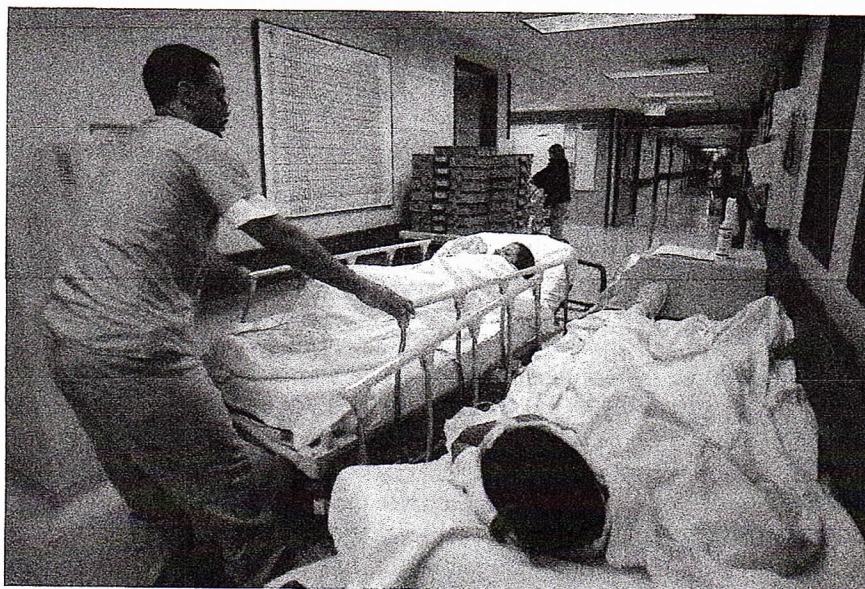# CHAPTER I | THE SOCIOLOGY OF HEALTH, ILLNESS, AND HEALTH CARE

Tony Gutierrez/AP Photo.

In 1996, at the age of 46, my friend Lara learned she had breast cancer. Once her doctor concluded from Lara's mammogram (a form of X-ray) that a lump in her breast seemed cancerous, events followed in quick succession. The next day, a surgeon removed a piece of the suspicious lump for testing. A few days later, Lara learned that the lump was cancerous. That week, she got her affairs in order and signed a "living will" specifying the circumstances in which she would want all treatment stopped and a "medical power of attorney" giving me legal authority to make medical decisions for her if she physically could not do so herself. These two documents, she hoped, would protect her from aggressive medical treatments that might prolong her suffering without improving her quality of life or chances of survival.

Two weeks after the initial tests, her surgeon removed the rest of the lump as well as the lymph nodes under her arm (where breast cancer most often spreads). The surgery went well, but the subsequent laboratory tests showed that the cancer indeed had spread to some of Lara's lymph nodes.

Yet in many ways, Lara was fortunate. Her breast cancer was detected at a relatively early stage, giving her a good chance of surviving. Although she had no husband or children to turn to, her friends proved uniformly supportive. She received health insurance through her employer and had no fears of losing either her job or her insurance.

Nevertheless, cancer changed Lara's life irrevocably, making it, at times, a nightmare. Having breast cancer shook Lara's faith in her body and changed her sense of her physical self. At the same time, her illness threatened her relationships with others. Despite the supportive responses she received from friends and co-workers, she feared, nevertheless, that they would drift away as her illness continued or that she would chase them away with her all-too-reasonable complaints, worries, and needs.

Although she had far better health insurance than many Americans have, her debts for items not covered by insurance mounted. In addition, she had to spend hours fighting her insurance company to obtain relaxation training and expensive but effective antinausea drugs to cope with chemotherapy's side effects. Yet the chemotherapy made her so ill she often found it difficult to function, let alone fight her insurance company. In addition, chemotherapy proved so toxic that it damaged her veins with each painful intravenous treatment. As a result, her doctors suggested inserting a semipermanent plastic tube into her chest wall so they could instead administer the chemotherapy through the tube. Although doing so would have reduced her pain, Lara rejected the suggestion because she felt that, with this sign of her illness physically attached to her body, cancer would become integral to her very self rather than merely one part of her life.

After a year of surgery, chemotherapy, and radiation, Lara's physical traumas ended, although it took another year before she regained her former energy. She remains free of any signs of cancer.

