1 Introduction

I used to work on the 19th floor of a building overlooking the Hudson River in upper Manhattan. I was often fascinated by the ever-shifting traffic patterns down below on the busy six-lane Henry Hudson Parkway. A rush-hour accident could bring three lanes of traffic to a halt when a knot of cars backed up behind police cars and ambulances. Unobstructed traffic going the other way would soon jam up, too, as drivers slowed their vehicles and craned their necks to see what had happened. The delays took longer to clear than to form, sometimes persisting an hour or more after an accident had been removed.

This memory of my traffic-observing days came back to me when I thought about how to explain the difference between a "group of individuals" and a "population." I remembered drivers in their vehicles down below, each making decisions about how fast and how close to follow the car in front, looking for a quick exit and trying to catch a glimpse of torn metal or bodies. The sum of the eagerness, frustration, and curiosity of this group of commuters was more than a series of momentary glances or flashes of brake lights. Individual drivers' thoughts and acts, added together over time, turned into traffic delays that themselves *created* additional glances and brake lights and sometimes even new accidents. Individual cars passed through, but their movement created traffic patterns that endured. Drivers and traffic followed related but different rules, and neither was reducible to the other.

I. Patterns of Disease and Patterns of Culture

Human reactions to disease also create patterns. Imagine a Peruvian fisherman who ate contaminated shellfish in January 1991, contracted cholera, and died. Individuals in his town gathered to wash the body and to mourn the deceased. They drank and ate together, finding companionship. But some of the participants were exposed to cholera in the shared water. Their travels after the funeral changed the likelihood of exposure for many others, and the number of people they saw and the

activities they undertook further influenced the spread of the disease. In April 1991, cholera broke out in mountain villages when recently infected but still asymptomatic workers from the coast traveled home to celebrate Easter. Their behavior as a group created patterns that could not be deduced from the sum of their individual actions. Individual decisions and epidemic patterns are partly separable but clearly linked.

Closely related to the kinds of individual decisions and behavioral patterns we have been talking about, culture also influences human health and the patterning of disease. Our total way of life (work, food, activities), combined with our learned behavior (including knowledge, lies, and misunderstandings), our techniques for adjusting to the environment, and our ways of feeling and believing all influence our susceptibility to illness. Some argue that they become written into our genes, and they certainly become written into our bone structure and musculature. Migrant farm workers, for example, have different diseases than coal miners, and Central American men who wield machetes all day for their whole lives often develop one arm longer than the other.

Bodies and pathogens are determined not just by physical actions but by beliefs about what is important. Beliefs are powerful motivators. The disproportionate mortality among infant girls in some South Asian nations is partly an outcome of cultural preferences for sons over daughters (Sen 1992). In cultures where injections are thought to be stronger than pills, a town might have several specialized injectionists on call to administer to the sick (Reeler 2000). And diagnostic preferences among physicians in different countries are responsible for some of the national differences in rates of depression, low blood pressure, and infant mortality (Payer 1988). Rates of morbidity (sickness) and mortality (death) are determined in part by cultural scripts that specify how, where, and when to behave in certain ways.

The influence of culture can be seen in how people care for symptoms before they receive a diagnosis. Groups vary in their willingness to undertake preventive measures; they vary in how they perceive and classify symptoms. Across the world, people employ diverse markers to decide who will be labeled disease-ridden or contagious; they differentially rank which diseases are seen as important or unimportant. What treatment, if any, sick people choose, whether they take medication, how they manipulate their diseases for other ends, whether therapy succeeds – culture influences diseases through these pathways as well as through the patterned work of nerves, muscles, and bones. Whether one thinks of body disorder as influenced by Chinese energy meridians, Tibetan pulses, Latin American hot/cold states, or immune system function is largely a product of where one is and with whom one interacts. Available healing traditions range from the grand and ancient ones of Chinese acupuncture

or Greek humoral pathology of blood and bile to more recent precepts of homeopathy or chiropractic in North America. Biomedicine is one particularly widespread form of therapy in the world today, which bases its treatments on a combination of empirical tests and custom. It is a cultural system like the others, often competing with them, less frequently collaborating.

