

A SOCIAL HISTORY OF  
CHRONIC ILLNESS IN AMERICA



**IN THE KINGDOM  
OF THE SICK**

LAURIE EDWARDS

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By the Same Author

A Note on the Author

*For Victoria,  
my joy*

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# Introduction

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When I was growing up in the 1980s and '90s, Boston's famed Longwood Medical Area was as much my place of education as the small parochial grammar school I attended. Some of my most vivid memories were of my mother driving me down Route 9 to my doctor appointments, past the strip malls and chain restaurants of the western suburbs, past the reservoir in Brookline, where the crimson autumn leaves formed a circle around the gray expanse of water. These morning drives are almost always sunny and autumnal in my memory; we would squint up as we were stopped at traffic lights, always worried about being a little late, always underestimating the drive or underestimating the likelihood of getting every red light through three or four towns.

If it was a good appointment, I'd leave with an antibiotic script for my ever-present ear and sinus infections, a follow-up appointment, or a referral for yet another specialist for my wheezy lungs. If it was a bad appointment, it would usually involve a CT scan, a blood test, or the scheduling of another surgery. Either way, we'd get in the car and head back down Route 9, usually too late for me to make it back to school—I knew this would happen but wore my uniform anyway—but just early enough to beat rush-hour traffic. We would talk about my upcoming surgery, or about the books I would get as presents for my recovery, or the classes I'd missed and the sleepover I hoped I'd make it to on the weekend.

But chronic illness? I don't remember hearing that term, and I certainly don't remember using it in reference to my own patient experiences. I lived in reaction to each illness event, never quite acknowledging the larger pattern.

It wasn't just another infection, another setback, another disruption. *It wasn't going to go away.*

Certainly, I don't blame the grade school version of myself for overlooking this distinction, or the high school and college version, either. Even if I knew it intellectually by then, emotionally it was another adjustment altogether. And I know I wasn't alone. In fact, I think this is the most daunting aspect of any chronic illness, whether you are the patient grappling with a diagnosis or a healthy person who hopes it never happens to you: It isn't going to go away.

Back then, I was a kid who was sick, who divided her time between school, friends and family, and doctors and hospitals. Now, I am an adult patient with lung and autoimmune diseases: primary ciliary dyskinesia (PCD), bronchiectasis, and celiac disease, among other conditions. I cough and wheeze a lot, and since I don't have the working cilia to flush out mucus and debris from my lungs and respiratory tract, I get a lot of infections that compromise my airways and my oxygenation. I have daily chest physical therapy, in which my lung lobes are "clapped" in several different positions. I take pills for a sluggish thyroid and use inhalers and nebulizers to help keep my airways open, and long-term antibiotics are a necessary evil in my world. I've spent far too many weeks of my life in the hospital, including the trauma unit and the ICU, but I've also done so much of what healthy people do: graduated high school and college; studied abroad for a year; pursued a graduate degree; and gotten married. I spent four long years trying to have a child and made it through a medically intensive and complicated pregnancy to deliver a healthy little girl. I work full time and have freelance work. These are the extremes that characterize life with chronic illness, and almost 130 million Americans contend with them to some degree.<sup>1</sup>

Much about chronic illness has changed since I was a child. People with cystic fibrosis, a disease similar to my own lung disease, have seen their life expectancy reach almost forty, and people with type 1 diabetes can use insulin pumps and continuous glucose monitors to control their blood sugar instead of relying on shots. It is now a mandate that clinical research trials include women and

minorities, and the thorny relationship between pain and gender is discussed more widely.<sup>2</sup> Children now spend more time watching television or using computers than playing outside, and First Lady Michelle Obama launched a campaign to fight against childhood obesity. Patients can e-mail their doctors and get text messages from their pharmacies, and social media platforms are now places where patients connect and advocate.

It is a whole different world, indeed. Cultural, scientific, political, and economic influences have changed how we classify and respond to the patient with chronic illness. Centuries ago, disease was thought to stem from an imbalance of bodily humors and fluids; infectious plagues were blamed on divine retribution; people with tuberculosis were shipped off to sanatoriums; and diseases like multiple sclerosis were considered nervous or hysterical disorders. In more recent decades patients with chronic illness conjured images of arthritic elderly patients, and cancer was still spoken of in metaphors and hushed tones, which Susan Sontag assailed in her polemic *Illness as Metaphor*.

When the idea for this book first took root several years ago, I was a young college English instructor teaching a debut course called “Constructions of Health in Contemporary Literature” to a group of college freshman interested in the health sciences. As we tackled such heavyweights as David B. Morris and Sontag, I worried about relevancy. Would my students see the connections between illness and culture, between the words we use to describe and assimilate illness and the actual patient experience? They might not have been as intrigued or riled up by the use of metaphorical language as I was, but relevancy was not something I needed to worry about, after all. They spoke of loved ones with cancer, and of depression and addiction. They were riveted by *Frontline’s Age of AIDS* documentary, and wondered how proceeds from the red Razr phones they saw advertised would really play into AIDS research, as the holiday commercials they watched touted. They saw the blurring of consumption, culture, and sickness, and they realized that the science they learned in other classes did not exist in the vacuum of the classroom or the laboratory.

In 1999 the scholar and medical historian Roy Porter asserted, “Disease is a social development rather than the medicine that combats it.”<sup>3</sup> Porter’s claim is equally germane today, even though, as my students and I discovered, the stakes have changed. Now, for as much knowledge as we have about the biological origins of many genetic, autoimmune, and viral disorders, still millions live with illnesses that aren’t merely “invisible” to others but are not easily identified in laboratories or imaging centers either. For as many technological and lifestyle resources as we have at our disposal, for as “good” as our health is compared to centuries past, larger numbers of us are sick.

“The medical arena is just a microcosm of society in general,” says Dr. Sarah Whitman, a psychiatrist specializing in the treatment of chronic pain, one of the most common and debilitating manifestations of chronic illness. The tensions surrounding sex, gender, socioeconomic status, and power that dominate our cultural consciousness are the same ones so instrumental to the emergence of chronic illness as social phenomenon. While female patients with CFIDS (chronic fatigue and immune dysfunction syndrome) are told their symptoms are the somatic manifestations of upper-middle-class social anxiety, patients with diseases as varied as HIV or type 2 diabetes labor under their own stigmas: that they are responsible for their preventable illnesses and that their lifestyle choices are subject to judgment by others. And of course, the rampant health disparities between rich and poor are drawn out in spectacularly dramatic fashion when it comes to chronic disease: fewer resources and less access to care equals less prevention, more disease progression, and a whole host of confluent problems. On the Internet and on television and radio programs, political debates about health care reform continue to rage on.

So how do we begin to unravel all of this?

Thirty years ago Susan Sontag famously wrote, “Illness is the night-side of life, a more onerous

citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and the kingdom of the sick ... sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizen of that other place.”<sup>4</sup> As the scope of chronic conditions continues to widen, Sontag’s distinction even more poignant. The statisticians and experts tell us that more and more of us do—or will—belong to that “other place.” For one, we live longer and have more interventional therapies available so we accumulate inevitable ailments of aging. For another, those with serious diseases have better diagnostics and treatments, meaning they too are living longer into adulthood with serious illness. On the whole, our lifestyle shifts also play a role in the irritatingly named “diseases of affluence.” Western society not only cultivates but exports cancer, obesity, coronary heart disease, hypertension, type 2 diabetes, and other chronic conditions to developing nations.<sup>5</sup>

As it did with the infectious and communicable diseases of the past, science is responsible for unshrouding the mysteries of chronic illness. In some cases, it has; but in many others, the competing forces of fear, guilt, and shame blur the clarifications science supposedly offers us. A gap still exists between the potential of science and technology to answer questions about disease and the social constructs we erect around notions of what it means to be ill.

