

Bulletin of the History of Medicine

Gert H. Brieger, & Jerome J. Bylebyl, Editors
The Johns Hopkins University

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Published quarterly in March, June, September, and December.

Prepayment is required. **Annual Journal Subscription:** \$40.00, individuals; \$119.00, institutions. **Foreign postage:** \$6.00, Canada & Mexico; \$12.80, outside North America. **Single-issue price:** \$12.00, individuals; \$36.00, institutions. Payment must be drawn on a U.S. bank in U.S. dollars or made by international money order. **Sales tax:** Residents of MD 5% / DC 5.75% / PA 6% / GA 4%. For orders shipped to Canada add 7% GST (#124004946RT). Call for information on becoming a member.



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EJHJ2003

What Is Disease? In Memory of Owsei Temkin

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SUMMARY: This essay outlines a contextual approach to disease (and thus medicine) in society. The work of Owsei Temkin is retrospectively evaluated and shown to rest on an assumed (if often implicit) contextualism. The key components of historical contextualism are then articulated, including the historicity of disease, the reification of specific disease categories in terms of language and social practice, and finally, in contemporary society, the value placed on diagnosis, the bureaucratization of disease, and a logically consistent focus on boundary management and boundary disputes. It is a contextualism that demands a role for the biological as well as the cultural, for practice as well as pathological theory.

KEYWORDS: boundaries, bureaucracy, contextualism, disease, Owsei Temkin, Ludwick Fleck, social construction

The last time I visited Owsei Temkin, I noticed a book on his bedside table, a study of German psychology between the world wars. When I asked about it, he shook his head and reflected with a smile that he had lived through the twenties in Germany, had read widely, yet never realized that he was living in that peculiar era called Weimar.¹ He was, of course, underlining the difference between the past as lived—elusive yet real—and history as retrospectively imposed and ordered. It reminded me of another aphorism I have heard him cite: There was a real past, he said; things happened—and then there was the historian's history, which has always had a complex and contingent relationship to that past.] ✓

This informal philosophy of history seems to me to be linked directly to Temkin's ideas about disease and society. He never doubted a biological

This essay is a somewhat revised version of a talk given at the Owsei Temkin Memorial Symposium held at the Johns Hopkins School of Medicine, 5 October 2002. The notes reflect some afterthoughts and clarifications.

1. The book was Anne Harrington, *Reenchanting Science: Holism in German Culture from Wilhelm II to Hitler* (Princeton: Princeton University Press, 1996).

component in disease, just as he never doubted that real things happened in a real past. But he was equally context oriented and, in that special sense, relativistic about the relationship between medicine's explanatory schemes and the phenomena those ideas sought to explain. Like historians re-creating and explaining the past, Temkin implied, physicians have always used the intellectual tools at their generation's disposal to make etiologic and therapeutic sense of (and to) those patients whose ailments they sought to assuage—to provide meaning where there would otherwise be only randomness.

Illness, Temkin argued, was that portion of suffering which we have historically chosen to assign to medicine. "When and where he [man] began to separate illness from other kinds of suffering we do not know," he argued in 1973, "and down to our own days the demarcation has remained uncertain."² Disease in this sense predated—in fact elicited—medicine, and medicine as social function necessarily predated that which we have come to call science. Although it is conventional to designate "sickness" and "health" as medical categories, he contended, "it is not easy to decide whether these categories themselves, though relating to biological phenomena, still belong in biology."³ Health and disease were neither scientific nor purely social concepts; they belonged to the peculiar hybrid world of medicine.⁴

In his revealing autobiographical essay, "The Double Face of Janus," Temkin emphasized his youthful and continuing interest in philosophy.⁵ But in invoking the term "philosophy" in its connection with medicine, he referred to the place of value and perception in human experience.

