INTRODUCTION

Diagnosing Twenty-First-Century Health Care

Medicine today comprises an unthinkably broad array of knowledge and skills, professions, coalitions, and interest groups, fears and promises, fantasies and soon-to-be-realities, concrete and virtual institutions, folklores and sciences.
—Arthur Frank, *The Renewal of Generosity*

Medicine has changed radically over the past fifteen years. Some of those changes are obvious and dramatic and have provided welcome benefits. Who doesn't welcome the availability of cholesterol-lowering drugs, joint replacements and arthroscopic surgery, the anti-retrovirals that have made AIDS a chronic, manageable illness, and so much more?

Other equally obvious and dramatic changes, however, have become the subject of widespread lament: too much life-sustaining but death-prolonging technology is being used at the end of life; drug companies are paying physicians to promote their products; expensive tests, devices, and procedures are overused; drug costs, especially for cancer treatment, have skyrocketed, yet the new drugs don't necessarily offer better results than existing treatments. Most everyone who has had intimate dealings with the U.S. health care system of late can add to this list of obvious and well-publicized problems.

However, many equally dramatic and relatively recent changes within the U.S. health care delivery system are far less visible—indeed I contend that they are very well hidden. But although they function well below the radar of scrutiny, these changes have not just complicated medical practice and health care delivery but actually have altered their very nature. They have also altered how and what we *think* about health per se and about the options we have for controlling our life span and that of our

loved ones. Therein lies the health care dilemma that patients, families, and providers by the millions face every day.

Today's Quandary: When, Where, and How to Draw the Line?

When faced with a life-threatening disease, most of us want the miracles of medicine to extend our lives into a vaguely perceived open-ended future. Yet we don't want to live too long, that is, into a medically prolonged period of suffering or suspension in some limbo, no longer who we were but not yet dead. The big problem, the intractable, increasingly apparent problem is that few know when that line between life-giving therapies and too much treatment is about to be crossed. The burden for knowing where that line sits, and then when and how to respond to it, rests first with doctors and the systems in which they work, yet neither the doctors nor the systems have been effective in recognizing it or foreseeing the consequences of crossing it. And so we find ourselves in a conundrum: the postwar baby boom generation grows older while confronting the old age of its parents; the oldest generation is living longer but not always better; and the widespread lament about *where* that line is located and what to do about it grows ever louder.

Thus the quandary for patients, families, and physicians is about how to live in the world of modern medicine and its life-giving tools, about getting the medicine we wish for but then having to live with the unsettling and far-ranging consequences.

This quandary, its origins, its drivers, and our troubled efforts to resolve it, are the focus of *Ordinary Medicine*. I focus on the ethical, cultural, and political forces driving health care delivery, forces that have made it difficult, if not impossible, to see the line between *enough* and *too much* or even to acknowledge that line's existence or its importance for patient care, medical practice, and the future of the health care system. Not only is this quandary often deeply unsettling for doctors, patients, and families, but it also lies at the crux of the impasse the United States has reached regarding health care reform. Only by *seeing* the way ordinary medicine works, the forces that shape the quandary as well as medicine's successes, can we hope to minimize that quandary and, in addition, work our way out of our untenable national situation.

Three Formative Developments

Three separate but interrelated societal developments that permeate the fabric of American society also control our health care quandary.

THE INCREASED ROLE AND INFLUENCE OF INDUSTRY

The first development is the rising power of the pharmaceutical and device industry, whose market-driven, market-expansion goals have a greater influence on the development and use of treatments than ever before. Industry largely determines which therapies will be investigated and which patient-consumer markets will be exploited. As a consequence its role in determining what doctors recommend and what patients ask for is also increasing. Biomedical research in the United States is a $100 billion enterprise that has approximately doubled in scope since 1999.

There has been a significant shift in the major source of research funding, from government to industry. In 1980, 32 percent of clinical research was funded by private pharmaceutical, medical device, and biotechnology companies. By the mid-1990s that figure had increased to over 50 percent; today it is 65 percent.

