PART II

The Meaning and Experience of Illness

Our commonsense understandings of the world tell us that illness is a purely biological condition, definable by objectively measured biological traits. As we will see in Part II, however, definitions of illness vary considerably over time and across social groups. In Chapter 5, we explore the social meanings of illness and consider how ideas about the nature and causes of illness have changed historically, from biblical explanations that attributed illness to punishment for sin to modern explanations that attribute illness to risky lifestyles. We also examine how defining something as an illness can act as a form of social control.

Whereas Chapter 5 discusses the meaning of illness in the abstract, Chapter 6 looks at the consequences of chronic illness, chronic pain, and disability for individuals. Beginning with a discussion of how Western society historically has treated those who have chronic illnesses and disabilities, we then consider the modern experience of illness and of chronic pain, including the processes involved in responding to initial symptoms, searching for mainstream or alternative therapies, and coming to terms with a changed body and self-image.

In Chapter 7, we examine parallel questions regarding mental illness. We begin by exploring what it means to call something a mental illness. Then we look at how and why mental illness is distributed among social groups; how Western society historically has treated persons with mental illnesses; and how individuals experience mental illness, from initial symptoms to treatment, to social status after treatment.

CHAPTER

5

The Social Meanings of Illness

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LEARNING OBJECTIVES

After reading this chapter, students should be able to:

- Understand how cultural explanations for illness have changed over the centuries.
- Compare the medical and sociological models of illness.
- Assess the impact of medicalization.
- Use and critique the concept of a sick role.

According to Lunesta.com, a website aimed at the general public and run by the company that manufactures the popular insomnia drug Lunesta:

> *Approximately 20 million adults in the U.S. suffer from insomnia—a medical condition in which difficulty falling asleep and/or staying asleep has a negative impact on the next day ... Symptoms [include] difficulty falling asleep, waking up frequently during the night, difficulty returning to sleep, waking up too early in the morning, unrefreshing sleep, daytime sleepiness, [or] difficulty concentrating.... It [insomnia] is a serious medical condition that can affect your mind and body [and cause] daytime fatigue, irritability, decreased feelings of well-being, decreased ability to concentrate, decreased ability to problem solve, [and] difficulty in making decisions.*

To encourage readers to seek (drug) treatment for sleep problems, the website not only stresses the need to seek medical help but also offers suggestions on what to say when seeking help from doctors; information on getting Lunesta at discounted prices; and web links to national nonprofit organizations (partly funded by pharmaceutical manufacturers) that focus on identifying and treating sleep problems.

Does this seem like a reasonable way to deal with sleep problems—many of which are caused by nonmedical issues such as working odd hours, job stress, an over-firm mattress, or watching late-night television? According to many doctors, the answer is yes. Diagnoses with insomnia have skyrocketed in recent years, following intensive marketing campaigns for these drugs—even though research suggests that they provide only a few extra minutes of sleep per night but can cause traffic accidents, crippling falls, and amnesia-like episodes during which individuals may eat, walk, engage in sex, or do other activities they would not consciously have chosen (Moloney, Konrad, and Zimmer, 2011).

This raises the question: What do we mean when we say that something is a disease? In this chapter, we examine the meaning of illness and disease. We look first at how people have explained illness across history and then at the medical and sociological models of what illness is and means. Then we consider how medicine can act as an institution of social control, highlighting the process through which behaviors or conditions become defined as illnesses, the consequences of these definitions for individuals and society, and the potential consequences of our growing reliance on genetic explanations for disease.

EXPLAINING ILLNESS ACROSS HISTORY

Throughout history, people have feared illness. To relieve their anxiety and make the world seem less frightening, they typically have sought explanations for why illness occurs and why it strikes some rather than others. Most often, these explanations defined illness as a deserved punishment for sinful or foolish behaviors and blamed individuals for their own illnesses (Brandt and Rozin, 1997; Weitz, 1991). Such explanations provide psychological reassurance by reinforcing people's belief in a "just world" in which punishment falls only on the guilty (Meyerowitz, Williams, and Gessner, 1987). For example, both the Jewish and Christian Bibles describe leprosy as punishment for sin. As a result, throughout the Middle Ages, Christian society required anyone diagnosed with leprosy to participate in a special mass for the dead, in which a priest would shovel dirt on the individual's feet to symbolize his or her civil and religious death. From then on, the individual was legally prohibited from entering public gathering places, washing in springs or streams, drinking from another's cup, wearing anything other than the special "leper's dress," touching anything before buying it, and so on (Richards, 1977:123–124).

By the early nineteenth century, pre-scientific ideas about illness had begun to erode as the idea grew, especially among the elite, that scientific principles controlled the natural order. According to the new scientific thinking, illness occurred when biological forces combined with personal susceptibility. Doctors (still lacking a concept of germs) argued that illness occurred when persons whose constitutions were naturally weak or had been weakened by unhealthy behaviors came in contact with dangerous **miasma**, or air "corrupted" by foul odors and fumes. As a result, whereas earlier theories had blamed illness on *immoral* behavior, these new theories blamed illness on *unhealthy* behavior.

As the history of cholera shows, however, these new ideas still allowed the healthy to blame the ill for their illnesses. Cholera first appeared in the Western world in about 1830, killing its victims suddenly and horrifyingly through overwhelming dehydration brought on by uncontrollable diarrhea and vomiting. Cholera is caused by waterborne bacteria generally transmitted when human wastes contaminate food or drinking water. It most often strikes poor persons because they are the most likely to lack clean water and to be weakened by insufficient food, clothing, or shelter.

To explain why cholera had struck, and why it struck the poor especially hard, early nineteenth-century doctors asserted that cholera could attack only individuals who had weakened their bodies through improper living (Risse,

1988; Rosenberg, 1987). According to this theory, the poor caused their own illnesses, first by lacking the initiative required to escape poverty and then by choosing to eat an unhealthy diet, live in dirty conditions, or drink too much alcohol. Thus, for example, the New York City Medical Council concluded in 1832 that "the disease in the city is confined to the imprudent, the intemperate, and to those who injure themselves by taking improper medicines" (Risse, 1988:45). Conversely, doctors (and their wealthy patrons) assumed that wealthy persons would become ill only through gluttony, greed, or by "innocently" inhaling some particularly noxious air. This theory of illness allowed the upper classes to adopt the new scientific explanations for illness while retaining older moralistic assumptions about ill people and avoiding any responsibility to aid the poor or the ill. In sum, instead of believing that immorality directly caused illness, people now believed that immorality left one *susceptible* to illness.