From online forums and patient blogs to social media, direct-to-consumer marketing by pharmaceuticals, and consumer health privacy concerns, technology asserts itself into the patient experience in numerous ways. For example, we can trade stories and swap advice; we can push for research or work to increase awareness of little-known disorders. Vaccinations against communicable diseases represent some of modern medicine’s greatest triumphs, yet perhaps nowhere has the sharing of anecdotal patient stories had more impact than in the controversy over childhood vaccination. Here, the power of the patient activist and new media is pitted against the established institutional authority of medicine, and just how this battle plays out will have profound consequences for us all.

As a health and science writer, I see trends like individual responsibility for behavior versus random chance or genetic mutations, consumption versus philanthropy, and the basic working definitions of what is “healthy” versus what is “sick” through the prism of journal articles and analysis. As a lifelong patient with multiple chronic illnesses, I see the physical realities of chronic illness as well as their emotional implications. Every day, I wake up, feed my child, take my medications, and put on the trappings of the well. I am her mother, first and foremost, and that does not change depending on my symptoms.

In front of a classroom of students or on the phone with a freelance client, I might be many things, but I am not sick. Even if they hear my hacking cough or notice the dark circles under my eyes, they do not know the reality of what goes on behind my front door, or in my doctor’s office or a hospital room. I am used to such deceiving appearances, and I depend on technology to keep up the façade when I need it.

On days when I feel worse, it is an active, deliberate choice to enter Sontag’s kingdom of the well, just as it is sometimes a conscious act to breathe, to focus on the rhythms of *inhale* and *exhale* and not the chortling wheezes and sticky congestion that make those motions so challenging. I am not alone in this daily negotiation, and beyond the numbers are the compromises and compensations made by all people living with some form of chronic condition.

*In the Kingdom of the Sick* is a combination of research, literature, and stories from patients across the chronic disease spectrum. Literary inspiration comes from many sources, from Katherine Anne Porter’s tale of the post–World War One influenza pandemic, “Pale Horse, Pale Rider”—which I first read in high school—to *A Life in Medicine*, a compilation edited by Dr. Robert Coles and others that includes fiction and nonfiction tales of treating patients, of living with illness, of fear, beauty, and mortality. The rich contents of *A Life in Medicine* piqued my interest while I was a graduate student.



and fledgling instructor. Books by Andrew Solomon, Paula Kamen, Roy Porter, David Rothman, and many, many others made me start asking questions.

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- What does it mean for patients that the definition of chronic illness is fairly static but its scope has changed so much?
- How will long-standing gender biases in the treatment and diagnosis of pain shift if we find more evidence to support biological differences between how women and men experience pain?
- How will technology change the doctor-patient relationship, and how will technology empower patients?
- Will patients with chronic illness ever see the type of focused mobilization that made the disability and HIV/AIDS movements a success?
- And, as Roy Porter queried, if disease is a social development as much as its treatments are, what will the experience of living with chronic illness be like as we move forward?

In a way, I see these writers as specialists, people who have focused on one topic (pain, disability, gender, cancer, autoimmune disease, etc.) masterfully. In writing about chronic illness, I am an inevitable generalist, someone who is pulling ideas together and looking at larger patterns among them in a different way. As such, *In the Kingdom of the Sick* is a big-picture book, focusing less on disease-specific symptoms and more on the universal aspects of the circumstances in which illness unfolds.

Though it is not a uniform linear history of disease, *In the Kingdom of the Sick* does focus primarily on the decades following World War Two, decades in which science, politics, and social justice all converged in such a way as to leave a lasting, transformative impression on the illness experience. I am not a sociologist, a historian, a physician, or a legal scholar. I am a lifelong patient with chronic illness who has always had health insurance, who has had access to some of the best hospitals in the world, and who nonetheless spent much of her life as a medical mystery within those hallowed institutions. Like it or not, I will take medication and have chest physical therapy for the rest of my life. I will never know what it is to be “healthy,” but I have learned that it is not worth the time and energy to lament or miss something you never had. I blog about chronic illness, I e-mail my doctor, and log medical data on my iPhone, and it is only through technology that I have spoken to or met anyone else with my rare disease, PCD.

As one of my interviewees, e-Patient Dave deBronkart, described it, today’s health care system is like a mobile with billions of pieces spinning around. Pulling at a thread will shift the other pieces around in a way that is complex and hard to predict. That analogy is at play in the chronic illness experience. Health care reform, direct-to-consumer pharmaceutical advertising, the influence of the environment and chemical exposure, socioeconomic factors, gender, politics, etc.—are all threads from the mobile, and each is interconnected to other threads. Here is where I stop pulling, stand still, and reflect on the threads that resonate most with me as a writer and as a patient with chronic illness.

If, as David B. Morris says, illness tells us more about an era or an individual than health does, we now find ourselves at an intersection, lodged between the promise of science and technology and lingering assumptions about people who are forced to dwell in the kingdom of the sick. What will their future look like? To hazard a guess, we must probe where attitudes about chronic illness came from, and where they stand today.

# Chapter 1

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## From Plato to Polio

### Chronic Disease in Historical Context

Thirty-year-old Melissa McLaughlin remembers in painstaking detail when she first became sick. It was late October 1994, and the then high school sophomore's crammed schedule reflected an active and passionate teenager: Advanced Placement courses, dance classes and competitions, the dance class she taught to younger students, babysitting her siblings, volunteering. As a competitive dancer, she depended on her body to keep up with her rigorous schedule, and it always had.

"Everything was normal," she says.

The weeks building up to the seismic shift that would turn the energetic teenager into a wheelchair-bound young woman living in constant pain were normal, if hectic. She threw a Halloween party for the dance students she taught, and sat for the PSATs. Her last "normal" day was spent with friends painting the walls of a homeless shelter. By the day's end, the whole group was sweaty, exhausted, and covered in paint.

"All of us were worn out, but I just never got better," McLaughlin says, describing how she went to sleep that night and woke up with a high fever and extreme fatigue and body aches. For the first few weeks, she slept twenty-two hours a day, and her doctors initially diagnosed her with mononucleosis. At this point, she, like her doctors and most people around her, figured with a few more weeks of rest she would be fine. That was how an acute condition like mono worked: you got it, you lived through it for a few weeks, and then it went away. Case closed. For many people, this is the trajectory we associate with illness. We are familiar with both ends of the spectrum: the short, acute infections and injuries of everyday life and the terminal cases of cancer, heart disease, or stroke that have a finite end. Chronic illness is somewhere in the middle, confounding and unfamiliar.

Weeks and months went by, and McLaughlin's improvement was minimal at best. She still slept several hours each day, only dragging herself into class half-days and often fainting when she was there. She could barely walk but tried to attend dance class anyway, only to fall asleep on a pile of mats in the corner. Her blood tests came back abnormal but not definitive, and as the months went on a variety of diagnoses were handed to her: chronic mono, Epstein-Barr virus, chronic fatigue syndrome (CFS), chronic fatigue and immune dysfunction syndrome (CFIDS). For each she was told there were no treatments, and the approach was reactive, treating symptoms and not causes. If she caught an infection—which was a regular occurrence—she was given antibiotics. If she had severe migraines, physicians prescribed migraine medication. When her extreme fatigue became even more overwhelming, they told her to get more rest. No one could explain how to make her better, and, just as frustratingly, no one could explain to her what had made her sick in the first place.