The clinical trials industry has mushroomed in recent decades. In 2000 the National Institutes of Health established a data bank of clinical trials information, ClinicalTrials.gov, listing some four thousand trials. By January 2014 its home page listed 159,000 ongoing clinical trials. Clinical trials have acquired strong influence beyond the laboratory. Since the turn of the millennium they have become a culturally prominent and powerful fixture in American life, further strengthening the role they play in ordinary medical practice. Patients *and their families*, increasingly adept at using the Internet to conduct research on diseases and treatments, have learned to view *participation* in clinical trials as disease treatment, as an individual right, and as the embodiment of hope.

THE PROLIFERATING NUMBER OF TREATMENT OPTIONS

The second development is the ever increasing number of treatment options to which doctors, patients, and their families *have access*. These readily available options (which are extremely difficult to say no to) contribute to the overuse of common therapies and diagnostic tools such as the MRI, colonoscopy, and cardiac defibrillator.

The increasing number of trials has generated ever more *evidence of therapeutic value*. Once this evidence is established for a new drug,

device, or procedure it is allowed to go on the market. The evidence and the market presence explicitly influence not only what physicians recommend but also what patients learn to want. Unfortunately studies show that new treatment options do not necessarily offer patients better health or a longer life span.

New technologies for diagnosis and treatment, once they are approved for use by the Food and Drug Administration and reimbursed by Medicare and other insurers, are almost always accepted by physicians and patients. Once accepted, they become standard and their use often spreads beyond the population for which the technology was devised. For example, when the implantable cardiac defibrillator (ICD) was introduced in 1985 it was a "treatment of last resort" for very specific heart problems. By 2005 it had become a common surgical tool to stave off death, even for the oldest patients. Similarly the artificial heart pump (left ventricular assist device, LVAD) has shifted from being an experimental device intended for temporary use to being a standard long-term solution for end-stage heart disease.

AMERICANS' PERSPECTIVE ON AGING AND THE TIMING OF DEATH

The third societal development orchestrating the health care dilemma is the profound impact our society's unrelenting prioritization of the use of new technologies has had on our perspective on aging and on death itself—especially with respect to the drugs, devices, and surgical procedures now available to treat what used to be end-stage diseases. In the United States today most deaths, regardless of a person's age, have come to be considered premature. Because medicine's tools can seemingly "add" time, the value of life has come to be measured, in large part, by its length. This has magnified our quandaries by reinforcing the desire for and rationality of intervening at ever older ages to extend life, regardless of the emotional and financial costs. The central role of high-tech life-prolonging treatments means life extension for many more older people, but it also means choosing among the available options, which often burdens patients and families with a heavy sense of responsibility for making the "right" choice. Will a treatment prolong the patient's life or simply prolong an unwanted kind of dying?

The apparent "good" of all new technologies and the burdens they create now meet an aging population. Over the past fifteen years the U.S. population in general, and therefore the patient population, has aged. In

2010, 13 percent of the population was over age sixty-five; 2 percent was over eighty-five. By 2050 those percentages will be 20 and 4 percent, respectively.

The surge of advanced treatments that keep lethal diseases at bay and our romance with new medical technologies go on relentlessly, with ever older persons on the receiving end and growing numbers of families caught in the tangle of emotional, financial, and organizational responsibilities of care. The particularly American ethos of "more is always better" underlies the high-tech and aggressive approaches to treatments. At the same time, fear, ambivalence, and complaints about *too much* proliferate.

The increase in the use of high-tech treatments for older patients is also reflected in ever increasing costs to the Medicare program and the nation. (Medicare is the federal program of health insurance available to persons sixty-five and older.) For example, the LVAD costs approximately $250,000—ten times more than the ICD. The number of patients over seventy-five who have been started on maintenance kidney dialysis has tripled in the past two decades, even though dialysis therapy does not necessarily improve quality of life or prolong life for elderly persons. Since 2001, when kidney transplantations from living donors first exceeded those from deceased donors, adult children have been donating their kidneys and parts of their livers to their parents and other older relatives with ever greater frequency.

Why bother to write a book about the quandary of crossing the line when so many millions of people in their later years have reaped the benefits of modern medicine? When so many have had their lives prolonged by cardiac procedures and cancer treatments? When so many live not only longer but better as a result of those treatments?

