

INTIMATIONS OF MORTALITY

In *Intimations of Mortality*, Barbara Reich offers an empirically based critique of the failures of end-of-life communication and decision-making in the United States. Using England and Canada as occasional foils, Reich explores why US physicians, patients, and families struggle to have the conversations necessary to provide seriously ill and dying patients with medical care consistent with their preferences. Reich also shows how a number of different factors – including payment mechanisms, liability fears, cultural phenomena, communication avoidance, death denial, and clinical uncertainty – impact physician-patient communication and medical decision-making, leave patients and families without the tools they need to make informed choices, and instead leave the default practices in place. Ultimately, this groundbreaking analysis unveils the interconnectedness of the many obstacles to better communication and decision-making at the end-of-life and offers much needed suggestions for improvement.

Barbara A. Reich is Professor of Law who has taught Bioethics, End-of-Life Law, and other Medical Law subjects for more than two decades. She is the author of numerous articles addressing end-of-life issues, including articles about the Theresa Schiavo case, racial disparities in health care delivery, informed consent and shared decision-making, advance directives, and cognitive challenges to making good medical decisions. Barbara is a graduate of Harvard Law School.

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Intimations of Mortality

MEDICAL DECISION-MAKING AT THE END OF LIFE

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To René
Ich suche nichts, weil ich Dich gefunden habe.

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Preface

Our mortality binds us together as individuals, families, communities, cultures, nations, and denizens of the earth. But each of us must write our own script for how to navigate life with the future certainty of death. How and when we write (and amend) that script very likely will influence both the physical and emotional experiences of how we die. While much of how we will die remains outside of our control, preparation for death throughout life can enhance the experience of life and make the foreknowledge of death less frightening and more familiar. Most people who survive childhood arrive at a point in adulthood where the thought of death is no longer a distant and abstract concept. Whether it is diagnosis with a life-threatening illness or the cumulative effects of aging, something puts each one of us into the position of having to face the road to death and to make decisions along that path. Or not. Some deliberately or unconsciously avoid making these decisions or even contemplating the future – because change is hard and everything must remain as it always was. Death is the ultimate change of circumstances.

We have a system of medical care undergirded with ethical principles and a legal system as backup to these principles that are meant to protect and guide patients through the complex medical decisions that often arise at the end of life. On the surface, both medicine and law look good – a combination of excellent scientific training, the latest technology, an emphasis on patient autonomy and physician beneficence, and related law ensure that patients receive the ‘best’ medical care. Right? Well, in ideal circumstances, yes. As in many countries and cultures, ethical principles and law in the United States support the right of patients to make medical decisions according to their own values. In most circumstances, the principle of autonomy allows an adult to choose whether to accept or to refuse medical treatment, including therapeutic care and life-prolonging technology. This autonomy principle is protected – in theory – via the legal doctrine of informed consent. So, while one person with a terminal illness might request all available medically appropriate care to prolong life, no matter what the costs or adverse effects, another person might choose no therapeutic care, preferring to focus solely on palliation of

symptoms. And a third person might seek a middle ground, agreeing to try therapy for the disease but then to discontinue that therapy when side effects or disease progression interferes too much with quality of life. Each of these paths is a valid choice under the ethical principle of autonomy and the law of informed consent.

And yet, for a country that has enshrined the autonomy principle in its culture and law, the United States struggles mightily with calibrating care to the wishes of individual patients. Comparisons of medical care that patients collectively receive at the end of life with a population-wide snapshot of prior expressed wishes indicate that patients in the United States are receiving far more life-prolonging and otherwise invasive interventions to stave off death than they would prefer. An ever-increasing body of empirical research backs this up: studies suggest that more than one-fifth of medical care provided in the United States is unnecessary, and that the consequent inappropriate use of burdensome or high-intensity medical technology at the end of life adversely impacts patients. Yet most dying patients say that they would prefer comfort care. Combine these two sets of data on actual practice versus patient preferences and we have a system that, statistically and for many individual patients, overutilizes unwanted medical technology at the end of life. This is not to say that physicians get it wrong every time, but this discrepancy suggests that many patients are receiving care that they do not want and that is also medically inappropriate. The reasons for this misalignment are many and complex – and are the primary subject of discussion in this book. The focus is on physician-patient (and family) communication and decision-making, including an attempt to understand the reasons why (according to the data) so many patients receive care at the end of life that they probably would not choose if they were better informed. To make this discussion more useful, I situate this question within the larger context of law, health systems, culture, dysfunctional politics, and cognitive barriers to good decision-making.

