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The (Ir)rationality of (Un)informed Consent

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Essay

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"Enough is as good as a feast."[1]

Imagine life as a long airplane flight. At birth, the plane gathers speed and lifts up into the air. In the early and middle years, if all goes well, it continues to gain altitude as we learn, grow, and establish some sort of career and family life. At some point, however, we achieve peak altitude and cruise at that height for a while. At some later point, the plane begins its descent and, eventually, approaches a landing strip. As the plane touches down and hurtles along the tarmac, its velocity decreases and it comes to a halt. The question many of us will face at the end of life is how long to spend in that final stage, decelerating on the landing strip. How much therapy and life-prolonging treatment is "enough" at the end of life?

Various public figures recently have generated interest in end-of-life matters. Brittany Maynard, a young woman with a brain tumor, spoke out about the lack of a medically-assisted-dying option in her home state of California—and moved to Oregon in order to obtain this assistance and avoid the inevitable and severe suffering associated with the end stages of her illness.[2] For every Brittany Maynard who faces

* Professor of Law, Western New England University School of Law. Thank you to the organizers of this symposium event for their excellent work and to René Reich-Graefe for his thoughtful comments. This essay is dedicated to the memory of my father, David Shepardson Pond.

[1] P.L. TRAVERS, MARY POPPINS (London, Harper Collins, 1934).

[2] *See* George F. Will, *Affirming a Right to Die with Dignity*, WASH. POST (Aug. 28,

death with pragmatism and dignity (while generating a good deal of public debate, admiration, and sympathy), there are the Larry Kings of this world who publicly rail against it.[3] In a recent interview, the 81-year-old King described the various measures he takes to stave off aging and acknowledged that he finds his own death unimaginable.[4] Ezekiel Emanuel has expressed yet another view—the desire to live a reasonably long life but to die before the usual disabilities of age overwhelm his functionality and ability to contribute to the world.[5] These various approaches to dying illustrate vastly different abilities to confront mortality. Interestingly, it is the 29-year-old rather than the 81-year-old who is ready to accept death, even to descend early to the landing strip. In one respect, all three approaches promote the autonomous wishes of the individual in question—to avoid suffering by curtailing the dying process; to live as long as possible no matter what the physical or psychic cost, hoping for an ever-lengthening landing strip; to die at the "optimal" time, navigating the narrow gap between premature and "too late" death. And yet, these three approaches to mortality also share a common theme: the desire to exert control over that which ultimately cannot be controlled—a desire for control that is fundamentally at odds with the layers of uncertainty described in this essay.

The increased utilization of therapies and life-prolonging technologies at the end of life and its attendant ill effects on the experience of dying has received a great deal of attention in recent years.[6] Several statis-

2015), https://www.washingtonpost.com/opinions/distinctions-in-end-of-life-decisions/2015/08/28/b34b8f6a-4ce7-11e5-902f-39e9219e574b_story.html.

[3] *See* Mark Leibovich, *Larry King Is Preparing for the Final Cancellation*, N.Y. TIMES MAG. (Aug. 26, 2015), http://www.nytimes.com/2015/08/30/magazine/larry-king-is-preparing-for-the-final-cancellation.html?_r=0.

[4] *See id*. ("I can't get my head around one minute being there and another minute absent."). King also would love to attend his own funeral, stating, "I would like the ceremony to begin, 'Today we are honoring a 160-year-old man who was caught in bed by an irate husband . . . .'" *Id*.

[5] *See* Ezekiel Emanuel, *Why I Hope to Die at 75*, ATLANTIC (Oct. 2014), http://www.theatlantic.com/magazine/archive/2014/10/why-i-hope-to-die-at-75/379329/. Emanuel persuasively critiques the American desire for "immortality" but his personal vision of dying in his prime epitomizes a kind of vanity that is equally troubling. He writes,

> [L]iving too long is also a loss. It renders many of us, if not disabled, then faltering and declining, a state that may not be worse than death but is nonetheless deprived. . . . *It transforms how people experience us, relate to us, and, most important, remember us. We are no longer remembered as vibrant and engaged but as feeble, ineffectual, even pathetic.*

Id. (emphasis added).

