliative care or no palliative care. *Id.* at 735–37. All of the patients received standard oncology treatment. *Id.* Quality-of-life scores were higher for the palliative care group and symptoms of depression were nearly two-and-a-half times more common in the nonpalliative care group. *Id.* The median survival was 30% longer for the palliative care group, which is counterintuitive, given that fewer patients in that group received aggressive care near the end of life. *Id.*

206. Aspinwall & Tedeschi, *supra* note 164, at 28–29 (“Within the cancer literature, we believe that focusing exclusively on one outcome—mortality—neglects a great deal about the process of living with cancer as a chronic and life-threatening illness. Quality of life, psychological well-being, and other factors related to coping with cancer and its treatment are important to study.”).

207. Andrea C. Phelps, *Religious Coping and Use of Intensive Life-Prolonging Care near Death Among Patients with Advanced Cancer*, 18 JAMA 1140, 1145 (2009) (citing Wright et al., *supra* note 3, at 1665).

208. See Morden et al., *supra* note 79, at 788.

reduced quality-of-life ratings, patients who receive aggressive care at the end of life also have modest, if any, clinical benefits.<sup>209</sup>

In a prospective, longitudinal, multi-site study (a part of the larger “Coping with Cancer” project) from 2002 to 2008, 396 advanced cancer patients and their caregivers were interviewed to determine which factors predicted increases in their quality of life.<sup>210</sup> This cohort study by Baohui Zhang et al., followed patients from enrollment to their death, which was a median of 4.1 months later.<sup>211</sup> Patients and caregivers were asked a number of questions seeking to assess their quality of life ratings in the last week of life.<sup>212</sup> This assessment consisted of ratings by the patient and caregiver in three areas: physical distress, psychological distress, and overall quality of life.<sup>213</sup> Together, they were added to create the primary “quality of life” outcome measure.<sup>214</sup>

The Zhang study found that patients who received any life-prolonging procedure or an ICU stay in the last week of life were much more likely to rate their quality of life at the end of life as significantly worse.<sup>215</sup> Patients who died in the ICU or hospital had even lower quality of life at the end of life.<sup>216</sup> Other studies relying on the same data have also found that more aggressive medical care was associated with worse patient quality of life and higher risk of major depressive disorder in the bereaved caregivers.<sup>217</sup> By contrast, those patients who transitioned to hospice care sooner rated their quality of life at the time of death as being higher.<sup>218</sup> One of the primary goals of hospice care is to make sure that the patient is physically and mentally prepared for her coming death, and that she dies in the way that she is most comfortable.<sup>219</sup> So it comes as no surprise that patients would

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209. See *id.* at 793 (“[R]esearchers have failed to find a survival benefit for elderly patients cared for in hospitals and regions with higher intensities of care.”).

210. Baohui Zhang et al., *Factors Important to Patients’ Quality of Life at the End of Life*, 172 ARCHIVES INTERNAL MED. 1133, 1133 (2012).

211. *Id.* at 1133–36.

212. *Id.* at 1135.

213. *Id.*

214. *Id.* at 1135–36. While providing an important starting point, other researchers have suggested that the term “quality of life” is under-examined as it relates uniquely to the terminally ill, and perhaps needs to be contextualized for this population. See Alan B. Zonderman & Michele K. Evans, *Improving Patients’ Quality of Life at the End of Life*, 172 ARCHIVES INTERNAL MED. 1142, 1143 (2012) (citations omitted) (“Although Zhang’s 3 items are surely related to the self-assessed value of life, there is ample room for more work in this area to characterize what QOL (quality of life) means for patients with terminal illnesses. . . . Although they measured several characteristics while patients were alive, none of the measures were assessed before the patients became ill or before they began treatment. This is important because dispositions and personality characteristics are related to self-rated QOL, particularly optimism, which is 1 facet of extraversion in the 5-factor model of personality. There is an accumulating literature suggesting that personality attributes are at least as important for predicting QOL as clinical factors, for example, in major colorectal surgery.”).

215. Zhang et al., *supra* note 210, at 1138.

216. *Id.*

217. Wright et al., *supra* note 3, at 1668.

218. Zhang et al., *supra* note 210, at 1134.

219. See *What Is Hospice?*, *supra* note 73.

be more at peace with their death if, at the very end of their personal war on cancer, they forewent another exhausting battle.

At the other end of the scale, patients who were less worried, who meditated or prayed, who were visited by clergy in the hospital, and who felt they had a “therapeutic alliance” with their physicians had higher quality of life at the end of life and were less likely to receive over-aggressive care.<sup>220</sup> However, it appears that once the meditation or prayer turns into strong religiosity, the scales tip in the other direction.

For example, a recent study looked at the connection between medical use at the end of life and religious coping and spiritual support.<sup>221</sup> It found that patients who rated their religious or spiritual needs as being supported to a large extent by their religious community were much *more* likely to receive EOL aggressive care, die in an ICU, and be less likely to access hospice care.<sup>222</sup> The authors posit that faith groups “may be unaware of the biomedical realities surrounding terminal illness” and thus may be unintentionally reinforcing false hope.<sup>223</sup> In keeping with U.S. religious demographics, most of the subjects in the study were Christian, a religion that maintains a strong belief in miracles.<sup>224</sup> The message from the religious community to “hope for a miracle” may therefore be at odds with any EOL guidance offered by the medical team.

In yet another study using the rich Coping with Cancer dataset, researchers sought to determine whether the location of death had an impact on the patients’ and caregivers’ quality of life.<sup>225</sup> The answer was yes.<sup>226</sup> Patients who died in an ICU or hospital experienced more physical and emotional distress and worse quality of life at the end of life compared with patients who died at home with hospice.<sup>227</sup> This is perhaps not surprising, as the majority of Americans indicate that their preferred place to die would be at home, not in an ICU.<sup>228</sup> But these preferences are often overwhelmed by the desire not to give up hope that the cancer can be cured.

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220. *Id.* at 1138.

221. Tracy A. Balboni et al., *Provision of Spiritual Support to Patients with Advanced Cancer by Religious Communities and Associations with Medical Care at the End of Life*, 173 JAMA INTERNAL MED. 1109, 1110 (2013).

222. *Id.* at 1113.

223. *Id.*

224. *Id.*

225. Alexi Wright et al., *Place of Death: Correlations with Quality of Life of Patients with Cancer and Predictors of Bereaved Caregivers’ Mental Health*, 28 J. CLINICAL ONCOLOGY 4457, 4457 (2010).

226. *Id.* at 4461.

227. *Id.*

228. Richard Morin, *Last Requests: How We Want to Die*, WASH. POST (Dec. 15, 1997), <http://www.washingtonpost.com/wp-srv/politics/polls/wat/archive/wat121597.htm>; see also Morden et al., *supra* note 79, at 786 (“When confronted with such poor survival chances [dying in one year] in the face of cancer and other illness, the average patient prefers to spend as much time as possible in a home-like setting with good control of pain and other symptoms.”).

Obviously when someone watches her loved one go through a bitter battle with cancer, the patient's process of dying can have a profound impact. Studies have revealed that when patients pursue intensive interventions right up until the moment they die, this puts added stress on the patient's family and friends.<sup>229</sup> Death in the ICU was associated with a heightened risk for post-traumatic stress disorder in caregivers compared with home hospice deaths (even after adjusting for the caregivers' preexisting psychiatric illnesses).<sup>230</sup> Similarly, when patients died in hospitals, their caregivers were at an increased risk for prolonged grief disorder compared with deaths at home or in hospice.<sup>231</sup> Relatedly, when the patients rated their quality of life at the time of death as higher, their caregivers were more likely to rank their own quality of life as better after the patient died.<sup>232</sup> While the focus of this Article is on doing what the patient would want if she were fully informed about her prognosis, it is useful to bear in mind that the information gap impacts others as well.

Given that over-aggressive care is generally not associated with reduced pain, anxiety, quality of life, or quality of death, it is even more startling that it is also not associated with large clinical benefits for terminally ill patients. Large observational studies have shown that patients may not be benefiting enough from intensive treatments to justify the risk. In any event, patients are not adequately informed about the low likelihood of any benefit.<sup>233</sup> Specifically, when it comes to ICU admissions for the terminally ill, clinical outcomes are not improving, and therefore may not be justified by their rising and exorbitant cost.<sup>234</sup> In a study of nearly 50,000 patients with lung cancer, researchers found that the percentage of those admitted to an ICU who survived hospitalization and were alive at six months did not improve from 1992 to 2005.<sup>235</sup> Of all the patients with lung cancer admitted to an ICU, nearly one-quarter died during the visit, half were discharged home, and the rest of the patients were discharged to a skilled nursing facility or hospice care.<sup>236</sup> An even better predictor for survival was the use of mechanical ventilation in these patients. Less than a fifth of those who received mechanical ventilation in the ICU were able to go home after their admission, and only 15% were alive within six months of being discharged.<sup>237</sup>

The same goes for using palliative chemotherapy in the last weeks of life. While studies show that it can improve the survival or quality of life for some

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229. Wright et al., *supra* note 3, at 1668–70.