2. Owsei Temkin, "Health and Disease," in idem, *The Double Face of Janus and Other Essays in the History of Medicine* (Baltimore: Johns Hopkins University Press, 1977), pp. 419–40, quotation on p. 419. Health and disease were and are exceedingly difficult to define. "A person suffering from an ordinary cold may declare himself ill," Temkin argued by way of example, "whereas the same person laid up with a broken leg may claim to be in perfect health" (ibid., p. 419).

3. Owsei Temkin, "The Scientific Approach to Disease: Specific Entity and Individual Sickness," in ibid, pp. 441–55, quotation on p. 448.

4. "Health and disease are medical concepts in the broadest sense. This means that man's life in its inseparable union of body and mind is seen under the aspects of possible preservation and cure. Thus they are distinguished from purely scientific concepts on the one hand and from purely social ones on the other" ("Health and Disease" [n. 2], p. 438).

5. He was hardly alone among his contemporaries. Philosophy was, after all, along with medicine and history, the third leg in the triangle-shaped logo that symbolized for Henry Sigerist the Leipzig Institute for the History of Medicine's social and intellectual mission. See Owsei Temkin, "Introduction," in *The Double Face of Janus* (n. 2), pp. 3–37, on pp. 8–9. Some of Sigerist's goals for the history of medicine have more recently surfaced under the rubric of bioethics.

He was a moral philosopher by temperament, not an epistemologist or metaphysician. And because he was both a moral philosopher *and* a student of medicine's past he was, I would argue, an obligate cultural historian. In medicine at least, meaning is always situated. It is not surprising that Temkin consistently focused on the historical specificity and clinical relevance of medical ideas.⁶ He saw the Hippocratic texts, for example, as bound together not by an internally consistent intellectual system, but by a "systematic context" that included the exigencies of practice (the emphasis on prognosis, for example, and diet) as well as a set of philosophical concepts. Similarly, to cite another example, Temkin saw the influence of surgery on medical thinking as growing directly out of the surgeon's lesion-oriented clinical tasks.⁷

Some of his readers have been misled by Temkin's skillful deployment of the history of ideas into classifying him as an intellectual historian—committed to the formal analysis of medical concepts, and abstracted from the physician's day-to-day realities. Such readings reflect the influence of his widely cited—and seemingly transhistorical—distinction between the ontological and physiological styles of understanding disease.⁸ The ontological view sees individual diseases as existing independently of their manifestations in any particular man or woman; the physiological view, on the other hand, sees disease as a fundamentally individual phenomenon, the consequence of uniquely configured factors in particular men and women interacting with their peculiar environmental

6. Temkin also saw the biological, like the cultural, as historically specific in its influence on medical thinking. Thus, for example, the influence of a particular era's disease ecology in shaping the way clinicians thought about the ills they treated. "Sydenham, the ontologist," as Temkin pointed out, "lived at the time of the great plague of London, and the plague, I understand, has little concern with individual variations" ("Scientific Approach" [n. 3], p. 455). One thinks, by way of contrast, of our generation of clinicians faced with an array of degenerative, and often interactive, ailments—and attracted by genetic models of pathobiology.

7. See Temkin, "Introduction" (n. 5), p. 13, for the "systematic context" as opposed to system argument. For the reference to surgery, see his much-cited essay: Owsei Temkin, "The Role of Surgery in the Rise of Modern Medical Thought," *Bull. Hist. Med.*, 1951, 25: 248–59. Similarly, in explaining why his projected history of irritability had grown so enormously in scope and time, Temkin explains that "it was not satisfactory to deal with irritability and irritation as concepts without asking what actual forms of behavior they represented at varying times" ("Introduction" [n. 5], p. 31).