[6] *See, e.g.*, INST. OF MED., DYING IN AMERICA: IMPROVING QUALITY AND HONORING INDIVIDUAL PREFERENCES NEAR THE END OF LIFE (2014),

tics provide a snapshot of trends in end-of-life care: Only about one-third of patients in the United States die at home.[7] We utilize significant amounts of hospital-based resources at the end of life,[8] often with little or no measurable benefit to dying patients. Many patients in the U.S. receive interventions such as cardiopulmonary resuscitation, ventilator support, or ICU care even when they are very near to death.[9] And these trends are not improving.[10] This pattern of utilization of care at the end of life comes with serious costs to patients, families, and society. Imminently dying patients receive costly and invasive therapeutic care and life-prolonging treatment even when it is very likely that the benefits in terms of enhanced quality of life, increased survival time, or other measurable physical outcomes are limited or non-existent.[11] In fact, the default model is to provide life-sustaining care and often to continue therapeutic treatment, unless the patient goes through the emotionally and intellectually taxing effort of either a properly informed or a rather unin-

http://iom.nationalacademies.org/Reports/2014/Dying-In-America-Improving-Quality-and-Honoring-Individual-Preferences-Near-the-End-of-Life.aspx (roundly criticizing the care of the dying in the United States); *see also* ATUL GAWANDE, BEING MORTAL 259 (2014) (arguing that medicine should refocus its goals from extending life to "enabl[ing] well-being").

[7] *See* Joan M. Teno et al., *Change in End-of-Life Care for Medicare Beneficiaries: Site of Death, Place of Care, and Health Care Transitions in 2000, 2005, and 2009*, 309 JAMA 470, 473 tbl.2 (2013) (concluding that, although only 24.6% of patients died in hospital in 2009 compared with 32.6% in 2000, percentages of deaths in long-term care facilities held steady at around 27% and deaths at home rose from 30.7% in 2000 to 33.5% in 2009). Estimates about deaths in hospitals vary. *See, e.g.*, YAFU ZHAO & WILLIAM ENCINOSA, HEALTHCARE COST AND UTILIZATION PROJECT, THE COSTS OF END-OF-LIFE HOSPITALIZATIONS 1 (Apr. 2010), http://www.ncbi.nlm.nih.gov/books/NBK53605/ (describing data from 2007 indicating that one-third of Americans died in hospital).

[8] *See* Teno et al., *supra* note 7, at 473 tbl.2 (noting that, in 2009, 29.2% of patients who died had received care in an ICU in the previous thirty days).

[9] *See* Amresh Hanchate et al., *Racial and Ethnic Differences in End-of-Life Costs: Why Do Minorities Cost More than Whites?*, 169 ARCHIVES INTERNAL MED. 493, 497–99 (Mar. 9, 2009) (surveying use of expensive end-of-life interventions among a large sample of Medicare beneficiaries and finding patterns of substantial expenditure on life-sustaining treatment in the final six months of life).

[10] The most recent data indicate that, in 2009, 28.4% of patients received hospice care for only three days or fewer before dying, an increase from 22.2% nine years earlier. Moreover, 29.2% of Medicare beneficiaries remained in an ICU during the final month of life compared with 24.3% in the earlier period. *See* Teno et al., *supra* note 7, at 471–73. *See also id.* at 473 tbl.2 (finding that 11.5% of patients had been hospitalized three or more times in the three months before death, up from 10.3% in the previous studied period).

[11] In a very recent study that attempts to measure physicians' perceptions of when they are delivering "futile" care to their patients, the data suggested that approximately 20% of patients in five critical care units studied were receiving futile or "probably futile" treatment. *See* Thanh N. Huynh et al., *The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care*, 173 JAMA INTERNAL MED. 1887, 1889 & fig.1 (Sept. 9, 2013).

formed consent process and opts out.[12] At the same time, we underutilize hospice and palliative care.[13]

This is no small problem, and it is growing larger as the population ages. Choices about end-of-life care impact many individuals among the millions who die in the United States each year.[14] Health care costs at the end of life are substantial.[15] Numerous medical organizations and advocacy groups have begun to address the problem of overutilization of care at the end of life through improved training for health care providers and efforts to educate patients, families, and the public in general about the need for advance care planning.[16] In the face of these pro-

[12] *See* Rachelle E. Bernacki & Susan D. Block, *Communication About Serious Illness Care Goals: A Review and Synthesis of Best Practices*, 174 JAMA INTERNAL MED. 1994, 1997 (Oct. 20, 2014) (explaining that "our health care system is oriented toward providing life-sustaining treatment, unless a patient actively chooses against it").