230. Wright et al., *supra* note 225, at 4461.

231. *Id.*

232. Wright et al., *supra* note 3, at 1670.

233. See, e.g., Christopher G. Slatore et al., *Intensive Care Unit Outcomes Among Patients with Lung Cancer in the Surveillance, Epidemiology, and End Results-Medicare Registry*, 30 J. CLINICAL ONCOLOGY 1686, 1687 (2012) (evaluating the outcomes of patients with lung cancer admitted to the ICU with the goal of promoting better patient–clinician conversations once there was a better understanding of the mortality trends and factors).

234. *Id.* at 1689 (“In this large observational study, the percentage of patients with lung cancer admitted to an ICU who survived hospitalization and who were alive at [six] months did not improve from 1995 to 2005.”).

235. *Id.* at 1690.

236. *Id.* at 1687.

237. *Id.*

terminal cancer patients, most solid tumors respond to only a limited number of anticancer drugs.<sup>238</sup> Therefore, the aggressive use of chemotherapy may result in more toxicity than clinical benefit. Recognizing the trap of false optimism, one research team surmised that this practice of “proposing new lines of treatment after successive therapeutic failures may be a way of avoiding discussion of prognosis and advance directives.”<sup>239</sup>

The tragic reality is that most terminal cancer patients who receive chemotherapy, surgery, or radiation are not going to be cured. These treatments *might* make them feel better, and help them live longer by a few weeks or months. On the other hand, these treatments might also make them feel worse, die sooner, likely reduce their quality of life, and it will almost never cure them. Given this, and given that most patients are not aware of this fact, physicians need to do more to correct the information gap that leads to false hope and encourages over-aggressive care.

Taken together, these findings tell us that the denial of death and over-aggressive care lead to a reduction in patients’ quality of life by exposing them to pain, toxicity, and anxiety with little clinical benefit. It can also reduce the quality of life of their caregivers. Because of this, physicians should be more careful when discussing EOL options with terminal cancer patients in order to make sure that patients are fully informed about the likely clinical and lifestyle benefits, if any, that they will receive from aggressive care. Specifically, physicians must not sugarcoat the patient’s prognosis to keep them buoyed for a long fight in the ICU or hospital.

### ***C. The Information Gap Is Driving Up the Cost of Healthcare.***

In addition to disrespecting patients by not fully informing them about the risks and benefits of their care, the elephant in the room is cost. This Article will now address the high cost of ICU care and chemotherapy, and how reimbursement for these services incentivizes the information gap. When patients incorrectly believe that they can be cured by these treatments, they are much more likely to agree to receive them. And aggressive cancer care at the end of life is some of the most expensive care that our system generates.<sup>240</sup> This Section will focus on chemotherapy, which is unique in many ways. But first, let us discuss the costs associated with the more general use of the ICU.

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238. Earle et al., *supra* note 177, at 1134 (citing John Ruckdeschel, *Is Chemotherapy for Metastatic Non-Small-Cell Lung Cancer “Worth It”?*, 8 J. CLINICAL ONCOLOGY 1293, 1293–96 (1990)).

239. *Id.*

240. Chemotherapy is among the most expensive medical treatments available. See Peter B. Bach et al., *In Cancer Care, Cost Matters*, N.Y. TIMES, Oct. 14, 2012, at A25 (noting that the median price for cancer drugs in 2010 dollars was \$10,000 per month, with some drugs costing up to \$35,000 per month); see also Neal J. Meropol & Kevin A. Schulman, *Cost of Cancer Care: Issues and Implications*, 25 J. CLINICAL ONCOLOGY 180, 180–86 (2007) (discussing the high cost of novel cancer treatments and how they affect different parts of the population).

1. *The High Cost of ICU Care and Its Furtherance Through the Information Gap*

One of the largest cost drivers in the hospital setting is the ICU, which, despite accounting for roughly 10% of the beds in U.S. hospitals, accounts for nearly one-third of total inpatient costs.<sup>241</sup> Much of the treatment that was described above as “over-aggressive” is administered via the ICU. Care provided through the ICU is estimated to cost three-to-five times more than care provided on a general medical floor.<sup>242</sup> Patients on ventilators account for a large component of this.<sup>243</sup> These patients incur a “disproportionately high share of the total cost of ICU treatment,” with those requiring more than three weeks of mechanical ventilation accounting for about *half* of all ICU costs.<sup>244</sup> In addition to the magnitude of the financial costs, prolonged ICU stays and mechanical ventilation predispose patients to a greater risk of hospital-acquired infection and death.<sup>245</sup> These costs may be justified if the clinical benefits are clear and the patient’s autonomy is respected. However, if the patient is providing consent to ICU treatment under false pretenses, or if the clinical benefit does not exceed the personal, emotional, or financial costs, then expensive ICU care is being improvidently given.

2. *The Unique Market for Chemotherapy and Financial Incentives to Deny Death*

The market and reimbursement for chemotherapy is unique. Thus, before describing how chemotherapy administration relates to the information gap, a little history of chemotherapy is necessary. Forty years ago, physicians could prescribe only a few dozen chemotherapy drugs, and they had to rely on clunky first-generation radiation tools.<sup>246</sup> Those early chemotherapy drugs were crude and very toxic. Some were derived from chemical warfare agents like mustard gas.<sup>247</sup> While treatment is much more effective now, with many more drugs to choose from, the drugs remain toxic; their delivery still requires oversight by trained technicians.<sup>248</sup> This means that many infusion drugs cannot be sold directly to patients. Instead,

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241. Joseph F. Dasta et al., *Daily Cost of an Intensive Care Unit Day: The Contribution of Mechanical Ventilation*, 33 CRITICAL CARE MED. 1266, 1266 (2005); see also Neil A. Halpern et al., *Critical Care Medicine in the United States 1985–2000: An Analysis of Bed Numbers, Use, and Costs*, 32 CRITICAL CARE MED. 1254, 1256–57 (2004) (“We document the increasing use and prominence of CCM (critical care medicine, or ICU) in the delivery of U.S. health care. Although the total number of hospitals, hospital beds, and inpatient days decreased, there was a dramatic increase in the number of CCM beds and days . . . [We] do not confirm unsubstantiated estimates that CCM accounts for 30% of hospital costs and 1–4% of the GDP. To the contrary, we showed that CCM costs ranged between 11.5% and 13.3% of hospital care costs and 0.45% and 0.56% of the GDP.”).

242. Dasta et al., *supra* note 241, at 1266; see also Halpern et al., *supra* note 241, at 1256–57.

243. Dasta et al., *supra* note 241, at 1271.

244. *Id.* at 1266.

245. *Id.*

246. Lee Newcomer, *Changing Physician Incentives for Cancer Care to Reward Better Patient Outcomes Instead of Use of More Costly Drugs*, 31 HEALTH AFF. 780, 780 (2012).

247. *Id.*

248. *Id.*

physicians must be dispensed and infused. This used to take place inside of hospitals, but to curb costs, chemotherapy delivery was transferred to professional clinics. Because physicians administer chemotherapy, they benefit directly from its sale.<sup>249</sup> The market for chemotherapy drugs is therefore unlike the market for other types of drugs, where the physician merely orders the prescription, it is filled at a pharmacy, and insurance pays for some portion of the drug.

**a. Oncologists Make Much More Money from Chemotherapy than from Meeting with Patients or Reviewing Their Care**

The delivery of chemotherapy allows oncologists to profit from the sale of the drugs that they prescribe; in any other context this sort of profit would be considered unethical or potentially illegal.<sup>250</sup> Oncology practice groups in the United States buy chemotherapy drugs at wholesale prices on the national market and sell them to patients. Before 2003, Medicare reimbursement for chemotherapy generated \$1.6 billion annually in profits to oncologists.<sup>251</sup>

Patients' insurance reimburses oncologists at some amount above what they usually pay for the chemotherapy.<sup>252</sup> Oncology services make a profit on each drug that is prescribed, with some drugs yielding large returns.<sup>253</sup> Profits can be particularly high when the average wholesale cost per dose is much lower than the amount the patient's insurance is willing to pay.<sup>254</sup> Additionally, because of the complexity in administration, Medicare pays physicians about twice as much to administer chemotherapy drugs as it does to administer nonchemotherapy drugs.<sup>255</sup> Private insurance tends to follow Medicare's lead, with private reimbursement

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249. *Id.*

250. OFFICE OF INSPECTOR GEN., U.S. DEP'T OF HEALTH & HUMAN SERVS., *A Roadmap for New Physicians: Fraud & Abuse Laws*, <http://oig.hhs.gov/compliance/physician-education/01laws.asp> (last visited Oct. 30, 2015) (noting that the federal Anti-Kickback Statute (42 U.S.C. § 1320a-7b(b)) "is a criminal law that prohibits the knowing and willful payment of 'remuneration' to induce or reward patient referrals or the generation of business involving any item or service payable by the Federal healthcare programs (e.g., drugs, supplies, or healthcare services for Medicare or Medicaid patients).").

