# *The Sociology of*
# HEALTH AND ILLNESS
## Critical Perspectives

SIXTH EDITION

PETER CONRAD

# The Sociology of Health and Illness

## CRITICAL PERSPECTIVES

Sixth Edition

Edited by

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# Preface

In the past four decades, medical sociology has grown from a rather esoteric subspecialty to a major area of scholarly and student interest. Twenty years ago, when the first edition of *The Sociology of Health and Illness: Critical Perspectives* (1981) was published, there were few good teaching sources available and none from a critical perspective. From the beginning, I was (and remain) committed to drawing on diverse sources: Articles are primarily by sociologists, but also by public health specialists, health activists, feminists, and social critics. Criteria in choosing selections are that they be interesting, readable, and make important sociological and conceptual points about health and health care. For each section, I provide substantive introductions that contextualize the issues at hand and highlight each selection's main points.

There are few areas in society changing as rapidly as the health care system. Health costs have risen more rapidly than virtually any other part of society, new treatments and technologies continually become available, more people have become "uninsured," professional power has declined while corporate power has increased, and pressures remain on the health care system to change in ways that are not always in the patients' interest. While health and medical care does not stand still for our sociological study, it is possible to examine the health system as it is being transformed.

The sixth edition of this book reflects the continuities and changes in the sociology of health and illness. Only nine of the selections from the original edition are still here twenty years later; the other forty were added in subsequent editions as older selections were dropped. When I produced the first edition, issues like environmental disease, HIV–AIDS, neonatal infant care, wellness programs, rationing, genetics, and managed care had not yet moved to the fore, but they are all central to this edition.

While I maintain the overall framework that has characterized this book since its inception, changes in health and medicine are reflected in this new edition. Eleven new selections are incorporated here. These selections provide greater coverage of health inequalities, the growth of illness survivorship, the impact of managed care on the medical profession and patients, the changing role of technology in dying, the privileging of the new genetics, and community initiatives toward breast care. I also include specially written addenda to update two existing selections and an entirely new debate on "The Relevance of Risk." Throughout, I continue to believe that a critical and conceptual sociological orientation is necessary to understand the problems with our health care system. The book's purpose remains to better understand issues underlying our health care dilemmas and to promote a more informed discussion on the continuing changes in health and health care.

# Acknowledgments

I am grateful to the many colleagues and adopters who have been kind enough to share their reactions to previous editions and whose comments helped to strengthen this sixth edition. I only wish there were space to include every worthy suggestion. Stimulating conversations with Stefan Timmermans, Phil Brown, Deborah Stone, Donald Light, and Chloe Bird, among others, helped clarify some of the issues in our changing health scene. An ongoing dialogue with Libby Bradshaw, my wife-partner and a physician committed to enlightening her students to the social context of medical care, helped keep me honest in relation to medicine while sharing many critical perspectives. Heather Jacobson deserves special thanks. Her thoughtful comments, excellent organization, and good cheer contributed to making this a stronger revision. Finally, thanks to the folks at Worth Publishers who took this book over from St. Martin's Press and have continued the commitment to high-quality publishing.

# Contents

# General Introduction

Three major themes underlie the organization of this book: that the conception of medical sociology must be broadened to encompass a sociology of health and illness; that medical care in the United States is presently in crisis; and that the solution of that crisis requires that our health care and medical systems be reexamined from a critical perspective.

## TOWARD A SOCIOLOGY OF HEALTH AND ILLNESS

The increase in medical sociology courses and the number of medical sociological journals now extant are but two indicators of rapid development in this field.[1] The knowledge base of medical sociology expanded apace so that this discipline moved in less than two decades from an esoteric subspecialty taught in a few graduate departments to a central concern of sociologists and sociology students (Bloom, 2000). The causes of this growth are too many and too complex to be within the scope of this book. However, a few of the major factors underlying this development are noted below.

