FRAMING DISEASE

Health and Medicine in American Society series

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INTRODUCTION
Framing Disease: Illness, Society, and History
CHARLES E. ROSENBERG

MEDICINE, an often-quoted Hippocratic teaching explains, “consists in three things—the disease, the patient, and the physician.” When I teach an introductory course in the history of medicine, I always begin with disease. There has never been a time that men and women have not suffered from sickness, and the physician’s specialized social role has developed in response to it. Even when they assume the guise of priests or shamans, doctors are by definition individuals presumed to have special knowledge or skills that enable them to treat men and women experiencing pain or incapacity, who cannot work and fulfill family or other social obligations.¹

But “disease” is an elusive entity. It is not simply a less than optimum physiological state. The reality is obviously a good deal more complex; disease is at once a biological event, a generation-specific repertoire of verbal constructs reflecting medicine’s intellectual and institutional history, an occasion of and potential legitimation for public policy, an aspect of social role and individual—intrapyschic—identity, a sanction for cultural values, and a structuring element in doctor and patient interactions. In some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it.²

In one of its primary aspects, disease must be construed as a biological event little modified by the particular context in which it occurs. As such it exists in animals, who presumably do not socially construct their ailments and negotiate attitudinal responses to sufferers, but who do experience pain and impairment of function. And one can cite instances of human disease that existed in a purely biological sense (certain inborn errors of metabolism, for example) before being disclosed by an increasingly knowledgeable biomedical community. Nevertheless, it is fair to say that in our culture a disease does not exist as a social phenomenon until we agree that it does—until it is named.³
And during the past century that naming process has become increasingly central to social as well as medical thought (assuming the two can in some useful ways be distinguished). Many physicians and laypersons have chosen, for example, to label certain behaviors as disease even when a somatic basis remains unclear, and possibly nonexistent—one can cite the instances of alcoholism, homosexuality, chronic fatigue syndrome, and "hyperactivity." More generally, access to health care is structured around the legitimacy built into agreed-upon diagnoses. Therapeutics too is organized around diagnostic decisions. Disease concepts imply, constrain, and legitimate individual behaviors and public policy.

Much has been written during the past two decades about the social construction of illness. But in an important sense this is no more than a tautology, a specialized restatement of the truism that men and women construct themselves culturally. Every aspect of an individual's identity is constructed—so, also, is disease. Although the social-constructionist position has lost something of its novelty during the past decade, it has forcefully reminded us that medical thought and practice are rarely free of cultural constraint, even in matters seemingly technical. Explaining sickness is too significant—socially and emotionally—for it to be a value-free enterprise. It is no accident that several generations of anthropologists have assiduously concerned themselves with disease concepts in non-Western cultures, for agreed-upon etiologies at once incorporate and sanction a society's fundamental ways or organizing its world. Medicine in the contemporary West is by no means divorced from such affinities.

Some of these social constraints reflect and incorporate values, attitudes, and status relationships in the larger culture (of which physicians, like their patients, are part). But medicine, like the scientific disciplines to which it has been so closely linked in the past century, is itself a social system. Even its technical aspects, seemingly little subject to the demands of cultural assumptions (such as, for example, attitudes concerning class, race, and gender), are shaped in part by the shared intellectual worlds and institutional structures of particular communities and subcommunities of scientists and physicians. Differences in specialty, in institutional setting, in academic training, for example, can all play a role in the process through which physicians formulate and agree upon definitions of disease—in terms of both concept formation and ultimate application in practice. In this sense, the designation "social history of medicine" is as tautological as "social construction of disease." Every aspect of medicine's history is necessarily "social," whether acted out in laboratory, library, or at the bedside.