As a medical anthropologist, I have spent more than twenty years watching this quandary play out and asking why it occupies so much of American political debate and cuts such a wide swath through the public conversation about control over the time for dying. Mostly the quandary is experienced by older persons, their families, and their doctors. In 2002 I began to observe older patients in specialty clinics, where they were most often offered life-prolonging therapies. I listened to hundreds of patients, physicians, and family members deliberate about what to do and heard them express their hopes, fears, and reasoning. Thus I have had a ringside seat on the evolution of their dilemmas about crossing the

line of "too much" and their desire to do everything possible to prolong life. Many patients ask their doctors what they themselves would do in similar situations, and doctors, notably, do not answer definitively.

I started tracing the themes that emerged in the clinic conversations about evidence and expectations, norms and standards, risks, hope and ambivalence, the urge to try everything and the demand to stop. The talk mostly settled on scientific evidence, standards of care, risk reduction, and necessary treatments, which led me to investigate how and why these have come to organize our "more is always better" approach to medicine. That quest, in turn, led me to think about the larger engines of the biomedical economy—the research and insurance industries (especially Medicare)—and their impact on what we do when life is at stake.

The Chain of Health Care Drivers: Four Invisible Controlling Factors

What emerged was my realization that there are unseen, determining forces, *a chain of health care drivers,* behind the dilemmas twenty-first-century American health care poses: Why do those of us caught up in the health care system often struggle so hard to decide what we want from potentially life-extending treatments? Why do we not know what to expect from them? Why do physicians prescribe specific treatments? Why do they sometimes go against their own professional values when making treatment decisions to prolong life? These quandaries are faced by millions every day—yet few if any of us can glean the lessons learned from the experiences of others. That is because the forces that determine the structure of the U.S. health care delivery system today are neither visible nor easily quantifiable, and what is hidden does not easily offer up the tools for understanding its nature. With those tools, doctors and patients might make different choices—choices that would promote significant system change.

Four primary drivers build on one another in a chain of events that governs medicine today. Those drivers and their effects on the practice of medicine and on the lives, health, and aging of all of us are the focus of *Ordinary Medicine*. Those drivers reveal the scope of our health care predicament and why we can't clearly see how to fix it. They show us what needs to be fixed and why. They are the key to restoring the primacy of the social good of medicine.

1. The initial driver is the biomedical research industry and its mushrooming clinical trials engine, which is churning out evidence of effective therapies at an unprecedented rate.
2. The committees that determine Medicare and private insurance payment policies evaluate that evidence to determine whether the therapy, device, or procedure in question should be reimbursable. If it is, physicians will prescribe it, insured patients will have access to it, and patients and families will want it.
3. Once a therapy is reimbursable by insurance, it almost instantly becomes a standard of care.
4. Finally, once therapies become standard, they also become ethically necessary and therefore difficult, if not impossible, for physicians, patients and families to refuse.

Health Care Drivers and the Ethical Field

The individuals seventy and older whom I sought out in high-tech treatment centers and the small, airless exam cubicles of community physicians' offices in several U.S. cities between 2002 and 2011 had life-threatening diseases.[1] Slowly over those years the determinative power of the chain of health care drivers became visible to me. And because I was observing human beings interacting in intimate and often desperate circumstances, what emerged was not just the structure of the chain but also its ethical underpinnings. It is a chain predicated on and imbued with ethical choices, political priorities, and economic commitments—in other words, it is based on and reflects cultural values. Not everyone's values, of course, but those that, through the political will of some, have become dominant in the health care arena.

These values dominate *all* of health care delivery today, not just health care for the elderly. Once one notices how strongly determinative these drivers are, however, it becomes perfectly clear that patients and families (and sometimes doctors) actually do not *decide* about treatments so much as they yield to procedures that the chain has made normal and ordinary. Everything I observed that affected patients and families on a human level—their options and rationales, emotions and ambivalence, their choices among the normal and normalized pathways of treatment and the ways that treatment goals impacted their experiences, sensibilities, and actions—proved to have these drivers and the values they represent as their common frame.