Yet cultural meanings are also local and contested. This aspect of culture highlights its dynamic, changing quality and gives weight to forces of change and interaction. From this perspective, culture is constantly being transformed. People within groups may be aware of group norms, but those norms themselves change over time, and people choose to reject the norms or manipulate their behavior within them. For example, human beauty standards, and their health-related consequences, change dramatically over time. The corset allowed one set of health problems (muscle atrophy, liver damage) to emerge, whereas a century later breast augmentation caused others (pain, scar tissue, implant rupture). Food preferences, time pressure, and large-scale industrial meal production combine to create a new epidemic of obesity based on "fast food" and sedentism.

Cultural categories not only change through time, but they also can be differentially manipulated by people interacting within a web of relationships embedded in a larger material and social context. In that context, individuals pick and choose different aspects of culture to form their own identities; they manipulate cultural symbols, transform them, and combine them in unexpected ways that can protect health or promote disease. Statements about "culture," whether made by local "natives" or well-intentioned "outsiders," need to be evaluated not only in terms of their content but also in terms of the purposes of those who assert them.

This book describes the connections between patterns of disease and patterns of culture to highlight the creative interdisciplinary ways by which researchers are confronting today's vexing and complex health challenges. By creating conversations across disciplines, students and practicing professionals are better able to collaborate across disciplines, design successful health interventions, and communicate more broadly and clearly with both professional and popular audiences (Dunn 1979). These processes will help develop more appropriate health policies, deepen understandings of disease causation and treatment, and create more effective actions to enhance health and prevent disease.

II. Epidemiology and Medical Anthropology

Both epidemiology and medical anthropology are scientific disciplines that search for patterns of disease and behavior. They both have humanity

at their core. The disciplines are separated by history and tradition – epidemiology tends to be statistical and quantitative, anthropology textual and qualitative, but this book brings them together. My vision of an integrated and interdisciplinary dialogue has been created, and is shared, by many like-minded anthropologists and epidemiologists who appreciate the value of collaborating on a common project. (See, for example, Fleck and Ianni 1958, Dunn and Janes 1986, Frankel et al. 1991, Hahn 1995, Inhorn 1995, and Dressler et al. 1997.)

Epidemiology is derived from the Greek *epi* meaning "upon," *demos* meaning "the populace or common people," and *logos* meaning "word." Epidemiology is literally the study of what is upon the populace, referring specifically to the burden of disease. Because epidemics were once the most obviously burdensome of diseases, the two words overlap. But epidemiology is more than the study of epidemics. It is more conventionally defined as the study of the distribution and determinants of disease in human populations. Members of this discipline produce descriptions of health and disease patterns and trends rather than laboratory experiments or case reports. They focus on populations using statistics and probabilities.

A significant part of the practice of epidemiology consists of trying to separate out the patterns of disease and exposure from patterns caused by data collection methods. Epidemiologic data can be subject to systematic error from influences such as fallible memory or faulty record-keeping. Such data also can systematically differ from true values based on age or sex of interviewer, sensitivity of behavior, or time since event. Epidemiologists try to minimize the likelihood that they will confuse patterns of systematic error with patterns generated from the health-related effects of age, diet, wealth, exercise, occupation, or other so-called risk factors that get such attention in the press.

Epidemiologists describe disease patterns using data about the past or data collected from the present into the future. They use *prospective* study designs to follow a group of people over time, tracking their exposure to potential causes of disease and observing whether rates of disease differ according to whether or not a person was exposed. For example, a study might track oral contraceptive use in a group of nurses over 15 years and conclude that their likelihood of getting breast cancer was influenced by whether they took birth control pills. *Retrospective* studies look at records or reports of people who already have a disease, comparing the proportion of people who do not have a prior history of a particular behavior or exposure with the proportion of those who do. For example, researchers might begin with a group of adults with lung cancer and compare the proportion of smokers and nonsmokers. Epidemiologists make these types of

comparisons to investigate the factors that increase (or reduce) people's probability of acquiring a disease.

When epidemiologists work across different countries and within diverse groups in a single country they come inevitably into contact with cultural difference. It is tempting to think that culture[1] can serve as a new explanatory variable, capable of predicting and explaining significant portions of observed variation in behavior and disease. That culture matters but should not be treated as a single variable is an important premise of this volume.

