ll

7, we examine parallel questions regarding mental illness. This
what people mean when we say something is a mental illness.
t how and why mental illness is distributed among social groups;
ociety historically has treated persons with mental illnesses; and
experience mental illness, from initial symptoms, to treatment,
fter treatment.

CHAPTER

5

The Social Meanings of Illness

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In 2003, the pharmaceutical company GlaxoSmithKline began a campaign to "alert" the public of the dangers of restless legs syndrome (RLS) (Woloshin and Schwartz, 2006). Television, Internet, and print advertisements asked consumers:

- *Do you feel a strong desire to move your legs from time to time, often when they make you uncomfortable?*
- *Do those sensations in your legs occur or get stronger when you are inactive?*
- *Does moving around or stretching help ease those uncomfortable sensations in your legs?*
- *Do those uncomfortable sensations feel their worst at night?*

Anyone who answered "yes" was warned that they might suffer from RLS and encouraged to seek medical treatment—specifically, the drug ropinirole, manufactured by GlaxoSmithKline.

Two months after these ads first appeared, a slew of articles and television news reports appeared in the media warning that one of every ten adults suffered from RLS and should seek treatment—all based on a press release from GlaxoSmithKline reporting results from one unpublished study it had funded (Woloshin and Schwartz, 2006). Many of the media reports recommended that individuals with restless legs seek information from the nonprofit Restless Legs Foundation; none mentioned that the foundation is primarily funded by GlaxoSmithKline (Woloshin and Schwartz, 2006).

More recently, Mirapex, a similar drug (with similar side effects), has also been touted for treating RLS by its manufacturer, Boehringer Ingelheim Pharmaceuticals. According to the drug's website (MirapexER.com):

> ***MIRAPEX may cause you to fall asleep without warning during daily activities, including talking, eating, and driving, which may result in accidents****.... When taking MIRAPEX-ER or MIRAPEX, hallucinations (unreal visions, sounds or sensations) may occur and you may sometimes feel dizzy, nauseated, faint or sweaty when you sit up or stand quickly ... Some patients have reported problems, such as gambling, compulsive eating, compulsive buying, and increased sex drive. (Emphasis in original.)*

Does this seem like a reasonable treatment for restless legs—especially when the restlessness can be "cured" by moving around or stretching? Is there anyone whose legs don't feel restless occasionally? Can restless legs really be a disease, in and of themselves?

According to many doctors, yes. 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 illness—two opposing ways of thinking about what illness 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 experienced and feared illness. To relieve their anxiety and make the world seem less capricious and 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).

The history of leprosy vividly illustrates this process. Both the Jewish and Christian Bibles describe leprosy as punishment for an individual's sin. Biblical explanations for leprosy, coupled perhaps with some awareness that leprosy was contagious, led Western societies for centuries to isolate affected individuals. Throughout the Middle Ages, Christian society required anyone diagnosed with leprosy to participate in a special mass for the dead, known as the lepers' mass. After the mass, 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 "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. As she writes, "Illness cannot exist in a body that has harmonious thoughts.... You cannot 'catch' anything unless you think you can, and thinking you can is inviting it to you with your thought" (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 do not 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 etiology*.	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—those in public health, pediatrics, and family practice are especially likely to question it—and is not rejected by all sociologists, but it is the dominant conception of illness in the medical world. The **sociological model of illness** summarizes critical sociologists' retort to the medical model of illness. This sociological model reflects sociologists' view of how the world currently operates, not how it ideally should operate. *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; that menopause is a "hormone deficiency disease" that, among other things, impairs the body's normal ability to regenerate bone; and that 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 U.S. 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 (Martin, 1987). 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 do not 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, U.S. 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 **etiology**, or 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. The doctrine of unique etiology 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, from the sociological 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.

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. 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, as social conditions have changed, activities formerly considered sins or crimes, such as masturbation, homosexual activity, or heavy drinking,

have become defined as illnesses. The same has happened to various natural conditions and processes, such as uncircumcised penises, male balding, aging, and pregnancy (Armstrong, 2000; Conrad, 2007; 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 3% 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) Neither doctors, consumer groups, nor pharmaceutical companies have sufficient influence to medicalize a condition on their own. Instead, successful medicalization depends on the interwoven interests and activities of these and other 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 children with ADHD if they have no signs of brain damage; are older than age 5; and are overactive, impulsive, or easily distractible (Conrad 2007; Diller, 1998). Before the 1960s, however, doctors rarely assigned the diagnosis because it could only be treated with dangerous, addictive amphetamines.