251. Mandy L. Gatesman & Thomas J. Smith, *The Shortage of Essential Chemotherapy Drugs in the United States*, 354 NEW ENG. J. OF MED. 1653, 1653 (2011) ("Before 2003, Medicare reimbursed 95% of the average wholesale price — an unregulated price set by manufacturers — whereas oncologists paid 66 to 88% of that price and thus received \$1.6 billion annually in overpayments.").

252. *Id.*

253. Reed Abelson, *Drug Sales Bring Huge Profits, and Scrutiny, to Cancer Doctors*, N.Y. TIMES (Jan. 26, 2003), <http://www.nytimes.com/2003/01/26/us/drug-sales-bring-huge-profits-and-scrutiny-to-cancer-doctors.html?pagewanted=all>.

254. Ernst Berndt & Joseph P. Newhouse, *Pricing and Reimbursement in U.S. Pharmaceutical Markets* 21 (Nat'l Bureau of Econ. Research, Working Paper No. 16297, 2010), <http://www.nber.org/papers/w16297.pdf>.

255. DANIEL LEVINSON, DEP'T OF HEALTH & HUMAN SERVS., *MEDICARE PART B CHEMOTHERAPY ADMINISTRATION: PAYMENT AND POLICY* (2009), <http://oig.hhs.gov/oei/reports/oei-09-08-00190.pdf>.

being tied to the amount Medicare decides to pay.<sup>256</sup> All together, this means that oncologists have much more at stake financially with chemotherapy administration than with the prescription of other types of drugs.<sup>257</sup>

While hopefully patients are treated in the process, chemotherapy is also *big* business. The sale of cancer drugs in the United States is now second only to the sale of drugs for heart disease, and the large majority (70%) of chemotherapy sales come from products that are on-patent.<sup>258</sup> The large pharmaceutical companies had originally ignored chemotherapy drugs, citing the fact that cancer patients do not live long enough to make the research and development investments worthwhile.<sup>259</sup> However, the pharmaceutical industry had a “eureka moment” in the mid-2000s, when marketing executives realized that Gleevec, a drug developed by Novartis to treat two obscure types of cancer, enjoyed one-year sales of \$2.2 billion.<sup>260</sup> Pharmaceutical companies soon discovered that there is almost no limit to how much money dying patients will pay for cancer drugs. Dying patients “will tolerate prices of tens of thousands of dollars a year, making drugs for even rare cancers into big moneymakers.”<sup>261</sup> This realization led to sharp increases in the availability, and price, of patented pharmaceutical drugs.<sup>262</sup> Figure 1 below from 2009 demonstrates how the cost of a month’s supply of cancer drugs at the time of approval by the FDA (in 2007 dollars) has increased sharply in the last decade.<sup>263</sup>

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256. See John W. Hill et al., *Law and the Healthcare Crisis: The Impact of Medical Malpractice and Payment Systems on Physician Compensation and Workload as Antecedents of Physician Shortages – Analysis, Implications, and Reform Solutions*, 2010 U. ILL. J.L. TECH. & POL’Y 91, 99.

257. See Jennifer Malin et al., *Medical Oncologists’ Perceptions of Financial Incentives in Cancer Care*, 31 J. CLINICAL ONCOLOGY 530, 533–35 (2012); see also Yu-Ning Wong, *Are Oncologists’ Financial Incentives Aligned With Quality Care?*, 31 J. CLINICAL ONCOLOGY 517, 517 (2013) (“If oncologists think that they will make more money by prescribing more, perhaps they will write more prescriptions. The rational choice theory of economics assumes that individuals will act in their own interest. Oncologists are no different; the current system is set up to reward prescribing more.”).

258. Thomas Smith J. & Bruce E. Hillner, *Bending the Cost Curve in Cancer Care*, 364 NEW ENG. J. MED. 2060, 2060 (2011).

259. Andrew Pollack, *New Drugs for Cancer Could Soon Flood Market*, N.Y. TIMES (July 5, 2006), [http://www.nytimes.com/2006/06/05/business/05drug.html?scp=4&sq=cancer%20and%20drugs%20and%20price%20and%20new&st=cse&\\_r=0#](http://www.nytimes.com/2006/06/05/business/05drug.html?scp=4&sq=cancer%20and%20drugs%20and%20price%20and%20new&st=cse&_r=0#).

260. *Id.*

261. *Id.*

262. However, the economic pressure on oncologists to prescribe expensive, brand-name drugs has recently led to shortages in common, cheaper, and generic chemotherapy agents. See Gatesman & Smith, *supra* note 251, at 1653.

263. Peter Bach, *Limits on Medicare’s Ability to Control Rising Spending on Cancer Drugs*, 360 NEW ENG. J. MED. 626, 626 (2009).



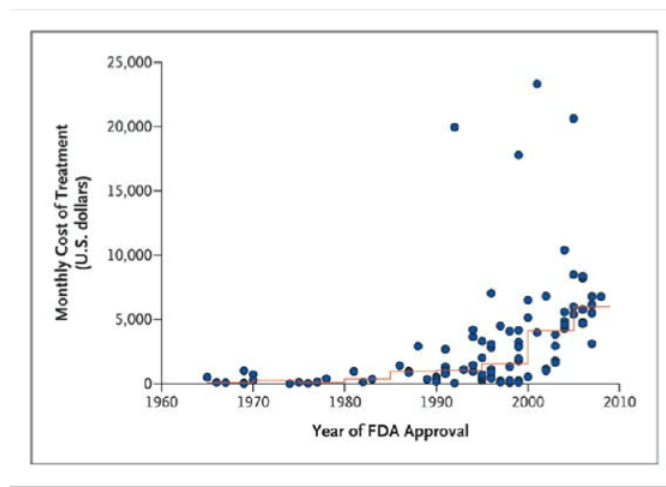


Fig. 1: Monthly Cost of Treatment (USD) from 1960–2010.<sup>264</sup>

Oncologists make more money from the sale of drugs than they do from meeting with patients and reviewing their symptoms.<sup>265</sup> This has inflated their salaries, making them increasingly dependent on the sale of chemotherapy drugs. Because the chemotherapy infusions are so profitable, many oncology practices are no longer prescribing regular oral pills that the patient could take at home.<sup>266</sup> To do so would cut into their infusion drug profits. As one oncologist put it bluntly, when you prescribe oral pills, “[t]he patients are still calling your nurses and talking about side effects, but there’s no payment for that.”<sup>267</sup>

In some cases, the price of cancer drugs appears to be rising faster than the health benefits associated with them. This means that cancer drugs are becoming less-and-less cost-effective.<sup>268</sup> Many new chemotherapies cost more than \$25,000 per year and increase life expectancy by just a matter of weeks or months.<sup>269</sup> Patients are thus “often faced with exorbitant costs, and physicians are increasingly placed in the undesirable position of having to help patients decide whether the potential benefits warrant the financial strain that these medications may generate.”<sup>270</sup>

264. *Id.* at 627. Figure Credit: Dr. Peter B. Bach & Memorial Sloan Kettering Cancer Center.

265. Gatesman & Smith, *supra* note 251, at 1653–55.

266. Andrew Pollack, *Doctors Face Fiscal Squeeze for Treatment*, N.Y. TIMES, Apr. 14, 2009, at A17.

267. *Id.*

268. Bach, *supra* note 263, at 626.

269. Corinna Sorenson, *Valuing End-of-Life Care in the United States: The Case of New Cancer Drugs*, 7 HEALTH ECON., POL’Y & L. 411, 411 (2012).

270. *Id.*

**b. Medicare Reimbursement for Chemotherapy Encourages Aggressive Care**

Medicare Part A covers institutional care in hospitals, skilled nursing facilities, nursing homes, and hospice.<sup>271</sup> Chemotherapy is covered under Medicare Part A if it is delivered to a Medicare beneficiary in one of these settings, while Medicare Part B covers chemotherapy that is administered in an outpatient clinic.<sup>272</sup> Most chemotherapy is delivered through Medicare Part B.<sup>273</sup> Medicare pays physicians about twice as much to administer chemotherapy drugs as it does to administer nonchemotherapy drugs.<sup>274</sup>

For a pharmaceutical company, being on a Medicare drug plan's formulary means that your drug can be administered to the majority of terminal cancer patients in the United States (those who are Medicare-eligible—e.g., over the age of 65).<sup>275</sup> So long as Medicare drug plans offer at least two choices for each type of drug, they can typically create their own formularies.<sup>276</sup> Being selected to be on a Medicare drug-plan formulary presents the keys to the kingdom for obtaining large national profits. In 2001, Medicare spent \$6.5 billion to purchase some 450 covered beneficiaries' drugs.<sup>277</sup> Seventy-five percent of these reimbursements went to physicians, mostly for the sale of chemotherapy.<sup>278</sup> Between 2005 and 2007, Medicare paid \$1.9 billion for chemotherapy administration services alone.<sup>279</sup>

The market for chemotherapy drugs was becoming, and remains, unsustainable. Under the system as it existed before 2003, Medicare reimbursed physicians at 95% of the average wholesale price of chemotherapy drugs, with the “wholesale price” being a value that was largely set by oncologists and

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271. *What Part A Covers*, U.S. DEP'T OF HEALTH & HUMAN SERVS., <http://www.medicare.gov/what-medicare-covers/part-a/what-part-a-covers.html> (last visited Oct. 3, 2015).