After spending many, many hours with physicians and older patients and their families, I also realized that the values and commitments that drive the entire health care enterprise—especially those of individualism, market-based approaches to health care services, and an instrumental or mechanistic view of medical "progress"—are so difficult to discern because they are exceptionally diffuse. Because they penetrate so much of American society and so heavily influence the patterns of biomedical research, medical treatment, and patient expectations, I think of them as forming an *ethical field*. This ethical field shapes health care policies, the development of biomedical technologies, and how evidence about treatment is produced and employed in clinical care. It is constituted also by what patients and families come to need and want. Ultimately the effects of the ethical field are seen in the physical caregiving tasks and emotional burdens placed on families. Its influence permeates every aspect of health care delivery and affects everyone: clinicians, patients, and families alike. Although it has grown increasingly dominant in recent decades, this ethical field has nonetheless already become, like the air we breathe, mostly unnoticed.[2]

Connecting the Quandary with "Ordinary Medicine"

The cacophony of voices and viewpoints I heard in the clinics—about whether to attempt to fix the body and with which tools, and about how to try to make patients "feel like themselves again"—led me to delve into the larger story, to learn why and how the problem of knowing when to stop treatment has been fraught with so much difficulty and has triggered such impassioned politics. I examined not only the components of the health care enterprise (evidence-based medicine, Medicare, etc.) but also the particularly American connections between individual rights and communal good and between politics and progress that characterize our contemporary society, drive the health care engine, and shape what happens to so many of us in later life.

I have coined the phrase *ordinary medicine* to serve as a shorthand reference that encompasses the wide range of features of the health care enterprise that must be looked at closely if we are ever to resolve the quandary about crossing the line. It reflects the hidden chain of connections among science, politics, industry, and insurance as well as the ethos that supports that chain. It emphasizes the fact that the driving features of our health care delivery system, and thus the practice

of medicine and what we want from it, have become taken for granted and routine.

Ordinary medicine is vast and fragmented and offers no inherent facility, no clue or advice for physicians with which to evaluate when *more* is not better and for putting on the brakes. And so our wonderful ability to extend life with medical technique—into ever greater old age—is now inextricably intertwined with the emotional burdens and dilemmas families must shoulder because they are responsible for deciding where the line of "too much" is located and what to do about it.

Is this an untenable societal burden? I am convinced that our medical practices define the kind of society we have, by which I mean that they show starkly how the commercial enterprise of health care delivery has far surpassed the *social good* as a function and goal of medicine. The dominance of private industry, the emphasis on new technologies regardless of cost, and the lack of equity in the distribution of medical care have created a vocabulary that we use to describe ourselves as psychological and cultural beings. It is a vocabulary that conflates "being medically eligible for" and "needing" a liver transplant, an implantable heart pump, or defibrillator beyond the age of, say, eighty. This conflation is possible only because today's medicine provides those tools and because such procedures have imperceptibly become "normal" at ever older ages. Twenty years ago one could not "need" those therapies because they did not exist. Ten years ago few anticipated that older persons would become the growth market for such therapies.

Life-Extending Therapies for Older People: The New Normal

By 2002 I had already begun to look carefully at medical interventions that were clearly prolonging lives—and doing so for greater numbers of older people.[3] I chose to focus on therapies that were becoming more common for patients over the age of seventy because the intersection of life-extending treatments with an aging population had already become the double-edged sword of medicine. Treatments for and in an aging society, and Medicare payment for those treatments, were driving health care for everyone in the United States. The ability to extend (and the potential to extend) already older lives is at once miraculous, desired, and taken for granted and a significant source both of individual quandaries about what to do and of the national struggle about the goals and the good of medicine.

As I investigated the use of organ transplantation, cardiac devices and procedures, and aggressive cancer treatments for older persons (reflected in the many case examples throughout this book), it was clear that cultural notions of what was *routine* were continuing to change even as I watched. Increasing numbers of older people were receiving these and other potentially life-extending medical treatments, and many were in treatment for long periods of time. Many of them were able to live longer and better as a result. This is what we all want. Others, regardless of the extent of intervention, did not have their lives prolonged by treatments, or their life was prolonged but so were extreme disability and suffering. Still others faced guilt and ambivalence in moving forward with or stopping aggressive therapies and were unable to choose between those pathways. (Today it is not easily evident which of these three groups is the largest.)