In the following pages I have, in fact, avoided the term social construction. I felt that it has tended to overemphasize functionalist ends and the degree of arbitrariness inherent in the negotiations that result in accepted disease pictures. The social-constructionist argument has focused, in addition, on a handful of culturally resonant diagnoses—hysteria, chlorosis, neurasthenia, and homosexuality, for example—in which a biopathological mechanism is either unproven or unprovable. It invokes, moreover, a particular style of cultural criticism and particular moment in time—the late 1960s through the mid-1980s—and a vision of knowledge and its purveyors as rationalizers and legitimators, ordinarily unwitting, of an oppressive social order. For all these reasons, I have chosen to use the less programmatic charged metaphor "frame" rather than "construct" to describe the fashioning of explanatory and classificatory schemes of particular diseases. Biology, significantly, often shapes the variety of choices available to societies in framing conceptual and institutional responses to disease; tuberculosis and cholera, for example, offer different pictures to frame for a society's would-be framers.

During the past two decades, social scientists, historians, and physicians have shown a growing interest in disease and its history. The attention paid social-constructionist views of disease is only one aspect of a multifaceted concern. Scholarly interest in the history of disease has reflected and incorporated a number of separate, and not always consistent, trends. One is the emphasis among professional historians on social history and the experience of ordinary men and women. Pregnancy and childbirth, for example, like epidemic disease have in recent years become an accepted part of the standard historical canon. A second focus of interest in disease centers on public health policy and a linked concern with explanation of the demographic change associated with the late-nineteenth and early-twentieth centuries. How much credit should go to specific medical interventions for the decline in morbidity and lengthening life spans and how much to changed economic and social circumstances? The policy implications are apparent: What proportion of society's limited resources should be allotted to therapeutic intervention, how much to prevention and social meliorism generally. Third is the rebirth in the past generation of what might be called a new materialism, in the form of an ecological vision of history in which disease plays a key role, for example, in the Spanish conquest of Central and South America. Fourth is the reciprocal influence of demography on a quantitatively oriented generation of historians and of history on a growing number of demographers. For both disciplines, the study of individual disease incidence provides a viable tactic for ascertaining the mechanisms underlying change in morbidity and mortality. Typhoid rates, for example, can tell us something rather more precise about municipal sanitation and public health administration than can aggregate annual mortality figures to which outbreaks of this waterborne disease may have contributed. Finally, and perhaps most widely influential, is a growing interest in the way disease definitions
and hypothetical etiologies can serve as tools of social control, as labels for deviance, and as a rationale for the legitimation of status relationships. Logically—and historically—such views have in the past generation often been associated with a relativistic emphasis on the social construction of disease. Such interpretations are one aspect of a more general scholarly interest in the relations among knowledge, the professions, and social power. The more critically inclined among such would-be sociologists of knowledge have seen physicians as articulators and agents of a broader hegemonic enterprise, and the “medicalization” of society as one aspect of a controlling and legitimating ideological system.

Often lost sight of in each of these emphases are, first, the process of disease definition, and second, the consequences of such definitions in the lives of individuals, in the making and discussion of public policy, and in the structuring of medical care. We have, in general, failed to focus on the connection between biological event, its perception by patient and practitioner, and the collective effort to make cognitive and policy sense out of this perception. Yet, this process of recognition and rationalization is a significant problem in itself, one that transcends any single generation's effort to shape satisfactory conceptual frames for those biological phenomena it regards as of special concern.

Where an underlying pathophysiological basis for a putative disease remains problematic, as in alcoholism, for example, we have another sort of framemaking, but one that nevertheless reflects in its style the plausibility and prestige of an unambiguously somatic model of disease. That is, the social legitimacy and intellectual plausibility of any disease must turn on the existence of some characteristic mechanism. This reductionist tendency has been logically and historically tied to another characteristic of our thinking about disease—its specificity. In our culture, the existence of a disease as specific entity is a fundamental aspect of its intellectual and moral legitimacy. If it is not specific, it is not a disease, and a sufferer is not entitled to the sympathy, and in recent decades often the insurance reimbursement, connection with an agreed-upon diagnosis. Clinicians and policymakers have long been aware of the limitations of such reductionist styles of conceptualizing disease, but have done little to moderate its increasing prevalence.