[13] *See* Teno et al., *supra* note 7, at 474 (noting that, although the use of hospice services has increased during the early 2000s, only 42.2% of Medicare beneficiaries with dementia and 59.5% of Medicare beneficiaries with cancer received hospice services at the time of death); Haiden A. Huskamp et al., *Discussions with Physicians About Hospice Among Patients with Metastatic Lung Cancer*, 169 ARCHIVES INTERNAL MED. 954, 955–56 (May 25, 2009) (finding that only half of patients with stage IV lung cancer had had any discussion with their physicians about hospice in the two months prior to death); Corita Grudzen & Deborah Grady, *Improving Care at the End of Life*, 171 ARCHIVES INTERNAL MED. 1202, 1202 (July 11, 2011) (discussing over-use of therapeutic interventions at the end of life and advocating that better quality care often requires emphasizing palliative measures and avoiding unavailing therapies that risk unnecessary suffering and iatrogenic harm).

[14] *See Deaths: Final Data for 2013*, CTR. DISEASE CONTROL & PREVENTION, http://www.cdc.gov/nchs/fastats/deaths.htm (last visited Mar. 2, 2016) (noting that 2,596,993 people died in 2013, equaling 821.5 deaths per 100,000 people).

[15] It is well documented that one-third of medical expenses for the last year of life are spent in the final month and that aggressive therapies and technologies in that final month account for nearly 80% of these costs. *See* Baohui Zhang et al., *Health Care Costs in the Last Week of Life: Associations with End-of-Life Conversations*, 169 ARCHIVES OF INTERNAL MED. 480, 480 (Mar. 9, 2009). Moreover, 30% of Medicare dollars spent pay for care for the 5% of Medicare beneficiaries who die each year. *See* Amber E. Barnato et al., *Trends in Inpatient Treatment Intensity Among Medicare Beneficiaries at the End of Life*, 39 HEALTH SERV. RES. 363, 364 (Apr. 2004).

[16] For example, the American Society of Clinical Oncology has published a "best practices" model that recommends a series of conversations with patients with terminal cancer diagnoses, with various components to the ongoing discussion at sequential visits. *See* Thomas J. Smith et al., *American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care into Standard Oncology Care*, 20 J. CLINICAL ONCOLOGY 880, 880 (2012) ("While a survival benefit from early involvement of palliative care has not yet been demonstrated in other oncology settings, substantial evidence demonstrates that palliative care—when combined with standard cancer care or as the main focus of care—leads to better patient and caregiver outcomes. These include improvement in symptoms, [quality of life], and patient satisfaction, with reduced caregiver burden. Earlier involvement of palliative care also leads to more appropriate referral to and use of hospice, and reduced use of futile intensive care."); *see also Mission & Vision*, AM. ACAD. ON COMM. HEALTHCARE,

foundly troubling trends, many commentators (myself included) have provided detailed critiques of how we die and how we can communicate better about dying. No one seems to have acknowledged, however, that this is very likely an insurmountable problem that will only get worse as our population ages.

There are various ways to evaluate whether a dying individual is receiving "the right amount" of therapy or life-prolonging technology. In our health care system, the primary measure—based on both ethical principles and the law of informed consent—is to provide treatment that is subjectively consistent with the patient's informed and autonomous wishes, values, and beliefs.[17] One can also ask whether the treatment improves physical outcomes objectively by prolonging life or improving quality of life,[18] or whether the cost of administering life-prolonging care at current levels is a wise expenditure of increasingly scarce health care dollars.[19] By any of these measures, many dying patients are receiving "too much" therapy and life-prolonging care.[20]

Many factors contribute to this situation, including a general cultur-

http://www.aachonline.org/About-AACH/Mission-Vision (last visited Mar. 2, 2016); ASS'N BEHAV. SCI. & MED. EDUC., http://www.absame.org/dcms/about (last visited Feb. 20, 2016) (providing information and resources for medical school and continuing medical education curricula).

[17] Schloendorff v. Soc'y of N.Y. Hosp., 105 N.E. 92, 93 (N.Y. 1914) ("Every human being of adult years and sound mind has a right to determine what shall be done with his own body . . . .").

[18] Recent evidence suggests that the answer to this question frequently is "no." More therapeutic and life-prolonging interventions at the end of life are associated with poorer outcomes. *See* Jennifer S. Temel et al., *Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer*, 363 NEW ENG. J. MED. 733, 736–38 (Aug. 19, 2010) (finding that patients recently diagnosed with lung cancer who began receiving palliative care immediately lived an average of three months longer than patients who received standard therapeutic treatment only); Matthijs Kox & Peter Pickkers, *"Less Is More" in Critically Ill Patients*, 173 JAMA INTERNAL MED. 1369 (June 10, 2013) (concluding, based on a meta-analysis of multiple clinical trials, that many common treatments for critically ill patients pose a high risk of iatrogenic harm compared with their potential benefit and ought to be used more cautiously).

