THE SOCIAL MEDICINE READER

Differences and Inequalities

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Volume 2, Third Edition

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VOLUME

2

THIRD EDITION

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Preface to the Third Edition

The eight editors of this third edition of the *Social Medicine Reader* include six current and two former members of the Department of Social Medicine in the University of North Carolina (UNC) at Chapel Hill School of Medicine. Founded in 1977, the Department of Social Medicine, which includes scholars in medicine, the social sciences, the humanities, and public health, is committed to the promotion and provision of multidisciplinary education, leadership, service, research, and scholarship at the intersection of medicine and society. This includes a focus on the social conditions and characteristics of patients and populations; the social dimensions of illness; the ethical and social contexts of medical care, institutions, and professions; and resource allocation and health care policy.

This two-volume reader reflects the syllabus of a year-long, required interdisciplinary course that has been taught to first-year medical students at UNC since 1978. The goal of the course since its inception has been to demonstrate that medicine and medical practice have a profound influence on—and are influenced by—social, cultural, political, and economic matters. Teaching this perspective requires integrating medical and nonmedical materials and viewpoints. Therefore, this reader incorporates pieces from many fields within medicine, the social sciences, and humanities, representing the most engaging, provocative, and informative materials and issues we have traversed with our students.

Medicine's impact on society is multidimensional. Medicine shapes how we think about the most fundamental, enduring human experiences—conception, birth, maturation, sickness, suffering, healing, aging, and death—as well as the metaphors we use to express our deepest concerns. Medical practices and social responses to them have helped to redefine the meanings of age, race, and gender.

Social forces likewise have a powerful influence on medicine. Medical knowledge and practice, like all knowledge and practice, are shaped by political, cultural, and economic forces. This includes modern science's pursuit of knowledge through ostensibly neutral, objective observation and experimentation. Physicians' ideas about disease—in fact their very definitions of

disease—depend on the roles that science and scientists play in particular cultures, as well as on the various cultures of laboratory and clinical science. Despite the power of the biomedical model of disease and the increasing specificity of molecular and genetic knowledge, social factors have always influenced the occurrence and course of most diseases. And once disease has occurred, the power of medicine to alter its course is constrained by the larger social, economic, and political contexts.

While the origin of these volumes lies in teaching medical students, we believe the selections they include will resonate with a broader readership from allied health fields, the medical humanities, bioethics, arts and sciences, and the interested public. The many voices represented in these readings include individual narratives of illness experience, commentaries by physicians, debate about complex medical cases and practices, and conceptually and empirically based scholarly writings. These are readings with the literary and scholarly power to convey the complicated relationships between medicine, health, and society. They do not resolve the most vexing contemporary issues, but they do illuminate their nuances and complexities, inviting discussion and debate.

Repeatedly, the readings throughout these two volumes make clear that much of what we encounter in science, in society, and in everyday and extraordinary lives is indeterminate, ambiguous, complex, and contradictory. And because of this inherent ambiguity, the interwoven selections highlight conflicts about power and authority, autonomy and choice, and security and risk. By critically analyzing these and many other related issues, we can open up possibilities, change what may seem inevitable, and practice professional training and caregiving with an increased capacity for reflection and self-examination. The goal is to ignite and fuel the inner voices of social and moral analysis among health care professionals, and among us all.

Any scholarly anthology is open to challenges about what has been included and what has been left out. This collection is no exception. The study of medicine and society is dynamic, with large and ever-expanding bodies of literature from which to draw. We have omitted some readings widely considered to be "classics" and have included some readings that are exciting and new—that we believe have an indelible impact. We have chosen to include material with literary and scholarly merit and that has worked well in the classroom, provoking discussion and engaging readers' imaginations. These readings invite critical examination, a labor of reading and discussion that is inherently difficult but educationally rewarding.

Volume 1, *Ethics and Cultures of Biomedicine*, examines experiences of illness; the roles and training of health care professionals and their relationships with patients; institutional cultures of bioscience and medicine; health care ethics; death and dying; and resource allocation and justice. Volume 2, *Differences and Inequalities*, explores health and illness, focusing on how difference and disability are defined and experienced in contemporary America and how social categories commonly used to predict disease outcomes—gender, race/ethnicity, and social class—shape health outcomes and medical care.

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Introduction

The selections that comprise volume 2 of the *Social Medicine Reader* introduce the fundamental sociocultural dimensions of health differences and inequalities. These include social and cultural shaping of the meanings of health, illness, and disease; social factors in the development of biomedical knowledge and systems of care; and structural explanations for why some social groups experience disproportionate burdens of disease and differences in care. Disease occurs, is felt, within a body, but it is also experienced beyond the body, in a cultural milieu, amid social relationships.

When individuals who belong to particular social groups have higher rates of disease, epidemiologists seek to explain these variations via risk factors. Yet concepts of disease and risk themselves reflect culturally specific assumptions about meanings of illness and causation, and about the validity and significance of group labels, including and especially those of age, gender, ethnicity, and race. An individual's experience of illness is best understood in the context of their society and culture. Similarly, explanation of the occurrence of disease through individual exposure or risk factors is enriched by broad consideration of the distribution and intensifications of such exposures or risks among families, communities, and social environments.

In order to examine social factors in health and disease, this second volume of the *Social Medicine Reader* draws on frameworks and findings from a variety of academic disciplines. These include sociocultural and medical anthropology, sociology, and the social history of medicine and science. Eight editors from diverse scholarly backgrounds have curated a diverse collection of essays, articles, stories, and poems to exemplify and illustrate social influences on health. The selections consist of empirical, conceptual, and literary materials about sociocultural markers such as gender, race, ethnicity, economic disadvantage, social status, religious affiliations, and associated differences and inequalities in health. Many of the selections have been used successfully as bases for discussion in medical school curricula and in undergraduate and graduate courses and can be adapted to fit courses and students in science, social science, and the humanities.

The readings in part I of this volume explore how various disabilities and other differences from bodily or behavioral norms are experienced and defined in America. Narratives of managing illness and disablement in a day or a lifetime contribute to textured biographical understandings of such differences. These accounts can challenge presumptions of sameness among people who are profoundly different, and presumptions of difference between the disabled and the "temporarily-abled" by bringing to the foreground unrecognized commonalities. Several selections address the roles of medicine and doctors in defining, mitigating, and eliminating differences and disabilities in historical context.