The rise of chronic illness as a central medical and social problem has led physicians, health planners, and public health officials to look to sociology for help in understanding and dealing with this major health concern. In addition, increased government involvement in medical care has created research opportunities and funding for sociologists to study the organization and delivery of medical care. Sociologists have also become increasingly involved in medical education, as evidenced by the large number of sociologists currently on medical school faculties. Further, since the 1960s the social and political struggles over health and medical care have become major social issues, thus drawing additional researchers and students to the field. Indeed, some sociologists have come to see the organization of medicine and the way medical services are delivered as social problems in themselves. In recent years, sociologists have been deeply involved in research on how to prevent HIV-AIDS and best stem the AIDS epidemic.

Traditionally, the sociological study of illness and medicine has been called simply medical sociology. Straus (1957) differentiated between sociology "of" medicine and sociology "in" medicine. Sociology *of* medicine focuses on the study of medicine to illuminate some *sociological concern* (e.g., patient–practitioner relationships, the role of professions in society). Sociology *in* medicine, on the other hand, focuses primarily on *medical problems* (e.g., the sociological causes of disease and illness, reasons for delay in seeking medical aid, patient compliance or noncompliance with medical regimens). As one might expect, the dichotomy between these two approaches is more distinct conceptually than in actual sociological practice. Be that as it may, sociologists who have concentrated on a sociology of medicine have tended to focus on the profession of medicine and on doctors and to slight the social basis of health and illness. Today, for example, our understanding of the sociology of medical practice and the organization of medicine is much further developed than our understanding of the relationship between social structure and health and illness.

One purpose of this book is to help redress this imbalance. In it, we shift from a focus on the physician and the physician's work to a more general concern with how health and illness are dealt with in our society. This broadened conceptualization of the relationship between sociology and medicine encourages us to examine problems such as the social causation of illness, the economic basis of medical services, and the influence of medical industries, and to direct our primary attention to the social production of disease and illness and the social organization of the medical care system.

Both disease and medical care are related to the structure of society. The social organization of society influences to a significant degree the type and distribution of disease. It also shapes the organized response to disease and illness—the medical care system. To analyze either disease or medical care without investigating its connection with social structure and social interaction is to miss what is unique about the sociology of health and illness. To make the connection between social structure and health, we

must investigate how social factors such as the political economy, the corporate structure, the distribution of resources, and the uses of political, economic, and social power influence health and illness and society's response to health and illness. To make the connection between social interaction and health we need to examine people's experiences, face-to-face relationships, cultural variations within society, and in general how society constructs "reality." Social structure and interaction are, of course, interrelated, and making this linkage clear is a central task of sociology. Both health and the medical system should be analyzed as integral parts of society. In short, instead of a "medical sociology," in this book we posit and profess a *sociology of health and illness.*[2]

## THE CRISIS IN AMERICAN HEALTH CARE

It should be noted at the outset that, by any standard, the American medical system and the American medical profession are among the best in the world. Our society invests a great amount of its social and economic resources in medical care; has some of the world's finest physicians, hospitals, and medical schools; is no longer plagued by most deadly infectious diseases; and is in the forefront in developing medical and technological advances for the treatment of disease and illness.

This said, however, it must also be noted that American health care is in a state of crisis. At least that is the judgment not of a small group of social and political critics, but of concerned social scientists, thoughtful political leaders, leaders of labor and industry, and members of the medical profession itself. But although there is general agreement that a health-care crisis exists, there is, as one would expect, considerable disagreement as to what caused this crisis and how to deal with it.

What major elements and manifestations of this crisis are reflected in the concerns expressed by the contributors to this volume?

*Medical costs* have risen exponentially; in four decades the amount Americans spent annually on medical care increased from 4 percent to nearly 14 percent of the nation's gross national product. In 1994, the total cost was over $1,035 billion. Indeed, medical costs have become the leading cause of personal bankruptcy in the United States.

*Access* to medical care has become a serious problem. An estimated 43 million people have no health insurance and perhaps an equal number are underinsured, so that they do not have adequate financial access to health care when they are sick. American health care suffers from "the inverse coverage law": the more people need insurance coverage, the less they are likely to get it (Light, 1992).

Increasing specialization of doctors has made *primary-care* medicine scarce. Fewer than one out of four doctors can be defined as primary-care physicians (general and family practitioners, and some pediatricians, internists, and obstetrician-gynecologists). In many rural and inner-city areas, the only primary care available is in hospital emergency rooms, where waits are long, treatment is often impersonal, continuity of care is minimal, and the cost of service delivery is very high.