272. *Your Medicare Coverage: Chemotherapy*, U.S. DEP'T OF HEALTH & HUMAN SERVS., <http://www.medicare.gov/coverage/chemotherapy.html> (last visited Oct. 3, 2015).

273. Gillick, *supra* note 10, at 45.

274. DEP'T OF HEALTH & HUMAN SERVS.: OFF. OF INSPECTOR GEN., ¶ 52,904 REVIEW OF MEDICARE PART B CHEMOTHERAPY ADMINISTRATION: PAYMENT AND POLICY, No. OEI-09-08-00190 (2009) [hereinafter INSPECTOR GENERAL REPORT], 2009 WL 9088078.

275. Gillick, *supra* note 10, at 44–46 (discussing Medicare's role in shaping what medications are taken by dying patients).

276. *Id.* at 45.

277. John K. Iglehart, *Medicare and Drug Pricing*, 348 NEW ENG. J. MED. 1590, 1590 (2003).

278. *Id.* at 1590–97.

279. LEVINSON, *supra* note 255 (noting that the rate of reimbursement for chemotherapy is so high that other drugs requiring complex administration have abused ambiguities in Medicare's policies to inappropriately seek reimbursement at the “chemotherapy rate”). This has led policymakers to recommend that CMS “establish a process to determine which specific drugs qualify for the chemotherapy administration payment rate,” and “ensure that drug administration claims are coded correctly and paid appropriately.” See INSPECTOR GENERAL REPORT, *supra* note 274.

manufacturers.<sup>280</sup> This meant that reimbursements were inflated. Thus, in 1997, reimbursements to physicians were on average about 30% *above the price that the physicians actually paid*.<sup>281</sup> In 2004, this dropped to an average of 22%.<sup>282</sup> This inflated reimbursement amounted to physicians receiving roughly \$1.6 billion annually in profits on chemotherapy.<sup>283</sup>

Congress finally addressed the largely unfettered market for chemotherapy in 2003, when it passed the Medicare Modernization Act (“MMA”).<sup>284</sup> Embedded within the MMA were provisions that attempted to bend the chemotherapy cost-curve.<sup>285</sup> Some of the measures of the MMA were intended to improve competition through increased choice.<sup>286</sup> Rather than allowing Medicare formularies to cover only two chemotherapy drugs, the MMA made “anti-neoplastic agents” (chemotherapy) exceptional, and it required Medicare drug plans to provide not just two options per type of drug, but nearly *every drug on the market*.<sup>287</sup> While drug-plans could previously assign higher co-pays to expensive chemotherapy drugs, following the MMA, they are now prohibited, by law, from keeping most cancer drugs off of their formularies.<sup>288</sup> In theory, this would facilitate free choice and competition, as drug plans could not exclude cheaper drugs with similar indications, but smaller profit margins, from their formularies. Of course, physicians control which chemotherapy drugs are recommended and ultimately prescribed. Expanding which drugs are on the Medicare formulary is therefore unlikely to improve patient choice—these reforms did not work.

### c. When Medicare Reimbursement Is Capped, Physicians Prescribe More Chemotherapy

The MMA capped the reimbursement for cancer drugs at 106% of the average cost of *actual* national sales of a drug.<sup>289</sup> This cap removed physicians’

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280. Phuong D. Nguyen, *A Review of Average Wholesale Price Litigation and Comments on the Medicare Modernization Act*, 9 QUINNIPIAC HEALTH L.J. 249, 250–51 (2006).

281. OFFICE OF INSPECTOR GEN., U.S. DEP’T OF HEALTH & HUMAN SERVS. EXCESSIVE MEDICARE PAYMENT FOR PRESCRIPTION DRUGS (1997), <http://oig.hhs.gov/oei/reports/oei-03-97-00290.pdf>.

282. U.S. GOV’T ACCOUNTABILITY OFF., MEDICARE CHEMOTHERAPY PAYMENTS: NEW DRUG AND ADMINISTRATION FEES ARE CLOSER TO PROVIDERS’ COSTS (2004), <http://www.gao.gov/new.items/d05142r.pdf>.

283. Renee Twombly, *Medicare Cost Containment Strategy Targets Several Oncology Drugs*, 96 J. NAT’L CANCER INST. 1268, 1268 (2004).

284. Medicare Prescription Drug, Improvement, and Modernization Act (MMA) of 2003, Pub. L. No. 108-173, 117 Stat. 2066 (codified as amended in scattered sections of 42 U.S.C.).

285. See generally Gillick, *supra* note 10 (analyzing various ways Congress has tried to regulate the chemotherapy market).

286. *Id.* at 45.

287. *Id.*

288. *Id.* at 45–46.

289. See 42 U.S.C. § 1395w-3a (2012) (providing the formula for calculating drug reimbursement amounts).

ability to dramatically mark-up the profits by inflating what they claimed they and others had paid.<sup>290</sup> Many were confident that this cap on reimbursement for chemotherapy drugs would plug a gaping hole in the Medicare drug budget.<sup>291</sup> While it did limit one type of market incentive (inflating their “price,” which inflated what Medicare would pay), it did nothing to prevent other profit-maximizing practices.<sup>292</sup>

Specifically, the MMA’s 106% reimbursement cap did not control volume manipulations.<sup>293</sup> It also did nothing to encourage physicians to perform a cost-benefit analysis and prescribe the best and cheapest drug for a patient’s needs. Given how significant drug sales had become to oncologists, if the price was reduced following the MMA, market participants could respond in two ways. Physicians could either increase the number of patients who received chemotherapy (volume), or switch from prescribing cheaper drugs (where the 6% mark-up was less) to more expensive drugs (where the 6% mark-up was greater in terms of absolute dollars).

Researchers studied changes to the chemotherapy market since 2003 and confirmed that both of these potential responses by physicians indeed occurred.<sup>294</sup> A study published in 2010 found that “when fees that affect a large share of physicians’ incomes decline, utilization increases (a “negative” relationship between utilization and fee changes).”<sup>295</sup> Looking at over 200,000 Medicare beneficiaries’ claims, the team found that those diagnosed with lung cancer were more likely to receive chemotherapy *after* the reform was passed.<sup>296</sup> Rather than reducing incentives for physicians to prescribe chemotherapy, the cuts in reimbursement led to increases in the volume of patients receiving this type of care by about 2.4%.<sup>297</sup> In other words, “[i]n the presence of asymmetric information, physicians may distort demand in socially sub-optimal but personally beneficial ways. In the U.S. context, debate over this issue centers on physician-induced demand (“PID”)—providing excessive care in response to financial incentives.”<sup>298</sup> The 2010 study confirmed that this PID occurs in the provision of chemotherapy drugs, and was exacerbated when the reimbursement was capped through the MMA.<sup>299</sup>

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290. Twombly, *supra* note 283, at 1268.

291. Lowell E. Schnipper & Neal J. Meropol, *Payment for Cancer Care: Time for a New Prescription*, 57 J. CLINICAL ONCOLOGY 1, 1 (2014).

292. *Id.*

293. *Id.* at 5–6.

294. Mireille Jacobson et al., *How Medicare’s Payment Cuts for Cancer Chemotherapy Drugs Changed Patterns of Treatment*, 29 HEALTH AFF. 1391, 1397 (2010).

295. *Id.*

296. *Id.*

297. *Id.* at 1394.

298. Mireille Jacobson et al., *Physician Agency and Competition: Evidence from a Major Change to Medicare Chemotherapy Reimbursement Policy 1* (Nat’l Bureau of Econ. Research, Working Paper No. 19247, 2013).

299. *Id.*

Physicians also responded to the provisions within the MMA by prescribing drugs with higher profit margins.<sup>300</sup> One such example comes from the drug leucovorin, which has been available from several manufacturers since 1952.<sup>301</sup> In 2008, the FDA approved an active l-isomer of leucovorin (levoleucovorin).<sup>302</sup> The newer isomer has *not been found to be any more effective* than generic leucovorin, but it is 58 times as expensive.<sup>303</sup> Predictably, manufacturing and prescriptions of the new drug eclipsed the cheaper one, and less than a year after its approval, widespread shortages of the cheaper leucovorin were reported.<sup>304</sup> As another example, the average wholesale price of Abraxane, a protein-bound version of paclitaxel, costs 19 times as much as the equally effective generic paclitaxel.<sup>305</sup> Because chemotherapy drugs are not subjected to the same cost-benefit controls as other Medicare drugs, the more expensive and equally effective drugs are more often prescribed.