In wanting to know how and why each of these responses, each of these outcomes had become so ordinary for an ever older cohort of patients, I began to understand that the answer to the problem of crossing the line for patients and families—and thus resolving the conundrum about the goals and good of medicine—lay somewhere within that very ordinariness. It is the ordinariness of today's medicine that needs to be examined—and altered—if we, as a nation, are ever to emerge from the impasse that is the fractured American health care system.

This ordinariness is in marked contrast with another development. For the approximately one-fifth of Americans who have Medicare insurance (those sixty-five and older), these life-extending treatments are generally available and relatively accessible. Their health care dilemmas center around which therapies to undertake and when to stop. Yet at least another fifth of our society (who are under sixty-five) has limited (often very limited) access to routine health care services. Their problems are different and are equally or arguably more pressing—for instance, whether to buy medications or groceries. Yet the problem about the confused goals of medical treatment is particularly apparent when we turn to the health care that older persons receive.

The Chain and Its Ethical Field: Shaping Medicine, Shaping Us

Medicine is part of society and can offer and deliver only what the science of the times and the political and economic priorities of the setting make available. Medical care in any location is influenced by

what patients expect and by how access to it is determined and organized. In addition to being shaped *by* particular social and historical circumstances, the contours of medical practice and the organization of health care delivery themselves shape societal goals and norms and individual expectations about what is fixable and should be fixed, and among whom.

Ordinary medicine—the chain of health care drivers and the ethical field that supports it—matters because it is a profoundly influential shaping tool in our society. It not only determines which therapies are available but also affects how and why we say yes (or sometimes no) to specific therapies. The chain and the ethical field are the mechanisms by which treatment standards become social standards. They are the governing agents of doctor and patient behavior. They chart our senses of obligation and responsibility to the ill among us, guide our expressions of love and duty, and are the source of our quandaries about where and when to draw the line. Ordinary medicine shapes our most personal experiences of growing older and, ultimately, undermines medicine's ability to function as a social good.

We have come to the point where every day in hospitals and clinics, at bedsides and kitchen tables, before and after receiving therapies, the hope of potentially life-prolonging treatment comes up against the possibility of a prolonged, unwanted kind of living and dying. An eighty-six-year-old man succinctly summarized the dilemma to me at one clinic I visited. Two years earlier, following a third heart attack, he had received an automatic implantable cardiac defibrillator:

> After I passed out and was taken to the hospital, the cardiologist said I should get an ICD. He said he wouldn't be doing his job right if he didn't say that I needed an ICD. He told me the two stents I had previously were blocked. So I agreed and he put it in. Now it seems the ICD has prolonged my life a little bit. But the longer it prolongs my life, the more other things are happening to me, that it can't correct. And you know, all the medicines, all the treatments, have side effects, and some of them are pretty bad. So which do you want? The question is, do you want to have the other things that are going wrong and the side effects, or do you want to end it all? And when? I haven't given up on medicine, but the body wears out and there's nothing you can do about that.

The Disconnected Worlds of Health Policy and Medical Practice

This patient was caught up in a situation I found all too common during the years I spent conducting the research that led to this book: it often seems that the policy and clinical worlds exist on different planets. While the chain of health care drivers dictated that he "needed" an ICD, the clinical picture—"all the other things that are going wrong and the side effects"—is much more complicated, nuanced. While listening to patients, families, and physicians interact in clinics over the years, I also attended health policy lectures at my university and read numerous policy reports about Medicare reform and the state of health care delivery. It became clear that policy analyses dwell in the world of charts, statistics, and projections. They report trends in services, illnesses, payments, and costs, and they concentrate on quantification—numbers of patients, diseases, medical errors, hospitalizations, nursing home and clinic visits, costs of treatment, trends in government and private insurance spending, and so on. They create models, algorithms, and programs for better health care delivery and cost-effectiveness and focus on the organization of service delivery, cost sharing, coverage, and eligibility standards. If we can only reduce or streamline or add something to or eliminate something from the system, the reports tend to emphasize, then our costs will go down or at least not rise as quickly, services will be more efficient, and perhaps patients will be served better.