[19] On this measure, it also appears that we are not spending health care dollars wisely. A recent analysis of health care costs concludes that up to 35% of Medicare dollars at the end of life and up to 12% of Medicare dollars in total are being spent on clinically unsupported treatments and procedures. *See* David Cutler et al., *Physician Beliefs and Patient Preferences: A New Look at Regional Variations in Health Care Spending* (Nat'l Bureau of Econ. Research, Working Paper No. 19320, 2013), http://www.nber.org/papers/w19320 (concluding that "cowboy doctors" were more likely to recommend intensive care beyond guidelines and that such doctors, rather than patient demand for care, were the primary driving force behind regional variations in the intensity of care provided to the dying).

[20] *See* Barbara A. Noah & Neal R. Feigenson, *Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent*, 36 PACE L. REV. (forthcoming 2016) (manuscript at 3) (on file with author).

al denial of death, physicians' professional culture and fear of liability, physician avoidance of discussions about prognosis, and payment incentives that encourage overutilization of medical technologies.[21] One particularly important cause, which is the focus of this essay, is the failure of physicians and patients to have timely, thorough, and honest conversations about care at the end of life. Here, one may posit that the better (though imperfectly) informed decisions resulting from these conversations can help reduce suffering and lead to care that more properly aligns with patients' well-considered values and preferences.[22] Because the default model is to provide life-sustaining care unless the patient opts out, conversations about prognosis and goals of care provide an essential opportunity for patients to convey to their physicians their values and preferences about care at the end of life. In the absence of these detailed discussions, physicians in our health care culture assume that patients want, and consistently default towards, medical interventions even when they are actively dying.[23]

The legal and ethical principle of informed consent creates a duty to inform patients of the risks and benefits of treatment and life-sustaining care (including likelihood of success measured by cure, palliation of symptoms, or extended life expectancy).[24] The remainder of this essay examines informed consent at the end of life in the context of the many uncertainties in which it necessarily operates, and attempts to explain some of the underlying reasons for its dysfunction. To be clear, informed consent to treatment and life-prolonging technologies, implemented with as much content and compassion as possible, remains the goal. But it is worth acknowledging the multiple, and often insurmountable, obstacles to making a "perfect" highest-utility decision in end-of-life care circumstances. We can only do our best to support making the "right" decision and, even then, we should do so with the knowledge that this decision

[21] *See id.* (manuscript at 6–12) (describing and discussing the contextual factors that drive overutilization of care at the end of life).

[22] In a recent paper, Neal Feigenson and I wrote about the implementation of informed consent law in end-of-life decision making and discussed various practices, including shared decision making and the use of informational videos, to improve patients' understanding of their choices. *See id.* (manuscript at 15–23).

[23] *See* Bernacki & Block, *supra* note 12, at 1995–97.

[24] *See generally* BARRY R. FURROW ET AL., HEALTH LAW § 3-11 (3d ed. 2015) (explaining that factors to be disclosed include diagnosis, nature and purpose of treatment, risks of treatment and, in some circumstances comparative data on the treating physician's skills, alternatives to the proposed treatment, prognosis with and without the treatment, and conflicts of interest); *see also* Noah & Feigenson, *supra* note 20 (manuscript at 22–27) (describing in detail the operation of informed consent law in the end-of-life context).

making will unavoidably remain subject to uncertainty and to our human limitations with regard to perfect rational choice.

Both physicians and patients frequently are reluctant to have these conversations, so the first challenge to making "good" choices at the end of life is to somehow ensure that these conversations *actually happen*. Patients generally rely on physicians to initiate conversations about end-of-life preferences,[25] and surveys indicate that the public wants physicians to discuss end-of-life issues.[26] Physicians, in general, are better positioned to initiate these conversations as repeat players with superior knowledge and no personal emotional implications beyond those that are part of their professional role. At the same time, our culture, which denies the reality of death and has little appetite for discussions about complex decisions at the end of life, presents a major obstacle to "good" decision making.[27] More generally, this culture of denial translates into a pervasive discomfort with the precarity of life and a concomitant desire to avoid thinking about mortality, at least until this becomes unavoidable. When these conversations *do* happen—even if we agree that "good" end-of-life decisions are decisions that reflect patients' values and preferences after a series of discussions with physicians to explain the options and their potential benefits and adverse effects, and even if physicians and patients are willing to have these conversations together—barriers to good decision making remain.