In part II of the volume, the focus shifts to ways in which illness, disability, and care are embedded in relationships, especially (but not exclusively) family relationships. Reading selections portray spouses, parents, and children amid tangled emotions, shifting roles, and obligations—through episodes of care, protection, recrimination, and mourning. Families and communities can intensify vulnerabilities or sustain resiliencies and thereby contribute to disparities in health.

Part III of the volume takes up ethnoracial and socioeconomic differences that produce and shape health inequalities. Uneven distributions of material resources, educational opportunities, work exposures, and stresses of discrimination and oppression are powerful social determinants of health. Ideologies and inequalities materialized in and enforced by macrosocial structures become embodied in individuals and communities. A substantial cluster of the readings in this part addresses the important matter of race—as a political or scientific construct, as a source of group identity or bias, as a signpost of structural vulnerability or violence.

The final section of the volume considers various institutional contexts of health care, including incarceration, public policy regarding chronic pain management and opioids, and U.S. national efforts toward health care reform. It concludes with a glimpse of nongovernmental forms of health care and humanitarian aid in the developing world.

The variety of readings in this volume can be addressed from many disciplinary perspectives, teaching styles, and formats. They can be reshuffled and recombined, stand together or alone, or be supplemented by other literature. The key to using these readings successfully is to approach them with flexibility—to provoke or shape the right questions, rather than give particular answers. Our hope is that both teachers and students of materials like these will go on asking questions and finding different and deeper answers throughout their lives.

Social and Cultural Contributions to Health, Differences, and Inequalities

Sue E. Estroff and Gail E. Henderson

Disease and health, birth and death, bodily suffering and debilitation are not the presumptive territory of laboratory scientists and clinicians in white coats. Scholars from the social sciences and humanities in the fields of social medicine, health humanities, sociomedical and health systems sciences, and structural competence deploy interdisciplinary tools to understand the experiences and meaning of illness, medical training and practice, and the historical, political, and structural, as well as biocultural influences on health status and disease. Here we introduce underlying concepts and perspectives foundational to social and cultural approaches to health and illness. The topics at issue are sometimes referred to as social determinants of health. We take the view that identifying and accounting for the complex synergies of the social and biological is an ongoing enterprise—promising and persuasive, but as yet an incomplete demonstration of causal, determinative certainty. The terrain includes work in medical sociology and anthropology, public health, social epidemiology, and intersectional studies of health disparity and inequality, disability, science and technology, sexualities, narrative in medicine, gender identity and expression, race and ethnicity, and disability.

These approaches have in common conceptual frameworks that include the following:

- the mutual molding of culture, social and institutional structures, biology, and illness;
- distinguishing between, but not detaching, disease as a pathological process and illness and treatment as lived experience;

- the impact of role expectations on how people who are ill or injured are seen by others and see themselves;
- and the ways that gender identity and expression, sex, socioeconomic status, race, and ethnicity are associated with disease and are indicators of broader economic, political, and cultural forces that influence a person's health status and exposure to or protection from illness and injury.

Here we use exemplars from an array of research and scholarship focused on the experiences of difference engendered by labels of disability and disease together with inequality in health status and health care related to social identities such as age, gender, and race, as well as the structural frameworks that define and maintain these identities.

Sociocultural influences on health and illness are prominent and observable in these areas, and now epigenetic analysis adds empirical documentation of the signature of social circumstances on the molecular as well as the social body (Kirkbride, Jones, Ullrich, and Coid 2014). Shields (2017: 224) describes how "social disadvantage 'gets under the skin'": "We have always known that poverty, child abuse, trauma, air pollution, and other adverse exposures were bad for people's health. By shedding light on the biological pathways through which such exposures are translated into concrete, measurable increased risk of various diseases, epigenetics research provides a useful tool for refocusing policy makers' attention back to the communities in which people live and work, and the daily quality of their lives that shape their health and those of their offspring."

Basic Concepts

The terms *social* and *cultural* are often used together, interchangeably, or as combined into a single word, *sociocultural*. These two words represent different disciplinary perspectives and reflect varied definitions, questions, and approaches to research. Increasingly, intersectional social science scholarship in health and illness integrates qualitative and quantitative methods and analytic techniques.

In this essay, the term *social* encompasses selected characteristics of a defined, organized group that can range in size from a family unit to a nation state. The characteristics of interest include: social institutions like families, schools, hospitals, and prisons; local and national political institutions and

mechanisms of social control and resource allocation; and systems of production, such as private or public ownership, manufacturing, agriculture, and the internet. These social institutions and socioeconomic systems structure opportunities that in turn affect health and health care for individual citizens and provide both obstacles and assistance to those unable to carry out normal functions due to disease or disability (Hansen, Bourgois, and Drucker 2014). Individuals are also part of social groups, such as religions, gender identities, sexes, social classes, races, and ethnicities; these are woven together by systems that reflect differential or hierarchical access to resources of wealth, power, and social status. Social groups may overlap with cultural groups, and when placed under scrutiny, many of these categories have fuzzy edges. Still, there are measurable and enduring differences in disease frequencies and health outcomes between (and within) social groups, however contested the definitions and however complex the reasons for these differences may be.

Culture can be viewed as an evolving collective product, a negotiable and negotiated template for leading and making sense of daily life. The properties of culture are values, rules, prohibitions, preferences, symbols, meanings, language, locations of power, and practices that guide how everyday life is lived and how extraordinary events are understood. Culture includes definitions of health and illness, life and death, responses to disease and injury, and how pain, discomfort, and disfigurement are experienced. These forms of knowledge are shared among a group of people, despite variations among them in interpretation of principles or in practices. Finally, culture is enduring at a fundamental level, but also changing in form and content over time, produced and reproduced by those who learn the rules and apply or alter them in daily living.

The idea of culture, as Comaroff and Comaroff (2004: 188) observe, has taken on increasing power as "peoples across the planet have taken to invoking it, to signifying themselves with reference to it, to investing it with an authority, a determinacy" that some scholars would dispute. Taking such a view can lead to stereotyping, or a cookie-cutter view of culture—a belief that it produces identical people with identical beliefs within particular groups. For example, race and sex-based stereotypes presume that one characteristic, such as darker skin color or a person's genitalia, play the lead role in defining anyone with that characteristic. Variation and individuality become "exceptions." In a clinical setting, stereotypes can be convenient but are often inaccurate and can be mistakenly deployed as a form of cultural competence.