There are no requirements either under Medicare or private insurance that physicians clinically justify the use of more expensive and equally-effective drugs. When two or more chemotherapy drugs are available in the United States, their purchase is not subjected to price controls or demonstrations of greater comparative efficacy, as is the case in other industrialized countries.<sup>306</sup> Thus, oncologists frequently substitute generics for higher-profit and brand-name drugs. As one commentator said, “[w]hy use paclitaxel (and receive 6% of \$312) when you can use Abraxane (for 6% of \$5,824)?”<sup>307</sup>

Oncologists insist that these tactics are necessary for their businesses to stay afloat.<sup>308</sup> Medical oncology is thought of as a “cognitive” specialty, meaning that it lacks attendant surgeries or procedures for which to bill. Unfortunately, insurance fee schedules do not reimburse well for patient consultation and the tracking of symptoms.<sup>309</sup> As the payments for office visits have been slashed, oncologists have increasingly relied on the profit margins from the sale of chemotherapy drugs to make up the difference.<sup>310</sup> Oncologists claim that without drug sales, their salaries would be lower than those for geriatricians (a notoriously poorly paid and unpopular specialty),<sup>311</sup> and they could not afford the expensive infrastructure that goes along with maintaining a first-rate cancer clinic.<sup>312</sup>

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300. *Id.*

301. Gatesman & Smith, *supra* note 251, at 1653–54.

302. *Id.* at 1654.

303. *Id.*

304. *Id.* at 1653–55.

305. *Id.*

306. Gautam Naik & Vanessa Fuhrmans, *How Americans May Subsidize Euro-Health Care*, WALL ST. J., Dec. 26, 2002, at A8.

307. Gatesman & Smith, *supra* note 251, at 1653–55.

308. James Robinson, *Providers’ Payment and Delivery System Reforms Hold Both Threats and Opportunities for the Drug and Device Industries*, 31 HEALTH AFF. 2059, 2061 (2012).

309. *Id.*

310. *Id.*

311. GAWANDE, *supra* note 12, at 36 (“[I]ncomes in geriatrics and adult primary care are among the lowest in medicine. And partly, whether we admit it or not, a lot of

#### d. Chemotherapies Are Not Subjected to Medicare's Typical Cost-Saving Measures

Chemotherapy is also unique in terms of its immunity from typical Medicare cost-savings measures. With other drugs, Medicare introduces price competition among drug manufacturers by designating certain classes of drugs as “interchangeable.”<sup>313</sup> This designation means that reimbursement for all interchangeable drugs is set at a weighted average of national prices, based upon the sales volume of each drug. This “blended reimbursement” encourages manufacturers to keep their prices low to be selected by providers for use within an interchangeable class of drugs. Unfortunately, regulations that are unique to cancer drugs prevent Medicare from designating related cancer drugs as interchangeable, which in turn means that each new drug requires its own unique payment rate.<sup>314</sup>

Chemotherapy is also immune from Medicare's “least costly alternative” (“LCA”) drug reimbursement system.<sup>315</sup> This LCA introduces price competition by reimbursing at the price of the least costly drug among all that are designated in a class as interchangeable, no matter which drug is actually used.<sup>316</sup> While the Medicare program once instituted LCA reimbursement for some clinically interchangeable prostate-cancer drugs,<sup>317</sup> LCA policies for all Part B drugs were discontinued in 2010 in response to a court ruling, which rendered LCA policy “unauthorized” under Medicare law.<sup>318</sup> A 2012 Inspector General study found that “[i]f LCA policies for [interchangeable hormone agonists for prostate cancer] had not been rescinded, Medicare expenditures would have been reduced by \$33.3 million over 1 year, from \$264.6 million to \$231.3 million. After LCA policies were removed, utilization patterns shifted dramatically in favor of certain costlier products.”<sup>319</sup> With this precedent, Medicare officials have no incentive to advocate LCA regimes for chemotherapy. Providers and pharmaceutical companies benefit from this climate that is unfriendly to typical cost-controls.

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doctors don't like taking care of the elderly.”); *see also* Gatesman & Smith, *supra* note 251, at 1653–55.

312. *See* Iglehart, *supra* note 277, at 1595–96.

313. Bach, *supra* note 263, at 627.

314. *Id.* at 630–31 (recognizing that regulations and related court cases have classified nearly all newer cancer drugs as “sole-source” drugs; drugs can only qualify as “multiple source,” and therefore eligible for being interchangeable, if there are “multiple compounds that are pharmaceutically, therapeutically, and biologically equivalent, as classified in the FDA's Orange Book of approved drugs.”).

315. *Id.* at 630.

316. *Id.* at 627.

317. *See id.* at 627–28. Specifically, the Office of the Inspector General estimated that in 2002, full use of LCA reimbursement for leuprolide acetate (Lupron, Abbott) and goserelin acetate (Zoladex, AstraZeneca) would have saved Medicare \$40 million, because the reimbursement rate for the least costly drug (goserelin acetate) was 27% lower than the alternative drug (leuprolide acetate).

318. OFFICE OF INSPECTOR GEN., U.S. DEP'T OF HEALTH & HUMAN SERVS. LEAST COSTLY ALTERNATIVE POLICIES: IMPACT ON PROSTATE CANCER DRUGS COVERED UNDER MEDICARE PART B, at 2 (2012), <http://oig.hhs.gov/oei/reports/oei-12-12-00210.pdf>.

319. Bach, *supra* note 263, at 627–28.

In some instances, if the effectiveness of a drug is eclipsed by its cost, Medicare may seek to cut costs by deciding not to cover that particular drug.<sup>320</sup> This cost-effectiveness review does not occur with chemotherapy. Despite the fact that many chemotherapy drugs have not been subjected to a cost-benefit analysis, Medicare must cover *any drug* used in an “anticancer chemotherapeutic regimen,” as long as the use is “for a medically accepted indication.”<sup>321</sup> The MMA law defines “medically accepted indication” broadly as uses approved by the Food and Drug Administration (“FDA”), uses listed in one of several drug compendia, or uses supported in the peer-reviewed medical literature.<sup>322</sup> So long as one of these criteria is met, Medicare is not allowed to withhold coverage of a particularly costly chemotherapy agent, even if a cheaper and equally effective drug is available.<sup>323</sup>

Some of these anticompetitive market practices are unique to chemotherapy, but some are not. Adding to the lack of competition, Medicare is not allowed to use its bargaining power to negotiate directly with any drug manufacturers to reduce prices.<sup>324</sup> Together with a lack of cost-benefit analysis and mandates to cover all chemotherapy agents on any Medicare formulary, it is no wonder that physicians prescribe the most expensive chemotherapy agents available.<sup>325</sup>

#### **e. Medicare Reimbursement Encourages Shifting Cancer Treatment from Community Clinics to the More Expensive Hospital Setting**

In addition to failing to require a cost-benefit analysis for the selection of chemotherapy *agents*, Medicare also fails to place any cost controls on the *setting* that is chosen for its administration. This leads to chemotherapy being administered in hospitals rather than community cancer clinics. A 2013 study quantifies the dramatic shift in cancer care toward the more costly hospital setting. Medicare reimbursements for chemotherapy administered in a hospital outpatient clinic have *more than tripled* since 2005 while payments to the cheaper community cancer clinics have decreased by 14.5%.<sup>326</sup> The study also found that between 2005 and 2011, chemotherapy administration performed in hospital outpatient settings for Medicare Fee-for-Service beneficiaries increased by more than 150% as compared to chemotherapy administered in community cancer

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320. *Id.*

321. *Id.* at 629–30.

322. *Id.*

323. *Id.*

324. *Id.* at 631.

325. *Id.* (observing that private insurers suffer many of the same negotiating limitations that drive prices up for Medicare users).

326. *New Study Shows Shift in Cancer Care to More Expensive Hospital Setting*, CMTY. ONCOLOGY ALL. (June 3, 2013) [hereinafter COA], <http://www.communityoncology.org/site/blog/detail/2013/06/03/new-study-shows-shift-in-cancer-care-to-more-expensive-hospital-setting.html>. For a copy of the referenced study, see Memorandum from The Moran Co. to Matthew E. Brow, The U.S. Oncology Network et al. (May 29, 2013) [hereinafter Moran Memorandum], [http://blog.communityoncology.org/userfiles/76/Moran\\_Site\\_Shift\\_Study\\_P1.pdf](http://blog.communityoncology.org/userfiles/76/Moran_Site_Shift_Study_P1.pdf).

clinics.<sup>327</sup> The reason is obvious—Medicare reimbursement is higher for chemotherapy provided in a hospital, despite the fact that community cancer clinics can safely provide the same service, at a much lower Medicare rate.<sup>328</sup> This massive increase in chemotherapy reimbursement increases the overall burden placed on the Medicare budget. Patients may also not be given a choice in determining the setting of their chemotherapy administration.