Despite the tremendous growth in medical knowledge about illness during the past 200 years, popular explanations for illness have remained remarkably stable. Theories connecting illness to sin continue to appear, as do theories that conceptualize illness as resulting from poorly chosen (although not necessarily sinful) behaviors and attitudes (Brandt and Rozin, 1997; Tesh, 1988). Parents still act as if colds are caused by playing in the rain rather than exposure to viruses, and public health authorities more often focus on urging people to exercise than on addressing the conditions (such as dangerous neighborhoods, lack of gyms, or the need to hold down two jobs) that keep people from exercising. Similarly, author Rhonda Byrne, in her hugely popular book *The Secret*, argues that individuals "attract" health, wealth, sickness, or poverty to themselves simply by thinking about these conditions (Byrne, 2006:130–132). In sum, theories of illness that focus on individual responsibility continue to reinforce existing social arrangements and to help us justify our tendency to reject, mistreat, or simply ignore those who have illnesses.

MODELS OF ILLNESS

But what do we mean when we say something is an illness? The answer is far from obvious. Most Americans are fairly confident that someone who has a cold or cancer is ill. But what about women whose bones have become brittle with age; men who have bald spots or enlarged prostates; or young boys who have trouble learning, drink excessively, or enjoy fighting? Depending on whom you ask, these conditions and actions may be defined as normal human variations, illnesses, bad character, or bad behavior. As this suggests, defining illness is not a simple task. In this section, we explore how doctors and sociologists approach these issues.

The Medical and Sociological Models of Illness

The **medical model of illness** refers to what doctors typically mean when they say something is an illness. This medical model is not accepted in its entirety by

KEY CONCEPTS

Medical and Sociological Models of Illness

Medical Model	Sociological Model
Illness is an objective label: All educated people agree on what is normal and what is illness.	Illness is a subjective category: Educated people sometimes disagree on what should be labeled illness.
Example: Female sexual dysfunction (FSD) is a biological disease characterized by lack of sexual responsiveness.	*Example:* FSD is a label given to women who are distressed by their lack of sexual responsiveness with their current sexual partner.
Illness is nonmoral: Conditions and behaviors are labeled illness scientifically without moral considerations or consequences.	Illness is a moral category: Conditions and behaviors are labeled illness when they are considered bad or abnormal.
Example: Labeling FSD an illness and labeling individuals as having FSD are neutral biological statements that don't reflect moral judgments of the condition or individual.	*Example:* We label sexual nonresponsiveness an illness because we find it repugnant, and we typically look down on those who have FSD.
Illness is an apolitical label: Politics have no impact on who or what is labeled illness.	Illness is a political label: Some groups have more power than others to decide what is an illness and who is ill.
Example: FSD was first identified by doctors through scientific research.	*Example:* The concept of FSD was promoted by pharmaceutical companies to sell drugs.
Each illness results from a unique biological cause.	Illness results from a combination of social and biological causes.
Example: FSD results from a biochemical imbalance best treated with a drug.	*Example:* Women's sexual problems often reflect psychological and interpersonal as well as biological problems.

all doctors, but it is the dominant conception of illness in the medical world. In contrast, the **sociological model of illness** offers a very different way of thinking about what illness means in practice (rather than ideally). This model is most often adopted by sociologists who take a critical approach, and is also sometimes adopted by health care workers who share sociologists' concerns about how social forces affect health and health care. *Key Concepts: Medical and Sociological Models of Illness* compares these two models using as an example female sexual dysfunction (FSD), a recently developed and still contentious diagnosis.

The medical model of illness begins with the assumption that illness is an objective label given to anything that deviates from normal biological functioning (Mishler, 1981). Most doctors, if asked, would explain that polio is caused by a virus that disrupts the normal functioning of the neurological system; menopause is a "hormone deficiency disease" that, among other things, impairs the

body's normal ability to regenerate bone; and men develop urinary problems when their prostates grow excessively large and unnaturally compress the urinary tract. By extension, the medical model assumes that each illness has specific features that any doctor can recognize (Mishler, 1981).

In contrast, the sociological model of illness begins with the statement that illness (as the term is actually used) is a *subjective* label, which reflects personal and social ideas about what is normal as well as scientific reasoning (Weitz, 1991). Sociologists point out that ideas about normality differ widely across both individuals and social groups. A height of 4 feet 6 inches would be normal for a Pygmy man, but not for an American man. Drinking three glasses of wine a day is normal for Italian women but could lead to a diagnosis of alcoholism in American medical circles. In defining normality, therefore, we need to look not only at individual bodies but also at the broader social context.

Moreover, even within a given group, "normality" is a range and not an absolute. The median height of American men, for example, is 5 feet 9 inches, but most people would consider someone several inches taller or shorter than that as still normal. Yet medical authorities routinely decide what is normal and what is illness based not on objective markers of health and illness, but on arbitrary, statistical cutoff points—deciding, for example, that anyone in the fourth percentile for height or the fiftieth percentile for cholesterol level is ill (Cohen and Cosgrove, 2009; Hadler, 2008).

Similarly, sociologists note, the process of assigning diagnoses to individuals is far from objective. For example, African American patients with chest pain often receive diagnoses of indigestion, whereas white patients more often receive diagnoses of heart disease. Meanwhile, French doctors often attribute patients' headaches to liver problems, whereas US doctors more often attribute them to neurological causes (Hoffman and Tarzian, 2001; Nelson, Smedley, and Stith, 2002; Payer, 1996).

Because the medical model assumes illness is an objective, scientifically determined category, it also assumes that moral judgments play no role in labeling conditions or behaviors as illnesses. Sociologists, on the other hand, argue that illness is inherently a moral category because deciding what is illness always means deciding what is good or bad. When, for example, doctors label menopause a "hormonal deficiency disease," they label it an undesirable deviation from normal. In contrast, many women consider menopause both normal and desirable, and enjoy the freedom from fear of pregnancy that menopause brings (Avis and McKinlay, 1991). In the same manner, when we define cancer, polio, or diabetes as illnesses, we judge the bodily changes these conditions produce to be both abnormal and undesirable rather than simply normal variations in functioning, abilities, and life expectancies. (Conversely, when we define a condition as healthy, we judge it to be normal and desirable.)