Although the quality of health and medical care is difficult to measure, a few standard measures are helpful. *Life expectancy,* the number of years a person can be expected to live, is at least a crude measure of a nation's health. According to United Nations data, the U.S. ranks seventeenth among nations in life expectancy for males and twentieth for females. *Infant mortality,* generally taken to mean infant death in the first year, is one of our best indicators of health and medical care, particularly prenatal care. The U.S. ranks twenty-first in infant mortality, behind such countries as Sweden, Finland, Canada, Japan, and the United Kingdom (United Nations Demographic Yearbook, 1996).

Our medical system is organized to deliver "medical care" (actually, "sick care") rather than "health care." Medical care is that part of the system "which deals with individuals who are sick or who think they may be sick." Health care is that part of the system "which deals with the promotion and protection of health, including environmental protection, the protection of the individual in the workplace, the prevention of accidents, [and] the provision of pure

food and water. . . ." (Sidel and Sidel, 1983: xxi–xxii).

Very few of our resources are invested in "health care"—that is, in *prevention* of disease and illness. Yet, with the decrease in infectious disease and the subsequent increase in chronic disease, prevention is becoming ever more important to our nation's overall health and would probably prove more cost-effective than "medical care" (Department of Health and Human Services, 1991).

There is little *public accountability* in medicine. Innovations such as Health Systems Agencies, regional organizations designed to coordinate medical services (now defunct), and Peer Review Organizations, boards mandated to review the quality of (mostly) hospital care, had limited success in their efforts to control the quality and cost of medical care. (The incredible rise in the number of malpractice suits may be seen as an indication not of increasing poor medical practice but of the fact that such suits are about the only form of medical accountability presently available to the consumer.) Numerous other attempts to control medical costs—in the form of Health Maintenance Organizations (HMOs), Diagnostic Related Groups (DRGs) and "managed care"—have also largely failed. The lastest attempt, "managed care," is changing how medicine is delivered. But it is not yet clear if it controls costs, and it is most unlikely to increase public accountability.

Another element of our crisis in health care is the *"medicalization"* of society. Many, perhaps far too many, of our social problems (e.g., alcoholism, drug addiction, and child abuse) and of life's normal, natural, and generally nonpathological events (e.g., birth, death, and sexuality) have come to be seen as "medical problems." It is by no means clear that such matters constitute appropriate medical problems per se. Indeed, there is evidence that the medicalization of social problems and life's natural events has itself become a social problem (Zola, 1972; Conrad, 1992).

Many other important elements and manifestations of our crisis in health care are described in the works contained in this volume, including the uneven distribution of disease and health care, the role of the physical environment in disease and illness, the monopolistic history of the medical profession, the role of government in financing health care, inequalities in medical care, the challenge of self-help groups, and possibilities of health care reform. The particularities of America's health crisis aside, most contributors to this volume reflect the growing conviction that the social organization of medicine in the United States has been central to perpetuating that crisis.

## CRITICAL PERSPECTIVES ON HEALTH AND ILLNESS

The third major theme of this book is the need to examine the relationship between our society's organization and institutions and its medical care system from a "critical perspective." What do we mean by a critical perspective?

A critical perspective is one that does not consider the present fundamental organization of medicine as sacred and inviolable. Nor does it assume that some other particular organization would necessarily be a panacea for all our health-care problems. A critical perspective accepts no "truth" or "fact" merely because it has hitherto been accepted as such. It examines what is, not as something given or static, but as something out of which change and growth can emerge. In contrast, any theoretical framework that claims to have all the answers to understanding health and illness is not a critical perspective. The social aspects of health and illness are too complex for a monolithic approach.

Further, a critical perspective assumes that a sociology of health and illness entails societal and personal values, and that these values must be considered and made explicit if illness and health-care problems are to be satisfactorily dealt with. Since any critical perspective is informed by values and assumptions, we would like to make ours explicit: (1) The problems and inequalities of health and medical care are connected to the particular historically located social arrangements and the cultural values of any society. (2) Health care should be oriented toward the prevention of disease and illness. (3) The priorities of any medical system should be based on the needs of the consumers and not the

providers. A direct corollary of this is that the socially based inequalities of health and medical care must be eliminated. (4) Ultimately, society itself must change for health and medical care to improve.