Instead, culture can be understood "less as a sign of racial marking or an alibi for difference than as the description of a more or less open repertoire of styles, a mode of conduct, a set of pragmatic values always under re(con)-struction . . . [as] a thoroughgoing qualification to everyday life." (Comaroff and Comaroff 2004: 198). The evolving vocabularies of gender identity and expression beyond the binary and accounting for race/ethnicity exemplify how emergent repertoires interrupt and reconfigure long-held Western categories and designations of experience and identity. It is helpful to think of culture as agreed-upon-enough to contribute to and to sanction recognizably patterned ideas about social categories like gender, age, and social status, and responses to disease, disability, or death.

Culture in Biology, Biology in Culture

Biology and culture do not stand in opposition, the one fixed and the other malleable. The biological, social, and cultural realms are intertwined profoundly. The claim is not that culture includes everything, but that nearly every part of biological and social life is culturally influenced, that life is *cultured*. In any locale, for example, the flora that are used for healing, the kind of crops that are grown, and the climate help to shape local customary practices, symbols, and beliefs. In turn, these customs and beliefs interpret or give symbolic meaning to the weather or food. For example, social hierarchies often determine how protein is distributed within a group—who gets what kind and amount of food—which may then influence health status and patterns of disease. Consider the origins and impact of "food deserts" in inner cities, how access to food can be a weapon of war, and the fragile status of school lunch programs in the face of politically determined budget cuts. For example, access to healthier food is lower in census tracts with predominantly non-Hispanic black residents than in areas with predominantly non-Hispanic white residents (CDC 2013). These structural processes reflect both inadvertent and deliberate allocations of resources based on fundamental notions of justice, fairness, and deservedness.

Illness is sensate. It is felt in the body through pain, discomfort, and loss or change of function. Illness and injury are embodied—seen, displayed, apparent to self and to others. How we feel, what we feel, what we identify as pain and discomfort and disfigurement are all learned and shaped in cultural context. Expected and ideal bodies are imagined within cultural parameters. The bioengineering of exoskeletons for people who cannot

walk, actual bionic limbs that permit their "owners" to mountain climb or return to the ballet stage, and laboratory-generated human tissue are realities, no longer science fiction. Indeed, these developments incite discussion of *transhumanism* or the fusion of biological and mechanical processes and the expanding meaning of being human.

We face the possibility, not just the aspiration, of the transhuman body when body parts fail and diseased kidneys are replaced with a lab-generated, donated, or purchased organ (Hogle 2005). Cosmetic surgery and Botox injections to rid the face of wrinkles, or liposuction to remove body fat, become the means to maintain or achieve new, culturally idealized bodily shape and function over a lifetime. At the same time, these and numerous other intensely marketed body-enhancing procedures are accessible only to those who can afford their purchase, and they contribute to the creation of evolving ideals about physical form, about age-expected and gender-associated bodies that are unequally achievable across populations. This interplay between medical technology and bodily expectations, and their reflection of and contribution to disparities in body possibilities, is an important arena for the mutual molding of culture and medicine (McNamee and Edwards 2006) in determining the nature of our bodies as "natural biological material" or something altogether different. Tomasini (2007: 498) alerts us that "at a very minimalistic level of analysis, the notion of human enhancement already entangles factual claims about how we can better humans with value claims about why we should/ought to do so."

Margaret Lock's (1994) work on aging and menopause in Japan and North America illustrates the intimate interactions between biology and culture. Lock finds that Japanese women physically experience menopause differently than American women. They do not report the "hot flashes" and emotional liability that Americans do. Rather, their primary sensations include aching joints and other bodily pains. Likewise, Japanese and American physicians differ widely in how they approach menopause. Their relationships with patients are embedded in cultural contexts with differing ideas about gender, authority, female biology, and aging. How can it be that Japanese women experiencing menopause actually *feel* differently from American women? Their aching shoulders are as culturally influenced *and* as real as are American and Canadian hot flashes, but all the women are going through the same biological process. Or are they?

The recognition of cultural influences on bodily experience is not confined to the social sciences. An investigator in a large clinical trial studying the impact of hormone replacement therapies on cognitive function (Espe-

land et al. 2004) was quoted as saying, "The true interpretation of menopause is cessation of menses from decreased production of female hormones. . . . And while, in our culture, it's often associated with hot flashes and other symptoms, in some other cultures women breeze right through it. There may be lots of factors here. . . . It's not my area of specialty. . . . It's been debated considerably" (Shamp 2004). This example of the inclusion of sociocultural influences on biological events by researchers outside the social sciences demonstrates the expanding application of interdisciplinary findings and perspectives to medicine.

Culture, Health, and Illness

The social and cultural worlds of the twenty-first century United States, its language, music, food, and its political figures and forces, are profoundly different than just half a century ago, when the idea of an "American culture," or a dominant white Anglo-Saxon tradition, was accepted by many as a given and desirable. Demographers predict that around 2044, no race/ethnic group as defined by the Census will have a majority share of the total population, and the United States will become a "'plurality' of racial and ethnic groups" (Colby and Ortman 2015: 9). For the first time since the colonization of the North American continent, no group will represent a numerical majority. We will become a "majority/minority" nation (Colby and Ortman 2015) wherein non-Hispanic whites do not represent a majority, though they are projected to remain the largest single group. Taking into account fertility rates and the age structure of various population groups, the crossover point to a no-majority population for children under 18 could occur as soon as 2020. The transformation of the U.S. population's cultural and race/ethnic legacies and practices will have a profound effect on the social epidemiology of health and illness, and thus on health care systems and providers.

Members of a dominant culture are inclined to view their own ways as logical and natural, to see "culture" as something that others have. *We* have values or principles, *they* have beliefs and customs. *We* have science and knowledge, *they* have traditions and myths. Yet, Western history, the social history of science and medicine, and the cultural study of health and illness challenge these dichotomies. As the United States evolves demographically and culturally, reliance on a dominant cultural repertoire in the domains of health and illness will become increasingly precarious, if not ill advised.