Physicians and patients want to make the "best" choices about medical care for terminal illness but, given their bounded rationality, lack the omniscience needed to calculate all future possibilities without error. All human decision making, including medical decision making, occurs under conditions of irreducible uncertainty and resultant ambiguity. Philosophers Samuel Gorovitz and Alasdair MacIntyre offer an interesting and relevant theory of the nature of physician fallibility.[28] As they recount it, fallibility in medical decision making and treatment arises out of three distinct causes. The first is ignorance based on a limited under-

[25] *See* Karen Hancock et al., *The Truth-Telling in Discussing Prognosis in Advanced Life-Limiting Illnesses: A Systematic Review*, 21 PALLIATIVE MED. 507, 514–15 (2007).

[26] *See, e.g.*, *Kaiser Health Tracking Poll: September 2015*, KAISER FAM. FOUND. (Sept. 30, 2015), http://kff.org/health-costs/poll-finding/kaiser-health-tracking-poll-september-2015/ (finding that 89% of those surveyed thought that doctors should discuss end-of-life care issues but that only 17% have actually had these discussions with a health care provider).

[27] *See generally* Barbara A. Noah, *In Denial: The Role of Law in Preparing for Death*, 21 ELDER L.J. 1 (2013) (discussing cultural, legal, and other reasons why patients and physicians avoid making end-of-life decisions).

[28] *See* Samuel Gorovitz & Alasdair MacIntyre, *Toward a Theory of Medical Fallibility*, 1 J. MED. & PHIL. 51 (1976)).

standing of the medical issue—the physician has full access to information and collects it but cannot subjectively fully understand it.[29] The second is ineptitude based on the physician's failure to access and follow available medical information—all of the information is available to arrive at a "correct" diagnosis and treatment plan but the physician, while capable of understanding the relevant information, fails to fully collect and process the information.[30] In either case, the physician either underperforms and fails to follow best practices or the physician suffers from and applies biases that interfere with a (boundedly) rational processing of the information. Both of these forms of fallibility can be overcome with better (i.e., more skilled, more careful, and more rational) effort.

By contrast, Gorovitz's & MacIntyre's third cause of fallibility is "necessary fallibility" in which that which must be understood scientifically in order to make the "best" decision simply cannot be known or predicted.[31] In this scenario, no physician, no matter how skilled, careful, conscientious, and rational, can provide a solution or "best" recommendation because the solution is (at least, *ex ante*) unknowable due to the unpredictability of the multiple (objectively unknown and unknowable) variables involved in any patient's prognosis or response to a particular treatment—in spite of the statistical averages or likelihoods that generally apply to the patient's diagnosis. This type of necessary fallibility applies to every patient and every diagnosis and prognosis because every patient's prognosis and future response to treatment remains subject to Knightian uncertainty.[32] Not only is this uncertainty humanly unavoidable, but the degree of uncertainty and its impact on patient outcomes is, *ex ante*, unknowable. Accordingly, even a most skilled, careful, conscientious and rational physician's judgment can be 100% wrong about a *particular* patient's prognosis or response to treatment.

More specifically, let's think for a moment about decisions with re-

[29] *Id*. at 65.

[30] *Id.* at 62–63.

[31] *Id.* at 63. "[W]e have provided a theoretical account of why it is that knowledge about the individual patient is not merely essential, but is always and necessarily potentially inadequate to the extent that damaging error may result from conscientious, well-motivated clinical intervention by even the best-informed physicians." Gorovitz & MacIntyre, *supra* note 28, at 65.

[32] Knightian uncertainty refers to the idea that there are types of future contingent events and probabilities that are not capable of being quantified; hence, they are irreducible to quantifiable risks. *See* FRANK H. KNIGHT, RISK, UNCERTAINTY, AND PROFIT ch. 7 (1921). For a discussion of the application of Knightian uncertainty and its impact on every mode of rational decision making, see generally René Reich-Graefe, *Calculative Trust: Oxymoron or Tautology?*, 4 J. TRUST RESEARCH 66, 70–71 (2014).

spect to a cancer treatment using radiation that has a hypothetical 70% chance of success and a 30% chance of "no success" based on past application and experience. It is known that radiation kills cancer cells—this is an example of a knowable fact that is also actually known—a "known known." It is also known that radiation will do damage to other parts of the body but not known what or how bad the damage might be in a particular person—this is an example of a "known unknown" contingent outcome. Based on the known knowns and known unknowns, a patient must make a decision about radiation treatment. The 70% chance of success only correlates with the known knowns and the known unknowns—and only as a statistical average for a homogenized group of past cancer patients. These statistical averages are still useful, however. As Lawrence Schneiderman has observed,

> Most of us probably would agree that if a treatment has not worked in the last 100 cases, almost certainly it is not going to work if it is tried again. . . . The experience of 100 cases is attainable in many areas of medicine. This proposal is . . . one that seeks reasonable consensus where absolute certainty is impossible and therapeutic benefit is the goal.[33]

But acknowledging this point is only the first step to accepting the full extent of uncertainty in making medical decisions.