THE SOCIOLOGY OF HEALTH, ILLNESS, AND HEALTH CARE: AN OVERVIEW

Lara's story demonstrates the diverse ways that illness affects individuals' lives. It also demonstrates the diverse range of topics that sociologists of health, illness, and health care can study.

First, sociologists can study how social forces promote health and illness and why some social groups suffer more illness than others do. For example, researchers have explored whether working conditions in U.S. factories help explain why poorer Americans get certain cancers more often than do wealthier Americans. Similarly, sociologists can study how historical changes in social life can explain changes in patterns of illness. To understand why rates of breast cancer have increased, some researchers have studied the possible impact of women's changing social roles, some have studied environmental pollution, and some have studied American's increased consumption of meat.

Second, instead of studying broad patterns of illness, sociologists can study the experiences of those, like Lara, who live with illness on a day-to-day basis—exploring, for example, how illness affects individuals' sense of identity, relationships with family, or ideas about what causes illness. Similarly, sociologists can study the experiences of health care providers. Some sociologists have analyzed how doctors' status and power has shifted over time, and others have investigated how power affects interactions between doctors, nurses, and other health care workers. Still others have examined interactions between health care workers and patients, asking, for example, how doctors maintain control in discussions with patients or whether doctors treat male and female patients differently.

Finally, sociologists can analyze the health care system as a whole. Sociologists have examined how health care systems have developed, compared the strengths and weaknesses of different systems, and explored how systems can be improved. For example, some have studied how U.S. health insurance companies can make it difficult for people like Lara to get needed care, explored why European countries do better than the United States at providing health care to all who need it, and examined whether European health care policies could work in the United States.

The topics researched by sociologists of health, illness, and health care overlap in many ways with those studied by health psychologists, medical anthropologists, public health workers, and others. What most clearly differentiates sociologists from these other researchers is the **sociological perspective**. The next section describes that perspective. The rest of this chapter provides an overview of the book, explains the types of sources used in researching it, and offers some pointers for evaluating those and other sources.

THE SOCIOLOGICAL PERSPECTIVE

Using a sociological perspective means focusing on social patterns rather than on individual behaviors. Whereas a psychologist might help a battered wife develop a greater sense of her own self-worth so she might eventually leave her abusive husband, a sociologist likely would consider therapy a useful but inefficient means of addressing the root causes of wife abuse. Most battered wives, after all, do not have

the time, money, or freedom to get help from psychologists. Moreover, even when therapy helps, it takes place only after the women have experienced physical and emotional damage. The sociologist would not deny that individual personalities play a role in wife battering, but would find it more useful to explore whether social forces can explain why wife battering is much more common than husband battering, or why battered wives so often remain with abusive husbands. Consequently, whereas the psychologist hopes to enable the individual battered wife eventually to leave her husband, the sociologist hopes to uncover the knowledge needed by legislators, social workers, activists, and others to prevent wife abuse in the first place.

As this example demonstrates, using the sociological perspective means framing problems as *public issues*, rather than simply *personal troubles*. According to C. Wright Mills (1959: 8–9), the sociologist who first drew attention to this dichotomy:

> [*Personal*] *troubles* occur within the character of the individual and within the range of his immediate relations with others; they have to do with his self and with those limited areas of social life of which he is directly and personally aware. Accordingly, the statements and the resolutions of troubles properly lie within the individual as a biographical entity and within the scope of his immediate milieu.... [In contrast, *public*] *issues* have to do with matters that transcend these local environments of the individual and the range of his inner life. They have to do with the organization of many such milieux into the institutions of an historical society as a whole.

For example, whenever a child dies from leukemia, it is a tragedy and a personal trouble for the child's family. If, on the other hand, several children in a neighborhood die of leukemia during the same year, it could suggest a broader public issue such as toxic contamination of the neighborhood water system. A sociologist would be likely to look for such a pattern, and to explore why, for example, polluting industries are more likely to build factories in poor, minority neighborhoods than in affluent, white neighborhoods. The sociological perspective, then, departs radically from the popular American belief that individuals create their own fates and that anyone can succeed if he or she tries hard enough.