While the details vary, her physical manifestations and diagnostic roadblocks could stand in for the experience of millions of Americans over the past few decades. The history of CFS/CFIDS and related "nebulous" conditions in this country is a controversial one; even now, consensus over its name is lacking, and although many advocates of the disease fight for education and awareness, detractors remain. In *Encounters with the Invisible*, CFS patient Dorothy Wall calls the condition "so blatantly unmedicalized, so subjective, another one of those so-called 'functional illnesses,' like irritable bowel syndrome, that have always plagued medical practitioners, presenting symptoms with no known cause."<sup>1</sup> From dissent over labels and diagnostic categories to research dollars and clinical trials, the combination of politics, science, and policy is a potent one.

In *All in My Head*, Paula Kamen focuses on the other phenomenon at play, one as relevant and entrenched in attitudes today as it was in centuries past: If you cannot cure the patient, then blaming the patient often follows suit. When we don't understand the source of the problem or how we can alleviate it, "the more psychological, spiritual, and moral meaning it takes on."<sup>2</sup> History reveals the foundation of this current pattern, as we will see, but when physicians adopt this mindset, it is particularly harmful. In comparing nineteenth-century tuberculosis and late-twentieth-century cancer, Susan Sontag wrote, "Any disease that is treated as a mystery and acutely enough feared will be felt to be morally, if not literally, contagious."<sup>3</sup>

This applies to chronic illness, too. We do not like being reminded that there are still limits to modern medicine, and that named conditions exist that might not kill us but will not go away. But when we add to this scenario those illnesses that we can't name or file under International Statistical Classification of Diseases and Related Health Problems (ICD-10) codes on medical billing forms, or conditions we can't put under our high-powered microscopes or see on advanced imaging tests, the fear—and, often, distaste—grows. Perhaps if the symptoms can be explained away by claiming the patient is just lazy, or is not making appropriate lifestyle changes, then blame can replace the other nagging emotion: *Maybe if it can happen to him or her, it could happen to me.*

And likely, it will happen to many people at some point in their life. Chronic illness affects nearly 50 percent of the population. By the year 2025, it is estimated that chronic illness will affect some 160 million Americans.<sup>4</sup> Some of the most common are heart disease, diabetes, cancer, and asthma, but that list is by no means exhaustive. Arthritis, lupus, multiple sclerosis, Crohn's disease, colitis, epilepsy, and thousands of other diseases cause ongoing symptoms and are treatable but not curable. Chronic illness is the leading cause of death and disability in this country, with seven out of every ten deaths attributed to chronic diseases. Eighty-one percent of hospital admissions are a result of chronic illness, as are 76 percent of all physician visits. These statistics come with a hefty price tag, too; 70 percent of a staggering \$2 trillion in health care costs in 2005 came from chronic diseases.

As the years passed, there was no doubt that Melissa McLaughlin dwelled in the kingdom of the sick. Her conditions weren't going away, and they caused ongoing quality-of-life problems and disability. Gradually, some of her diagnoses got more specific: the combination of CFIDS and fibromyalgia explained the fatigue and the pain. Postural orthostatic tachycardia syndrome (POTS), a dysregulation of the autonomic nervous system that interferes with heart rate and other functions, explained the fainting and cardiac issues. Neurally mediated hypotension (NMH), an inability to regulate blood pressure often found in patients with CFIDS, and hypo-gammaglobulinemia, which increases the risk of infection, were also added to the list.

However, if she thought that since she now had many labels and acronyms attached to her symptoms the skepticism of others she encountered toward her pain or her treatment options would improve significantly, she was mistaken.

"I had a friend once who said that my illnesses were the hippest thing about me. I'm no trendsetter, but I had CFIDS before it was cool, according to him," she says, aware of the antipathy that still surrounds the diagnosis of CFIDS. "Some doctors still sniff at the CFIDS/FM diagnoses, call them trash-barrel diagnoses. I say, that's fine, but unless you know what it really is, then you're not really helping anything, are you?" she asks.

And therein lies one of the most compelling tensions history reveals: the quest to understand the nature of illness from a biological perspective versus the quest to understand illness from a personal perspective.

For Emerson Miller, a forty-eight-year-old who is HIV-positive, his experience of illness has been no less challenging than Melissa McLaughlin's. Where chronic pain conditions and autoimmune

disorders often prove difficult to isolate, the test for HIV/AIDS is all too definitive. Fifteen years ago after Miller had suffered from a flu-like illness that left him seriously ill, doctors tested him and found an incredibly high viral load. It was the mid-1990s, and doctors were flush with excitement over the newly approved triple drug cocktail used to treat HIV/AIDS, though no one knew the long-term effects of the drugs and back then, incorrect dosing was still a significant problem. At the time of his diagnosis, this barely registered.

“I was so ill that I didn’t care, I didn’t care if I had three weeks to live,” he says. It was a very different dynamic than the immediate experience of those patients who may feel okay but choose not to get tested because of known risk factors or disclosure of illness from present or past partners. Miller recognizes this distinction acutely; in his job as a patient coordinator and advocate at AIDS Action Committee of Massachusetts in Boston, he witnesses firsthand the process of diagnosis, acceptance, and ongoing treatment of this next generation of HIV patients. The population is far more diverse now than it was in the early days of the “gay plague”—IV drug users, young heterosexual patients, and an increasing number of African-American and Hispanic females are just some of the groups who join homosexuals as sub-populations with very different needs—but some things remain the same. Despite many permutations, the stigma associated with HIV/AIDS and more specifically with the means of transmission that has characterized the HIV/AIDS epidemic since its beginning is still a predominant theme in living with the disease. It isn’t simply a matter of prevailing societal norms of the healthy versus the sick that many of us experience. Miller describes an intricate hierarchy of blame or perhaps judgment, too: gay people are better than drug users, while hemophiliacs and those whose illness can’t be attributed to lifestyle are innocent.

I often see a related form of hierarchy when it comes to suffering: patients who are quick to claim that their pain and “battle scars” are worse than those of other patients are an unfortunate reality in waiting rooms, support groups, and Internet forums. Both scenarios create internal divisions that weaken one of the greatest assets patients have in a healthy world: the solidarity of the illness experience.

“There is still a lot of shame about homosexuality. Even at my age ... there is still a lot of shame,” Miller says. “In my opinion, everybody is still a patient.”

The dismissal, skepticism, and controversy surrounding Melissa McLaughlin’s diagnosis and the social stigma and internal hierarchy of illness in Emerson Miller’s story are evidence of even greater shifts in the trajectory of modern chronic disease. On the one hand, McLaughlin’s chronic pain experience rings true to the experiences of millions of patients, particularly women, living with conditions as disparate as migraine/chronic daily headache, irritable bowel syndrome, reflex sympathetic dystrophy (RSD) (also called complex regional pain syndrome, or CRPS) and many other conditions still tinged with the shadow of psychosomatic illness. In her memoir of chronic daily headache and Western attitudes toward pain and gender, Paula Kamen contemplates her “greater privilege to complain,” and reflects on her grandparents, who, like most everyone else at the time, were too caught up in survival to focus on maladies such as headaches.<sup>5</sup> For that generation, infectious disease was a greater threat to mortality, and we will see the consequences of that loss of urgency and immediacy in later chapters.

One of the shifts has been in the doctor-patient relationship, which has certainly gone through drastic changes from the “doctor as God” complex of earlier times. Throughout much of the twentieth century it was still common practice for doctors of cancer patients to tell their families the diagnosis, rather than giving the patient the information. We expect more collaboration from our physicians now, and we bring more information to the encounter ourselves. If we have the wherewithal and resources to do so, many of us will shop around and find a better fit rather than

settling for a negative relationship with our health care providers.