The patient's decision based on the statistical 70% chance of benefit described above, however, also entirely ignores the additional category of "unknown unknowns"—those contingent future variables impacting patient outcomes that are objectively unknowable at the time of decision making.[34] To make as rational a decision as possible, physicians and patients must acknowledge that unknown unknowns may always exist and may substantially impact the prognosis calculus and that they do not and rationally cannot know the extent of the unknown unknowns or how they might apply to the patient's particular case. The 70-30 success ratio might have only a 10% application in the particular case due to un-

[33] *See* Lawrence J. Schneiderman, *Defining Medical Futility and Improving Quality of Care*, 8 BIOETHICAL INQUIRY 123, 125 (2011) (adding that "in the end, we all will have to accept some empirical notion of medical futility or else throw all commonsense to the wind").

[34] *Cf.* KARL R. POPPER, THE LOGIC OF SCIENTIFIC DISCOVERY 280 (1961) ("The old scientific ideal of *episteme*—of absolute certain, demonstrable knowledge—has proved to be an idol. The demand for scientific objectivity makes it inevitable that every scientific statement must remain *tentative forever*. It may indeed be corroborated, but every corroboration is relative to other statements which, again, are tentative. Only in our subjective experiences of conviction, in our subjective faith, can we be 'absolutely certain.'"), *cited in* Schneiderman, *supra* note 33, at 124 n.1.

known unknowns unique to the patient, i.e., that this patient, because of variables, is 90% likely not to fall into the 70-30 benefit-risk calculus that applies to the broader population of like patients. Notwithstanding this non-quantifiable-in-advance Knightian uncertainty (of known unknowns and unknown unknowns), patients who desire to live will form expectations[35] based on statistical averages, although these expectations may be irrational. Physicians, when they fail to acknowledge to themselves or disclose to patients this form of necessary fallibility, become complicit in patients' demanding and receiving potentially ineffective and harmful care.

In the specific context of medical decision making, the concept of clinical uncertainty is one form of necessary fallibility. Patients facing terminal illness frequently want their treating physicians to advise them as to the "best" treatment for their illness or condition. The problem is that, for multiple reasons, there is often no obvious "best" approach for any particular patient at any particular time. First, patients must understand that what is "best" depends at least to some extent on the patient's own goals of care. While one patient may be seeking maximal life extension no matter what the costs in terms of adverse effects, increased suffering, or medical dollars, another patient may prefer to focus on maintaining physical and intellectual functionality even at the cost of a potentially shorter lifespan. For this latter group of patients, the prospect of loss of meaningful ability to interact with the world might drive decisions to focus more on palliation of symptoms than on life prolongation. Second, clinical uncertainty means that the ability of physicians and patients to make rational calculations about the comparative desirability of various options within the context of the patient's subjective goals of care is always limited by the imperfections of predictive data on therapeutic response, adverse effects, and prognosis.[36]

[35] *See* Niklas Luhman, *Familiarity, Confidence, Trust: Problems and Alternatives*, *in* TRUST: MAKING AND BREAKING COOPERATIVE RELATIONS 94, 97 (Diego Gambetta ed., 1988) ("You cannot live without forming expectations with respect to contingent events and you have to neglect . . . the possibility of disappointment . . . because it is a very rare possibility, but also because you do not know what else to do. The alternative is to live in a state of permanent uncertainty.").

[36] *See generally* JEROME GROOPMAN, HOW DOCTORS THINK (2007) (discussing clinical uncertainty in diagnosis and treatment recommendations); *see also* George A. Diamond, *Future Imperfect: The Limitations of Clinical Predictive Models and the Limits of Clinical Prediction*, 14 J. AM. C. CARDIOLOGISTS 12A (1989) (describing different ways in which statistical regressive models to predict clinical outcomes can go awry). Prognosis for meaningful recovery in many medical circumstances, such as for stroke patients, requires a discussion between physician and patient of complex variables such as the likelihood of regaining de-

It is, therefore, impossible to determine with any rational certainty a "best" or "optimal" treatment before the fact. Even after the fact, uncertainty will remain—who is to say that a different treatment might not have been better? Patients (and perhaps physicians) mistakenly view these sorts of decisions like forks in the road at which one can take a "right turn" or a "wrong turn" when they are in fact more like a river delta into which multiple rivers flow but all of which end up in the sea. Choosing the best treatment is very different from a financial investment in which one attempts to buy the "best" stock. With stock investing, one can look at past data and make a bet. If the initial money invested creates a return, one can assess retrospectively whether the chosen stock gave the best return on investment by comparing how the money would have performed if invested in a different stock. With humans and medical treatment, by contrast, one can never look back and assess with any certainty whether a different choice would have been "better"—because humans can only make the investment once and with no ability to compare alternative outcomes. Moreover, as soon as a treatment decision has been made and implemented, biases will often kick in in order to shore up confidence in the decision. At some point, patients have to make a decision and begin (or forgo) treatment, and they naturally crave reassurance that they are doing the "best" thing. These decisions are perhaps "informed" to the extent that physicians provide information about likelihood of success, but the concept of "informed" is greatly limited by the fallibility factors described above.