The United States has always been a culturally diverse society, home to Anglo-Saxon, Slavic, African, Asian, and Mediterranean groups with evident linguistic and cultural boundaries. Ethnicity and cultural diversity are now center stage in the politics, economy, social life and health care of the twenty-first century. The 2000 Census for the first time allowed respondents to choose more than one race/ethnicity category. The number of people who describe themselves as representing two or more races is the fastest growing segment of the U.S. population. In the 2010 Census the number of respondents who considered themselves "multiracial" was 6.9 percent of the population. The number of black/white biracial respondents more than doubled, and Asian/white respondents grew 87 percent (Pew Research Center 2015). The re-emerging multicultural and ethnically diverse society of this century adds to the importance of understanding health, illness, and medical practice as both product and producer of larger social and cultural domains.

As much as change is anticipated and often lauded, each age or era develops a sense of inevitability about itself, about its ways and ideas. And so we have about ours, particularly in the ways that we regard knowledge in science and medicine as immutable. Yet, illness categories, both lay and scientific, are, at base, cultural categories and as such change over time.

Examining illness categories as evolving cultural constructs leads us to investigate how new diagnoses emerge, expand, or gain unprecedented prominence among the public or within medicine. The development of Prozac in 1987 spawned a now massive market for antidepressant and other psychotropic drugs that offer the opportunity and demand for enhanced or elevated moods and increased happiness in life. The possibilities for increasing well-being courtesy of psychotropic drugs changed how we view moods and the meaning of sadness and melancholy as part of daily living. Familiar emotions, the blues, and distress are redefined as diseases in order to "treat"' them with this and other drugs. This process is called medicalization. The medicalization move, whether it involves highly energetic and distractible children in school, or sexual approaches that violate individual consent and dignity or that we view as excessive, relocates responsibility and authority—responsibility migrates from the sensate individual to hidden bioprocesses, and authority migrates from the secular to the medical/professional. Hansen and colleagues (2014) introduce the concept of the "pathologization of poverty" that "shifted indigent populations to a form of financial support that is increasingly medicalized—requiring a medical or psychiatric diagnosis to qualify a patient for disability payments." In this scenario, financial and material needs are legitimated only by a

clinically verified inability, rather than by undiagnosed socioeconomic deprivations.

Medicalization is complicated and multidirectional. As Rose (2007: 702) points out: "This process is not a brute attempt to impose a way of recoding miseries, but the creation of delicate affiliations between subjective hopes and dissatisfactions and the alleged capacities of the drug." The direct marketing of prescription drugs to consumers also influences what and who gets defined as pathological, problematic, and treatable. There are, for example, incessant media invitations to ease the heretofore "normal" aches and pains of aging by renaming them as osteoarthritis—which can be controlled by a variety of drugs or repaired by surgery. A medical vocabulary replaces social or sensate terminology. A similar dynamic is apparent in the defining and redefining of so-called attention deficits and hyperactivity disorders, but it occurs primarily in clinical and educational settings (Lakoff 2000). Did school-age children have such disorders forty years ago? Does the availability and widespread use of drugs to "treat" attention disorders influence their identification? What role might increased class size and a shortage of teachers in primary schools play in the definition of "problem" behaviors among students? The rise in public recognition of Asperger's Syndrome and the autism spectrum among adults is further illustrative of medicalization, this time fueled in part by people who suddenly "recognize themselves" when reading about the disorder (Harmon 2004). In these ways, evolving medical terminology enters into public discourse and everyday vocabulary, which in turn furthers both the medicalization and often bureaucratization of human difference.

The process of defining something heretofore unlabeled or known by a secular term as a disease or medical problem reflects ongoing ambiguity and disagreement about the role of will and personal responsibility in preventing dysfunction or maintaining health. Deeply rooted Western ideologies about independence, individualism, and mastery over nature also underlie many of the moral conflicts that arise in and from medicalization. The conflicting cultural logic is as follows: On the one hand, if a drug or medical procedure can treat or alleviate a problem, then it must be biologically based, and therefore not attributable to personal failure. On the other hand, many treatable, verified diseases and injuries may result from voluntary behaviors such as smoking, drinking, taking opioids, downhill skiing, or playing professional football.

The widely varied conceptions and representations of HIV/AIDS throughout its brief history also reveal the signature of culture, politics, and social

forces. Much of the discussion and debate about immigration is seasoned with reference, explicit and nuanced, about the dangers of infection and other forms of harm from cultural "others." HIV/AIDS in the initial years of the epidemic evoked a mixture of moral, spiritual, virological, neurological, and social explanations. Paul Farmer's (1992) study of Haitian understandings of HIV/AIDS describes the centrality of blame and accusation, constituting the "third epidemic"—worse than the disease, in American and Haitian views. Accusations of sorcery arose in a Haitian village to account for the disease. The American public feared that the virus was introduced by infected Haitian immigrants. Haitians countered with conspiratorial ideas about U.S. motivations to weaken or defame impoverished black immigrants who would carry the affliction home. Fears of contagion and pollution by outsiders or malevolent others are shared by Americans and Haitians alike. Like homelessness and poverty, HIV/AIDS now infects more women and children of color in the United States than persons who are homosexual, yet HIV/AIDS bears the mark of sinfulness for some because of the first people who were infected.

In Africa, HIV/AIDS has always been a "heterosexual" disease, but because of its spread by prostitutes, it acquired yet another moral valence. In fact, the sensitivities associated with the main routes of HIV/AIDS transmission—risky sexual behaviors and the use of illegal drugs—coupled with the deadly nature of the disease, have created one of the most powerful examples of stigma and discrimination in the recent history of human disease. Ominous viral diseases like Ebola, Zika, and HIV/AIDS provide both a window into and a mirror reflecting deeply held values and ideas about order, pollution, and good and bad.