In the clinic, on the other hand, doctors and nurses are doing what they think is best for *this* patient right *now*. Their decisions depend on clinical and scientific evidence, technical skills, the diagnostic and treatment tools available to them and to the patient, their overall level of experience, and what they know about the patient's condition and life. Their goals are to treat disease, reduce risks, and prolong the life in front of them, or at least to make that life more comfortable.

Occasionally the worlds of policy and the clinic meet in a way that is visible to many, and the results are broadly regarded as positive. Recent examples include the use of checklists to reduce infections in hospitals, the consolidation of services and financial arrangements in "medical homes" and physician groups in order to reduce costs and the fragmentation of care, attempts to standardize treatments that have been proven effective, and the broadening of the spectrum of treatments that are included in some hospice coverage.

However, with regard to the expanding array of lifesaving therapies for older persons, it seems that the policy experts do not know what goes on in the clinic with respect to the difficult choices to be made, standard treatments, the press to treat, or the demands of physician and family responsibility. Because policymakers do not attend to those things, they cannot take into account the deeply rooted connections this book examines: connections between, for example, individual responsibility and technological innovation, between medical necessity and Medicare reimbursement, between doctors' recommendations and the clinical trials industry.

Clinicians, on the other hand, have not been and cannot be concerned primarily (or at all) with cost savings (though many are turning some of their attention to costs now). They cannot alter deeply rooted practice patterns on their own; in fact many physicians and nurses have told me that there are alterations they cannot make but "society" should make. Such changes might, for example, address whether to admit very old persons who are nearing the end of their life to hospital intensive care units for aggressive therapies; whether to start kidney dialysis for frail, demented, and/or very sick elderly persons; whether to implement age restrictions for organ transplantation; whether to suggest repeated rounds of chemotherapy for those at advanced ages.

The clinical world's interconnected yet often unseen entrenchment in powerful economic, political, and social forces determines the practice of medicine and the lives of patients, and it is one reason why health care reform has been so elusive in the United States. Its disconnection from the policymaking world has bothered me for a long time. By showing how the links in the chain connect to escalating expectations about health and life in old age, I hope to open a passageway for communication between the two worlds.

The Intersection of Ordinary Medicine and Our Aging Society: Progress or Postprogress?

Employing the most sophisticated medical treatments for octogenarians, nonagenarians, and older has come to seem normal, ordinary, and necessary. Almost unthinkable thirty years ago, these developments are now taken for granted at the same time that increasing numbers of patients and families pay a price in suffering and in the disquiet that accompanies the feeling, the knowledge of having crossed the line.

As a result our society has arrived at a point where choosing not to undergo heart surgery, chemotherapy, or organ transplantation, for example, or deciding against a feeding tube, implantable cardiac device, or kidney dialysis when one is eighty or beyond often seems somehow suspect—to patients, families, and doctors alike. Physicians' thinking, health care financing (which is driven by our system of Medicare reimbursement), and the culture and structure of medical treatment all point toward saying yes when the newest therapies and diagnostic tools are offered. Saying no to potentially lifesaving therapies seems like refusing to take the path of progress that medicine has trod for the past two centuries and must be explained and justified to oneself and others because it does not seem rational or ethical. As things stand now, for those who have Medicare insurance, it is simply *easier* to start receiving therapies than to say no to them, thus pushing doctors, patients, and families toward ever more intervention.