Doctors proved far more willing to diagnose ADHD, however, once the amphetamine Ritalin (methylphenidate) appeared on the market in the 1960s (Conrad, 2007). Ritalin has fewer short-term side effects than other amphetamines have and, in the short term, improves the ability to concentrate, reduces the tendency to act impulsively, and increases willingness to accept discipline among most who use it (regardless of their mental health). Yet Ritalin is far from a panacea. Chemically, it acts much like cocaine (Vastag, 2001). Its immediate side effects can include addiction, loss of appetite, sleep deprivation, headache, and stomachache. Its long-term side effects may include cancer (Davis, 2007), and its long-term benefits seem minor at best: The little available research suggests that it does not improve users' chances of graduating from high school, holding a job, refraining from illicit drugs, or avoiding trouble with the law (Diller, 1998). Nevertheless, a massive (and ongoing) media campaign by pharmaceutical manufacturers succeeded in "selling" ADHD to both doctors and the public.

Pediatricians proved a ready audience for this marketing campaign, which promised a way to boost their flagging income and prestige. This market further increased in 1987, when the diagnosis was expanded to include adults as well as children and to include girls who daydream as well as boys who "act out" (Mayes, Bagwell, and Erkulwater, 2009).

Like pediatricians, many teachers readily adopted the concept of ADHD, if for different reasons (Diller, 1998). Faced with cuts in staffing and larger classes at the same time that school boards began placing an increased emphasis on testing and competition at earlier and earlier ages, many teachers began looking with favor on drugs that made their students more manageable. In addition, diagnosing a student with ADHD shifts blame for poor student performance from teacher to student. Not surprisingly, the suggestion to place a child on Ritalin now often comes initially from a teacher (Diller, 1998).

Parents, too, often are relieved to find an explanation other than poor parenting for their children's behavioral or educational problems. In addition, parents hope to remove blame from their children, reduce the chances of legal sanctions against their children, and stimulate research on treatment. Finally, parents hope that having their children diagnosed with a disability—ADHD—will give their children the protections built into federal antidiscrimination statutes: access to special educational services plus protection against suspension or expulsion for any disciplinary problems potentially related to ADHD (Conrad 2007; Diller, 1998). For these reasons, wealthy white children are much more often diagnosed with ADHD than are poor nonwhite children. Currently, 6% of U.S. teenagers are taking Ritalin or related drugs—twice as many as were doing so in 1999 (Gu, Dillon, and Burt, 2010).

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, U.S. 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' rights to health is more important than women's rights 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* (on page 112) explores how the growing acceptance of the idea of "fetal rights" is affecting pregnant women who use illicit drugs.

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 depends 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 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

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.

Since 1990, about 300 pregnant women—most of them drug users, most nonwhite, and almost all poor—have been arrested or involuntarily hospitalized to force them to follow medical advice (Johnson, 2004). 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.

Opponents of forced intervention further argue that doctors cannot necessarily make better decisions than mothers do because they cannot understand fully the circumstances in which mothers make those decisions. For example, many women continue to use drugs during pregnancy only because they cannot obtain access to treatment programs, which usually are expensive, have long waiting periods, and will not accept pregnant women. In addition, to enter a treatment program, women almost always have to leave their existing children with relatives or in foster care. Yet leaving children with relatives or in foster care may place children at greater risk than having a drug-using mother, given that women often begin drug use because of problems in their families and that foster care sometimes results in physical, sexual, or mental abuse.

Opponents of forced intervention also argue that the benefits of intervention do not justify the costs to women's civil liberties (Roth, 2003; Toscano, 2005). Once we decide that women must put their fetuses' welfare above their own, where do we draw the line? Given that tobacco poses a far greater threat to fetuses than does any illicit drug, do we prosecute or hospitalize women who continue to smoke during pregnancy? What about women who continue to eat junk food rather than eating healthy meals?

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 do not 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. Yet no court has ever charged a man with fetal abuse. These facts have led some to question whether the concept of fetal rights has emerged not to protect fetuses or children but to restrict women's lives.

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?

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 cannot 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. For example, no single gene causes Alzheimer's disease, breast cancer, heart disease, or diabetes. These diseases do occur more often in some families than others, which suggests some sort of genetic predisposition. However, research increasingly suggests that genes "express" themselves differently in different environments. For example, stressful conditions can "turn on" certain 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).

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 cannot 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.

The rise in genetic research and testing raises the potential for genetic controls far beyond anything now available. Relatively few persons oppose programs to prevent the birth of children with Tay-Sachs disease, which causes initially healthy children to deteriorate totally—both mentally and physically—and to die between the ages of 3 and 5 years. Yet many geneticists hope in the future to expand vastly the number of conditions for which genetic tests are run. Already many fetuses are aborted simply because they are female, as Chapter 4 described (Lawn, Cousens, and Zupan, 2005; Zhu et al., 2009). Would the world really be a better place if we could abort fetuses because they would be mentally slow or predisposed toward fatness?

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 cannot 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 do not.

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, 2002). It remains important

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

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 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 cannot 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 cannot 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, 2002). 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' 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 do not 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: (1) sickness is considered beyond individual control, (2) sick persons are considered to have legitimate reasons for not fulfilling their normal social roles, (3) sick persons must recognize that sickness is undesirable and work to get well, and (4) sick persons should seek and follow medical advice.
13. Critics of the sick role model challenge each of the four parts of that model, 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.