While economic concerns dominated the health policy debate in the 1980s, the development of critical perspectives on health and illness are central to the reform of health care in the 1990s (Mechanic, 1993). Bringing such critical perspectives to bear on the sociology of health and illness has thus informed the selection of readings contained in this volume. It has also informed editorial comments that introduce and bind together the book's various parts and subparts. Explicitly and implicitly, the goal of this work is to generate awareness that informed social change is a prerequisite for the elimination of socially based inequalities in health and medical care.

## NOTES

1. Until 1960 only one journal, *Milbank Memorial Fund Quarterly* (now called *Health and Society*), was more or less devoted to medical sociological writings, although many articles on medicine and illness were published in other sociological journals. Today five more journals focus specifically on sociological work on health, illness, and medicine: *The Journal of Health and Social Behavior; Social Science and Medicine; International Journal of Health Services; Sociology of Health and Illness; Health.* So do the annual volumes *Research in the Sociology of Health Care* and *Advances in Medical Sociology.* Such medical journals as *Medical Care* and *American Journal of Public Health* frequently publish medical sociological articles, as do various psychiatric journals.
2. Inasmuch as we define the sociology of health and illness in such a broad manner, it is not possible to cover adequately all the topics it encompasses in one volume. Although we attempt to touch on most important sociological aspects of health and illness, space limitations preclude presenting all potential topics. For instance, we do not include sections on professional socialization, the social organization of hospitals, and the utilization of services. Discussions of these are easily available in standard medical sociology textbooks. We have made a specific decision not to include materials on mental health and illness. While mental and physical health are not as separate as was once thought, the sociology of mental health comprises a separate literature and raises some different issues from the ones developed here.

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# PART 1 THE SOCIAL PRODUCTION OF DISEASE AND ILLNESS

Part 1 of this book is divided into five sections. While the overriding theme is "the social production of disease and the meaning of illness," each section develops a particular aspect of the sociology of disease production. For the purposes of this book, we define *disease* as the biophysiological phenomena that manifest themselves as changes in and malfunctions of the human body. *Illness,* on the other hand, is the experience of being sick or diseased. Accordingly, we can see disease as a physiological state and illness as a social psychological state presumably caused by the disease. Thus, pathologists and public health doctors deal with disease, patients experience illness, and ideally clinical physicians treat both (cf. Cassell, 1979). Furthermore, such a distinction is useful for dealing with the possibility of people feeling ill in the absence of disease or being "diseased" without experiencing illness. Obviously, disease and illness are related, but separating them as concepts allows us to explore the objective level of disease and the subjective level of illness. The first three sections of Part 1 focus primarily on disease; the last two focus on illness.

All the selections in Part 1 consider how disease and illness are socially produced. The so-called *medical model* focuses on organic pathology in individual patients, rarely taking societal factors into account. Clinical medicine locates disease as a problem in the individual body, but although this is clearly important and useful, it provides an incomplete and sometimes distorted picture. In the face of increased concern about chronic disease and its prevention (U.S. HHS, 1991), the selections suggest that a shift in focus from the internal environment of individuals to the interaction between external environments in which people live and the internal environment of the human body will yield new insights into disease causation and prevention.

## The Social Nature of Disease

When we look historically at the extent and patterns of disease in Western society, we see enormous changes. In the early nineteenth century, the infant mortality rate was very high, life expectancy was short (approximately forty years), and life-threatening epidemics were common. Infectious diseases, especially those of childhood, were often fatal. Even at the beginning of the twentieth century the United States' annual death rate was 28 per 1000 population compared with 7.3 per 1000 today, and the cause of death was usually pneumonia, influenza, tuberculosis, typhoid fever, or one of the various forms of dysentery (Cassell, 1979: 72). But patterns of *morbidity* (disease rate) and *mortality* (death rate) have changed. Today we have "conquered" most infectious diseases; they are no longer feared and few people die from them.

Chronic diseases such as heart disease, cancer, and stroke are now the major causes of death in the United States (see Figure 1-3).