These developments have led me to characterize U.S. health care, ordinary medicine, as exemplifying what I call "postprogress." If progress refers to the long-held Enlightenment idea and ideal that rationality and its tools can unequivocally improve life and reduce suffering, then postprogress characterizes today's medicine and the quagmire it often creates, especially regarding the prioritizing and effects of ever more technology use in our aging society. Postprogress acknowledges that the value of life prolongation has come up against the dilemma of extending the life span past a point that people want. Postprogress suggests that technical ability and more and more interventions, while they extend wanted life for many, also bring with them existential quandaries about one's own relationship to medicine, to suffering, to *more* life, and to the apparent control that can be exercised over the timing of death. Medicine's abilities and interventions are accompanied as well by societal concerns about the present and future financial solvency of the health care delivery system. Postprogress is our uneasy, pervasive, contemporary condition.

My first task in this book is to trace the sources and effects of the chain and its ethical field so that its diffuse locations in American institutions, technological developments, clinical practice, and consumer health care desires can be better understood. My second task is to analyze the ways the socioethical changes taking place in medical care and the systems that support it are affecting the quality of our individual experience. On

the way I explore some of the difficult issues facing health care delivery today (especially certain new technologies and procedures and their open-ended use) and a few of the ways age does and does not matter. I also touch on elements of clinical, policy, and bioethics discussions that get minimized or erased in the face of the lure of life-extending treatments.

Thus *Ordinary Medicine* is an account of the four parts of the determinative chain of health care drivers and the ethics and politics that surround it. I describe how medicine for the elderly shapes health care for everyone. I trace the effects of the chain on the sensibilities of the patients, families, and doctors I met on their journeys through the health care system. Nearly every reader of this book will recognize elements of their own journey through our health care system.

Chapter 1, "Ordinary Medicine in Our Aging Society: The Dilemma of Longevity," describes the chain of connections among science, industry, and insurance that defines our predicament and shapes how treatments emerge, become available to patients, and then are deemed to be wanted and necessary. The chapter also introduces the field of ethical choices that is inherent in the operation of this chain. Such ethical choices determine the goals of clinical research, which therapies are considered appropriate, and how doctors and patients respond. For example, Medicare reimbursement policies do not provide cost constraints or age limits for certain treatments, and there is an imperative for doctors to offer treatments to patients that they would not choose for themselves. Importantly, because broad-based ethical choices both underlie and are embedded within the chain, their role as drivers of U.S. health care is hidden and remains largely unexamined.

Focusing on the point where medical technology and our aging population intersect, this chapter describes how the chain of health care drivers strengthens the bureaucracy of medicine, heightens the importance of risk awareness in medicine and society, and reinforces the rationality of extending life at ever older ages with more and more interventions. Taken together these developments create the predicament introduced in this chapter and central to the book: patients, families, and physicians all find themselves caught up in a system in which *more* and *yes* are so entrenched that saying no to it involves negotiation, pleading, and grappling with deep emotional consequences.

Chapter 2, "The Medical-Industrial Complex I: Evidence-Based Medicine, the Biomedical Economy, and the Ascendance of Clinical Trials," examines two components of the vast engine of biomedical research

from which therapies emerge: the phenomenon of evidence-based medicine, that is, the proactive and transparent application of the best (and newest) published scientific research findings about medical treatments, and the business of clinical trials. These two components are the apparatuses of truth-making in medicine. They define what counts as "good" medicine. Through them research findings from experimental studies are converted into best evidence for treatment. That conversion is the first of the four transformations that constitute contemporary medicine. It affects all the others and thus affects what happens to patients and families.

Chapter 3, "The Medical-Industrial Complex II: Access, Industry, and the Clinical Trials Phenomenon," shows how evidence from clinical trials emerges, how those findings determine insurance reimbursement patterns and then treatment standards, and how those in turn organize the work of physicians. This chapter ends with a look at the specter that hangs over these engines of innovation and evidence: the fact that the pharmaceutical and biotech industries and the for-profit market for technologies all have a growing impact on shaping research agendas, and thus on shaping treatments.

Chapter 4, "'Reimbursement Is Critical for Everything': Medicare and the Ethics of Managing Life," turns to the Medicare insurance system, whose reimbursement policies and decisions convert best evidence into available treatments—the second transformation in the chain of health care drivers. Beyond their role as the gatekeepers to treatment for those sixty-five and older, Medicare reimbursement decisions organize the next two transformations in the chain as well. Once a therapy is eligible for reimbursement, it almost instantly undergoes the third transformation and becomes standard for everyone; then, in the fourth transformative move, it becomes necessary. That is, reimbursement legitimates which interventions *should* be employed to treat which conditions. Medicare dictates the way treatment practices unfold for millions of persons in the United States. Its policies are instrumental to the ways seniors experience old age and dying and everyone else experiences what to need, want, and expect from medicine.