Similarly, whenever we label someone ill, we suggest there is something undesirable about that person. By definition, an ill person is one whose actions, abilities, or appearance don't meet social **norms**: expectations within a given culture regarding proper behavior or appearance. Such a person is typically considered less whole and less socially worthy than those deemed healthy. Illness, then, like virginity or laziness, is a **moral status**: a social condition that we believe indicates the goodness or badness, worthiness or unworthiness, of a person.

From a sociological standpoint, illness is not only a moral status (such as crime or sin) but also a form of **deviance** (Parsons, 1951). To sociologists, labeling something deviant does not necessarily mean that it's immoral. Rather, deviance refers to behaviors or conditions that socially powerful persons within a given culture *perceive*, whether accurately or inaccurately, to be immoral or to violate social norms. We can tell whether behavior violates norms (and therefore whether it's deviant) by seeing if it results in **negative social sanctions**. This term refers to any punishment, from ridicule to execution. (Conversely, **positive social sanctions** are rewards, ranging from token gifts to knighthood.) These social sanctions can be enforced by parents, police, teachers, and peers, as well as doctors. Later in this chapter, we'll look at some of the negative social sanctions imposed against ill persons.

For the same reasons that the medical model doesn't recognize the *moral* aspects of illness labeling, it doesn't recognize the *political* aspects of that process. Although doctors sometimes participate actively in these political processes—arguing, for example, that insurance companies should cover treatment for newly labeled conditions such as fibromyalgia—few doctors recognize how politics underlie the illness-labeling process in general. In contrast, sociologists point out that any time a condition or behavior is labeled an illness, some groups will benefit more than others, and some groups will have more power than others to enforce the definitions that benefit them. As a result, open political struggles often emerge around illness definitions (a topic we'll return to later in this chapter). For example, US vermiculite miners who were constantly exposed to asbestos dust in their work and who now have strikingly high rates of cancer have fought with insurance companies and doctors in clinics, hospitals, and the courts to have "asbestosis" labeled an illness. Meanwhile, the mining companies and the doctors they employed have argued that no such disease exists and that the high rates of cancer in mining communities are merely coincidences (Schneider and McCumber, 2004).

Finally, the medical model of illness assumes that each illness has not only unique symptoms but also a unique biological cause (Mishler, 1981). Modern medicine assumes, for example, that tuberculosis, polio, and other infectious diseases are each caused by a unique microorganism. Similarly, doctors continue to seek limited and unique causes of heart disease and cancer, such as high cholesterol diets and exposure to toxins. Yet even though illness-causing microorganisms exist everywhere and environmental health dangers are common, relatively few people become ill as a result. By the same token, although cholesterol levels and heart disease are strongly correlated among middle-aged men, many men eat high-cholesterol diets without developing heart disease, and others eat low-cholesterol diets but die of heart disease anyway. Belief in unique biological causes discourages medical researchers from asking why individuals respond in such different ways to the same health risks and encourages researchers to search for **magic bullets**—a term used by Paul Ehrlich, discoverer of the first effective treatment for syphilis, to refer to drugs that almost miraculously prevent or cure illness by attacking one specific etiological factor.

In sum, to sociologists who work from a critical perspective, illness is a **social construction**, something that exists in the world not as an objective condition, but *because we have defined it as existing*. This doesn't mean that the virus causing measles does not exist or that it doesn't cause a fever and rash. It does mean, though, that when we talk about measles as an illness, we have organized our ideas about that virus, fever, and rash in only one of the many possible ways. In another place or time, people might conceptualize those same conditions as manifestations of witchcraft, as a healthy response to the presence of microbes, or as some other illness altogether. To sociologists, then, *illness*, like *crime* or *sin*, refers to biological, psychological, or social conditions subjectively defined as undesirable by those within a given culture who have the power to enforce such definitions.

MEDICINE AS SOCIAL CONTROL

In everyday life, we use the word *medicine* to refer to the drugs that doctors prescribe. But we can also use the word *medicine* to refer to the world and culture of doctors. For example, we might say that modern medicine is an exceedingly complex enterprise or that modern medicine primarily focuses on treating disease rather than on looking for environmental causes of illness. Even more broadly, sociologists refer to medicine as an *institution*. Sociologists use the term **institution** to refer to enduring social structures that meet basic human needs, such as the family, religion, and education. When we talk of medicine as an institution, we refer to the world and culture of doctors as well as to the economic, social, and political underpinnings of that world. We might, for example, talk about how the power of medicine *as an institution*—doctors, hospitals, the medical way of thinking about the world, and so on—has grown over the past century. Importantly, sociologists (and others) increasingly talk about *biomedicine* as an institution. **Biomedicine** refers to the ways in the which medicine, science and technology often now work together as one social institution—an institution that can increase or reduce the power of medicine as an institution (Clarke et al., 2003, 2010). (For simplicity's sake, we will primarily use the term *medicine* in this book.)

One of the central concepts in the sociology of health and illness is the idea that medicine is, among other things, an institution of social control. **Social control** refers to the formal and informal methods used by a social group to ensure that individuals conform to social norms and to protect the existing balance of power among groups. When we say that medicine is an institution of social control, we are saying that medicine is a basic structure of our society that sometimes serves to "keep people in line." For example, doctors have the power to decide whether someone is a malingerer who should be shunned or is truly ill and deserves sympathy. In such a situation, doctors act as **social control agents**: individuals or groups (such as parents and religious leaders) that enforce social norms. *Contemporary Issues: Citizenship and Biomedicine* explores how the broader institution of biomedicine now plays a powerful role in deciding who can become a US citizen.

CONTEMPORARY ISSUES

Citizenship and Biomedicine

Becoming a US citizen is a long and difficult process. Each year, however, the United States allows some refugees and immigrants to bypass the usual procedures if they are the spouse, parent, or young child of a US citizen. Increasingly, however, the federal government has mandated that individuals must first prove their family relationship through expensive genetic testing (Dove, 2013; Lakhani and Timmermans, 2014).