In his essay “How To Speak Postmodern: Medicine, Illness, and Cultural Change,” David B. Morris writes that a distinguishing characteristic of postmodern illness (“postmodern” here refers roughly to the period following World War Two) is that the narrative surrounding illness now often involves the patient.<sup>6</sup> A postmodern view is one that must move beyond the biomedical model of illness that dominated much of the early and mid-twentieth century, a model based on the idea that the body and its ailments can be described in the language of physics and chemistry. That is, disease is something we cure using all the tools at our disposal.<sup>7</sup> This model serves acute illness and injury well, but it falls short for patients who live with ongoing disease.

Given the success in immunization, antibiotic development, and understanding of microbial diseases that characterized the decades following World War Two, this biomedical view of medicine is not surprising. However, with today’s technological innovation and the social interaction made possible by Web 2.0, whereby patients are willing to not only swap stories but also experiment with alternative treatment therapies, Morris offers up what he calls a biocultural model as a better fit. Here illness exists at the “crossroads” of biology and culture, a confusing landscape where all parties involved are increasingly aware of the limits of the rigid biomedical model.<sup>8</sup> This idea of a crossroad is an ever-shifting point at which cultural expectations and assumptions about illness meet scientific inquiry and innovation.

McLaughlin’s and Miller’s stories are glimpses of this biocultural crossroads. In the former, we see the reservations ascribed to symptoms and conditions that cannot be verified with a blood test or a lab report. In the latter, we see a disease that is easily identified through testing, whose origins we can trace and whose biology is explored in research laboratories and hospitals around the world. The diagnostic processes are opposites, yet their stories are bound by shared themes and, ultimately, shared experiences.

In tackling these issues, I face challenges of scope and context. Before we can look at the emergence and ongoing adjustments in how we perceive *chronic* disease, we need to establish a basic historical understanding of disease itself. How have scholars, scientists, and physicians thought of the body? What does it mean to be sick? To have a meaningful conversation about the present, we need some context of our past.

## **Ancient Thinkers with Modern Reach**

The Hippocratic oath to “do no harm” takes on added complexity when we factor in the extraordinary means and life-prolonging machines available to us now, but Hippocrates (ca. 460–ca. 377 B.C.) was responsible for more than the pledge so many of us recognize today. He was the first healer in antiquity to move away from the notion that illness and disease were caused by supernatural powers or cosmic forces that could destroy populations at will and who required sacrifices, prayers, and cajoling to spare people. Instead, Hippocrates relied on the power of observation and redefined the role of the healer as a true clinician, one who paid close attention to patients’ symptoms in order to understand the nature of their diseases. In removing health and illness from the gods and insisting on natural causes and natural cures, Hippocrates caused a profound shift in agency to take place.<sup>9</sup> No longer were patients solely at the mercy of mercurial gods, and no longer were their healers merely present to patch wounds or amputate limbs. This rational, observational medicine centered on the patient, not the disease, and Hippocrates and his followers were interested less in the specifics of singular diseases and more in understanding the natural course of an illness.<sup>10</sup>

The distinction between illness and disease is one that comes up repeatedly in the broader history of chronic illness, with disease being the objective, evidence-based experience of being sick and illness being the subjective, lived experience of patients. In Hippocrates' time, disease was believed to result when an imbalance of the body's natural forces, or humors, occurred. Blood came from the heart and was warm and wet; bile came from the spleen and was black, cold, and dry; phlegm came from the brain and was wet and cold; and lastly, yellow bile, which came from the liver, was warm and dry.<sup>11</sup> While centuries of discovery and understanding would eventually disprove the notion of the four humors, fundamental aspects of Hippocratic medicine still resonate today: diseases manifest differently from individual to individual, and a patient's lifestyle and environment play large roles in determining the course of a disease.<sup>12</sup> The Hippocratics' view was actually quite simple: health represented equilibrium, while illness represented an upset to that harmony.<sup>13</sup>

Influenced by the work of Hippocrates, Plato (ca. 428–ca. 348 B.C.) also believed that a disruption in the body's natural forces—earth, fire, water, and air—caused disease, and that the physician's duty was to advance health by harmonizing body and soul.<sup>14</sup> The mind-body connection and the phrase “sound mind, sound body” that we see and hear often these days, particularly in the growing popularity of complementary and alternative treatments and relaxation techniques, is evident in the Platonic ideal of medicine. As Plato transmitted to us in *The Republic*, Socrates (ca. 470–399 B.C.) viewed health in similar terms, maintaining that virtue, beauty, and spiritual health are mutually dependent, unlike disease, ugliness, and weakness.<sup>15</sup> Like Hippocrates, Plato involved the patient in his treatment of disease—not relying on divine intervention—and also invoked the patient's at least partial responsibility for disease. Platonic healing depended on “the elimination of all evil from body and soul by means of a change in the way of living,” whereby the success or failure of treatment also rests with the patient.<sup>16</sup>

Since more of his writing survived than did that of the ancient Greeks, Roman physician Galen (A.D. 129–ca. 199) remains the most prolific ancient writer on medical subjects. He employed the Hippocratic theory to try to understand the nature of disease, and his work with animal cadavers—coupled with his fame and self-promotion—led to misunderstandings of human anatomy that would circulate for a thousand years.<sup>17</sup> Like others of his time, he believed blood was produced in the liver and his penchant for extreme bloodletting, sometimes until the point of lost consciousness, was derived from the mistaken belief that since women bled monthly and appeared to suffer fewer illnesses than men, bloodletting was an effective way to rid the body of disease. The pulse was another favored topic of inquiry for Galen, but lacking the correct physiological understanding of human anatomy and the circulatory system, his books and writings promoted ideas that would not be disproved until the nineteenth century.<sup>18</sup> The power of his fame and accessibility perpetuated incorrect information about disease, similar to today's landscape in which technology and social media make it possible to widely disperse information and research that may lack accurate substantive evidence.

While ancient times were characterized by the desire to understand the nature of disease and tie it to physiological imbalances as well as lifestyle, the Middle Ages, influenced by the spread of Christianity, reflected a spiritual understanding of disease and plague as wrought by sin. This is a marked shift from the more naturalistic and rational practice of classical medicine. Early Christian thought emphasized the split between the body and the soul (not the body and the mind), a divine purpose and plan for everything, and the implicit subordination of medicine to religion. Physicians were not healers in the same sense; they tended to the body, while priests were concerned with the more important matters of the soul.<sup>19</sup>

Illness and suffering were viewed as punishment or a test of one's faith, but the early Church also manifested a mission of healing.<sup>20</sup> Since the body was created in the image of God and ultimately belonged to Him, He had the power to heal. The resurrection of Jesus Christ and the glory that waited for the faithful at the Final Judgment were the greatest examples of God's power. The Gospel of Saint Luke, himself a physician, points to several miracles in which the healing power of Christ and his disciples triumphs over bodily disease, including restoring sight to the blind and raising the dead back to life. As Europeans struggled to survive and assimilate the great plagues of the first three centuries of the Christian Era, the notion that "illness is a consequence of sin and not a physical malady to be studied and analyzed as the Greeks did" was rooted in Biblical scripture.<sup>21</sup>

Christianity was just one of many faiths undergoing adaptation as a result of the changing world. There is more emphasis here since some of the themes popular in the Christian response to suffering and disease are still evident today. Even the word *stigma* itself, one so heavily associated with current experiences with disease, has its roots in early Christian tradition. A literal meaning conjures up images of the physical markings of crucifixion, but as psychologist Gregory M. Herek notes, more complex definitions include literal or metaphorical marks that infer an individual is "criminal, villainous, or otherwise deserving of social ostracism, infamy, shame, and condemnation."<sup>22</sup>

Prior to the Black Death in the fourteenth century, it had been eight hundred years since Europe had last been besieged by major epidemics. The collapse of the Roman Empire meant less travel and commerce with Asia and, therefore, less contact with new diseases and infections. Now, with fourteenth-century towns like Venice and Genoa emerging as centers of trade and travel with more distant lands, the opportunity for disease and epidemics to infiltrate a new population was ripe. Increased commerce meant increased urbanization, and poor sanitation and overcrowded conditions meant the population was particularly susceptible to communicable diseases. This relationship between changes in the way people live and work is a constant in the social history of disease.