Chapter 5, "Standard and Necessary Treatments: The Changing Means and Ends of Technology," shows how the press for new technologies in U.S. health care complicates the goals of medical practice in our aging society. In examining three types of treatment—the implantable cardiac defibrillator, kidney dialysis, and liver transplantation—I show how tech-

nological innovations and interventions become standard and necessary. I show also how they influence our thinking about which conditions are the logical, rational targets for particular therapies, which patients need them, and what we come to want from them. Questions about how to measure successful treatment and what constitutes therapeutic benefit loom large here, and each patient's story illustrates the quandary of determining how one should live in relation to the tools of medicine as one grows old.

Chapter 6, "Family Matters: Kidneys and New Forms of Care," demonstrates how patients and families become caught up in the world of kidney transplantation, especially living donor transplantation. Living kidney donation, in particular from an adult child to a parent, has become a normal cultural practice and a routine social fact that, for many, guides how love and obligation are expressed. As scientific evidence emerged that transplants from living donors have comparatively high success rates and that transplantation can be and is successful in older persons, that evidence provided the basis for expressing love and obligation through living donation.

The world of transplantation is just one arena in which today's medicine shapes love, obligation, and other sensibilities about how to live. Chapter 7, "Influencing the Character of the Future: Prognosis, Risk, and Time Left," examines four decision-making moments regarding treatment options. I show how prognosis and risk assessment organize doctors' practices and patients' and families' experiences with respect to remaining time, the control of time, and the relationship of medical interventions to "time left." By offering prognoses, medicine instructs us to imagine different future scenarios, and then it insists that we choose among them.

Chapter 8, "For Whose Benefit? Our Shared Quandary," returns to the example of kidney transplantation because it so dramatically illustrates how fairness, realized in equitable access for all, has been reinvented in our aging society through medical procedures. The growing demand for kidneys among older patients has created a fairness and access problem because older persons are receiving an increasingly greater proportion of the total number of available deceased donor kidneys, which contributes to greater scarcity for younger patients in need. The ordinariness of organ transplantation at older ages links issues of scarcity and the right to health with notions of the public good and a broadened conception of public health.

In my conclusion, "Toward a New Social Contract?," I emphasize how our predicament is emblematic of other trends in American society. How we shape the values and directions of the health care delivery enterprise will determine—and reveal—the kind of society we create in the coming years. Because the trends that have brought us to this point are entrenched and ongoing—especially the dominance of private industry in health care services, the priority given to technology use regardless of cost, and the lack of equity in the distribution of medical care—they continue to derail the practice of medicine, indeed the entire health care delivery enterprise, as a social good.

My investigation of how our cultural values, including political and economic forces, shape the chain of health care drivers has two primary goals. One is to show how much those drivers determine about medical care and thus about contemporary life. The other, by extension, is to try to shed needed light on how the very logic, the unexamined ordinariness of ordinary medicine, impedes the kind of health care reform Americans say they want—reform that would bring preventive care, chronic care, and basic acute care services to more people while, at the same time, reducing costs.

The work of medicine, the burden of responsibility that patients and families shoulder about crossing the line (to potentially more life or death), and the existential and societal question about how to live in relation to medicine's tools all urgently demand that we give deep consideration to our heath care enterprise's reigning logic, its organizational drivers, and the values that support it. By unveiling the hidden workings of our predicament, I hope *Ordinary Medicine* will facilitate steps toward establishing a renewed sense of trust in U.S. medicine and an understanding of what has led to our current impasse. My interactions in the clinics I visited over many years made it clear that our untenable health care enterprise affects us all very deeply and that the case for fixing it is strong. What also became clear is that in order to fix it, we must understand clearly why the system—as it affects our aging society—is so badly broken. The answers are to be found here.