The data here point in the same direction. Medicare policies create perverse economic incentives that are anticompetitive. Current Medicare reimbursement rates favor those who provide unnecessarily aggressive care in unnecessarily costly environments. The ICU is reimbursed at a higher rate than hospice, and providers may be prosecuted for referring someone to hospice if it turns out that she outlives her prognosis. Doing surgical procedures and placing ventilators and feeding tubes are all reimbursed quite well, while discussing whether or not to do the procedure is not reimbursed at all. Administering chemotherapy in a hospital is unwarranted, but pays much better than the equally effective community clinic. Physicians who order more expensive chemotherapy in cases where there is marginal clinical utility will reap the rewards of a system that has ineffective cost controls. These perverse incentives will devastate our already crippled Medicare and healthcare budgets, but they are all propped up and reinforced by our cultural denial of death. Few question the financial motivations of physicians ordering aggressive or unnecessary care when their patients and loved ones are not yet mentally or spiritually prepared for death. In the short-run, it is a perfect system for oncologists. In the long-run, it is completely unsustainable. The sooner we realize that death is part of the life cycle, the better off we will be—psychologically, fiscally, and spiritually.

Why did Congress and regulators agree to treat chemotherapy treatments as exceptional? The answer may be that the disease seems scarier, less predictable, and more democratic in its wrath. As more people are affected by the death of a loved one to cancer, Congress is more likely to fund research and expand coverage for cancer treatments, like chemotherapy.

Of course, a more cynical view is that there is some form of “agency capture” at work. Agency capture describes a phenomenon of corruption where a regulatory agency, here the CMS, may be passing regulations that are favorable to an industry it is intended to regulate, instead of serving the public good.<sup>329</sup> While it is in the interest of cancer patients to have access to a broad range of drug treatments, this only serves their interest if they actually have a choice in their treatment and the alternative that is chosen is more effective. The public interest is not served by collectively overpaying for cancer treatments and restricting patient choice.

While it is difficult to track conversations and promises that might be made between pharmaceutical companies, oncology groups, and policymakers, we can track the money that is legally exchanged. From 2006 to the present, 18 large

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327. COA, *supra* note 326; Moran Memorandum, *supra* note 326.

328. *Id.*

329. See Rachel E. Barkow, *Explaining and Curbing Capture*, 18 N.C. BANKING INST. 17, 17–19 (2013) (defining agency capture).



institutional lobbyists reported lobbying on specific issues related to chemotherapy.<sup>330</sup> This money was probably used to influence Congress to pass House Bill 1392 and Senate Bill 1221 (an Act to ensure more appropriate payment for drugs under Medicare Part B), House Bill 3095 (Medicare Reimbursement for Chemotherapy Drugs), and House Bill 1844 (the “Comprehensive Cancer Care Improvement Act”).<sup>331</sup> Given that 57 firms lobbied for some issue related to oncology generally in the same time period, there is evidently a great deal of lobbyist activity related to cancer and chemotherapy.<sup>332</sup> However, with the information that is public, it is not yet possible to determine whether the agencies were indeed captured by the rents that were paid by these lobbyists. Until public interest watchdogs make Freedom of Information Act requests, it will be difficult to determine the extent of any Medicare agency capture by the pharmaceutical and oncology lobbies. Regardless, even absent concrete data proving agency capture, there is clearly something else guiding Medicare’s decisions in this space that does not appear to be motivated by public health or fiscal responsibility.

#### IV. LEGAL WAYS TO CURB FALSE HOPE AND THE COST CURVE

Our culture generally denies death but seems to be even more reluctant to acknowledge its presence in the face of terminal cancer. For cultural, psychological, legal, and financial reasons, cancer patients receive overly aggressive care at the end of life. This aggressive care involves receiving chemotherapy and surgeries within the final weeks of life, being admitted to the ICU, being referred to hospice within the last week of life, and typically results from never having anyone discuss with the patient how she would like to die. In addition to driving up healthcare costs, these aggressive interventions usually reduce the quality of patients’ remaining lives and do little to improve their prognosis. In fact, many patients live longer when they are appropriately referred to hospice or palliative services instead of pursuing aggressive care.<sup>333</sup> Finally, and most distressing, this aggressive care is often provided under false pretenses, as the patients assume the treatments can cure their cancers, even though the providers hold out no such hope for a cure.

The problem is complex and cultural—but it is also legal. While the law can do little to effect a sea change in our cultural denial of death, it certainly can operate within its own regulatory parameters to: (1) discourage the reimbursement of aggressive care, and (2) make sure physicians are incentivized to discuss EOL

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330. OPENSECRETS.ORG, <http://www.opensecrets.org/> (click “Influence and Lobbying” drop-down menu in top frame of homepage; then select lobbying from the drop-down options; select “Issue/Specific Issue” from the “Search database by:” option in the left frame; enter “Chemotherapy” in the search field; click search button for results).

331. *Id.* The list of lobbyists includes pharmaceutical companies, hospital groups, corporate healthcare consultants, oncology practice groups, and community cancer facilities. *Id.*

332. OPENSECRETS.ORG, <http://www.opensecrets.org/> (click “Influence and Lobbying” drop-down menu in top frame of homepage; then select lobbying from the drop-down options; select “Issue/Specific Issue” from the “Search database by:” option in the left frame; type “Oncology” in the search field; click search button for results).

333. GAWANDE, *supra* note 12.

care with their patients. In the following Section, I will suggest a few concrete legal mechanisms for encouraging behavior that honors an individual's spiritual and emotional needs, while focusing on endpoints that promote quality of life, not "survival at any cost."<sup>334</sup> In other words, I will summarize and elaborate upon the proposals made throughout this Article that discourage overly aggressive cancer care.

#### *A. Medicare Should Reimburse for EOL Conversations*

The number one way we can correct the information gap and make sure patients are receiving the care they desire at the end of life is by reimbursing EOL conversations. Despite the fact that federal law (the Patient Self-Determination Act (the "PSDA")) requires inpatient facilities to discuss advance directives with patients,<sup>335</sup> there is currently no Medicare reimbursement mechanism for this. As a result, patients typically just receive a few handouts upon admission. Given that there is no financial incentive to have an actual conversation with patients, the PSDA to date has not been an effective means for eliciting EOL goals of care. Some private insurers have already started reimbursing EOL conversations between physicians and patients.<sup>336</sup>

One of the roles of the American Medical Association ("AMA") is to create billing codes for medical services.<sup>337</sup> In August of 2014, the AMA created codes for EOL conversations and submitted them to Medicare.<sup>338</sup> One of these new billing codes covers the first 30 minutes of face-to-face time with the patient and/or surrogate to discuss advance directives and EOL care.<sup>339</sup> An additional code is provided for each additional 30 minutes of EOL planning.<sup>340</sup> There is no guarantee that CMS will adopt the change, but if it does, this decision will also "set the standard for private insurers, encouraging many more doctors to engage in these conversations."<sup>341</sup> An important development occurred on this front in July 2015. Medicare *finally* announced plans to reimburse doctors for EOL counseling with patients.<sup>342</sup> This move would improve the frequency, though perhaps not the depth, of these important conversations.

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334. Zonderman & Evans, *supra* note 214, at 1143.

335. See *infra* Section IV.A (discussing the Patient Self-Determination Act).

336. Belluck, *supra* note 146 ("Bypassing the political process, private insurers have begun reimbursing doctors for these 'advance care planning' conversations as interest in them rises along with the number of aging Americans.").

337. AM. MED. ASS'N, *CPT Process – How a Code Becomes a Code*, <http://www.ama-assn.org/ama/pub/physician-resources/solutions-managing-your-practice/coding-billing-insurance/cpt/cpt-process-faq/code-becomes-cpt.page> (last visited Oct. 3, 2015).

338. Belluck, *supra* note 146.

339. Lara Pullen, *New End-of-Life Discussion Codes a Step Toward Reimbursement?*, MEDSCAPE MED. NEWS (Sept. 19, 2014), <http://www.medscape.com/viewarticle/832017>.

340. *Id.*

341. *Id.*

342. Belluck, *supra* note 146.

This is a critical first step. In order to protect patient's preferences and discourage aggressive EOL care, Medicare *should* reimburse for EOL conversations. Multiple studies show that EOL conversations result in patients having higher quality of life and death, and with some diagnoses they actually live longer.<sup>343</sup> Incidentally, these conversations also result in patients using fewer health care resources, and this may involve resources that the patients themselves did not want to use.<sup>344</sup> Having EOL conversations can reduce unwarranted and unwanted over-aggressive care. The main reason these conversations are not taking place is because physicians are rational financial actors and have no financial incentive to engage in an already difficult topic. This needs to be reversed.