The reciprocal influence of cultural conceptions, social sentiment and policy, and medical practice regarding people with disability is also well demonstrated by remarkable changes since 1915, when Helen Keller (herself unable to see or hear) supported "weeding the human garden" by letting infants with severe anomalies die. "Surely they must admit that such an existence is not worthwhile. It is the possibilities of happiness, intelligence and power that give life its sanctity, and they are absent in the case of a poor, misshapen, paralyzed, unthinking creature" (Keller 1915). A century later, several governors publicly apologized to the thousands of people with intellectual and developmental disorders, formerly known as retarded, who were sterilized without consent until the mid-1970s. While we might use a different vocabulary at present, and while the possibilities for and inclusion of people with disabilities have expanded by orders of magnitude, similar calculations

are undertaken now in ultrasound suites and physician and genetic counselors' offices. What makes a life "worth living" is not a question that can be addressed with technology alone (Ginsburg and Rapp 2013).

By the 1960s the care and treatment of persons with severe physical and mental disabilities changed dramatically (Grob 1991). Institutions for "mentally retarded" and mentally ill persons all but emptied, and even the most seriously impaired individuals now live and receive treatment in community settings. However, far too many have now taken up residence in other places of confinement and exclusion—jails, prisons, and hospital emergency rooms—or the street (Dorner and Mittendorfer-Rutz 2017).

These changes took place because of a confluence of forces: the development of effective drugs and treatment modalities; civil rights litigation and resulting legal requirements for the "least restrictive" treatment; the fiscal motivations of public mental health authorities seeking to reduce the expense of inpatient treatment and institutional confinement; and self-advocacy and advocacy from relatives of persons with severe disabilities. Some people with disabilities now have a larger presence in the media, the workplace, and in the overall consciousness of society at large. The Paralympic Games epitomize both a more inclusive era, along with a persistent affinity for exceptionalism as a credential for social merit—a mascoting of people who "overcome" their deficits. Just as important, clinical practice and the medical assessment of disabilities have changed dramatically as a result of changes brought about in part by social forces, including technology. Had these individuals remained confined in institutions, their capacities to work or to lead meaningful lives might have remained unacknowledged.

Vocabulary matters. "People-first language" is the exemplar—based on the idea that saying "person with" mitigates the erasure of personhood that comes from saying "an alcoholic" or "a schizophrenic." Clinical terminology also matters: a transformation is underway as the terms of an established gender identity and expression and sexualities are replaced by a vocabulary that is more granular, accurate, and reflective of the dignity and sensibilities of people to whom they are applied.

The efforts of advocates and professionals to alter public and scientific conceptions of and language related to problems like substance misuse, alcohol abuse, and psychiatric disorders do not always work the same cultural territory. The shift from "mental retardation" to "intellectual developmental disorder" was initiated by consumer and advocacy organizations and adopted into law, and it is now reflected in clinical diagnostic language and classifications.

Recognition of the unintended stigmatizing consequences of language motivated the authors of the most recent *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) of the American Psychiatric Association to change the terminology used for drug and alcohol disorders. The work group had extensive discussions on the use of the word "addiction." There was general agreement that "dependence" as a label for compulsive, out-of-control drug use has been problematic. It was confusing to physicians and resulted in patients with normal tolerance and withdrawal being labeled as "addicts." Patients suffering from severe pain had adequate doses of opioids withheld because of fear of producing "addiction" (Regier, Kuhl, and Kupfer 2013). As a result, DSM terminology changed from dependence and addiction to "alcohol use disorder" with severity subclassifications. Despite being titled *Facing Addiction in America*, the language in the 2016 surgeon general's report reflects this shift (DHHS 2016). The introduction to the report reads: "All across the United States, individuals, families, communities, and health care systems are struggling to cope with substance use, misuse, and substance use disorders. Substance misuse and substance use disorders have devastating effects, disrupt the future plans of too many young people, and all too often, end lives prematurely and tragically. Substance misuse is a major public health challenge and a priority for our nation to address" (U.S. DHHS 2016: 1).

Disease and Illness

Culture and social relationships are deeply implicated in the recognition, experience, and treatment of illness. Social scientists have found it useful to make a distinction between *disease* as a pathological process and biological condition, and *illness* as the personal, socially, and culturally influenced subjective experience of impairment or pathology (Young 1995). Within this framework, multiple sclerosis is the disease, and feeling tired, or unable to climb steps, as well as being treated as an object of pity, curiosity, or suspicion, and facing discrimination in employment, all constitute the illness. While calling attention to personal experience and pathophysiology as concurrent and legitimate processes, the disease-illness concepts may, however, reinforce an unnecessary separation of biology from culture and of body from person (Taussig 1980).

How people who are sick and those around them respond to illness is part of a cultural code that is learned, often without noticing. No matter what kind of healing system prevails, there are well-understood codes of

conduct for "*illness* behaviors" (Mechanic 1962). Illness behaviors are those practices that accompany disease and dysfunction—from eating chicken soup to chanting all night to appease an offended spirit. Illness behaviors are learned, and although they change over time, American illness behaviors still reflect ancient humoral medicine principles of balance: of hot and cold, and wet and dry. Thus many Americans explain the onset of an upper respiratory infection with a story of getting overtired, getting wet and cold, not eating enough—not keeping the balance—even though they are aware of the viral nature of most colds.

While the reach of biomedicine is global, a minority of the world's population rely solely or even primarily on biomedical care or adhere to Greek humoral beliefs about disease. Ayurvedic, traditional Chinese, and spiritist medical traditions—to name only the most prominent—are also used along with biomedicine by a large proportion of the world population. So-called alternative and complementary medicine, often consisting of techniques borrowed from these traditions, is increasingly popular in the United States and among mainstream clinicians as treatment for chronic musculoskeletal pain, for example.

Accounting for Disease and Illness

Illness has multiple narrators (Hawkins 1993). Many are clinicians and physicians who through scholarly publication (Decker 1998) or literary rendering (Williams 1936; Holt 2014) have written about disease in general and spoken for and about specific patients. This tradition continues in the scientific and literary world as physicians tell their own stories and narrate the experiences of their patients (Gawande 2002; Vonnegut 2010). Major medical journals regularly publish physician narratives of clinician-patient relationships or situations that are indelible, wrenching, or celebratory (Grouse 1997; Anonymous 2016). Various efforts to apply the resulting insights to clinical practice and doctor-patient relationships are proposed in the genre of narrative medicine (Kleinman, Eisenberg, and Good 1978; Charon 2004). Descriptive, biographical, autobiographical, and ethnographic accounts of illness and healing also have a long history in medical anthropology and qualitative sociology, along with gender studies and other health humanities (Liebow 1993).