The government, of course, has both a need and an obligation to prevent immigration fraud. At the same time, relying on DNA testing leads to a different set of problems (Dove, 2013; Lakhani and Timmermans, 2014). Most basically, it enshrines biomedical information as uniquely accurate and meaningful: more important than legal documents, a parent's sworn statement, or a child's obvious desire to be reunited with the adults he or she loves. Similarly, it implicitly declares that we are all defined by our genes. In addition, it defines family in narrow terms, omitting stepchildren and adopted children. Yet in many other cultures, it is common for adults to informally adopt nieces, nephews, cousins, or others when parents die or are unable to care for them. This is especially true in war-torn areas like those where most refugees were born. Relying on genetic testing also has the effect of denying legitimacy to polygamous families, in which all wives may consider all children born into the family to be their own. Finally, mandated genetic testing can rip apart—rather than unite—families when it reveals that a child is not genetically related to a man long assumed to be his or her father.

In the next sections, we will see how doctors, as agents of social control, both decide which conditions or behaviors should be labeled illness and press sick people to get well and return to normal social roles.

Creating Illness: Medicalization

The process through which a condition or behavior becomes defined as a medical problem requiring a medical solution is known as **medicalization** (Conrad, 2007). For example, during the nineteenth century most Americans considered chronic drunkenness to be a sin, but by the mid-twentieth century many instead considered it a form of mental illness. Similarly, over the last few decades various natural conditions and processes, such as uncircumcised penises, male balding, aging, loss of sexual desire, and pregnancy have all increasingly come to be seen as medical problems (Armstrong, 2000; Conrad, 2007; Hartley, 2006; Rosenfeld and Faircloth, 2005). The term *medicalization* also refers to the process through which the definition of an illness is *broadened*. For example, when doctors expanded the definition of osteoporosis to include anyone with low bone density, rather than only individuals who had experienced unusual bone fractures, the number of persons diagnosed with osteoporosis almost doubled (Grob and Horwitz, 2009).

For medicalization to occur, one or more organized social groups must have both a vested interest in medicalization and sufficient power to convince others (including doctors, the public, and insurance companies) to accept their new

definition of the situation. Not surprisingly, doctors often play a major role in medicalization because medicalization can increase their power, the scope of their practices, and their incomes. For example, during the first half of the twentieth century, improvements in the standard of living coupled with various public health measures substantially reduced the number of seriously ill children. As a result, the market for pediatricians declined, and their focus shifted from serious illnesses to minor childhood illnesses and well-baby care. Pediatrics thus became less well paid, interesting, and prestigious. To increase their market while obtaining more satisfying and prestigious work, some pediatricians have expanded their practices to include children whose behavior concerns their parents or teachers and who are now defined as having attention-deficit hyperactivity disorder (ADHD) (Conrad, 2007). Doctors have played similar roles in medicalizing crooked noses, obesity, drinking during pregnancy, impotence, and numerous other conditions (Grob and Horwitz, 2009; Loe, 2004).

In other instances, however, doctors have actively opposed medicalization (Swoboda, 2008). This by definition is the case with any **contested illness**: distressing and painful symptoms that affected individuals believe constitute an illness even though many doctors disagree. For example, fibromyalgia is characterized by many common symptoms, including pain, dizziness, insomnia, and headache. Moreover, no blood test or X-ray can identify an individual as having fibromyalgia. As a result, many doctors question whether it really is a disease. The same is true for chronic fatigue syndrome, multiple chemical sensitivity, and Gulf War syndrome, among others. In these cases, consumers often press for medicalization to get validation for their experiences, stimulate research on treatments and cures, and get health and disability insurance coverage for their problems (Barker, 2005, 2008; Conrad, 2007). The rise of the Internet has made it much easier for such consumers to find each other, reaffirm each other's sense that they suffer from a real illness, and lobby for medicalization.

Another major force in battles over medicalization is **managed care organizations (MCOs)**. MCOs (discussed in detail in Chapter 8) are health insurance providers that restrain costs (and ideally improve quality of care) by monitoring closely the health services given to patients. MCOs either support or oppose medicalization, depending on which tactic best protects their interests (Conrad, 2007). For example, in the past, MCOs typically rejected requests for gastric bypass surgeries to help obese patients lose weight, implicitly arguing that obesity was a personal rather than a medical issue. More recently, MCOs have started approving these surgeries in hopes of reducing their long-term costs for obesity-related disease.

The final major force behind medicalization is the pharmaceutical industry (Conrad, 2007). The industry has a vested economic interest in medicalization whenever it can sell a drug as a treatment (Cohen and Cosgrove, 2009; Conrad, 2007; Rothman and Rothman, 2003). For example, in 1985, the pharmaceutical company Genentech patented a genetically engineered human growth hormone designed to increase height in children with pituitary gland defects. Such defects, however, are rare. To expand the market for its drug, Genentech sponsored in-school screening programs that identified the shortest three percent of students

and then informed the students' parents that the students might benefit from hormone treatment. That treatment, however, carried significant side effects and only increased height in children with pituitary defects.

Case Study: Working Together to Medicalize Attention-Deficit Hyperactivity Disorder (ADHD) Successful medicalization often depends on the interwoven interests and activities of multiple interest groups. The history of ADHD illustrates this process.

Scientists have yet to discover any biological markers (such as viruses or genes) for ADHD (Furman, 2009). As a result, doctors instead diagnose individuals with ADHD if they are overactive, impulsive, or easily distractible but show no evidence of brain damage (Conrad 2007).

The diagnosis only became popular in the 1960s, following a massive advertising campaign for Ritalin (methylphenidate). That campaigned aimed to convince both doctors and the public that ADHD was a real disease and that Ritalin was a safe treatment. Ritalin is indeed safer than other amphetamines and can, in the short term, improve individuals' concentration, impulse control, and discipline. But it may cause addiction, loss of appetite, sleep deprivation, headache, stomachache, and cancer (Davis, 2007; Vastag, 2001), and does *not* improve individuals' chances of graduating high school, holding a job, avoiding drug abuse, or avoiding trouble with the law (Diller, 1998).