Framing Disease

Disease begins with perceived and often physically manifest symptoms. And medicine's historical origins lie in sufferers' attempts to find restored health and an explanation for their misfortune. That search for healing counsel constituted the historical basis for the physician's social role. And an essential aspect of this role developed around the healer's ability to put a name to the patient's pain and discomfort. Even a bad prognosis can be better than none at all; even a dangerous, but familiar and understandable, disease can be emotionally more manageable than a mysterious and unpredictable affliction. It is certainly so from the physician's point of view. Diagnosis and prognosis, the intellectual and social framing of disease, have always been central to the doctor-patient relationship.

The process of framing inevitably includes an explanatory component; how and why did a man or woman come to suffer from a particular ailment? Physicians since classical antiquity have always found intellectual materials at hand with which to explain phenomena they have been asked to treat, imposing some speculative mechanism or another on an otherwise opaque body. The study of an entity or symptom cluster over time indicates the truth of this particular truism.

Physicians have always been dependent on time-bound intellectual tools in seeking to find, demonstrate, and legitimate patterns in the bewildering universe of clinical phenomena they encounter in their everyday practice. In ancient times, for example, references to cooking provided a familiar source for a metaphorical understanding of the body's metabolism, the aggregate functions of which determined the physiological balance that constituted health or disease. Now, at the end of the twentieth century, familiarly automatic immune mechanisms, or the delayed and subtle effects of virus infections are often used to explain diffuse chronic symptoms. To a physician in the late eighteenth and early nineteenth centuries, as we have suggested, humoral models of balance were particularly important—and used to rationalize such therapeutic measures as bleeding, purging, and the lavish use of diuretics. With the emergence of pathological anatomy in the early nineteenth century, hypotetical frameworks for disease were increasingly fashioned in terms of specific lesions or characteristic functional changes that would, if not modified, produce lesions over time. Fermentation had already provided an experimental basis for metaphors explaining epidemic disease, suggesting the ways in which a small quantity of infectious material might contaminate and bring about pathological change in a much larger substrate (as in the atmosphere, water supply—or a succession of human bodies). The germ theory created another kind of framework for imposing a more firmly based taxonomic order on elusive configurations of clinical symptoms and postmortem findings. It seemed only a matter of time before physicians would be able to understand all those mysterious ills that had puzzled their professional predecessors for millennia; the relevant pathogenic microorganisms need only be found and their physiological and biochemical effects deciphered. This was an era, as is well known, in which energetic physicians "discovered" microorganisms responsible for almost every ill known to mankind.
The major point seems obvious. In crafting an explanatory framework physicians employ a sort of modular construction, using intellectual building elements available to their particular place and generation. But the resulting conceptions of disease and its hypothetical origin are not simply abstract knowledge, the stuff of textbooks and academic debates. They inevitably play a role in mediating doctor-patient interactions. In earlier centuries lay and medical views of disease overlapped to some extent, so that shared knowledge tended to structure and mediate interactions between doctors, patients, and families. Today, knowledge is increasingly specialized and segregated, and laypersons are more likely to accept medical judgments on faith. Diagnostic procedures and agreed-upon disease categories are thus all the more important. They guide both the physician's treatment and the patient's expectations.11

Disease as Frame

Once crystallized in the form of specific entities and seen as existing in particular individuals, disease serves as a structuring factor in social situations, as a social actor and mediator. This is an ancient truth. It would hardly have surprised a leper in the twelfth century, or a plague victim in the fourteenth. Nor, in another way, would it have surprised a "sexual invert" at the end of the nineteenth century. These instances remind us of a number of important facts. One is the role played by laypersons as well as physicians in shaping the total experience of sickness. Another is that the act of diagnosis is a key event in the experience of illness. Logically related to this point is the way in which each disease is invested with a unique configuration of social characteristics, and thus triggers disease-specific responses. Once articulated and accepted, disease entities become "actors" in a complex network of social negotiations. Such negotiations have had a long and continuous history. The nineteenth century may have changed the style and intellectual content of individual diagnoses, but it did not initiate the social centrality of disease concepts and the emotional significance of diagnoses once made.