In a sense, the medical chart/record is a biography of the patient, written by many authors, except patients themselves. These third-person, scholarly

or medical expert storytellers are sometimes joined or countered by a substantial chorus of first-person narratives and reflections of illness and injury (Styron 1990; Mairs 1996; Grealy 1994). Second-person stories, those written by relatives and loved ones of people who have various debilitating or fatal conditions (Bayley 1999; Neugeboren 1997), are equally abundant and compelling. This tells us that the experiences of injury, illness, treatment, birth, death, and not-so-everyday life, give rise to multiple versions and are not conveyed wholly by a one-dimensional perspective or account. There is no undisputed sole authority; only the collective experiences, recollections, sensations, vocabularies, and points of focus among the participants.

Explanatory model elicitations (Kleinman 1980) evoke a specific kind of accounting of illness that asks patients about the terminology they use for a disease or their pain; their ideas about etiology; their ideas about how a particular illness works; how long they think it will last; their expectations for the outcome of treatment; their account of the severity of the problem and its impact on their daily lives (e.g., Estroff et al. 1991). Few individuals have consistent, well-developed "models" of their physical or psychological problems, so the explanatory model concept may be most useful as a way to invite a patient to give their account or narrative of themselves and their pain and illness in a clinical setting.

Sick Roles

Illness is situated in and defined by the roles that individuals are expected to play in society. The most enduring articulation of this perspective is sociologist Talcott Parsons's (1951) idea of the sick role. Parsons described expectations for people who are ill that are based on American values of responsibility, independence, and productivity. First, if the illness is severe enough, a person is excused from normal social role responsibilities. People are permitted to stay home from school or work if ill, for example. The second component of the sick role is that a person who is ill deserves to be taken care of, by either family or social institutions, in order to get well.

Third, people who are infirm are expected to consider illness as undesirable and are obligated to try to get well—to seek treatment, to change diet, quit smoking, or to follow doctor's orders. Rejecting or not meeting this expectation—refusing treatment for drug use, for example—may lead to loss of the "deserving-of-help" status. In 1994, federal legislation was passed that strictly limited disability income support for people with substance use

disorders and revoked the benefit for those who did not comply with treatment. In 1995, persons with substance use disorders were excluded from eligibility for disability benefits altogether. Here, the emphatic medicalization of "addictions" within biomedical practice did not influence public sentiment or policy regarding the moral status of addicted persons. Cultural ideas about responsibility and will overrode the medical mantle of deservedness vis-à-vis disease.

Similarly, exemption from responsibilities because of illness is hotly contested in the case of mental illness. In the realm of criminal law, "diminished capacity" and "not guilty by reason of insanity" are legal concepts that express the cultural exemption from full responsibility if a person is sick. Recent U.S. history provides examples of assailants of public officials as well as persons who kill scores of children in schools or other public spaces. At this intersection of medical and legal concepts and processes, we express both therapeutic and punitive responses to the perpetrators. Their incomprehensible acts must arise from illness, but we still seek to punish them for these acts. Increasingly, states are replacing their not guilty by reason of insanity statutes with "guilty and mentally ill" legislation. This may represent a shift in basic cultural frameworks about illness and responsibility and reflects a notion that punitive and therapeutic practices cannot be combined when the social fabric is deeply wounded.

People who have other enduring and disabling conditions encounter difficulties when they "try to get well" but cannot. Their inabilities often become the object of intense scrutiny when they seek public assistance via Social Security Disability Insurance or require substantial resources to attend school, for example, because of an underlying cultural formulation about legitimate need and deservedness. The formula derives from the sick role. Those who cannot get well or who need assistance because of medically determined pathologies are deemed deserving. When there is a possibility that lack of will is involved, that a person fails to try to improve or become more productive, public benevolence is held in abeyance.

Sex, Gender, Health, and Illness

In addition to cultural perspectives on gender identity and expression, the social life of gender and sex in health requires consideration. Differential health outcomes for men and women are common in all nations, but the specifics of those differences vary considerably. In developing nations, infec-

tious disease and political and ethnic warfare have taken an enormous toll and are the leading causes of morbidity and mortality. Life expectancy for men and women is similar; but striking differences are found in literacy, political rights, and economic resources, all of which are related to access to health services and health outcomes (World Bank 2004). Studies in the United States and other industrialized countries focus on why women report higher levels of illness and use medical services more frequently, even when reproduction-related conditions are excluded, while men seek health care less frequently and often in later stages of disease (Doyal 2001). Women live longer than men and men have higher mortality rates for all major causes of death—heart disease, cancer, infectious and parasitic diseases, and accidents, poisonings, and violence (Waldron 1990). Women live longer than men even during famine and epidemics (Zarulli et al. 2018).

Explanations for these sex and gender differences in morbidity, mortality, and use of health care include individual and societal factors. Some research locates the causes in biology. The earlier onset of coronary heart disease for men, for example, is often attributed to the protective effect of estrogen in premenopausal women, and the later onset for women is associated with different complications. Nonbiological explanations for gender difference in rates of heart disease include variation in risk factors such as smoking (Waldron 1990), personality traits associated with heart disease, and one's level of social "connectedness" (Lasker, Egolf, and Wolf 1994). Many studies have also examined whether differences in referral, diagnosis, and treatment might explain different outcomes. In the case of heart disease, most studies of referral and treatment have shown that when potential confounders are taken into account, gender differences are not significant. Bickell and colleagues (1992) demonstrated that when admitted to hospitals with moderately serious heart disease, women undergo fewer procedures than men, but it is not clear whether they received less appropriate care or whether men were overtreated.

There is strong evidence that different rates of mortality and morbidity and the use of health care services are related to the social roles that men and women play (Ratcliff 2002; Zarulli et al. 2018). These social roles often influence activities such as diet, smoking, alcohol and drug use, and exposure to occupational and environmental hazards (Verbrugge 1989; Waldron 1990). Differential socialization of men and women—particularly in the United States with its "rugged individualist" role model for young men—was associated with differences in risk-taking behaviors and integration into social networks, which provide a buffer against illness (Berkman and Syme 1979).

Going to the doctor may be a sign of weakness for many men, while for women, seeking help is appropriate behavior.