I argue throughout this book that epidemiologists should devote the same attention to culture that they have given to "social" factors over the past few decades. Social epidemiology is the branch of epidemiology that most directly attends to the health-related effects of social organization, and in many ways it most closely approximates the goals I outline in this book. Social epidemiologists look at the health effects of income, wealth, job stress, class, social support, inequality, and occupation. They define societies as groups of people who interact in specific ways, live in specifiable places, and share some common set of values. My treatment of "culture" parallels how epidemiologists use the word "society." But it leads to closer scrutiny of the unexamined assumptions behind epidemiologic variables and measurements, takes more account of international variability, and attends more often to the influence of categories and perceptions.

The concept of a *cultural epidemiology* focused on the health-related effects of behavior and belief also merits attention. This book emphasizes culture more than society because I want to argue for a complementary alternative to social epidemiology, one that focuses attention on disease classification, meaning, risk, and behavior in addition to social variables such as income, marital status, and occupation. Culture is less widely appreciated in the epidemiological worldview, but it has explanatory power and effectiveness comparable to the concept of society. Culture can be a slippery concept; it both contains and describes many meanings. For

[1] The concept of *culture* has a long history, and the word itself has a long list of definitions. The anthropologist Clyde Kluckhohn (1949) provides several competing definitions, including "the total way of life of a people," "learned behavior," "a set of techniques for adjusting both to the external environment and to other people," and "a way of thinking, feeling, and believing." Clifford Geertz has defined culture as a set of symbols that are organized into systems of meaning. He wrote, "Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning" (1973:5). One can distinguish between culture as a set of patterns *for* behavior and the patterns *of* behavior that emerge from a group following a set of cultural rules over time, akin to the traffic patterns I describe at the beginning of this chapter.

research or policy purposes it is sometimes better unpacked and transformed into smaller, better-defined, operational categories. It is nevertheless useful as an orienting framework, and this book will show how this can be done and why it matters.

Like epidemiologists, medical anthropologists also search for patterns, but they find them in culturally patterned responses to disease. Medical anthropologists study the afflictions facing humankind and how human groups organize themselves to treat and explain the causes of suffering. They analyze the understanding and interpretation of healing, illness, and health, as well as the environmental, biological, behavioral, and cultural determinants of disease. To do so, they use a variety of methods, including long- and short-term fieldwork, structured observations, open-ended interviews, and a variety of survey and group interview techniques.

Both epidemiology and medical anthropology have domestic and international applications. Traditionally, epidemiologists tended to study problems within their national borders, whereas medical anthropologists tended to study foreign cultures. But diseases rarely respect human borders, and human beings often cross them. As epidemiologists increasingly examine patterns of diseases across borders, and as medical anthropologists increasingly look at cultural diversity within borders, their geographic scopes have converged. This book therefore will refer to a broad range of studies undertaken both within the United States and worldwide (and see Coimbra and Trostle 2004 for related work about Latin America).

Neither anthropology nor epidemiology is a monolithic discipline. Each comprises multiple theoretical orientations using a varied but limited set of common research methods. Some medical anthropologists emphasize the interpretation of suffering; others assess physical and social adaptations to high altitude. Some epidemiologists study disease strains in a single town, others the movement of diseases across the globe. Thus some themes within each discipline may lend themselves more readily to collaboration.

Although my accent in this book is on collaboration between the disciplines, I also emphasize the unique and separate contributions of each one. I do this for three reasons: first, the history and nature of interdisciplinary collaboration between anthropology and epidemiology are still relatively unexplored. It is therefore important to highlight what methods and theories each discipline has contributed to prior joint studies. Second, when interdisciplinary collaboration is effective but still marginal, a focus on disciplines makes it easier to explore the separate contributions of each side toward helping or hindering that collaboration. Third, I argue that even though medical anthropology and epidemiology do have

many "joint ventures," training programs and research incentives do not yet push the fields together as often as they could and should. In the absence of a long interdisciplinary tradition, I hope that my examples and claims for the relevance of one discipline might spark enthusiasm among adherents of the other.