Bubonic plague, the cause of the Black Death, was thought to infect humans from the fleas carried by rats, though modern experts believe some human-to-human transmission was possible, given how quickly it wreaked havoc. Killing an estimated twenty million people, the Black Death remained Europe's most catastrophic epidemic, having wiped out a quarter of the population.<sup>24</sup> The impact of such devastation on the European psyche is telling. It had become "a crucible of pestilences, spawning the obsessions haunting late medieval imaginations: death, decay, and the Devil ... the Grim Reaper and the Horsemen of the Apocalypse."<sup>25</sup> Unfortunately, responses to the Black Death are predictable through the lens of history. To the many who believed the plague was the work of divine retribution, acts of self-flagellation, prayer and fasting, and the religious persecution of Jews and others outside the faith were seen as appropriate defenses. Roy Porter recounts the horrific fate of thousands of Jews locked in a wooden building and burned alive, one of many instances of retaliation and violence during the Black Death.<sup>26</sup> Physicians, powerless to effect any substantive treatment for individual patients, could do little to quell the public health debacle unfolding.

French philosopher Michel Foucault's *Panopticism*, published in English translation in 1977, deals graphically with response to plague, describing the total lockdown enforced—the census, the front doors locked and checked by specially appointed officials, the total submission of medical and police decisions to the magistrates. Order trumps chaos, power dominates disease. Given the rapid transmission and onset of the infection, and the lack of concrete physiological understanding of it, the extreme situation Foucault depicts in seventeenth-century France is understandable, if unappealing. Twenty-first-century movies like *I Am Legend* or *Contagion* tap into similar fears over uncontrollable outbreaks and the fragility of human life in the face of pathogens we cannot fight.

Medieval attitudes toward disease and the body perceived women as the “faulty version” of the male who were weaker because “menstruation and tearfulness displayed a watery, oozing physicality ... Women were leaky vessels ... and menstruation was polluting.”<sup>27</sup> As patient narrative, research and history will illustrate, gender remains an incredibly important variable in the chronic illness experience. Partly, this is because more females than males manifest chronic and autoimmune conditions. However, throughout history, deeply ingrained ideas about women as unreliable narrators of their pain and symptoms, as weaker than men, and as histrionic or otherwise “emotional” have had a profound impact on their ability to receive accurate diagnoses and appropriate care.

On the heels of the devastation wrought by the plagues of the Middle Ages, the Renaissance and Enlightenment were periods of progress and advancement. The invention of the printing press and the resulting printed health material made knowledge about the human body and disease (however incomplete) widely available for the first time. The gains in health literacy that printing made possible over time marked a huge shift in the understanding and treatment of diseases.

By the eighteenth century, physicians still couldn’t isolate the cause of infectious disease, so Hippocratic thoughts about individual responsibility for illness continued to dominate mindset. American physician Benjamin Rush emphasized the importance of getting the patient’s history directly from the source, and focused on all the daily habits and behaviors that might play a role in the patient’s illness. His interest in the association between chronic disease and lifestyle are significant, as is his division between acute and chronic disease.

“In chronic diseases, enquire their complaints far back and the habits of life ... Pay attention to the phraseology of your patients, for the same ideas are frequently conveyed in different words,” Rush counseled his peers.<sup>28</sup> With acute illness, the precise daily habits that took place the week preceding the manifestation of symptoms were particularly important. Rush’s emphasis on patient history as a primary diagnostic tool took place in the context of improved standards of living and transportation across Europe and in the United States, which meant a now-predictable rise in diseases associated with indulgence and inactivity. Relying so heavily on patient history and lifestyle was logical, particularly since there was little else physicians could point to in order to assign cause (or blame) for disease. Other popular theories of the time included a focus on environment and external factors like squalid living conditions and dank areas, though those too brought in associations about wealth, status, and worth. Still, as a precursor to more current attitudes toward patients with chronic disease, this link with lifestyle and behavior is a key concept to carry forward.

The greatest dichotomy of this time period, however, was that while physicians gained new skills and attained a more elevated status, patients themselves saw little benefit from these developments. Even the early use of the microscope shows an interesting lack of focus on the patient, and a divergence from medical research as inherently therapeutic: while physicians used microscopes to study tissue, it wasn’t until the nineteenth century’s breakthroughs in bacteriology that microscopes were used in the process of treating patients.

## **Disease in the Nineteenth and Early to Mid-Twentieth Centuries**

Simply put, the nineteenth century was the century of the germ. Until physicians could see disease under the microscope, the same kind of guesswork that characterized disease and its treatments from its classical roots persisted. For example, well into the nineteenth century physicians believed that illness came from miasmas—the gases that seeped out from subway systems, garbage dumps, and open graves.<sup>29</sup> The changes wrought by the Industrial Revolution and the emergence of capitalism



affected virtually every part of daily life. More people moved to cities and worked in factories, and overall improvements in employment availability and children who could contribute economically to their families meant an increase in population growth. From unsafe working conditions to slums where infectious disease found places to thrive, a now-familiar historical pattern emerged: the technology that yielded improved transportation and innovations in production also paved the way for a new wave of communicable disease and social anxiety.

A fundamental shift in the understanding of disease—and in the way we perceived patients with communicable and other diseases—began with Louis Pasteur’s identification of bacteria and the role of germs in causing infection. Before that, leeches, laxatives, and brandy were among the most common cures of the day.<sup>30</sup> By 1881, Pasteur had perfected the vaccination method, though it wouldn’t be until 1954 that a polio vaccine suitable and effective for humans was introduced. Nineteenth-century attitudes toward vaccines prevented universal vaccinations from happening. As we will see when we explore current perspectives on vaccines and autism, the combination of fear that the government was encroaching on civil liberties and concern over the safety of the procedures that characterized the opposition to vaccines looms heavily in our twenty-first-century consciousness. The difference between society’s perspectives then and now is that in the years between vaccines have largely eliminated many of the most harmful public health risks, such as polio and smallpox.

Vaccination is an approach to disease prevention so profound that it is in large part responsible for the emergence of chronic illness as a domestic public health and social issue in the twentieth century. Enough people did not die or become crippled and incapacitated from infectious disease that they began living long enough to acquire and suffer from chronic conditions. For example, from 1930 to 1980, self-reported illnesses rose by 150 percent, a clear indication that a population that lived long wasn’t necessarily *feeling* better—and an idea that figures prominently in the social history of chronic disease.<sup>32</sup>

Pasteur’s work on germ theory ushered in the burgeoning field of microbiology. Using this theory, Pasteur’s contemporary Robert Koch was able to identify the bacteria that caused both cholera and tuberculosis (TB).<sup>33</sup> These infections were scourges, particularly in heavily populated urban areas, and brought with them many unfavorable associations and connotations. Perhaps one of the most famous representations of TB appears in Susan Sontag’s extended comparison of it to cancer. While cancer was once associated with a repressed personality and middle-class anxiety, TB was the stuff of excess emotion and poverty. In *Illness as Metaphor*, Sontag observed that “TB is a disease of time; it speeds up life, highlights it, spiritualizes it ... TB is often imagined as a disease of poverty and deprivation—of thin garments, thin bodies, unheated rooms, poor hygiene, inadequate food ... There was a notion that TB was a wet disease, a disease of humid and dank cities.”<sup>34</sup> This process of how identifying the origin of a disease changes the perceptions of patients living with it—or, *fails* to change the perception of patients—is one we still grapple with two centuries later.