Necessary fallibility encompasses the idea that a patient's ability to make truly informed decisions about end-of-life care is limited by the patient's (and physician's) own abilities to process complex information rationally.[37] In addition, both physicians and patients also regularly em-

grees of physical function and this, too, is difficult to predict as a scientific matter because there are so many variables. A meta-analysis of data from multiple studies on the recovery of stroke patients who were receiving mechanical ventilation found that prognosis was generally poor, with 58% of these patients dying within 30 days, but that a minority of patients survived without severe disability. *See* Robert G. Holloway et al., *Prognosis and Decision Making in Severe Stroke*, 294 JAMA 725, 725–27 & tbl.1 (Aug. 15, 2005). The authors of this study caution that physicians can be unrealistically optimistic or pessimistic in various circumstances and argue that physicians should think carefully about how they convey prognostic evidence. *See id.* at 729 & tbl.3 (offering the example of explaining to a patient a surgical intervention as giving a person "a 50% better chance of an improved outcome" versus that same intervention increasing the person's chance "of an improved outcome from 5% to 7.5%" (internal quotation marks omitted)).

[37] *See* Herbert A. Simon, *A Behavioral Model of Rational Choice*, 69 Q.J. ECON. 99 (Feb. 1955) (describing the limitations of humans to process information due to limited access to data and limitations of intellectual calculative abilities as bounded rationality).

ploy biases and heuristic shortcuts that will further interfere with boundedly rational informed decision making. Optimism bias constitutes one example of this sort of limitation in the context of decisions about treatment and life-prolonging technologies for those with life-threatening illness. Patients tend to think they will be among the fortunate one percent who greatly outlive the statistical prognosis for their disease or who respond unusually well to an otherwise non-curative therapy.[38] Patients also frequently discount the likely non-curative value of certain invasive treatments, either because this information is not included in the informed consent conversations or, as is relevant here, because they have accidentally or deliberately failed to understand that it is impossible to predict with any accuracy the effects of the treatment in a particular case.[39] With the plane already decelerating on the landing strip, these patients wonder whether and how it can take off again. Physicians also tend to be unduly optimistic, overestimating the remaining life expectancies of seriously ill patients and conveying prognoses in overly optimistic terms.[40]

The fear of death and denial of mortality constitute the flipside and ultimate driver of unreasonable optimism and make confronting these ineluctably imperfect choices, reasoning through them in the context of personal beliefs and goals of care, and then making an informed but rationally never perfect choice very difficult. Truly informed consent re-

[38] *See* Lynn A. Jansen et al., *Unrealistic Optimism in Early-Phase Oncology Trials*, 33 IRB: ETHICS & HUMAN RES. 1 (2011) (finding that, although participants in an early phase trial understood that the treatment would not cure their cancer, a majority of those surveyed nevertheless exhibited an optimism bias in believing that the experimental drug would control their disease and that they would experience only benefits from the drug and no side effects).

[39] With respect to chemotherapy for metastatic cancer, one study found that 69% of patients with lung cancer and 81% of patients with colorectal cancer mistakenly believed that the chemotherapy they were receiving was likely to cure their disease. *See* Jane C. Weeks et al., *Patients' Expectations About Effects of Chemotherapy for Advanced Cancer*, 367 NEW ENG. J. MED. 1616, 1619–20 (Oct. 25, 2012) (noting, however, that "[p]aradoxically, patients who reported higher scores for physician communication were also at higher risk for inaccurate expectations" regarding the curative potential of chemotherapy).