Acknowledging the validity of individual preferences for various pathways to death is important, but it ignores the fact that many people avoid entirely the thinking process that is necessary to make robust, well-informed decisions about which pathway to choose because the thought of death is uncomfortable to confront. Many patients avoid making decisions in advance. If the decision not to decide is the result of a voluntary and considered choice to accept mortality by relinquishing attempts to exert control over death and the dying process, then perhaps all is well, at least for the dying person – though the medical technology juggernaut may still result in an undesirable and perhaps harmful prolongation of the process. If, however, the non-decision arises out of a reluctance to confront mortality, then the non-deciders likely do themselves a disservice, not only at the time of death but throughout the life that precedes it.

Modern medical care often can stave off death for quite a while (though often with significant cost to quality of life), and the default model in the United States is to provide therapeutic treatment and life-prolonging interventions unless the patient

affirmatively opts out. Why is this the case? The answer to that question is complicated. Conversations about prognosis and the potential utility of various treatments provide an essential opportunity for patients to convey to their physicians their preferences about care at the end of life – and for physicians in turn to explain to patients the potential value of various medical options – their harms and prospective benefits. We may be tempted to assume that the better (though imperfectly) informed decisions resulting from these conversations can help reduce avoidable physical and emotional suffering and lead to care that aligns with patients' well-considered values and preferences. The problem with the prior sentence is that while it may be theoretically correct, it rarely reflects the reality of physician-patient communication and decision-making. Individually, physicians, patients, and families struggle to have candid, substantive, and timely discussions about necessary choices in the face of life-threatening illness. In the absence of these discussions, physicians in our health care culture frequently provide full-on medical interventions, even when patients are actively dying, because no one – patient or family member – has told them to stop.

The common purpose of the following chapters is to understand this communication problem better in all of its multilayered complexity, to situate the challenges of physician-patient communication within the broader health care system, law, and culture in which they occur, and to consider feasible and realistic individual and system-wide improvements to end-of-life decision-making. To that end, this book considers several interrelated layers of inquiry that may appear to belong in separate books but are, in reality, very much intertwined. One question that this book will explore is whether and how the universal access to care along with other health care structures in Canada and the United Kingdom produce superior end-of-life care for patients in these countries. (Of course, this in turn begs the question of what constitutes 'superior' care, but there is some agreement on that question.) Rest assured that this is *not* a book about health care system reform, though some discussion of the topic is necessary to understand the financial, governmental, political, and cultural context in which physicians in the United States provide medical care. The United States is obviously very different from Canada and the United Kingdom, not only because we lack universal access to health care but more broadly because the complexity and dysfunctionality of our health care insurance and regulatory systems, along with intractable political schisms, make reform extremely challenging. Health care reform would be great for many reasons, but it would not effectively resolve our collective difficulties with end-of-life communication and decision-making.

A variety of other systemic and individual factors contribute to a pattern of poor physician-patient communication and high-intensity care at the end of life – what some have called the 'conveyer belt' of medicine. Systemic problems, such as mechanisms of health care reimbursement and liability concerns among physicians, add pressure to provide potentially inappropriate care. At the same time, cultural

attitudes toward mortality play a significant role – many admire and praise the model of the patient as a ‘fighter’ in a ‘battle’ against death. And denial of mortality is common. Physicians’ professional culture, focusing oftentimes too much on cure over care, perpetuates many of these dysfunctionalities. On top of these problems, Black and other racial and ethnic minorities distrust the health care system (with good reason) and may therefore experience an added communication burden regarding end-of-life decisions. And in addition to all of these obstacles, there are the mostly unacknowledged cognitive barriers to ever knowing what the ‘best’ choice is for many seriously ill patients. Only when physicians, patients, and families acknowledge the rational limitations of decision-making for life-threatening illness can the serious work of communicating and decision-making begin. This book considers all of these obstacles to ‘good’ end-of-life decisions and suggests what we can do, individually and collectively, to get to ‘better’. ‘Best’ nearly always remains unknowable.

I am not a trained philosopher, an expert in decision theory, or a health care professional. I come at this topic from the perspective of a legal academic with an interest in the multi-causal aspects of poor communication and decision-making by and for adults at the end of life.^{*} Although most of my days are spent teaching and writing about law, this book discusses law only as a framing structure and foundation (along with ethical principles) for the process of decision-making at the end of life. As the book will demonstrate, law does not do a very good job of addressing the problems discussed here. Law, with very narrow and limited exceptions, is not the answer. The book attempts to reach several audiences and so makes some compromises along the way. It is a book written for all interested parties – patients and their caretakers, academics, clinicians, and policy makers – and anyone else who would like to understand the reasons why confronting mortality and making decisions at the end of life is so difficult (apart from the obvious).