In W. Somerset Maugham’s revealing early-twentieth-century short story “Sanatorium,” the assumptions about the “typical” TB patient are powerfully laid bare. In describing one of the patients sent to recover from TB in a sanatorium, the author writes, “He was a stocky, broad-shouldered, wiry little fellow, and the last person you would ever have thought would be attacked by T.B ... He was a perfectly ordinary man, somewhere between thirty and forty, married, with two children. He lived in a decent suburb. He went up to the City every morning and read the morning paper; he came down from the City every evening and read the evening paper. He had no interests except his business and his family.”<sup>35</sup> All the things that make this patient a surprising candidate—he is gainfully employed, stable, married; in short, a respectable man with respectable middle-class tastes and aspirations—what stand out here. He did not *deserve* his unlikely affliction.

The public health response to disease outbreak in America also reflected the nation's emerging evangelical bent. Since disease was thought to be due to poor hygiene and unsanitary conditions, clean living was not just a health issue but a moral one as well. It fell to religious philanthropists to preach against the sins associated with unclean living, from drinking and immoral behavior to the alleged vices of atheism and greed. Such actions further demarcated the healthy—middle- and upper-class religious activists—from the ill, those languishing in slums whose slovenly living conditions and lifestyle choices made them culpable in their sickness. Being able to source the origin of infectious disease to its microbial roots was the first step in breaking down such misconceptions.

Other nineteenth-century developments that influenced the experience of chronic illness today include the advent of anesthesia, the beginning movement toward patient advocacy, and the professionalization of nursing. Until the 1840s, physicians had no effective, safe way to lessen the pain of surgery. The introduction of nitrous oxide, chloroform, and ether produced immense relief from the pain of surgical intervention. It also reflected a shift in physicians' attitudes toward patients and a higher priority on alleviating suffering.

Another advancement in the consideration of the patient can be traced to the nursing profession. Prominent figures like Florence Nightingale and Clara Barton exemplified the holistic approach to patient care that characterizes nursing, and represented a marked departure from the tendency of other medical professionals to focus on singular aspects of a patient's condition (i.e., the cause or the treatment). Galvanized by the suffering of soldiers, Nightingale was stalwart in her work to improve living and sanitary conditions for her patients. The patient as an individual, entitled to respect and compassion, was a concept made flesh by Nightingale and the cadre of professional nurses she mentored. Likewise, activists like Dorothea Dix and Alice Hamilton worked to make public the deplorable living conditions and inhumane treatment of the mentally ill and the urban poor.<sup>36</sup> This indicated a new interest in health-care advocacy, a concept that would wholly redefine the lives of many different types of patients more than a hundred years later, most especially those with chronic diseases.

The world was still in the grip of deadly epidemics, though, as witnessed by the staggering transcontinental death toll of the 1918 influenza pandemic. Updated research suggests that the strain of the influenza virus that sprang up during the 1918–19 flu season killed between thirty and fifty million people globally, and killed an estimated 675,000 Americans. World War One had killed fewer people than the flu pandemic.<sup>37</sup>

Successes in identifying infectious disease and the post–World War Two development of antibiotic therapy led to the assumption that though infections might still cause temporary discomfort, they were no longer a serious threat to either survival or quality of life.<sup>38</sup> Was this a sign of naïveté? Arrogance? Optimism? Or perhaps, a combination of all three? With the benefit of hindsight, the weakness of this position is easy to see: for one, antibiotics only treat certain strains of bacteria, and are not effective at treating the many viruses that still pose a threat to public health. In addition, as we see all too frequently today with infections like methicillin-resistant *Staphylococcus aureus* (MRSA) and flesh-eating *Streptococcus*, bacteria evolve into strains resistant to the medications developed to treat them. As a patient with a compromised immune system who is prone to infections, I know firsthand the danger of antibiotic resistance. As a preschooler, I spent several weeks in an isolation room in a hospital, tethered to an IV pole to receive Vancomycin, the drug used to treat staph infections like the one I had spreading from my ears to my brain. Knowing that some staph infections are now resistant to Vancomycin, a powerful “end-of-the-line” treatment for these life-threatening infections, scares me. Similarly, with only a few antibiotic options left that reliably treat my lung infections, resistance is not just a buzz-worthy topic for me; it is a real concern.

For better and worse, twentieth-century experiences with diseases like polio forever altered the way we view medical science's ability to treat disease. At last, humanity could respond to the infectious epidemics that had wreaked havoc for centuries and do more than merely identify them—we could actually *prevent* them. Outside the spheres of public health and research, we don't hear or talk too much about polio anymore; its omission in our lexicon is a luxury modern medicine affords us. But for the generation forced to dwell in iron lungs and the legions permanently crippled by polio, its specter was menacing. Many of the illnesses we grapple with today are a product of the way we live and work, just as living and working conditions in the past contributed to the rise of polio. Roy Porter deftly characterized the complex relationship between human progress and disease when he wrote, "Thus to many, from classical poets up to the prophets of modernity, disease has seemed the dark side of development, its Jekyll-and-Hyde double; progress brings pestilences, society sickness."<sup>39</sup>

Though ancient in origin, the emergence of polio as a major medical threat in the 1900s can be traced directly to the processes of urbanization. Spread through infected fecal matter, the dominant strains of the polio virus were introduced early on to infants who dwelled in crowded homes with rudimentary plumbing, sanitation, and hygiene. Once more modern forms of sanitation and waste removal and treatment were developed in the 1900s, the immunity that early exposure to the virus gave patients happened less frequently.<sup>40</sup> As immunity decreased, incidence of the more serious manifestation of polio, paralytic polio, which involved the nervous system, increased. By the 1950s polio kicked up most severely during the warm summer months and primarily affected children. Parents fled urban areas and communities banned the use of public swimming pools.<sup>41</sup> The year 1952 brought with it the worst polio epidemic in American history; 58,000 cases were reported, including 3,145 deaths.<sup>42</sup>

That same year, 1952, Jonas Salk tested the first polio vaccine. He used a dead virus injected into patients to help build up natural immunity, and in 1954 more than one million children were given ten vaccinations.<sup>43</sup> Since polio was a disease that primarily affected children, treating it was a cause particularly vaunted by the American public. Children are understandably at the top of the illness hierarchy. By the late 1950s, a live virus was used to produce an oral vaccine, which was more popular since it meant patients didn't need any shots. The World Health Organization (WHO) made full eradicating polio a worldwide effort in 1985.<sup>44</sup>

Industrialization and urbanization were responsible for the emergence of diseases like polio, but changes in the way people communicated were responsible for spreading public health goals, too. Disease wasn't just about scientific theories; it was a social phenomenon. The America that emerged after World War Two was fighting a war in Korea and was consumed with the Cold War and McCarthyism, and a new form of technology brought these events—and, more importantly, the intellectual and emotional basis for them—into the home. Television was an important player in spreading the "gospel of health" and promoting newly focused public health and medical research goals. A well-run state depended on people adopting a preferred public health agenda, and mass communication of health literature allowed that to happen.<sup>45</sup> Putting health information in the hands of the general public took it out of the exclusive domain of the doctor in the laboratory or operating room and brought it into the realm of the patient's narrative and subjective experience.