Despite these problems, pediatricians proved a ready audience for this marketing campaign, which promised a way to boost their flagging income and prestige. Teachers, too, began recommending that certain students get tested (and treated) for ADHD, in part because the drugs could make students more manageable, and the diagnosis could shift blame for student problems away from the teachers themselves (Diller, 1998). Meanwhile, parents hoped that diagnosis with ADHD would move blame for their children's school or behavior problems away from both their children and their parenting skills. Finally, parents hoped that diagnosis would give their children the benefits federally guaranteed to any children with disabilities: special educational services plus protection against suspension or expulsion for disciplinary problems related to ADHD (Conrad 2007; Diller, 1998).

Currently, 11 percent of US schoolchildren—and almost 20 percent of high school boys—have been diagnosed with ADHD, and sales of drugs to treat it have more than doubled in the last few years (Schwarz and Cohen, 2013). In addition, diagnoses have spiked among toddlers, even though official definitions of ADHD limit it to children age four or over (Schwarz, 2014).

Unintended Consequences of Medicalization In some circumstances, medicalization can be a boon, leading to social awareness of a problem, sympathy toward those diagnosed with an illness, and the development of helpful treatments. Persons with epilepsy, for example, lead far happier and more productive lives now that their seizures are treated with drugs rather than treated as signs of demonic possession. But defining a condition as an illness does not necessarily improve the social status of those who have that condition. Those who use

alcohol excessively, for example, continue to experience social rejection even when alcoholism is labeled a disease. Moreover, medicalization also can lead to new problems, known by sociologists as **unintended negative consequences** (Conrad, 2007).

First, once a situation becomes medicalized, doctors become the only experts considered appropriate for diagnosing the problem and for defining appropriate responses to it. As a result, the power of doctors increases while the power of other social authorities (including judges, the police, religious leaders, legislators, and teachers) diminishes. For example, now that troublesome behavior by children is increasingly diagnosed as ADHD, parents, teachers, and the children themselves have lost credibility when they disagree with this diagnosis. Similarly, doctors are now given considerable authority to answer questions such as who should receive abortions or organ transplants, how society should respond to drug use, and whether severely disabled infants should receive experimental surgeries, while the authority of the church and family members to answer these questions has diminished.

As this suggests, medicalization significantly expands the range of life experiences under medical control. For example, the natural process of aging is increasingly regarded as a medical condition. Doctors now scrutinize all aspects of the aging body and recommend psychological tests to measure mental decline, hormones to improve virility, cosmetic surgery for wrinkles, and more (Conrad, 2007).

Second, once a condition is medicalized, medical treatment may seem the only logical response to it. For example, if woman battering is considered a medical condition, then doctors need to treat women and the men who batter them. However, if woman battering is considered a social problem stemming from male power and female subordination, then it makes more sense to arrest the men, assist the women financially and emotionally, and work for broader structural changes to improve all women's status and options.

Third, when doctors define situations in medical terms, they reduce the chances that these situations will be understood in *political* terms. For example, China, Pakistan, and other countries have removed political dissidents from the public eye by committing them to mental hospitals. By so doing, these governments discredited and silenced individuals who might otherwise have offered powerful dissenting voices. In other words, medicalization allowed these governments to **depoliticize** the situation: to define it as a medical rather than a political problem.

Fourth, and as the examples of China and Pakistan illustrate, medicalization can justify involuntary treatment. Yet treatment sometimes harms more than it helps. For example, since the 1980s, US doctors have legally forced small numbers of women to submit to cesarean deliveries, in which babies are surgically removed from their mothers' uteruses rather than delivered naturally through the vagina (Daniels, 1993; Roth, 2003). In these cases, doctors argued successfully that childbirth is a dangerous medical condition rather than a natural process, that doctors are better qualified than pregnant women to judge fetuses' needs, and that fetuses' right to health is more important than women's right to control their own bodies. Yet the rate of cesarean section in the United States is twice that recommended by the World Health Organization, suggesting that doctors are far too ready to perform this potentially life-threatening surgery. *Ethical Debate: Medical Social Control and Fetal Rights* explores how the growing acceptance of the idea of "fetal rights" is affecting the lives of pregnant women.

Medicalization and the "Potentially Ill" In addition to creating new illnesses, medicalization has also led to labeling increasing numbers of individuals as "potentially ill" (Boyer and Lutfey, 2010; Conrad, 2005; Scott, Wood, and Gray, 2005). The **potentially ill** are individuals identified as having an above average risk of illness, whether because of age, stress level, tobacco use, family history, medical test results, or other factors.

The risks faced by the potentially ill vary substantially. Some learn that they carry a gene guaranteed to cause a fatal disease. Many more, however, learn that they have a condition such as high cholesterol that may increase their risk of illness. The numbers of such individuals continues to increase as corporations develop more tests for risk factors and as doctors (often reimbursed per test) adopt such tests. Similarly, the ranks of the potentially ill have expanded as pharmaceutical companies have encouraged both doctors and consumers to expand their ideas about health risks and to adopt treatments for those risks. For example, pharmaceutical companies have worked not only to broaden the definition of osteoporosis but also to create a new category, osteopenia, for those at *risk* of osteoporosis. Because *osteoporosis* refers to the risk of bone fractures caused by low bone density, osteopenia is essentially the *risk* of a *risk* of a health problem.

As this suggests, the health benefits of learning that one is potentially ill depend on the magnitude of the identified risk and the effectiveness of available treatments (Scott et al., 2005). Those benefits, however, must also be balanced against the psychological distress caused when people without any symptoms learn that illness might strike at any moment (Marteau and Richards, 1996). In addition, some of these individuals experience the stigma of illness without any of the benefits that those who have illnesses may receive, such as legal protection from discrimination.

The Rise of Demedicalization The problems inherent in medicalization have fostered a (much smaller) countermovement of **demedicalization** (Conrad, 2007). A quick look at medical textbooks from the late 1800s reveals many "diseases" that no longer exist. For example, nineteenth-century medical textbooks often included several pages on the health risks of masturbation. One popular textbook from the late nineteenth century asserted that masturbation caused "extreme emaciation, sallow or blotched skin, sunken eyes, ... general weakness, dullness, weak back, stupidity, laziness, ... wandering and illy defined pains," as well as infertility, impotence, consumption, epilepsy, heart disease, blindness, paralysis, and insanity (Kellogg, 1880:365). Today, however, medical textbooks describe masturbation as a healthy part of human sexuality.