Yet as conceptions of maleness and femaleness evolve, these connections require reexamination. Many of these factors combine to affect disease rates in complex and interesting ways; however it is also important neither to oversimplify the relationship between sex, gender, and health, nor to stereotype sex and gender roles and socialization processes, either within one society or in comparison to other sociocultural conceptions of gender.

Contemporaneous with these findings is the increasing plasticity of the categories of gender itself and the enlarging and energetic presence of an array of sexualities in the social and political landscape. There are now more than 50 terms for gender identity and expression and the vocabulary continues to expand (National LGBT Health Center Education Center 2018). People who consider themselves transgendered or transsexual do not fit conventional binary social categories of gender and face specific health risks and obstacles in clinical care (James et al. 2016). Same-sex couples have fought legal and political battles for recognition and access to traditional social institutions such as marriage and parenthood. Nonetheless, assisted reproduction via medical technology such as artificial insemination, and hormonal and surgical alteration of primary and secondary sex characteristics, has contributed to challenging these conventions and blurring the lines around gender and sex roles. Gender has traditionally been viewed as a basic social category, clearly determinable and obviously immutable. As ideas about and the enactment of gender continue to expand, this mainstay category will continue to be challenged.

Social Factors and Inequality

Over time, different religions, cultures, and scientific and other academic disciplines have taken various approaches to defining the causes of disease and examining why some people or groups tend to be more at risk than others (Braveman, Egerter, and Williams 2011; Dickman, Himmelstein, and Woolhandler 2017; CDC 2013). Epidemiologists describe the frequency and distribution of disease in a population and focus on immediate risk factors that predict disease occurrence. The logic of this perspective is that the more closely related a risk factor is to the biological mechanism of disease, the more likely it is to account for the occurrence of that disease, and the more useful it will be in developing an effective clinical intervention.

Classic causal pairs include mosquito bites and malaria, walking barefoot in snail-infested waters and schistosomiasis, and living in close quarters with TB-infected people and tuberculosis. Some of the foundational work in epidemiology (Cassel 1976) features the importance of cultural influences on health-related behaviors. In addition, epidemiological perspectives on chronic conditions involve more complex webs of social explanatory factors than are required to explain some acute diseases (Krieger et al. 1993). Nevertheless, the principal focus of epidemiology has been on the immediate determinants of disease.

In contrast, social epidemiologists and social scientists focus on the structure and social processes of societies and find that rates of disease can be predicted by knowing the characteristics of a society's class structure (Townsend and Davidson 1982; Navarro 1990), its rate of social change (Durkheim 1951; Cassel 1976), and group characteristics within a society, such as race/ethnicity, gender, sex, and age (Braveman et al. 2011). Cultural influences are integrated into this view at both societal and individual levels. Scholars have also debated whether the degree of income inequality that characterizes a society as a whole exerts an independent effect on individual health outcomes, perhaps through increased social disruption or crime (Kawachi, Kennedy, and Wilkinson 1999), though other evidence has demonstrated no independent effect (Mackenbach 2002).

In this broader view of disease causation, differential exposures to biological risks are influenced by one's position in society, and differential responses to biological risks are affected by one's overall social and economic environment, which in turn influences one's health care environment. As early as 1910, a local government board in England pronounced, "No fact is better established than that the death rate, and especially the death rate among children, is high in inverse proportion to the social status of the population" (Antonovosky and Bernstein 1977: 453). Numerous studies since then have confirmed the relationship between socioeconomic status and health outcomes, finding that every step up the social class ladder is accompanied by an incremental improvement in health status as well (Bor, Cohen, and Galea 2017; McKeown 1976; Marmot, Kogevinas, and Elston 1987; Mechanic 2000). As a result, social scientists increasingly define social conditions as "fundamental causes" of disease, observing that they persist in being linked to morbidity and mortality even as the actual diseases that people suffer may change over time (Link and Phelan 1995).

Bourgois and colleagues (2017: 299) introduce the concept of structural vulnerability to "highlight the pathways through which specific local hierarchies

and broader sets of power relations may exacerbate an individual patient's health problems." They propose an "applied pragmatic approach to intervening on these forces by identifying obstacles to healthy lifestyles and treatment adherence outside the clinic and facilitating access to care inside the clinic."

Although debates about the nature and causes of illness and health may seem academic, there are real political consequences. Individuals are members of social classes, races, ethnicities, genders, and age groups, all of which entail a differential risk of illness and mortality and directly increase or decrease their chances of suffering illness or premature death. Yet when differences in individual behavior are linked to these group characteristics and used to explain higher risks for morbidity and mortality, the tendency is to conclude that people have or get the health they deserve. Research that takes a broader approach, focusing on the structure of society and the health risks of living in poverty and of being a racial or ethnic minority in America demonstrates that health is not solely the result of individual initiative or failure. Rather, it is also the product of society and society's economic and cultural forces, including greater exposures to toxic work and living environments, racism, lack of adequate food, and limited education and medical care (Washington 2006).

Special Problems of Race and Ethnicity in the United States

Some authors have suggested that the health differences between non-Hispanic whites and minorities in the United States are an expression of the pervasive health disadvantage that always accompanies being in the lower social classes, where a disproportionate number of minorities find themselves. Research continues to document a high correlation between race and ethnicity and the indicators that are frequently used to measure social class: income, education, and occupation—particularly for African Americans. In fact, Dressler (1993) argues that race as defined by skin color actually determines or defines one's social class in America. Yet paradoxical findings have also been observed, such as the low rates of infant mortality among Hispanics, despite their low incomes and relative lack of health insurance coverage (Scriber 1996).

A number of factors complicate this issue. Most health status data, such as mortality rates, disease prevalence and incidence, and data on health services utilization, continue to be collected by race and ethnicity (increas-

ingly difficult to recognize or categorize accurately) rather than by measures of social class. Traditionally, medical researchers have used race and ethnic group categories as shorthand terms or proxies for social class, despite increased awareness of the flaws inherent in this assumption. This reliance on race and ethnicity makes it difficult to estimate the contribution of social class to health status. Alternate terminology based on a more accurate understanding of race and ethnicity has yet to be developed. Consequently, much of the current debate in the United States about health inequalities has been framed as disparities among different racial and ethnic groups, with little attention given to how contested these categories themselves have become. Furthermore, the practice of using race and ethnicity interchangeably, with different definitions or absent definition altogether, has created additional problems in interpreting the findings of research (Braun et al. 2007; Braun and Saunders 2017).