It is in this context that we reconsider Melissa McLaughlin's chronic fatigue syndrome and fibromyalgia, or Emerson Miller's HIV, the latest additions to an increasingly widening scope of conditions we can treat but we cannot cure.

"The fact that you're just not going to get better seems unbelievable to most people, I guess," says Melissa McLaughlin. One frustration for her is people who can't understand that patients cannot

control or fix everything. “It’s easier for them to believe that there is something you can control . . . There must be something you can do that you aren’t doing! Eating raw foods, forcing yourself to exercise, thinking your way out of it, trying the latest drugs that promise a cure in their commercials—something should work, and if you’re not better, then you’re not working hard enough. It’s frustrating because it’s everywhere (even, sometimes, in my own mind), and it’s just wrong. It’s just wrong: I can’t think or eat or exercise my way out of these illnesses, no matter how hard I try.” Even Melissa’s doctor followed suit, urging her to exercise more often even though it made her pain and fatigue much worse.

On the other hand, we have our great fear of HIV, the infectious disease that does not bend to our will. Shame is often embedded in its mode of transmission, and so far its wily ability to mutate has made it impervious to the very same vaccination process that revolutionized modern medical science. Emerson Miller doesn’t believe he will see a cure in the lifetime of current researchers, and, in fact, he worries that the progress we have made may actually have a negative impact on the search for a cure and on vigilance against the spread of HIV.

“I don’t want the sense of urgency to go away,” he says, hoping that the knowledge there is a drug cocktail that can effectively reduce viral load does not mean people will take the disease less seriously, particularly those who may contract the virus through preventable life choices.

The journey from Plato and Socrates to the Enlightenment and Industrialization to more modern public health advances is a circuitous one. By the middle of the twentieth century, the ability of scientists, physicians, and public health officials to alter the course of diseases that once devastated the population made it possible for people to adapt their thoughts on illness and disability; no longer were they considered to be inevitable and immovable components of daily life. This attitude would have strong repercussions for the next generation of patients, the ones touched by the other big medical emergence of the postmodern era: chronic illness. The period immediately after World War Two was a time of what scholar Gerald Grob describes as irresistible progress, a time when it seemed like science was on the brink of curing so much of what ailed us.<sup>46</sup> With so many concrete victories in point, the existence of illnesses that would not go away—chronic conditions that were somehow beyond the reach of medical science—would appear that much more unpalatable.

## Chapter 2

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# An Awakening

## Medicine and Illness in Post–World War Two America

Every semester, when I ask my health sciences students to define what medical ethics means to them, I usually hear the same chorus of responses: treating the patient as a whole person. Advocating for the patient. My nursing students often chime in with the term “non-maleficence”—avoiding doing harm to the patient. They often share examples of when those ethics were challenged without divulging personal details, since patient confidentiality is taken seriously in our classroom, thanks to the Health Insurance Portability and Accountability Act (HIPAA) of 1996. Teenage patients who want a course of treatment different from what their parents want for them, or an elderly patient’s wishes not being respected by the next of kin tasked with difficult decisions, are common examples. Usually, it is when we explore instances of perceived lapses in judgment or ethics that we circle around to the more exhaustive understanding of why the students choose to define ethics as they do.

Perched over Boston’s bustling Huntington Avenue in our fourth-floor classroom at Northeastern University, steps from Harvard teaching hospitals like Brigham and Women’s and Beth Israel Deaconess Medical Center, as well as other renowned institutions like Children’s Hospital, the Dana-Farber Cancer Institute, and the Joslin Diabetes Clinic, we are all fortunate. When I need to, I can take a left down Huntington Avenue, walking past the take-out restaurants and dive bars with dollar wine specials, past where the E Line street-level trolley cuts through the main thoroughfare, filled with high school students, nurses and medical residents, young mothers with children in strollers, and college students with iPod ear buds. When I walk through Brigham’s main revolving door I am no longer a writer and health sciences writing lecturer; I am a patient with a rare disease who depends on the innovative treatments and technology at hospitals like this. Quite literally, I am crossing Sontag’s threshold from the kingdom of the well into the kingdom of the sick. In many respects, I know the kingdom and its attendant customs and interactions more intimately than I do the realm of the health care professional. Appointments and hospital admissions are frequent in my world, and the diagnostic tests, procedures, and treatments I sign consent forms for are a routine part of my life.

My students often make this same walk down Huntington to their respective clinical and co-op placements, field placements the school arranges, minutes from their dorms and apartments and the classrooms and labs. They learn about patient care in some of the most medically advanced and prestigious research hospitals in the world. They too cross into another kingdom, shedding the college student personas and adopting the mindset of the health care apprentice. We each have our roles, and it is easy to forget that not all patients and providers have access like this.

My students’ definitions of medical ethics are on point, but it isn’t without more probing and more discussion that we land upon the topics of informed consent and patients’ rights. I think this is partially a good thing; they see these principles at work so regularly in their rotations that the principles are just that: routine. Lists of patients’ rights are posted on hospital walls and in emergency room bays throughout hospitals. Informed consent for procedures big and small often—not always but often enough—entails a quick overview and a dash of a perfunctory signature. But every now and then, a student will question what we often take at face value.

How informed is consent if, say, the patient doesn’t have a good grasp of English and there isn’t time for a translator, or the resources to provide one? To what extent do patients who have no health insurance and therefore limited ability to seek different care have their basic rights upheld? How

helpful or equitable are online resources if they assume a digital literacy and access that some patients don't have?

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Most often, it is when something goes wrong that we stop and think about the potential risks listed on the procedures we agree to undergo, or consider just what it means to be treated with respect and dignity regardless of our origin, religion, or financial status. Because those of us with appropriate access to consent forms and patients' rights have the luxury to navigate a medical establishment that is at least moderately successful in upholding these basic promises, we don't have to stop and consider them as much as we might otherwise.

The ethical treatment of patients may depend in part on whether we think our illnesses say more about us than our health. On the surface, if we are just looking at obesity rates, cardiovascular diseases, or a decline in physical activity precipitated by a digital lifestyle, it is easy to claim that yes, perhaps they do. If we consider the association between the environment in which we live and the risk of developing certain cancers and other conditions, then that is another layer of probability. However, the question probes at something much deeper than that. If our illnesses reveal strength or weakness in us, then so too does the way we treat the individual patient living with illness.

In the decades just following World War Two and leading up to the social justice movements of the 1960s and '70s, many of the concepts most of us take for granted had a fairly egregious track record. Informed consent was at best an afterthought, at worst deliberately ignored, and medical decision making was too often deeply skewed toward those with power. The 1950s and '60s were a pivotal turning point in patients' rights, ethics, and medical decision making. For patients living with chronic and degenerative diseases, the timing of this was critical.

## **Chronic Illness as an Emerging Priority**

On the heels of World War Two, America was coming down from the heady throes of patriotism and was exposed to more innovative medical technology. The establishment of the independent, nonpartisan National Commission on Chronic Illness in May 1949<sup>1</sup> indicated a growing awareness of the demands of chronic disease. The Commission on Chronic Illness was a joint creation of the American Hospital Association, the American Medical Association, and the American Public Welfare Association<sup>2</sup> and its initial goals included gathering and sharing information on how to deal with the "many-sided problem" of chronic illness; undertaking new studies to help address chronic illness; and formulating local, state, and federal plans for dealing with chronic illness.<sup>3</sup> This included plans to dispel society's belief that chronic illness was a hopeless scenario, create programs that would help patients reclaim productive space in society, and coordinate disease-specific groups with a more universal program that would more effectively meet the needs of all patients with chronic illness, regardless of diagnosis.<sup>4</sup>

These goals indicate that when chronic illness was emerging as a necessary part of the postwar medical lexicon, it was seen as a social issue, not just a physical or semantic one. Many of these goals are the same ones patients and public health officials point to today, signaling that either the commission was particularly forward-thinking—or, that we have yet to mobilize and systematically address the unique needs of the chronically ill the way other movements have mobilized in the past.