The sociological perspective can help us identify critical research questions that might otherwise go unasked. For example, in the book *Forgive and Remember: Managing Medical Failure*, sociologist Charles Bosk (2003: 62–63) described a situation he observed one day on "rounds," the time each day when recently graduated doctors (known as residents) and more senior doctors jointly examine the patients on a service, or ward:

> Dr. Arthur [the senior doctor] was examining the incision [surgical cut] of Mrs. Anders, a young woman who had just received her second mastectomy. After reassuring her that everything was fine, everyone left her room. We walked a bit down the hall and Arthur exploded: "That wound looks like a walking piece of dogshit. We don't close wounds with continuous suture on this service. We worked for hours giving this lady the best possible operation and then you screw it up on the closure. That's not how we close wounds on this service, do you understand? These are the fine points that separate good surgeons from butchers, and that's what you are here to learn. I never want to see another wound closed like that. Never!" Arthur then was silent, he walked a few feet, and then he began speaking again: "I don't give a shit how Dr. Henry [another senior

doctor] does it on the Charlie Service or how Dr. Gray does it on Dogface; when you're on my service, you'll do it the way I want."

Dr. Arthur and the residents he supervised undoubtedly viewed this situation as a personal trouble, requiring a personal solution—the residents seeking to appease Dr. Arthur, and Dr. Arthur seeking to intimidate and shame the residents into doing things the way he considered best. Similarly, depending on their viewpoint, most nonsociological observers probably would view this as a story about either careless residents or an autocratic senior doctor. Sociologists, however, would first ask whether residents and senior doctors typically interact like this. If they do, sociologists then would look for the social patterns underlying such interactions, rather than focusing on the personalities of these particular individuals. So, for example, based on his observations in this and other cases, Bosk discovered that cultural expectations within the medical world regarding authority, medical errors, and the importance of personal, surgical experience gave Dr. Arthur and the other supervising doctors power and allowed them to humiliate residents publicly and to set policies based more on personal preferences than on scientific data.

Whereas Charles Bosk studied relations among doctors, sociologist Kristin Barker (2008) looked at interactions among individuals who believe they have fibromyalgia. Fibromyalgia is a relatively new disease label given to individuals who experience a wide variety of disabling symptoms. Because there are no biological tests for fibromyalgia, many doctors doubt whether it really is a disease.

To explore what it means to live with fibromyalgia, Barker looked at posts to an online fibromyalgia support group. In a typical post, a woman named Sarah wrote:

> My new doctor appointment was today. Was not good!! First of all she is 4 months out of medical school. She looked over my chart and immediately wanted to change all medications that I am taking…. [Then she said,] "Now about your fibromyalgia, I will not prescribe pain killers for fibro." I sat there with my mouth open. She went on to tell me the fresh-out-of-med-school approach to fibro is exercise, diet. I said what about the pain? She proceeded to tell me the pain was "ALL IN MY HEAD, THERE IS NO PAIN, YOU JUST IMAGINE THERE IS." My first thought was [to] jump up out of this chair and slap the B——!! Instead I said "You are an idiot"!! Then I walked out.

Depending on one's perspective, Sarah's post either suggests an ignorant and insensitive doctor or a rude patient with delusions of grandeur. To a sociologist, however, this post raises several interesting questions that go beyond these individuals to look at the surrounding culture and social structure. Barker, for example, explored how the online support group increased the power of patients relative to doctors, how the broader social structure nevertheless allowed doctors to control most interactions with patients, and how these struggles between doctors and patients reflected wider social questions regarding what constitutes an illness and how illness definitions come to be accepted or rejected.

In sum, the sociological perspective shifts our focus from individuals to social groups and institutions. One effect of this shift is to highlight the role of power. *Power* refers to the ability to get others to do what one wants, whether willingly or unwillingly. Power is what allowed Dr. Arthur to treat his residents so rudely and what allowed Sarah to reject her doctor's advice. Because sociologists study groups

rather than individuals, the sociological analysis of power focuses on why some social groups have more power than others, how groups use their power, and the consequences of **differential** (i.e., unequal) access to power, rather than on how specific individuals get or use power. For example, sociologists have examined why doctors as a group proved more successful than nurses did in obtaining the power to control their working conditions and how recent changes in the health care system have limited doctors' power. Similarly, sociologists have explored how *lack* of power exposes poor persons and disadvantaged minorities to conditions that promote ill health, while limiting their access to health care.