How, then, should race and ethnicity be defined and used? Despite considerable controversy, conceptual and empirical scholarship, and policy statements suggesting that race is not a meaningful biological term (Lee, Mountain, and Koenig 2001), medical texts, clinical literature, and research routinely use race without definition or explanation. When health differences are documented, unless otherwise argued, race is usually understood or implied as a biological rather than a social or cultural variable (Schwartz 2001). This view has been reinforced by the increasingly common application of race to genetic and pharmacogenomic research, reifying already problematic categories (Lee et al. 2001; Duster 2003).

Much scholarship (LaVeist and Gibbons 2001, Williams 1999; van Ryn 2002) has been devoted to identifying the various factors that "race" and "ethnicity" do represent, and advocates that researchers adopt more specific measures in studies of health disparities. When factors such as individual lifestyle and behaviors, cultural beliefs, physiologic measures, geographical location, insurance coverage, education, and income are included in studies, the remaining health differences may be attributed to the effects of racial bias or discrimination. Compared to whites, minorities perceive higher levels of racial discrimination in medical care and research settings and express greater mistrust of physicians and medical research (Corbie-Smith, Thomas, and George 2002; Lillie-Blanton et al. 2000). Estimating how and to what extent bias and discrimination are implicated in health disparities outcomes is both challenging and complex. Increasingly, researchers are undertaking systematic studies of the doctor-patient encounter to delineate the nature and scope of intended and unintended bias (Roter and Hall 1992; Van Ryn 2002).

The importance of this research was reinforced by the Institute of Medicine report, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* (Institute of Medicine et al. 2003) and the CDC's *Health Disparities and Inequalities Report—United States, 2013* (CDC 2013), which found consistent evidence of disparities in health care in a remarkable range of illnesses and services, and which demonstrated that when social and economic factors are accounted for, there are still significant health differences between minorities and whites. The evidence "overwhelmingly links greater social disadvantage with poorer health" (Braveman et al. 2011). Upstream factors such as education, neighborhood conditions, working conditions, income and wealth, race and racism, environmental conditions, and stress are implicated in the transgenerational transfer of poor health outcomes. These outcomes include disproportional social-disadvantage-linked asthma, diabetes, obesity, periodontal disease, premature birth, suicide, and cancer screening and treatment, and cigarette smoking to name only a few (CDC 2013). These differences occur in the context of broader historic and contemporary social and economic inequality, and they provide evidence of persistent racial and ethnic discrimination in many sectors of American life.

Conclusion

Health inequalities both reflect and reflect on the societies within which they exist. They may be seen as morally problematic; or they may be seen as unfortunate, but not necessarily unfair. Some identify inequality itself as a pathology (Kawachi et al. 1999), or what Paul Farmer (1999) refers to as our "modern plague," and advocate greater economic equality as a pathway to improved health. Regardless of the moral stance one takes about health inequality, it is likely to be the focus of ongoing attention in the near future, both in the United States and worldwide.

Global health inequalities have long been seen as unchangeable facts of life: there is one level of health and health care for wealthy countries and another for resource-poor nations. However, spurred by controversies in the field of infectious diseases, including outbreaks of Ebola and Zika, this view has begun to change. Debates over the ethical conduct of clinical research in international HIV/AIDS and Zika trials have also contributed to this perspective shift as research in the context of extreme poverty and lack of access to life-saving drugs came to be seen as potentially exploitative (Benatar 2001, 2002; Participants in the 2001 Conference on Ethical Aspects of Research

in Developing Countries 2002; Arras 2004). The SARS epidemic in 2003 provided further momentum for the emerging view of an interdependent global population. Together, HIV/AIDS and SARS have demonstrated how connected and vulnerable the world's people are when confronted with a deadly infectious pathogen.

In the United States, contradictions between our ethic of equality and the substantial inequities in access to health insurance and health care await resolution. Hansen and colleagues (2014: 11) describe the pathologizing of poverty, wherein disability-based income becomes "a new survival strategy in this era of medicalized poverty which for some has permitted a stable home, a way to avoid street violence, reduce illegal drug consumption. . . . [B]ecause it is one of the few available routes to stable survival income . . . in the context of poverty, using disability and illness to gain benefits can be . . . a viable harm reduction strategy in a post-welfare state that offers few alternative solutions to unemployment." Social science critiques focus on individual experiences of difference and disability and social conditions that underlie disparate health outcomes for population groups. But researchers and their approaches to science are also situated in the same societies that produce the inequalities, and, as we have argued, sometimes reproduce these same inequalities.

The view that science is morally neutral and should be free of political constraint is challenged by other deeply held beliefs about privacy, autonomy, and the sanctity of life. New possibilities to make choices about life and death, and about altering bodies, come at a rapid pace courtesy of medical technologies. Each innovation spawns more possibilities and often as much controversy. Then the social fabric and cultural frameworks among us serve as reference points. Yet they shift because we do. Can social arrangements and cultural conceptions keep pace with medical science and practice?

Developments in genetics and the Human Genome Project (HGP) illustrate this question. Originally, the HGP promoted the "sameness" of human beings, emphasizing that we all share 99.99% percent of the same sequences of DNA. However, geneticists have now turned to investigations of "difference," relying upon roadmaps within the human genome to identify patterns of genetic variation linked to common diseases. What impact will these new scientific and technological forces have on the contested category of race? How can we avoid reinforcing a prior ideology about human difference, and avert the use of science and medicine to divide, rank and control people (Washington 2006)? Will countervailing science and a new

willingness to confront the broader, societal sources of health disparities in our society (Institute of Medicine et al. 2003) construct a new dialogue about race?

The intellectual and moral challenges we continue to create reinforce the need for physicians, patients, and medical, social science, and humanities scholars whose understandings and training are both broad and deep. Continued improvement of the health of individuals, groups, and nations rests in large part on multidisciplinary, multidimensional research and practice. One of the best allies we have in facing the perils and enticements ahead is the ability to view medicine in society, and society in medicine, and to continually reflect critically on what this means.

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