The expansion of diagnostic categories in the late-nineteenth century created a new set of putative clinical entities that seemed controversial at first and introduced a new variable in defining the feelings of particular individuals about themselves, and of society about those individuals. Inevitably, these often contentious social negotiations evoked questions of value and responsibility as well as epistemological status. Was the alcoholic a victim of sickness or of willful immorality? If sickness, what was its somatic basis? And if a mechanism could not be demonstrated, could it simply be assumed? Was an individual sexually attracted by members of the same sex simply a depraved person who chose to commit unspeakable acts, or a personality type whose behavior was in all likelihood the consequence of hereditary endowment?

Such dilemmas are not simply an incident in the intellectual history of medicine but, more generally, an important—and revealing—aspect of changing social values as well as, of course, a factor in the lives of particular men and women. This style of social negotiation is very much alive today, as physicians and society debate issues of risk and lifestyle, and as government and experts assess deviance and evaluate modes of social intervention. The historian can hardly decide whether the creation of such diagnoses was positive or negative, constraining or liberating, for particular individuals; certainly the creation of homosexuality as a medical diagnosis, for example, altered the variety of options available to individuals for framing themselves and their behavior, its nature and meaning. It offered the possibility, for better or worse, of construing the same behaviors in a new way and of shaping a novel role for the physician in relation to these behaviors.

But this is true not only of such morally and ideologically charged diagnoses. A late-twentieth-century diagnosis of heart disease becomes, to cite a commonplace example, an important element of an individual's life, to be integrated in ways appropriate to personality and social circumstance. Diet and exercise, anxiety, denial and avoidance, and depression can all become involved in that integration. Once diagnosed as an epileptic, to cite another example, in centuries before our own—or as a sufferer from cancer or schizophrenia or in our generation—an individual became, in part, that diagnosis. In this sense, chronic, or "constitutional," illness plays a more fundamental social role (in both economic and intrapsychic terms) than the dramatic but episodic epidemics of infectious disease that have so influenced the historian's perception of medicine; we have paid too much attention to plague and cholera, too little to "dropsies" and consumption.

From the patient's perspective, diagnostic events are never static. They always imply consequences for the future and often reflect upon the past. They constitute a structuring element in an ongoing narrative, an individual's particular trajectory of health or sickness, recovery or death. We are always becoming, always managing ourselves, and the content of a physician's diagnosis provides clues and structures expectations. Retrospectively, it makes us construe past habits and incidents in terms of their possible relationship to present diagnosis.

The technical elucidation of somatic disease pictures has steadily added to—and refined—our vocabulary of disease entities. The nineteenth century saw a host of such developments. The discovery of leukemia as a distinct clinical condition, for example, gave a new suddenly altered identity to individuals the microscope disclosed as incipient victims. Before that diagnostic option became available they might
have felt debilitating symptoms—but symptoms to which they could not put a name. With that diagnosis, a patient became an actor in a suddenly altered narrative. Every new diagnostic tool has the potential for creating similar consequences, even in individuals who had felt no symptoms of illness. Mammography, for example, can suggest the presence of carcinoma in the absence of symptoms. Once the radiological suggestion is confirmed, an individual's life is irrevocably changed. A rather different scenario is acted out in less ominous diseases. Our knowledge of the existence, epidemiological characteristics, and clinical course of chickenpox, for example, constitutes an important social resource. A fevered child suddenly covered with angry eruptions could be extremely alarming to its parents had they not had prior knowledge of that clinical entity called chickenpox and its generally benign and predictable course.

Communities as well as individuals and their families necessarily respond to the articulation and acceptance of explicit disease entities and to an understanding of their biopathological character. Perceptions of disease are context-specific, but also context-determining. For example, when it was recognized in the mid-nineteenth century that typhoid and cholera were discrete diseases spread through the water supply, policy choices were reframed not only in practical engineering terms but in political and moral ones. Vaccination, to cite another example, provided a novel set of choices for philanthropists, government policy makers, and individual physicians. Concepts of disease and its causation and possible prevention always exist in both social and intellectual space.