Like medicalization, demedicalization often begins with lobbying by consumer groups. For example, medical ideology now defines childbirth as an

ETHICAL DEBATE

Medical Social Control and Fetal Rights

In October 2006, 20-year-old Tiffany Hitson gave birth to a healthy baby girl. The next day, after traces of marijuana and methamphetamine were found in her baby during routine testing, Hitson was arrested for "chemically endangering" her child. Hitson spent most of the next year in state prison.

Since her arrest, doctors have helped prosecutors to charge eleven other poor or working-class women in the same rural, Alabama county with child endangerment after drugs were detected in a newborn's system or after authorities learned that a pregnant woman was using drugs (Nossiter, 2008). So far, none of the women have had the money or the confidence to risk a trial and so all instead have pleaded guilty.

Over the last decade, hundreds of pregnant women—most poor and nonwhite—have faced criminal sanctions or been forced to endure medical treatments (Eckholm, 2013). These actions reflect a growing tendency among doctors, lawyers, and the general public to view mother and fetus as separate beings, with separable and sometimes conflicting rights, and to see the fetus rather than the mother as obstetricians' primary patient (Roth, 2003). Given that doctors have an ethical and a legal obligation to protect children from parents who abuse them, should doctors have a similar obligation to protect fetuses even if it means superseding mothers' wishes?

Those who argue in favor of medical intervention find it illogical to protect children from bodily harm *after* birth but to deny them protection that might ensure their health *before* birth. Children born prematurely, addicted to drugs, or with birth defects because their mothers did not follow medical advice may lead short, painful lives or may survive with mental or physical disabilities. In addition, caring for these children costs hospitals and taxpayers money. Those costs alone, one could argue, give the medical and legal systems the right to intervene when women endanger their fetuses.

Others, however, have raised several objections to placing **fetal rights** above mothers' wishes. First, critics question whether medical intervention really is necessary. For example, almost all well-structured research studies on mothers' drug use during pregnancy have found that it causes little if any long-term harm to children (Roth, 2003; Singer et al., 2002). Second, drug withdrawal also can endanger fetuses, as can threats of legal sanctions that discourage pregnant women from seeking health care altogether. Third, opponents argue that doctors can't necessarily make better decisions than mothers do because they can't understand fully the circumstances in which mothers make those decisions. For example, many women continue to use drugs during pregnancy only because they can't obtain access to treatment programs, which usually are expensive, have long waiting periods, and won't accept pregnant women.

Finally, some argue, the concept of fetal rights put an undue burden on women (Roth, 2003; Toscano, 2005). Although we require parents to guard their children's health and welfare, we don't require them to donate kidneys, bone marrow, or even blood for their children's sake. Why, then, should we require women—and only women—to protect their fetuses? After all, when fathers drink alcohol, use illicit drugs, smoke cigarettes, or work in legal or illegal chemical laboratories, both sperm and fetuses can be harmed, but no man has ever been charged with fetal abuse. This has led some to conclude that the idea of fetal rights is aimed more at controlling women rather than at protecting children.

Sociological Questions

1. What social views and values about medicine, society, and the body are reflected in the concept of "fetal rights"? Whose views are these?
2. Which social groups are in conflict over this issue? Whose interests are served by promoting fetal rights? Whose interests are harmed?
3. Which of these groups has more power to enforce its view? What kinds of power do they have?
4. What are the intended consequences of this policy? What are the unintended social, economic, political, and health consequences of this policy?

inherently dangerous process, requiring intensive technological, medical assistance. Since the 1940s, however, some American women have attempted to redefine childbirth as a generally safe, simple, and natural process and have promoted alternatives ranging from natural childbirth classes to hospital birthing centers, to home births assisted only by midwives. Similarly, and as described in Chapter 7, gay and lesbian activists have at least partially succeeded in redefining homosexuality from a pathological condition to a normal human variation. More broadly, innumerable books, magazines, television shows, and popular organizations now exist that focus on teaching people to care for their own health rather than (or in addition to) relying on medical care.

Genetic Research and Social Control

The potential for medicine to act as a form of social control continues to grow as scientists learn more about human genes—and as the public increasingly believes that genes hold the key to health and illness. The shift toward increasingly defining genes as the cause of human disease, behavior, and differences is known as **geneticization** (Shostak, Conrad, and Horwitz, 2008). Geneticization is a form of medicalization.

Genes affect health in two ways: by *causing* "true" genetic diseases and by increasing individuals' *predisposition* to develop disease. True genetic diseases, such as hemophilia, only occur if an individual has a specific gene (Williams and Sternthal, 2010). Although doctors can't cure these diseases, genetic testing does provide affected individuals with the opportunity to learn whether they, their children, or (for pregnant women) their fetuses carry a disease-causing gene.

Individuals who learn through testing that they are not at risk certainly benefit by gaining peace of mind and the ability to plan their futures. Others, though, learn that they are guaranteed to eventually develop a genetic disease, a prospect that some find overwhelming (Marteau and Richards, 1996). It is hard, for example, to imagine how it can help individuals to learn at age 21 that by their forties they will develop Huntington's disease, a devastating

neurological disorder that invariably causes progressive insanity, total disability, and death.

Even these individuals, though, gain some options and benefits. They can commit to living life to the fullest, make wills, or otherwise plan for their futures. They also can choose to avoid becoming pregnant; to abort any fetuses that carry the defect; or to continue a pregnancy to term, knowing that the fetus carries the defect and hoping that this foreknowledge will better prepare them for the birth of an ill or disabled child. Finally, they can try to have a healthy child who is biologically theirs by surgically removing the woman's eggs from her body, mixing them with the man's sperm in the laboratory, having a doctor test the resulting fetuses for genetic defects, and implanting only nondefective fetuses in the woman's uterus. This strategy is rare because the physical, financial, and psychological costs are extremely high, and the odds of success are low.