***B. Medicare Should Designate Some Chemotherapy Agents as Interchangeable, and Require Justification for Ordering More Expensive Equivalents***

Another way to bend the curve would be for Congress to pass legislation requiring physicians ordering chemotherapy agents to prescribe the LCA within a class of drugs designated by Medicare as interchangeable. Alternatively, Congress may require a threshold showing of cost-justification before new and expensive chemotherapy agents are reimbursed. As discussed above, there are many drugs that have the same clinical effectiveness, but physicians routinely order the costlier drug that yields them higher reimbursements.<sup>345</sup> Most other Medicare drugs are already subjected to some form of cost-effectiveness rule, but chemotherapy drugs fascinatingly are exempt. These cost control measures would remove incentives for physicians to prescribe the costlier drugs and could save Medicare millions of dollars every year.

***C. Medicare Could Reimburse at Lower Rates for Procedures Conducted Within 48 Hours of a Patient's Death***

Another means of curbing the trend of over-aggressive care is more controversial and is being mentioned for the first time here. This approach would weaken the incentive to perform surgeries, place ventilators, and admit terminal patients to the ICU in the last 48 hours of life, by reducing the rates of reimbursement for this type of care if it turns out to be provided in this timeframe (or another pre-determined timeframe). Of course, the push-back to this idea would come from the fact that physicians cannot predict when someone will die with any certainty. While true, it is often reasonably apparent to a physician in an ICU when a patient is crashing and very near death; this reimbursement-rate reduction would discourage those physicians from encouraging patients to undergo chest compressions, tracheotomies, and feeding tubes in the last few days of life.

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343. J. Randall Curtis et al., *End-of-Life Care in the Intensive Care Unit*, 186 AM. J. RESPIRATORY CRITICAL CARE MED. 588, 589 (2012).

344. *Id.* at 589–90. Specifically, the researchers focused on whether the team could help the patient achieve her *own* goals of care, even with an ICU admission. *Id.* at 588–89. These are likely patients with “an expected quality of life after critical illness that the informed patient would find unacceptable or for whom the ICU would represent a burden of care that they would not choose to endure.” *Id.* at 588.

345. *See, e.g.*, Section III.C.2.d

The reduction in reimbursement would ideally not be drastic but would provide some means for physicians to internalize the cost of their aggressive care in the last few days of a patient's life.

***D. A Metric Should Be Added for HCAHPS Questionnaires Related to Patient Awareness of Purpose of Care***

It was mentioned above that physicians who have frank EOL conversations with their patients are more likely to be rated as "poor" in their communication on national consumer surveys.<sup>346</sup> These surveys were created by the federal Department of Health and Human Services, and were intended to give consumers information to compare hospitals on quality metrics. Dubbed "HCAHPS" (Hospital Consumer Assessment of Healthcare Providers and Systems), the survey represents the first national, standardized survey of patients' perspectives of their hospital care.<sup>347</sup> Results of the survey are public and are published on Medicare's website. Logistically, the HCAHPS survey is given to a sample of adult patients between 48 hours and 6 weeks after their outpatient service or discharge, and asks them about such things as their communication with nurses and doctors, the responsiveness of staff, the cleanliness and noise level of the hospital environment, how their pain was managed, communication about medicines, discharge information, etc.<sup>348</sup> The survey is not limited to Medicare beneficiaries, but the results impact Medicare reimbursement.<sup>349</sup> Starting in October 2012, a small percentage (1%) of Medicare reimbursement was tied to "value-based purchasing" bonuses.<sup>350</sup> These bonuses were determined by comparing hospitals both on their *adherence* to clinical performance guidelines (70% of weighted score) as well as their HCAHPS scores (30% of weighted score).<sup>351</sup> Hospitals are already putting a great deal of resources into improving their HCAHPS scores—from adding air fresheners in the hallways and giving patients earplugs, to pressuring office managers to shorten patient wait times.

While the data are still preliminary, the reported negative impact on HCAHPS scores presents yet another incentive for physicians to avoid EOL conversations. To cut against this, this Article recommends that CMS add new questions to the HCAHPS survey that capture whether physicians have had thorough EOL conversations with terminal patients, and whether patients were given the opportunity to discuss their EOL preferences. Negative answers to these questions would directly impact the ultimate HCAHPS scores, which would in turn impact a hospital's bottom line. As physicians are already encouraged by their

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346. Weeks et al., *supra* note 20, at 1622.

347. See HCAHPS SURVEY (2014), <http://hcahpsonline.org/files/HCAHPS%20V9.0%20Appendix%20A%20-%20Mail%20Survey%20Materials%20%28English%29%20March%202014.pdf>; see also HCAHPS FACT SHEET (2013), [http://www.hcahpsonline.org/files/August\\_2013\\_HCAHPS\\_Fact\\_Sheet3.pdf](http://www.hcahpsonline.org/files/August_2013_HCAHPS_Fact_Sheet3.pdf).

348. Nina Geiger, *On Tying Medicare Reimbursement to Patient Satisfaction Surveys*, 112 AM. J. NURSING 11, 11 (2012).

349. *Id.*

350. *Id.*

351. *Id.*

institutions to improve HCAHPS scores, this provides a very real means of encouraging, or at least not discouraging, EOL conversations.

***E. Hospitals Should Appoint an EOL Counselor for Patients***

While some hospitals already see the value in encouraging EOL conversations, there often is not *one person* who is charged with ensuring that they occur. As discussed above, oncologists resist discussing EOL care with their terminal patients out of a fear that they will be seen as giving up on the shared recovery plan. They also have financial incentives not to have these conversations. Intensivists may resist having EOL conversations because they do not have the same intimate relationship with the patient as oncologists. Nurses may desire having these conversations but are concerned that this is not their role. Again, this is a delicate dance where no one wants, or is required, to take the lead.

This Article therefore advocates the use of EOL counselors for terminal patients. These counselors would be trained in communicating with patients about their EOL goals of care. Far from operating as the sinisterly dubbed “death panels” in disguise, these counselors would elicit patient preferences about their EOL care.<sup>352</sup> They would ask the patients questions about their desired quality of life, how they would like to die, and what type of care they would like to receive. They would communicate the general risks and benefits of various treatment options, using multimedia accounts of actual, typical cases, to explain to patients the potential outcomes of different treatments. The counselors could come from backgrounds in social work, nursing, or some combination of the two. The salaries of EOL counselors should be completely independent, ensuring that there is no personal financial incentive to encourage or discourage certain types of care. The primary role of the EOL counselor would be to initiate the difficult conversations about death, ask questions about the patient’s values, and document the patient’s preferences in their chart. This may or may not result in an enforceable advance directive. Susan Block described the ideal process:

You sit down. You make time. You’re not determining whether they want treatment X versus Y. You’re trying to learn what’s most important to them under the circumstances—so that you can provide information and advice on the approach that gives them their best chance of achieving it.<sup>353</sup>

To this latter goal, EOL counselors should be present at weekly oncology rounds and should be in regular communication with all of the physicians treating terminal cancer patients.

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352. See Joshua E. Perry, *A Missed Opportunity: Health Care Reform, Rhetoric, Ethics and Economics at the End of Life*, 29 MISS. C. L. REV. 409, 411 (2010) (“[A]s finally passed by Congress and signed by the President in the early spring of 2010, the bill did not contain [a Medicare reimbursement code for EOL counseling] because it had become politically toxic and widely misunderstood as creating bureaucratically-administered government ‘death panels.’”).

353. Atul Gawande, *Letting Go*, NEW YORKER (Aug. 2, 2010), <http://www.newyorker.com/magazine/2010/08/02/letting-go-2>.

At any time a competent patient could seek to revise their EOL preferences by requesting a meeting with the EOL counselor. While some may be troubled by the idea of these “death counselors,” medicine cannot ignore the role of death in guiding health care decision-making. Physicians have to manage patients’ deaths every single day. We are robbing them of the resources to properly do so by failing to incorporate the reality of death into treatment discussions. We are also robbing patients of the ability to have their last wishes honored. Responsible institutions can no longer afford to cave in to the political and cultural rhetoric of “death panels” and death denial.

***F. Providers in Accountable Care Organizations Should Be Educated on Value of EOL Conversations***

Accountable Care Organizations (“ACOs”) have their own reasons to reduce the provision of overly aggressive care. ACOs are thought of as “Managed Care 2.0” and consist of networks of providers that contract with insurance plans.<sup>354</sup> In an ACO, primary care providers are in charge of patient care and are held accountable for the cost and quality of patient outcomes.<sup>355</sup> Unlike the Health Management Organizations (“HMOs”) of the 1990s, “75% of an ACO must be owned by member health care providers and governed by a board elected from these providers.”<sup>356</sup> ACOs are similar to HMOs, as they vet the necessity, quality, value, and delivery of care, including cancer care.<sup>357</sup> These organizations have the opportunity to benefit financially from their savings to Medicare if they cut costs *while offering high-quality care*. Medicare has provided the prototype for this form of managed care, but private insurance companies are also forming ACO-like agreements with providers.<sup>358</sup> Because of their cost-sensitive and evidence-based infrastructure, providing information to ACOs on the negative consequences of providing over-aggressive care to cancer patients at the end of life will be more effective than providing education to providers who do not operate within an ACO. This could provide yet another model for reducing health care costs.