Individuality of Disease

Disease is irrevocably a social actor, that is, a factor in a structured configuration of social interactions. But the boundaries within which it can play its social role are often shaped by its biological character. Thus, chronic and acute diseases present very different social realities, both to the individual, to his or her family, and to society. In a traditional society, for example, one either survived or died of plague or cholera. Chronic kidney disease or tuberculosis, by contrast, may entail long-term welfare problems for a community and economic and personal dilemmas for particular families. In the case of a chronic disease like tuberculosis or mental illness, for example, institutional programs and policies mediate the complex relationship among patients, families, medical staff, and administrators.

The biological character of particular ills defines both public health policies and therapeutic options. Acute and chronic ills obviously con-
Disease as Social Diagnosis

For centuries disease—both specific and generic—has also played another role, that of helping to frame debates about society and social policy. Since at least biblical times the incidence of disease has served as both index of and monitory comment on society. Physicians and social commentators have used the difference between “normal” and extraordinary levels of sickness as an implicit indictment of pathogenic environmental circumstances. A perceived gap between the “is” and the “ought to be,” between the real and the ideal, has often constituted a powerful rationale for social action. The meaning of a particular policy stance to contemporaries might well be thought of as the outcome or aggregate of comparisons between what is and what ought to be; the actual is always measured against the presumably attainable ideal.

Late-eighteenth- and early-nineteenth-century military surgeons worried, for example, about the alarming incidence of camp and hospital disease; the frequency of death and disabling sickness in a youthful male population underlined the need for reform in existing camp and barrack arrangements. Social critics in Europe’s new industrial cities pointed to the prevalence of fevers and infant deaths among tenement dwellers as evidence of the need for environmental reform; the instructive and unquestioned disparity between rural and urban morbidity and mortality statistics presented a compelling case for public health reform. Between the mid-eighteenth century and the present this telling disparity has always played a role in discussions of public health and social environment.

One could easily cite scores of parallel instances. Disease thus became both the occasion and the agenda for an ongoing discourse concerning the interrelationship of state policy, medical responsibility, and individual culpability. It is difficult indeed to think of any significant area of social debate and tension—ideas of race, gender, class, and industrialization—in which hypothetical disease etiologies have not served to project and rationalize widely held values and attitudes. The debate has hardly ceased, as the recent outbreak of AIDS so forcefully emphasizes.

Unity and Diversity

In a much-quoted essay of 1963, the medical historian Owein Temkin traced the history of “The Scientific Approach to Disease: Specific Entity and Individual Sickness.” He organized his analysis of disease concepts around two distinct yet interrelated orientations. One he termed the “ontological” view of disease: the notion that diseases existed as discrete entities with a predictable and characteristic course (and possibly cause) outside of their manifestation in the body of any particular patient. The other he called “physiological”: the view of disease as necessarily individual. Common sense and several centuries of accumulated knowledge tell us that these ways of thinking about disease are separable primarily for analytical purposes; it seems apparent that we do and perhaps must regard diseases as entities apart from their bodily manifestations in particular men and women. At the same time we are well aware that disease as a clinical phenomenon exists only in particular bodies and family settings.

Temkin’s distinction parallels another, emphasized perhaps most prominently in recent years by Arthur Kleinman, between illness as experienced by the patient and disease as understood by the world of medicine. Both the Temkin and Kleinman formulations deal with the fundamental distinction between the specific and the general, the personal and the collective. In a sense, of course, these distinctions—ontological versus physiological, disease versus illness, biological event versus socially negotiated construction—are defensible primarily for analytical and critical purposes. In reality, we are describing and trying to understand an interactive system, one in which the formal understanding of disease entities interacts with their manifestations in the lives of particular men and women. At every interface, between patient and physician, between physician and family, between medical institutions and medical practitioners, disease concepts mediate and structure relationships.