In most cases, however, instead of directly *causing* disease, genes merely increase the *probability* of disease. In these cases, disease occurs when genes *combine* with environmental factors, in a process known as an **epigenetic effect** (Landecker and Panofsky, 2013). For example, stressful conditions can "turn on" illness-causing genes and weaken the effectiveness of illness-preventing genes, thus increasing risks of depression, heart disease, and other illnesses (Shanahan, Bauldry, and Freeman, 2010). This explains why identical twins may not get the same genetic disease, even though their genes are identical (Roberts et al., 2012).

Genetic testing for this second sort of "genetic" disease can benefit individuals if it motivates those who test positive to take potentially health-preserving actions. For example, women who learn that they carry the BRCA-1 gene, and thus have an increased risk of breast cancer, might choose to adopt a low-fat diet or to have their breasts removed prophylactically.

On the other hand, researchers so far have had little success in treating genetic factors (Wade, 2010). Yet individuals identified through genetic testing as having an illness or being at high risk for illness may lose their jobs, health insurance, or life insurance, even if they are healthy and despite laws banning such discrimination (Council for Responsible Genetics, 2001). Moreover, genetic tests can't tell how soon or how severely an individual with a particular gene will contract a given disease. Increasingly, too, tests are identifying genetic anomalies whose effects, if any, are unknown. As a result, individuals often must make life plans with little knowledge of what their futures (or their fetuses' futures) will be like.

Social Control and the Sick Role

So far, we have looked at how medicine functions as an institution of social control by defining individuals as sick or defective. Medicine can also work as an institution of social control by pressuring individuals to *abandon* sickness, a process first recognized by Talcott Parsons (1951).

Parsons was one of the first and most influential sociologists to recognize that illness is deviance. From his perspective, when people are ill, they can't perform

the social tasks normally expected of them. Workers stay home, homemakers tell their children to make their own meals, students ask to be excused from exams. Because of this, either consciously or unconsciously, people can use illness to evade their social responsibilities. To Parsons, therefore, illness threatened social stability.

Parsons also recognized, however, that allowing some illness can *increase* social stability. Imagine a world in which no one could ever "call in sick." Over time, production levels would fall as individuals, denied needed recuperation time, succumbed to physical ailments. Morale, too, would fall while resentment would rise among those forced to perform their social duties day after day without relief. Illness, then, acts as a kind of pressure valve for society—something we recognize when we speak of taking time off work for "mental health days."

From Parsons's perspective, then, the important question was how did society control illness so that it would increase rather than decrease social stability? His emphasis on social stability reflected his belief in the broad social perspective known as **functionalism.** Underlying functionalism is an image of society as a smoothly working, integrated whole, much like the biological concept of the human body as a homeostatic environment. In this model, social order is maintained because individuals learn to accept society's norms and because society's needs and individuals' needs match closely, making rebellion unnecessary. Within this model, deviance—including illness—is usually considered **dysfunctional** because it threatens to undermine social stability.

Defining the Sick Role Parsons's interest in how society allows illness while minimizing its impact led him to develop the concept of the **sick role.** The sick role refers to social expectations regarding how society should view sick people and how sick people should behave. According to Parsons, the sick role as it currently exists in Western society has four parts. First, the sick person is considered to have a legitimate reason for not fulfilling his or her normal social role. For this reason, we allow people to take time off from work when sick rather than firing them for malingering. Second, sickness is considered beyond individual control, something for which the individual is not held responsible. This is why, according to Parsons, we bring chicken soup to people who have colds rather than jailing them for stupidly exposing themselves to germs. Third, the sick person must recognize that sickness is undesirable and work to get well. So, for example, we sympathize with people who strive to recover from illness and question the motives of those who seem to revel in the attention illness brings them. Finally, the sick person should seek and follow medical advice. Typically, we expect sick people to follow their doctors' recommendations regarding drugs and surgery, and we question the wisdom of those who don't.

Parsons's analysis of the sick role moved the study of illness forward by highlighting the social dimensions of illness, including identifying illness as deviance and doctors as agents of social control (Shilling, 2001). It remains important partly because it was the first truly sociological theory of illness. Parsons's research also has proved important because it stimulated later research on interactions

KEY CONCEPTS

Evaluating the Sick Role Model

Elements of the Sick Role	Model Fits Well	Model Fits Poorly
Legitimate reason for not fulfilling obligations	Appendicitis, cancer	Undiagnosed chronic fatigue
Individual not held responsible	Measles, hemophilia	Herpes, lung cancer
Individual should strive to get well	Tuberculosis, broken leg	Diabetes, epilepsy
Individual should seek medical help	Strep throat, syphilis	"24-hour flu," cold

between ill people and others. In turn, however, that research has illuminated the weaknesses of the sick role model.

Critiquing the Sick Role Model Many recent sociological writings on illness—including this textbook—have adopted a **conflict perspective** rather than a functionalist perspective. Whereas functionalists envision society as a harmonious whole held together largely by socialization, mutual consent, and mutual interests, those who hold a conflict perspective argue that society is held together largely by power and coercion, as dominant groups impose their will on others. Consequently, whereas functionalists view deviance as a dysfunctional element to be controlled, conflict theorists view deviance as a necessary force for social change and as the conscious or unconscious expression of individuals who refuse to conform to an oppressive society. Conflict theorists, therefore, have stressed the need to study not only deviants but also social control agents.

The conflict perspective has helped sociologists to identify the strengths and weaknesses in each of the four elements of the sick role model (see *Key Concepts: Evaluating the Sick Role Model*). That model declares that sick persons are not held responsible for their illnesses. Yet, as we saw earlier in this chapter, society often *does* hold individuals responsible for their illnesses (Freidson, 1970). In addition, ill persons are not always considered to have a legitimate reason for abstaining from their normal social tasks. Certainly, no one expects persons with end-stage cancer to continue working, but what about people with arthritis or those labeled malingerers because they can't obtain a diagnosis after months of pain, increasing disability, and visits to doctors (Glenton, 2003; Ziporyn, 1992)?