There are no quick fixes. The already vast and burgeoning body of literature on the topic of death and dying demonstrates that point quite well. Many experts are hard at work devising ways to excise the excess from medical care in the United States, and I do not pretend to have better answers than they do. But an improved understanding of *what* is happening – systemically and individually among patients and physicians – and *why* it is happening may help physicians, patients, and families communicate more effectively and make decisions along the pathway to death that more closely reflect the authentic and realistic preferences of the patient. Getting to ‘better’ also may incrementally improve care for the seriously ill at a system-wide level, to the benefit of future patients. Improving care for the dying obviously will require some changes of culture and customary practice in medicine. So I will add

^{*} Throughout the book, I omit consideration of decision-making for severely ill and disabled infants and children. I also sidestep discussion of medical aid in dying (popularly known as “physician-assisted suicide”), mainly because the focus of the book is on communication between physicians and patients rather than the ethics of various end-of-life options.

a caveat: much of the argument in the book rests on a foundation of empirical evidence, but we are each of us an ‘n’ of one. The critiques and recommendations that follow are not aimed at any individual physician or patient or family member. Many individuals acknowledge the fact of mortality, communicate well, and make end-of-life decisions with courage, grace, and dignity. These same individuals very likely live their lives with the same qualities. The human instinct for survival is very powerful, and patients will quite rightly endure a lot in exchange for more life. The trick is knowing when to say ‘when’ (and that thinking process can be cultivated in advance).

This is not a book about ‘how to die well’ but rather a book about ‘how to think well about dying’. Thinking well about dying requires two elements: an understanding of the health care system’s deficiencies and of how doctors communicate with patients and a willingness to acknowledge mortality as an ineluctable part of life (and to live and make decisions accordingly). For the young and the fortunately healthy, there is little cause to contemplate the prospect of death, at least not often. Perhaps the death of a grandparent, parent, or friend brings mortality into sharp focus for a time, but it tends to recede into the background of daily life. As we grow older, the thought of mortality creeps into mind more frequently until, finally, it is a little bird singing into ears that grow deaf. How we cope with these ever more frequent intimations of mortality throughout our lives colors the days that become the weeks and months and slippery years – and determines how well prepared we are to face death.

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The title of this book is a riff on Wordsworth’s “Ode: Intimations of Immortality from Recollections of Early Childhood” (1807). Portions of this book draw on the following previously published work (some of which was published under my former name, Barbara A. Noah):

- Surrogate Decision-Making: Clinical Uncertainty, Rational Apathy, and the Problem of Trust, 15 *Ethics, Medicine & Public Health Journal* (Oct.–Dec. 2020)
- Rational Patient Apathy, 49 *Seton Hall Law Review* 535–628 (2019) (with René Reich-Graefe)
- Potential Utility of an Independent Decision-Making Board for Seriously Ill Patients Lacking Decisional Capacity, 6 *Ethics, Medicine & Public Health Journal* 63–71 (July–Sept. 2018)
- Removing Obstacles to a Peaceful Death, 23 *Elder Law Journal* 197–233 (2018) (with Kathy Cerminara)
- The (Ir)rationality of (Un)informed Consent, 34 *Quinnipiac Law Review* 691–704 (2016)
- Avoiding Overtreatment at the End of Life: Physician-Patient Communication and Truly Informed Consent, 36 *Pace Law Review* 737–800 (2016) (with Neal Feigenson)
- A Better Death in Britain? 40 *Brooklyn Journal of International Law* 870–915 (2015)
- Two Conflicts in Context: Lessons from the Schiavo and Bland Cases and the Role of Best Interests Analysis in the United Kingdom, 36 *Hamline Law Review* 239–264 (2013)
- In Denial: The Role of Law in Preparing for Death, 21 *Elder Law Journal* 1–31 (2013)
- The Role of Race in End-of-Life Care, 15 *Journal of Health Care Law & Policy* 349–378 (2012)

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- The Role of Religion in the Schiavo Controversy, 6 *Houston Journal Health Law & Policy* 319–346 (2006)
- Politicizing the End of Life: Lessons from the Schiavo Controversy, 59 *University of Miami Law Review* 107–134 (2005)

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