For example, from an anthropological perspective, epidemiology is one particular system of knowledge production; it is, in short, a culture. By analyzing the categories and assumptions of epidemiologists, anthropologists see that epidemiologists work within a system of rules and expectations just as do acupuncturists, chiropractors, or shamans. Anthropologists use the term "reflexivity" to refer to their efforts to understand their own assumptions, biases, and conventions. But without the benefit of cross-cultural comparison or a tradition of reflexivity, epidemiologists might find it harder to see cultural influences in their own work. Most of their studies are done in and for their own familiar cultures, are based in biomedical theories of illness causation, and are justified within a particular research framework that celebrates empirical tests and falsifiable hypotheses. For these reasons, epidemiologists are likely to describe the rules of their research as dictated by the scientific method not by cultural rules about professional identity, the qualities of a good measurement, or the effect of politics in science.

One way to notice that epidemiologists are embedded in culture is to think about what influences their measures of disease. Statistical tests, research designs, risk factor definitions, and disease definitions all rise and fall in popularity, and their use is not governed solely by "objective" assessments of their appropriateness for a given question. For example, clinical journals have published multiple and competing recommendations about what kinds of statistical tests should be presented (Sterne and Davey Smith 2001). Computer-based statistical packages and geographic information systems make complex tests and visual representations of quantitative data available to many scientists, when formerly they were available only to a few. Cheap digital storage on computers facilitates collecting and linking massive quantities of patient information, and privacy laws sometimes help and sometimes hinder the use of that information. The categories used to define and thereby "see" human groups vary over time, as shown by the change over the past three decades in U.S. census categories from Black/White/other to self-identified multiethnic categories (U.S. Bureau of the Census 2001a). And the proportion of important clinical studies that involve epidemiologic research varies dramatically from country to country (Takahashi et al. 2001), evidence that the discipline's power and prominence is not everywhere the same.

III. Applying an Integrated Cultural-Epidemiological Approach

Culture influences the patterning of disease through many pathways, ranging from who is counted to what is noticed to where people obtain help for suffering. Its influence can be seen in the varying ways parents try to protect their children from the common cold, as well as in the differential power of epidemiology across nations. More complete understanding of the range of cultural influences on disease patterning will come as more frequent and profound interactions take place between the disciplines of medical anthropology and epidemiology, among others. Some examples of existing collaborative projects are summarized in this volume. As a start, let us consider a cultural approach to a biomedically accepted entity, epilepsy, and an epidemiological approach to a "culture-specific syndrome," *ataque de nervios*.

People's understandings about disease and therapy influence disease patterns in ways that epidemiologists may not always appreciate. Two very basic concepts in epidemiology, the description of human disease in terms of *incidence* and *prevalence*, can be used to illustrate this suggestion. *Incidence* is the number of people developing a disease over a particular period of time; an incidence rate compares the number of new cases of disease within a defined time period with the total number of susceptible people in a defined population. Incidence matters because it measures the rate of disease change in a population. If epidemiologists want to know how rapidly a disease is developing or disappearing, or to figure out why new cases are appearing, they need to know the incidence of the disease and investigate incident cases. Incidence can be thought of as measuring the force or pressure of disease: it describes how quickly disease moves through populations.

Prevalence, on the other hand, is the number of people having a disease at a particular point in time, and a prevalence rate compares the number of existing cases with the total population. Prevalence can be thought of as measuring the weight, rather than the force, of disease. Prevalence matters because it measures the burden of disease on a population. If epidemiologists want to plan treatment programs or measure the needs of people with a disease in some defined place (no matter whether they have had the disease for a long or a short time), then they need to know the prevalence of the disease.

Prevalence is partly influenced by disease duration. If a disease lasts a long time in an individual, such as diabetes or asthma, the prevalence of that disease in the population will usually be larger than its incidence because more people in the population have the disease at one point in

time than develop the disease over a period of time. If a disease like chickenpox or an acute respiratory infection lasts a short time in an individual, incidence in a population will often be larger than prevalence because many people can get the disease over time but fewer will have it at any particular point in time.