[40] *See* Nicholas A. Christakis & Elizabeth B. Lamont, *Extent and Determinants of Error in Doctors' Prognoses in Terminally Ill Patients*, 320 BRIT. MED. J. 469, 470–71 (Feb. 19, 2000) (finding that, in predicting patients' remaining life expectancies, physicians were correct only 20% of the time and were over-optimistic 63% of the time and concluding that a closer doctor-patient relationship was associated with over-optimistic predictions); Elizabeth B. Lamont & Nicholas A. Christakis, *Prognostic Disclosure to Patients with Cancer Near the End of Life*, 134 ANN. INT. MED. 1096, 1099 (2001) (finding that, in communicating expected survival times to patients with terminal cancer, physicians were frank with patients only 37% of the time, provided deliberately inaccurate survival estimates 40.3% of the time and preferred to offer no estimate for 22.7% of the patients studied).

quires both courage and an understanding of the limits of knowledge, knowability, and rationality. So in every case, the ethical value of autonomy is to some extent a construct that assumes patients have endless time to process endless amounts of perfect and complete information to make a perfectly rational end-of-life decision. This is simply not the case.

If a physician is completely honest, he or she must recognize and accept that necessary fallibility is impossible to overcome. In general, the word "fallibility" implies incompetence or failure, but in the context of necessary fallibility, the use of the word is inapt and actually harmful. There is nothing morally wrong with necessary fallibility, and physicians should not let this sort of uncertainty inhibit them from either disclosing the limits of knowledge to patients or from acknowledging to themselves that this sort of limit is okay and indeed inevitable.[41] Both statistically and rationally it is clear that, in predicting the future, doctors can and will get it wrong without *being* wrong. Physicians are mortals with bounded rationality like the rest of us. In this sense, the whole idea of "best" treatment does not apply (either objectively with respect to medical data or subjectively with respect to a particular patient). Perhaps, it is some underlying sense of this unavoidable "fallibility" that leads physicians and patients to want to do "everything" (and thus unwittingly reinforce their optimism biases). Nevertheless, physicians must do the best they can. For these reasons, they have an ethical obligation to take the lead in initiating discussions about treatment choices and the use of life-prolonging technologies.

And so, the title of this essay attempts to capture the idea that informed consent has its limits, but also that avoiding the effort to achieve truly informed consent is an irrational choice because it risks serious negative outcomes for patients. The cultural tendency to avoid thinking too much about mortality, even when one is terminally ill, together with

[41] *Cf.* Gorovitz & MacIntyre, *supra* note 31 at 64–65 (discussing, in the context of claims about medical malpractice, the point that injury is no proof of a physician's culpability). The authors write,

> If physicians were to act as if they recognized this point, they might become far less reluctant to acknowledge, systematize, and learn from injury. But that would require a widespread willingness on the part of patients also to acknowledge the point, and thereby to lower their expectations about what physicians can accomplish . . . .

Id. at 65. I suggest here that the same analysis applies to physician recommendations with respect to end-of-life interventions. Acknowledging fallibility would be a good thing for both physicians and patients if both can understand that this sort of fallibility does not also imply culpability.

physician avoidance of truthful and thorough conversation about the risks, benefits, and alternatives to treatment and life-sustaining therapy, means that many dying patients will make an irrational choice to remain un(der)informed. When physicians take the path of least resistance and let this un(der)informed state continue, they do their patients no favors.[42]

We all need to form some expectations about the future in order to function in the present,[43] but the trick is not to get too attached to these expectations (whether it is flight path, time at cruising altitude, landing strip length or similar aspects of the future). Those people who acknowledge on a daily basis the uncertainty of the future and the precarity of life are probably going to be more readily able to accept the idea of terminal illness and to make treatment decisions that are both well-informed (as to known knowns, known unknowns, and the unknowable impact of unknown unknowns) and consistent with their individual values and goals of care. And accepting uncertainty—about prognosis or efficacy of treatments—will be easier for patients whose physicians also acknowledge and discuss the uncertainty that is inherent and unavoidable in virtually all complex medical care decisions. Physicians themselves, by the very nature of their work, live with clinical uncertainty and life's precarity every day and sharing this reality with their patients is more likely to bring patients and physicians together in a collaborative decision-making team than to destroy hope or leave patients feeling abandoned. It also can optimize the rationality of patients' informed consent and thus their confidence in having made a proper choice under the most challenging of circumstances.

[42] Of course, these sorts of conversations are necessarily emotionally challenging, and more so if the patient exhibits reluctance. *See* Elisa J. Gordon & Christopher K. Daugherty, *'Hitting You Over the Head': Oncologists' Disclosure of Prognosis to Advanced Cancer Patients*, 17 BIOETHICS 142 (2003) (describing the results of a small focus group discussion with physicians in which many expressed reluctance to convey statistical details about prognosis because they felt that the information would seem too abrupt and would interfere with patients' hope). But without some information about what is knowable about the patient's prognosis, patients are more likely to consent to treatment that provides no benefit while simultaneously exposing them to serious adverse effects.

[43] *See* Luhman, *supra* note 35.