Still, the Commission on Chronic Illness was an important concrete step in the process to recognize and address chronic illness. It defined chronic illness as any impairment characterized by at least one of the following: permanence, residual disability, originating in irreversible pathological alteration, or requiring extended care or supervision.<sup>5</sup> Now, we have many variations of the same theme

Sometimes, the length of time symptoms must persist differs; sometimes, the focus is on ongoing treatment rather than supervision. Rosalind Joffe, a patient with chronic illness who is a life coach specializing in helping executives with chronic illness stay employed, offers three important characteristics experts agree are often found in chronic illness: the symptoms are invisible, symptom and disease progression vary from person to person, and the disease progression and worsening or improvement of symptoms are impossible to predict.<sup>6</sup> I've always found the "treatable, not curable" mantra a helpful one in discussing chronic illness, since it allows for all those variances in diagnosed disease course, and outcomes. In some cases, treatment could be as simple as an anti-inflammatory drug to manage mild arthritis or daily thyroid medication to correct an imbalanced thyroid hormone level. At the other end of the spectrum are diseases like cystic fibrosis, where the treatment progresses to include organ transplantation (which is a life-extender, not a cure).

To get a sense of just how broad the spectrum of what we could define as chronic illness is, consider sinusitis, a very common chronic condition affecting some thirty-one million patients annually.<sup>7</sup> Its frequency, duration, and treatment (because even those who undergo surgery for it are rarely fully cured) technically fit the basic meaning of a chronic illness, a prime example of the utility of substituting "condition" for "illness." However, sinus congestion is not the ailment we usually associate with chronically ill patients. That this umbrella term reaches far enough to encompass AIDS is a telling shift and adds to that basic premise that chronic illness is treatable, not curable.

More than being a straightforward counterpart of acute illness, the very notion of chronic illness is one rooted in social and class consciousness. Ours is a society that values youth, physical fitness, and overachievement. By the middle of the twentieth century, this elevation of the importance of the perceptions of others played out in rigid social conformity, as well as in anxiety about the loss of conformity. Scholars and writers of the time worried that people were living in "slavish compliance" with the opinions of others—neighbors, bosses, the corporation, the peer group, the anonymous public. Given the external events of the time—McCarthyism, the Cold War, the space race—it is not hard to see why maintaining the status quo and the cloak of homogeneity would have been appealing to many, and why in the ensuing years, so many would rebel from that same conformity.

As I write this, the term "self-improvement" conjures up images of extreme dieting and aggressive cosmetic surgeries and enhancements more often than it does industriousness or work ethic. In fact, the drive for perfection often spurs the desire for short cuts or immediate results our technology-driven culture makes possible. If science can improve on imperfections, shouldn't we take advantage of its largesse? The middle of the twentieth century ushered in the idea that we must somehow stand up across all social and professional strata in our lives. News headlines are filled with stories of track stars' adventures in surgical reconstruction, and daytime television commercials are rife with weight loss ads and other enhancement products that offer big rewards with supposedly little risk. The upsurge in enhancement technologies is what physician, philosopher, and bioethicist Carl Elliott calls the American obsession with fitting in, countered by the American anxiety over fitting in too well. The very nature of chronic illness—debilitating symptoms, physical side effects of medications, the gradual slowing down as diseases progress—is antithetical to the cult of improvement and enhancement that so permeates pop culture.

Autoimmune diseases, which affect nearly twenty-four million Americans,<sup>9</sup> are a prime example of chronic illnesses that defy self-improvement. At their core, autoimmune disorders occur when the body mistakenly begins to attack itself. The concept first took root in 1957, but in *The Autoimmune Epidemic*, Donna Jackson Nakazawa points out that it wasn't until the 1970s that the concept gained widespread acceptance. While heart disease, cancer, and other chronic conditions had been tracked for decades, as late as the 1990s no government or disease-centered organization had collected data on

how many Americans lived with the often baffling conditions that make up autoimmune diseases. The mid-twentieth-century America in which the notion of autoimmune disease made its debut represents a pivotal time period in the evolution of chronic illness. The country had just moved past the frenetic pace of immunization and research that followed World War Two. Patients' rights and informed consent began to be recognized as important issues, particularly with the emerging fields of organ transplantation, and those topics plus the advent of managed care plans in the 1960s each contributed to the beginning of a marked change in how medicine and society looked at disease.

With autoimmune diseases, the specific part of the body that is attacked manifests itself in a wide variety of conditions, from the joints and muscles (rheumatoid arthritis and lupus) to the myelin sheath in the central nervous system (multiple sclerosis) to the colon or muscles (Crohn's and polymyositis). It isn't so much a question of whether autoimmune disorders are "new" conditions as it is a question of correctly identifying them and sourcing the origin of that fateful trigger. Sometimes something as innocuous as a common, low-grade virus can be the trigger that jumpstarts the faulty immune response, and research suggests many of us carry genes that leave us more predisposed to developing autoimmune disease. However, when we look at alarming increases in the number of patients being diagnosed with conditions like lupus, the role of the environment, in particular the chemicals that go into the household products we use, the food we consume, and the technology we employ every day, is of increasing significance.

Nakazawa takes a strong position on this relationship: "During the four or five decades that science lingered at the sidelines ... another cultural drama was unfolding in America, the portentous ramifications of which were also slipping under the nation's radar. Throughout the exact same decades science was dismissing autoimmunity, the wheels of big industry were moving into high gear across the American landscape, augmenting the greatest industrial growth spurt of all time."<sup>11</sup>

It is simply not possible to discuss disease in purely scientific language. Culture informs the experience of illness, and living with illness ultimately shapes culture. From the interconnectedness of the way we work and communicate virtually to the way we eat to the products we buy, the innovations that has so drastically changed the course of daily life and culture has an unquestionable impact on health and on the emergence of disease. Technology and science inform culture as well, and culture in turn influences what research we fund, and how we use technology.

If we look at current perspectives and definitions of chronic illness from the Centers for Disease Control and Prevention (CDC), there is a telling change in focus from earlier iterations. In detailing the causes of chronic disease, which current data suggest almost one out of every two Americans live with, the CDC listed lack of physical activity, poor nutrition, tobacco use, and alcohol consumption as responsible for much of the illness, suffering, and premature death attributed to chronic diseases in 2010.<sup>12</sup> Given that heart disease, stroke, and cancer account for more than 50 percent of deaths annually, and each is linked to lifestyle and behaviors, it is not a surprise that these four factors are highlighted.<sup>13</sup> Such emphasis implies something more than merely causation. It denotes agency on the part of patients whose choices and behaviors are at least somewhat complicit in their illnesses. This parallels older attitudes toward infectious diseases: if patients weren't living a certain way (in squalor) or acting a certain way (lasciviously), they wouldn't be sick. At the same time, it separates certain chronic conditions and the patients who live with them from the forward momentum of medical science: we can kill bacteria, we can eradicate diseases through vaccination, we can transplant organs, but the treatment and prevention of many conditions is the responsibility of the patient.

Questions of correlation and causation depend on data. It was during the post-World War Two time period that the methodical collection of statistics on chronic disease began. In the America President Dwight D. Eisenhower inherited in the 1950s, the average lifespan was sixty-nine years. Huge trials



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