A. A Cultural Epidemiological Study of Epilepsy

In the nineteenth century, Oliver Wendell Holmes, Sr., Professor of Anatomy at Harvard, said, "If I wished to show a student the difficulties of getting at the truth from medical experience, I would give him the history of epilepsy to read" (Holmes 1860). The same could be said of AIDS or of sickle cell trait today, but even 150 years ago epilepsy had a long, convoluted, and contradictory history. The medical historian Owsei Temkin's book, *The Falling Sickness* (1971), recounts how epilepsy has been seen variously over time as a disease caused by spirits, demons, gods, nature, and human will, although physicians now speak quite confidently about this syndrome that they know, measure, diagnose, and treat. The cultural meanings of epilepsy have affected whether and how it becomes visible to epidemiologists and what this means for estimates of its incidence, prevalence, causes, and outcomes.

Epilepsy is the most common serious condition seen by neurologists. It is estimated to have an annual incidence of about 50 per 100,000 in industrialized countries and a prevalence of about 5 to 6 per 1,000 (Hauser and Kurland 1975). The lifetime risk of any individual having a seizure is about 5%. For physicians, epilepsy is a brain disorder characterized by recurrent seizures caused by abnormal electrical activity (uncoordinated electrical discharges) in the brain. From a clinical point of view, epilepsy is the name for a group of disorders characterized by recurrent seizures, which can manifest as jerking motions of particular limbs, sensations and thoughts, or convulsions of the whole body.

Neurologists think of epilepsy as having two components: the seizures themselves and their underlying cause. They can treat the seizures with anticonvulsant medication, but they can rarely explain why seizures develop in the first place. When a patient asks, "Why me?," the doctor often does not know. Nor can a doctor specify when the seizures might stop. Physicians label epilepsy a chronic disease, yet patients experience seizures as sporadic and (usually) unpredictable events. They wonder how long they must be seizure-free to be considered epilepsy-free, and they wonder how they will know whether they are seizure-free while they remain on anticonvulsant medication. This combination of factors – uncertainties about the cause, the prognosis, and the end

point – encourages people with epilepsy to develop their own explanations for the condition and to adjust their medications accordingly.

So how can the concept of culture help us understand incidence and prevalence? A cultural-epidemiological approach shows that local meanings and management strategies for this disease influence the number and severity of cases that come to the attention of epidemiologists and thus help to determine whose disease gets counted and how disabling the disease looks. It employs both of the meanings of culture introduced earlier in this chapter: a set of beliefs and practices learned and transmitted through time, and a set of contingent processes subject to manipulation and change. Through the prism of epilepsy, and of seizures more generally, we can see how symptoms and prognosis, personal and social reactions, and categorization and measurement all help to create patterns of disease in populations.

Olmsted County, Minnesota, has been the site of an important epidemiologic study of epilepsy in the community since the mid-1950s. Almost all residents of Olmsted County receive their health care from the Mayo Clinic in Rochester, Minnesota, and other health facilities in the county also make their records available for study by Mayo personnel. When I worked at Mayo in 1985 I studied the medical records of 199 county residents aged 18 to 59 who received care for epilepsy. I interviewed 127 adults from this group who had active epilepsy (defined as having had a seizure or taken anticonvulsants within five years prior to January 1, 1980). My objective was to understand the differences between physician and patient perspectives on epilepsy, its impact, and its care.

Interviewees were asked a series of closed and open-ended questions about how they managed their condition, what they thought had caused it, what others thought of it, and what differences it had made in their lives. Some of the respondents used biomedical language to describe their condition, labeling their seizures as grand or petit mal and talking about seeing the results of brain scans or brain waves. But they also used a large variety of nonmedical terms to describe their seizures, including fainting or dizzy spells, zonking out, passing out, sleeping spells, blackouts, popping off, and jumps. Some attributed seizures to stress, diet, or emotional pressure, even when physicians were unable to confirm such connections. Seventy-nine percent of 127 people mentioned classical biomedical categories (illness, trauma, physiologic problems) as the ultimate cause of their seizures (i.e., why they were susceptible to having seizures), even though physicians identified causes in only 14% (Trostle 1987:24–28). When explaining what triggered particular seizures, these respondents