Medicine usually receives credit for the great victory over infectious diseases. After all, certain scientific discoveries (e.g., germ theory) and medical interventions (e.g., vaccinations and drugs) developed and used to combat infectious diseases must have been responsible for reducing deaths from those diseases, or so the logic goes. While this view may seem reasonable from a not too careful reading of medical history, it is contradicted by some important social scientific work.

René Dubos (1959) was one of the first to argue that social changes in the environment rather than medical interventions led to the reduction of mortality by infectious diseases. He viewed the nineteenth-century Sanitary Movement's campaign for clean water, air, and proper sewage disposal as a particularly significant "public health" measure. Thomas McKeown (1971) showed that biomedical interventions were not the cause of the decline in mortality in England and Wales in the nineteenth century. This viewpoint, or the "limitations of modern medicine" argument (Powles, 1973), is now well known in public health circles. The argument is essentially a simple one: Discoveries and interventions by *clinical medicine* were not the cause of the decline of mortality for various populations. Rather, it seems that social and environmental factors such as (1) sanitation, (2) improved housing and nutrition, and (3) a general rise in the standard of living were the most significant contributors. This does not mean that clinical medicine did not reduce some people's suffering or prevent or cure diseases in others; we know it did. But social factors appear much more important than medical interventions in the "conquest" of infectious disease.

In the keynote selection in this book, John B. McKinlay and Sonja M. McKinlay assess "Medical Measures and the Decline of Mortality." They offer empirical evidence to support the limitations of medicine argument and point to the social nature of disease. We must note that mortality rates, the data on which they base their analysis, only crudely measure "cure" and don't measure "care" at all. But it is important to understand that much of what is attributed to "medical intervention" seems not to be the result of clinical medicine per se (cf. Levine et al., 1983).

The limitations of medicine argument underlines the need for a broader, more comprehensive perspective on understanding disease and its treatment (see also Tesh, 1988), a perspective that focuses on the significance of social structure and change in disease causation and prevention.

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# 1 MEDICAL MEASURES AND THE DECLINE OF MORTALITY

*John B. McKinlay and Sonja M. McKinlay*

. . . by the time laboratory medicine came effectively into the picture the job had been carried far toward completion by the humanitarians and social reformers of the nineteenth century. Their doctrine that nature is holy and healthful was scientifically naive but proved highly effective in dealing with the most important health problems of their age. When the tide is receding from the beach it is easy to have the illusion that one can empty the ocean by removing water with a pail.

R. Dubos, Mirage of Health, *New York: Perennial Library,* 1959, p. 23

## INTRODUCING A MEDICAL HERESY

The modern "heresy" that medical care (as it is traditionally conceived) is generally unrelated to improvements in the health of populations (as distinct from individuals) is still dismissed as unthinkable in much the same way as the so-called heresies of former times. And this is despite a long history of support in popular and scientific writings as well as from able minds in a variety of disciplines. History is replete with examples of how, understandably enough, self-interested individuals and groups denounced popular customs and beliefs which appeared to threaten their own domains of practice, thereby rendering them heresies (for example, physicians' denunciation of midwives as witches, during the Middle Ages). We also know that vast institutional resources have often been deployed to neutralize challenges to the assumptions upon which everyday organizational activities were founded and legitimated (for example, the Spanish Inquisition). And since it is usually difficult for organizations themselves to directly combat threatening "heresies," we often find otherwise credible practitioners, perhaps unwittingly, serving the interests of organizations in this capacity. These historical responses may find a modern parallel in the way everyday practitioners of medicine, on their own altruistic or "scientific" grounds and still perhaps unwittingly, serve present-day institutions (hospital complexes, university medical centers, pharmaceutical houses, and insurance companies) by spearheading an assault on a most fundamental challenging heresy of our time: *that the introduction of specific medical measures and/or the expansion of medical services are generally not responsible for most of the modern decline in mortality.*