A CRITICAL APPROACH

Although the concept of power underlies the sociological perspective, some sociologists do not emphasize power in their research and writing. Instead, they essentially take for granted the way power is distributed in our society, examining the current system without questioning why it is this way or how it might be changed. For example, some sociologists have investigated whether lower-class persons are more likely than upper-class persons to suffer mental illness without first questioning whether definitions of mental illness might reflect upper-class views regarding socially unacceptable behaviors.

Those sociologists, on the other hand, who do not take for granted existing power relationships and who instead focus on the sources, nature, and consequences of power relationships can be said to use a critical approach. Critical sociologists recognize that, regardless of how power is measured, men typically have more power than do women, adults more power than do children, whites more power than do African Americans, heterosexuals more power than do gays and lesbians, and so on. Critical sociologists who study health, illness, and health care have raised such questions as how this differential access to power affects the likelihood that members of a social group will live in healthy conditions and have access to quality health care.

Critical sociologists also emphasize how social institutions and popular beliefs can reflect or reinforce the existing distribution of power. For example, many researchers who study the U.S. health care system have looked simply for ways to improve access to care or quality of care within that system, such as offering poor people subsidized health insurance or providing financial incentives to doctors who practice in low-income neighborhoods. Those who use a critical approach have asked instead whether we could provide better care to more people if we changed the basic structure of the system, such as by removing the profit motive from health care to reduce the costs of care for everyone.

Similarly, critical sociologists have drawn attention to how doctors' power and authority enable them to frame our ideas about health, illness, and health care. Most basically, these sociologists have questioned the very terms *health, illness,* and *disability* and have explored whether such terms reflect social values more than they reflect objectively measurable physical characteristics.

In any sociological field, therefore, those who adopt a critical approach will ask quite different research questions than will others. Within the sociology of health, illness, and health care, this approach translates largely to whether sociologists limit their research to questions about social life that doctors consider useful—a strategy

referred to as **sociology *in* medicine**—or design their research to answer questions of interest to sociologists in general—a strategy referred to as the **sociology *of* medicine** (Straus, 1957). Research using the latter strategy often challenges both medical views of the world and existing power relationships within health care.

To understand the difference between sociology *in* medicine and sociology *of* medicine, consider the sociological literature on patients who do not follow their doctors' advice. Because doctors typically define such patients as problems, over the years many sociologists (practicing sociology *in* medicine) have adopted this view and so have sought to determine how to get patients to comply with medical advice. In contrast, sociologists *of* medicine have looked at the issue of compliance through patients' eyes. As a result, they have learned that patients sometimes ignore medical advice not out of stubbornness or foolishness but because their doctors have not clearly explained how or why to follow the prescribed regimens. In other circumstances, patients have ignored medical advice because the emotional or financial costs of following that advice seem to outweigh the potential health benefits. Similarly, whereas those practicing sociology in medicine have studied various aspects of the experience of *patienthood*, those practicing sociology *of* medicine instead have studied the broader experience of *illness*, which includes but is not limited to the experience of patienthood. The growing emphasis on sociology of medicine and on the critical approach has led to a proliferation of research on the many ways illness affects everyday life and on how ill individuals, their families, and their friends respond to illness.

CHAPTER ORGANIZATION

This textbook demonstrates the breadth of topics included in the sociology of health, illness, and health care. The text covers both micro-level issues (those occurring at the level of interactions among individuals and small groups) and macro-level issues (those occurring at the level of the society as a whole). Part One discusses the role social factors play in fostering illness and in determining which social groups experience which illnesses. Chapter 2 describes the major causes of preventable deaths in the United States and how they have changed over time, including both long-standing problems, such as cancer, and emerging problems such as severe acute respiratory syndrome (SARS) and drug-resistant tuberculosis. This chapter demonstrates how social as well as biological factors affect health and illness. Building on this basis, Chapter 3 describes how age, sex, gender, social class, race, and ethnicity affect which Americans get ill with which illnesses. Finally, Chapter 4 explores the nature and sources of illness in the poorer countries of Asia, Africa, and Latin America.

Part Two analyzes the meaning and experience of illness and disability in the United States. Chapter 5 explores what people mean when they label something an illness, as well as how people explain why illness occurs. This chapter also looks at the social consequences of defining behaviors and conditions as illnesses. With this as a basis, Chapter 6 first explores the meaning of disability, and then offers a sociological overview of the experience of living with chronic pain, chronic illness, or disability, including the experience of seeking care from either medical doctors or