Other aspects of the sick role model are equally problematic. The assumption that individuals will attempt to get well fails to recognize that much illness is **chronic** and by definition not likely to improve. Similarly, the assumption that sick people will seek and follow medical advice ignores the many people who lack access to medical care or who can't afford to take time off from work or purchase medications when ill. In addition, it ignores the many persons, especially those with chronic rather than **acute** conditions, who have found mainstream health care of limited benefit and who therefore rely mostly on their own experience and knowledge and that of other nonmedical people. Similarly (and understandably), it could not anticipate the ways the Internet has enabled lay people—both sick and well—to seek health information on their own and, occasionally, to challenge or ignore medical advice as a result (Shilling, 2001). Finally, the concept of a (singular) sick role ignores how gender, ethnicity, age, and social class affect the response to illness and to ill people. For example, women are both *more* likely than men are to seek medical care when they feel ill and *less* likely to have their symptoms taken seriously by doctors (Council on Ethical and Judicial Affairs, 1991; Steingart, 1991).

In sum, the sick role model is based on a series of assumptions about both the nature of society and the nature of illness. In addition, the sick role model confuses the experience of *patienthood* with the experience of *illness* (Conrad, 1987). The sick role model focuses on the interaction between the ill person and the mainstream health care system. Yet interactions with the medical world form only a small part of the experience of living with illness or disability, as the next chapter shows. For these among other reasons, research using Parsons's conception of the sick role has declined over time.

IMPLICATIONS

The language of illness and disease permeates our everyday lives. We routinely talk about living in a "sick" society or about the "disease" of violence infecting our world, offhandedly labeling anyone who behaves in a way we don't understand or don't condone as "sick."

This metaphoric use of language reveals the true nature of illness: behaviors, conditions, or situations that powerful groups find disturbing and believe stem from internal biological or psychological roots. In other times or places, the same behaviors, conditions, or situations might have been ignored, condemned as sins, or labeled crimes. In other words, illness is both a social construction and a moral status.

In many instances, using the language of medicine and placing control in the hands of doctors offers a more humanistic option than the alternatives. Yet, as this chapter has demonstrated, medical social control also carries a price. The same surgical skills and technology for cesarean sections that have saved the lives of so many women and children now endanger the lives of those who have cesarean sections unnecessarily. At the same time, forcing cesarean sections on women potentially threatens women's legal and social status. Similarly, the development of tools for genetic testing has saved many individuals from the anguish of rearing children doomed to die young and painfully but has cost others their jobs or health insurance.

In the same way, then, that automobiles have increased our personal mobility in exchange for higher rates of accidental death and disability, adopting the language of illness and increasing medical social control bring both benefits and

costs. These benefits and costs will need to be weighed carefully as medicine's technological abilities grow.

SUMMARY

1. Throughout history, explanations for illness have commonly blamed ill persons for their illnesses. Such explanations encourage policy makers to ignore how social and environmental factors can foster illness.
2. Illness is a social construction—not something that simply exists in the world as an objective condition, but something that exists *because we have defined it as existing*. To sociologists, the term *illness* refers to biological, psychological, or social conditions that are subjectively defined as undesirable by those who have the power to enforce their definitions.
3. Illness is a moral status and a form of deviance. We label individuals ill when they don't meet our social norms for behavior, ability, or appearance.
4. The medical model of illness assumes that illness is an objective label, applied scientifically, without moral judgment or political bias. That model also assumes that each illness is caused by unique biological forces.
5. The sociological model of illness regards illness as a social construction, a moral category, and a political label, and emphasizes that what is labeled illness changes over time and space.
6. Medicine is an institution of social control. The institution of medicine acts as social control whenever it defines behaviors and conditions as deviant and pressures individuals to seek health care and strive to get well.
7. The process through which a condition or behavior becomes defined as an illness requiring a medical solution is known as medicalization; the reverse process is known as demedicalization. Four groups that often play prominent roles in fights over medicalization are doctors, consumers, the pharmaceutical industry, and managed care organizations.
8. Medicalization can reduce stigma, increase social awareness, and encourage medical research. It can also cause unintended negative consequences, such as increasing the power of doctors at the expense of other social groups, depoliticizing dissent, and justifying medical—and only medical—treatment.
9. Contested illnesses are combinations of distressing and painful symptoms that affected individuals believe constitute an illness even though many doctors disagree. Examples include fibromyalgia and multiple chemical sensitivity.
10. Genetic research and testing have increased the potential for medicine to act as a form of social control, especially because of geneticization: the shift toward assuming that genes cause human disease, behavior, and differences. Genetic testing brings both benefits and problems to individuals and society.

11. The "potentially ill" are individuals identified as having an above average risk of illness, whether because of age, stress level, tobacco use, family history, medical test results, or other factors.
12. The sick role model refers to social expectations regarding how society should view sick people and how sick people should behave. The sick role has four parts. First, sickness is considered beyond individual control. Second, sick persons are considered to have legitimate reasons for not fulfilling their normal social roles. Third, sick persons are expected to recognize that sickness is undesirable and are therefore expected to work to get well. Finally, the sick role assumes that sick persons should seek and follow medical advice.
13. Critics of the sick role model challenge each of the four parts of that model. They note that the model best fits acute rather than chronic illness, and suggest that the model confuses the experience of being a *patient* with the much broader experience of *illness*.

REVIEW QUESTIONS

1. What does it mean to say that illness is a social construction and a moral status?
2. How have explanations for illness changed over time, and how have explanations for illness blamed ill people for their illnesses?
3. What is the medical model of illness, and what are some of the problems with that model?
4. What is medicalization, why does it occur, and what are some of its consequences?
5. Who are the potentially ill? What are the consequences of being labeled potentially ill?
6. How can genetic research and testing lead to social control? What is geneticization?
7. What is the sick role model, and what are some of the problems with that model?

CRITICAL THINKING QUESTIONS

1. Do the four characteristics of the "sick role" apply to persons who have high cholesterol but no known evidence of heart disease? Do they apply to persons who learn that they have a gene that carries with it a high chance of developing breast cancer? Explain your answers.
2. Psychiatrists apply the diagnosis of premenstrual dysphoric distress syndrome to women who each month experience depression and anger before

menstruating. How might women benefit from psychiatry's decision to label this condition a disease? How might women be harmed by it?

3. Researchers have identified a gene that, if present, indicates that a person has a significant risk of developing Alzheimer's disease at a young age. Alzheimer's disease causes people to gradually lose their memory and mental abilities. Imagine that you are a family practice doctor. Explain to a concerned patient two arguments for and two arguments against getting tested for the gene.

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