In different historical epochs and cultures, there appear to be characteristic ways of explaining the arrival and departure of natural vicissitudes. For salvation from some plague, it may be that the gods were appeased, good works rewarded, or some imbalance in nature corrected. And there always seems to be some person or group (witch doctors, priests, medicine men) able to persuade others, sometimes on the basis of acceptable evidence for most people at that time, that they have *the* explanation for the phenomenon in question and may even claim responsibility for it. They also seem to benefit most from common acceptance of the explanations they offer. It is not uncommon today for biotechnological knowledge and specific medical interventions to be invoked as *the major reason* for most of the modern (twentieth century) decline in mortality.[1] Responsibility for this decline is often claimed by, or ascribed to, the present-day major beneficiaries of this prevailing explanation. But both in terms of the history of knowledge and on the basis of data presented in this paper, one can reasonably wonder whether the supposedly more sophisticated explanations proffered in our own time (while seemingly distinguishable from those accepted in the past) are really all that different from those of other cultures and earlier times, or

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any more reliable. Is medicine, the physician, or the medical profession any more entitled to claim responsibility for the decline in mortality that obviously has occurred in this century than, say, some folk hero or aristocracy of priests sometime in the past?

## AIMS

Our general intention in this paper is to sustain the ongoing debate on the questionable contribution of specific medical measures and/or the expansion of medical services to the observable decline in mortality in the twentieth century. More specifically, the following three tasks are addressed: (a) selected studies are reviewed which illustrate that, far from being idiosyncratic and/or heretical, the issue addressed in this paper has a long history, is the subject of considerable attention elsewhere, attracts able minds from a variety of disciplines, and remains a timely issue for concern and research; (b) age- and sex-adjusted mortality rates (standardized to the population of 1900) for the United States, 1900–1973, are presented and then considered in relation to a number of specific and supposedly effective medical interventions (both chemotherapeutic and prophylactic). So far as we know, this is the first time such data have been employed for this particular purpose in the United States, although reference will be made to a similar study for England and Wales; and (c) some policy implications are outlined.

## BACKGROUND TO THE ISSUE

The beginning of the serious debate on the questionable contribution of medical measures is commonly associated with the appearance, in Britain, of Talbot Griffith's (1967) *Population Problems in the Age of Malthus*. After examining certain medical activities associated with the eighteenth century—particularly the growth of hospital, dispensary, and midwifery services, additions to knowledge of physiology and anatomy, and the introduction of smallpox inoculation—Griffith concluded that they made important contributions to the observable decline in mortality at that time. Since then, in Britain and more recently in the United States, this debate has continued, regularly engaging scholars from economic history, demography, epidemiology, statistics, and other disciplines. Habakkuk (1953), an economic historian, was probably the first to seriously challenge the prevailing view that the modern increase in population was due to a fall in the death rate attributable to medical interventions. His view was that this rise in population resulted from an increase in the birth rate, which, in turn, was associated with social, economic, and industrial changes in the eighteenth century.

McKeown, without doubt, has pursued the argument more consistently and with greater effect than any other researcher, and the reader is referred to his recent work for more detailed background information. Employing the data and techniques of historical demography, McKeown (a physician by training) has provided a detailed and convincing analysis of the major reasons for the decline of mortality in England and Wales during the eighteenth, nineteenth, and twentieth centuries (McKeown et al., 1955, 1962, 1975). For the eighteenth century, he concludes that the decline was largely attributable to improvements in the environment. His findings for the nineteenth century are summarized as follows:

> . . . the decline of mortality in the second half of the nineteenth century was due wholly to a reduction of deaths from infectious diseases; there was no evidence of a decline in other causes of death. Examination of the diseases which contributed to the decline suggested that the main influences were: (a) rising standards of living, of which the most significant feature was a better diet; (b) improvements in hygiene; and (c) a favorable trend in the relationship between some micro-organisms and the human host. *Therapy made no contributions, and the effect of immunization was restricted to smallpox which accounted for only about one-twentieth of the reduction of the death rate.* (Emphasis added, McKeown et al., 1975, p. 391)

While McKeown's interpretation is based on the experience of England and Wales, he has examined its credibility in the light of the very different circumstances which existed in four other European countries: Sweden, France, Ireland, and Hungary (McKeown et al., 1972). His interpretation appears to withstand this cross-examination. As for the twentieth century (1901–1971 is the period actually considered),