Although we have begun to study the history of disease and have cultivated a growing appreciation of the potential significance of such studies, much remains to be done. As I have tried to argue, the study of disease is a multidimensional sampling device for the scholar concerned with the relation between social thought and social structure. Although it has been a traditional concern of physicians, antiquarians, and moralists, the study of disease is still comparatively novel for social scientists. It remains more an agenda for continued research than a repository of rich scholarly accomplishment. We need to know more about the individual experience of disease in time and place, the influence of culture on definitions of disease and of disease on the creation of culture, and the role of the state in defining and responding to disease. We need to understand the organization of the medical profession and the provision of institutional medical care as in part a response to particular patterns of disease incidence and attitudes toward particular ills. This list could easily be extended, but its implicit burden is clear enough. Disease is both a fundamental substantive problem and an analytical tool, not only in the history of medicine but in the social sciences generally.
NOTES

1. Portions of this essay are repeated or adapted from the author’s “Disease in History: Frames and Framers,” Milbank Quarterly 67 (suppl. 1, 1989):1–15 and are reprinted with permission.

2. Disease can and must also be seen as a taxonomy—with individual ailments arranged in some order—impairing structure. For a more general discussion, see Charles E. Rosenberg, “Disease and Social Order in America: Peasantries and Expectations,” Milbank Quarterly 64 (suppl. 1, 1986):34–55.

3. In the sense I have been trying to suggest, an inborn error of metabolism unknown to a generation’s clinicians was not, in fact, a disease but rather an analogy in the realm of pathology to the tree falling in the forest with no ear to hear.

4. The emergence of AIDS and the intractability of certain psychiatric conditions made visible by the deinstitutionalization movement have both played an important role in underlining the need to factor in biopathological mechanisms in understanding the particular social contexts that frame particular diseases. Physicians and social scientists concerned with such issues necessarily inhabit what might be called a postrelativist moment; neither biological reductionism nor an exclusive social constructionism constitute viable intellectual positions. See Charles E. Rosenberg, “Disease and Social Order,” passim.

5. There is, of course, an abundant sociological literature in this area, particularly in relation to psychiatric diagnoses. The work of Evelyn Coffman has been particularly associated with this emphasis. He also used the “frame” metaphor in his well-known Frame Analysis: An Essay on the Organization of Experience (Cambridge: Harvard University Press, 1974) though in a somewhat different context.

6. The very different modes of transmission imply different relationships to relevant ecological and environmental factors.


8. Among the most influential works in this area have been A. W. Crosby, Jr., The Columbian Exchange: Biological and Cultural Consequences of 1492 (Westport, CT: Greenwood Press, 1972); Crosby, Ecological Imperialism: The Biological

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10. This characteristic helps explain the ambiguous status of psychiatry in medicine—and the enthusiasm that greeted recent somatic explanations of behavioral and behavioral pathology.

11. Contemporary particular advocacy groups may represent in part a response to this asymmetrical distribution of knowledge—and thus power.

12. With today’s sophisticated laboratory medicine and screening of populations at risk, we have created an assortment of pre- or protodisease states accompanied by a difficult assortment of personal and policy decisions. Is the middle-aged male with a high cholesterol level a sufferer from disease? What are his personal responsibilities, and those of society, on his behalf?

13. It might be objected that the “actor” metaphor is inappropriate, implying volition and autonomy; strictly, only people can be actors. Perhaps disease might be more accurately considered a “script,” specifying future behaviors. I prefer the actor metaphor because of its emphasis on the way disease concepts exert influence as independent factors, constraining the options of human actors in social situations.


15. The physician’s diagnostic situation can reflect another sort of biological reality, the endemic incidence of disease in a particular society. The distribution of sickness constitutes a background against which, and in terms of which, the physician evaluates the comparative plausibility of diagnostic options.

16. Which is not to suggest that the need for decisions in some particular cases precludes conflict in other, parallel instances.


18. Temkin himself was careful to note that he employed the terms “physiological” and “ontological” for brevity’s sake. “The Scientific Approach to


PART 1

FRAMING DISEASE