***G. Physicians’ Significant Financial Investment in Chemotherapy Must Be Stopped***

As it is, oncologists make a significant portion of their income from chemotherapy, and this “chemotherapy commission” gives them a financial incentive to over-prescribe.<sup>359</sup> Many oncologists are over-prescribing chemotherapy. While this may not be intentional, the current reimbursement system encourages them to provide the most expensive chemotherapy treatments,

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354. Anish Mehta & Roger Macklis, *Overview of Accountable Care Organizations for Oncology Specialists*, 9 J. ONCOLOGY PRAC. 216, 217 (2013).

355. *Id.*

356. *Id.* at 216–17.

357. *Id.*

358. Elliott S. Fisher et al., *A Framework for Evaluating the Formation, Implementation, and Performance of Accountable Care Organizations*, 31 HEALTH AFF. 2368, 2368 (2012).

359. *See supra* Section III.C.2.

as many times as possible. There are a few ways that Medicare could remove this perverse incentive.

The first way is to remove physicians from the reimbursement of chemotherapy entirely. Because administering chemotherapy typically no longer requires the oversight of an oncologist, CMS could change the Medicare Part B regulations to treat chemotherapy like all other drugs. In this way, oncology groups would not directly buy or sell chemotherapy drugs. They would, however, lose a substantial source of revenue. But returning them to the role of prescriber, as opposed to buyer/seller, eliminates the perversity of physician-induced demand.

Presently, oncologists who work in high-acuity hospitals have an incentive to keep the provision of chemotherapy in-house, as the reimbursement rates are higher. To address the concern that the reimbursement for hospital-administered chemotherapy is eclipsing that of community clinics, Medicare could experiment with reimbursing chemotherapy at the same lower rate when it is provided in the expensive hospital setting. This could substantially save costs.

#### ***H. Reimbursement for Cancer Treatments Could Be Reduced if They Do Not Comport with Evidence-Based Guidelines***

Medicare could also consider reducing chemotherapy at a lower rate if it is delivered too late in a terminal cancer patient's treatment. One way to measure this would be to key reimbursement to the National Comprehensive Cancer Network ("NCCN") guidelines. If the chemotherapy regime was considered too aggressive by the NCCN's empirically-tested guidelines, then Medicare would reimburse for the provision at a much lower rate. This would provide yet another source for reducing physicians' incentives to provide overly aggressive care, while still allowing for overly aggressive care to be provided and reimbursed on a case-by-case basis.

#### ***I. Allow Hospice Patients to Receive Limited Nonpalliative Treatments***

Presently, in order to receive the hospice benefit, Medicare and Medicaid patients have to give up life-prolonging health care, no matter how inexpensive or minimal.<sup>360</sup> Terminal patients are often not ready to forego treatments such as transfusions, certain nonhospice approved medicines, removal of fluid in the lungs, or outpatient radiation. The inability to access some basic treatments furthers the sense that hospice is where you go to die, or when you decide to "give up." This hinders enrollment and is in part why "fewer than half of eligible Medicare beneficiaries use hospice care and most only for a short period of time."<sup>361</sup>

There are a few things that could be done to mitigate the problem of low or late hospice enrollment. One method is to better incorporate palliative services into a broader continuum of care. This would avoid abrupt changes in the course of medical treatment and make both the move to hospice, as well as the *discussion*

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360. *Medicare Care Choices Model*, CTRS. FOR MEDICARE & MEDICAID SERVS., <http://innovation.cms.gov/initiatives/Medicare-Care-Choices/> (last visited Oct. 4, 2015).

361. *Id.*

about moving to hospice, less emotionally and physically jarring.<sup>362</sup> Legally, changes could be made to Medicare's hospice benefits to allow hospice beneficiaries to continue to receive basic and inexpensive outpatient care. This outpatient care might include such things as radiation or blood transfusions, but would not include surgeries, ICU visits, or chemotherapy. Medicare has already started piloting a similar program<sup>363</sup>—the “Medicare Care Choices Model.”<sup>364</sup> This pilot project will begin with over 140 Medicare-certified hospices and is expected to enable as many as 150,000 eligible Medicare beneficiaries with advanced cancers and other terminal diseases to receive life-prolonging as well as comfort care.<sup>365</sup> Expanding this pilot project would be another way to curb the provision of overly aggressive care at the end of life.

#### ***J. Development of Better Prognostic Tools for Oncologists***

Simple in theory, but perhaps difficult in the current funding climate, the National Institutes of Health and Institute of Medicine should dedicate large amounts of money to creating better prognostic tools. Prognosticating is imperfect, and could be made better by tracking patients longitudinally to see who improves and based upon which observable metrics. These tools would ideally be based on large population studies and include cancer genotype, when relevant, so that oncologists and cancer patients have a better sense of this particular individual's likely response to such things as chemotherapy. It is, of course, quite likely that the average treatment outcome for all stage IV nonsmall-cell lung cancer patients would be different based on the patient's age, mobility, genotype, cognitive impairment, abnormal heart rhythms, exercise routine, smoking history, gender, etc. Researchers are already doing this, and prognosticating has improved.<sup>366</sup>

For example, one research team demonstrated that a patient's mobility is a reliable and simple proxy for her underlying disease progression. Asking “how did you get to the doctor's office today?” can tell the team quite a bit about how sick the patient is and how likely she is to respond to assorted treatments.<sup>367</sup> A more elaborate approach calls for looking at performance scores on various metrics.<sup>368</sup> Specifically, having more time pass before progression of the cancer and having an Eastern Cooperative Oncology Status score (based upon a set of criteria used to assess how the disease affects the daily living abilities of the

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362. Rebecca McAteer et al., *Palliative Care: Benefits, Barriers, and Best Practices*, 88 AM. FAM. PHYSICIAN 811, 812 (2013).

363. *Id.* at 811–12.

364. Press Release, U.S. Dep't of Health & Human Servs., CMS Announces Medicare Care Choices Model Awards (July 20, 2015), <http://www.hhs.gov/news/press/2015pres/07/20150720a.html>.

365. *Id.*

366. Keith T. Flaherty et al., *Improved Survival with MEK Inhibition in BRAF-Mutated Melanoma*, 367 NEW ENG. J. MED. 107 (2012); Laurie E. Gaspar et al., *Small-Cell Lung Cancer: Prognostic Factors and Changing Treatment over 15 Years*, 13 CLINICAL LUNG CANCER 115 (2012); Pierre Soubeyran et al., *Predictors of Early Death Risk in Older Patients Treated with First-Line Chemotherapy for Cancer*, 30 J. CLINICAL ONCOLOGY 1829, 1829–34 (2012).

367. Kiely et al., *supra* note 120.

368. *Id.*



patient) of less than two were each independently associated with the patient living longer.<sup>369</sup> Another tool included 18 predictor instruments.<sup>370</sup> The ultimate assessment was not meant to deny elderly patients access to intensive care, but rather to help begin objective conversations with families about the dying process.<sup>371</sup> With better prognostic tools, the team felt it would be easier to discuss whether an ICU visit or further intensive treatment would be likely to improve the patient's condition or quality of life.<sup>372</sup> Other studies have looked at variables such as lymphocyte (white blood cell) counts or lactate dehydrogenase (a particular enzyme) levels.<sup>373</sup> Multiple regression analysis has confirmed that low and high counts of these last two factors, respectively, are independent predictors of a shorter-than-average overall survival time.<sup>374</sup> More funding for these types of studies will empower physicians with better data to confidently predict the life expectancy for the patient.

## V. CONCLUSION

This Article presents problems of enormous magnitude; thankfully, it also provides a modest means of cutting against those problems. The denial of death that has developed in American culture for the last several decades has been exacerbated by the development of amazing life-saving technologies and medicines. In the domain of cancer treatment, these drugs and devices have been harnessed to inject much needed hope into the war on cancer. However, the legal incentives have inadvertently encouraged physicians to mask terminal cancer patients' prognosis to the point where many are receiving overly aggressive care at the end of life with the false hope that they can be cured. This Article recommends concrete legal changes, mostly to Medicare reimbursement policies, to mitigate the provision of overly aggressive care. These suggestions need not all be pursued for improvements in EOL cancer care to be achieved. But each imperfect step provides an important means of responding to the existing legal mechanisms that encourage our cultural denial of death, false hope, and potentially unwanted aggressive cancer care at the end of life.

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369. *Id.*

370. *Id.*

371. Magnolia Cardona-Morrell & Ken Hillman, *Development of a Tool for Defining and Identifying the Dying Patient in Hospital: Criteria for Screening and Triaging to Appropriate Alternative Care (CriSTAL)*, 5 *BMJ SUPPORTIVE & PALLIATIVE CARE* 78, 79 (2015).

372. *Id.*

373. Oliver Trédan et al., *Validation of Prognostic Scores for Survival in Cancer Patients Beyond First-Line Therapy*, 11 *BMC CANCER* 95, 95 (2011).

374. *Id.*