8. Temkin, "Scientific Approach" (n. 3). This much-discussed essay originally appeared in 1963 in *Scientific Change: Historical Studies in the Intellectual, Social, and Technical Conditions for Scientific Discovery and Technical Invention from Antiquity to the Present*, ed. Alistair C. Crombie (New York: Basic Books, 1963), pp. 629–47. This essay remains, among Temkin's many works, the one most likely to have been read by nonspecialists.

circumstances. Because this schematized typology underwrites powerful and value-imparting narratives, it has developed a historiographic life of its own (benefitting from the same seductive utility as the distinctions between lumpers and splitters, or hedgehogs and foxes). The ontological view has become associated with a celebratory history of postmortem and laboratory-initiated progress, a reductionist trajectory of increasing understanding and mastery of nature, while the physiological has been associated with skeptical, clinical, holistic points of view—and their opposition has resonated with the value-laden antinomies of science vs. art, laboratory vs. bedside, reductionism vs. holism, realism vs. nominalism. Temkin, however, felt that this thematic dichotomy of physiological as opposed to ontological, although useful as an analytic tool, was not a sufficient explanation or description of any particular moment or incident. “The question: does disease exist or are there only sick persons? is an abstract one,” he cautioned,

and, in that form, does not allow a meaningful answer. Disease is not simply either the one or the other. Rather it will be thought of as the circumstances require. The circumstances are represented by the patient, the physician, the public health man, the medical scientist, the pharmaceutical industry, society at large, and last but not least the disease itself.⁹

Disease should, that is, be understood in context, as a time- and place-specific aggregate of behaviors, practices, ideas, and experiences.¹⁰

9. Temkin, “Scientific Approach” (n. 3), p. 455. His use of the words “disease itself” implies what might be described as a nonrelativist position: “the picture of the disease as an entity devoid of individual features has a very real existence,” he explained, “though we must leave it to the metaphysician to determine the nature of this particular form of existence” (ibid).

10. “Experience” should be understood as including the biological as well as the cognitive and the emotional. There are a number of styles or emphases in the historical and ethnographic study of disease that might be termed “contextual.” The term can (and should) imply material and institutional as well as cultural and intellectual factors. A larger understanding of contextualism, in fact, demands that these seemingly disparate realms be seen as necessarily interactive and mutually constitutive. But this program is dauntingly inclusive; even-contextually oriented historians almost always choose to emphasize one aspect over another in their work. Temkin’s approach foregrounds explanatory concepts. His colleague, friend, and fellow Leipzig student Erwin Ackerknecht can also be termed a contextualist, for example, but Ackerknecht’s classic study of malaria demonstrates another style of contextualism—one that might be called ecological, focusing on the socio-economic, climatic, and geographic as well as intellectual factors that resulted in changing malaria incidence: cf. Erwin Ackerknecht, *Malaria in the Upper Mississippi Valley, 1760–1900* (Baltimore: Johns Hopkins Press, 1945). Yet these varied contextualisms are not logically inconsistent—even as they foreground different aspects of a complex and multidimensional world of ideas, practices, and things.

Among those actors were and are the biological factors that ordinarily (if elusively) underlie a sufferer’s felt symptoms. Diseases have, according to Temkin, a somatic individuality—but one always construed in cultural and historical terms.¹¹ Thus, for example, he felt that every ailment has its particular moral and emotional profile, a profile not unrelated to its characteristic symptoms. “We do not easily think of dysentery as carrying spiritual value,” he noted wryly, suggesting that medical historians might find a promising field in the creation of a “moral nosology” . . . as a systematic study of the stigmata and values that have been connected with individual diseases.¹²

Temkin was, as I have emphasized, an eclectic and a contextualist—a believer in what might loosely be termed a gestalt approach to understanding disease as at once a biological and a social phenomenon. There are many advantages to such an inclusive approach, but perhaps most important, it is a framework that makes it impossible to ignore the precise relationships between a suffering individual and the culture that provides meaning for his or her—necessarily idiosyncratic—pain.

11. It is no accident that both Ludwik Fleck (six years older) and the youthful Temkin wrote specifically about the worldview assumptions that shaped early modern perceptions of syphilis. Nor is it an accident that Temkin was a good friend of Norbert Elias (five years older). Elias too was concerned, though in a more self-consciously sociological way, with the historical linkages among the body, cultural perception, and human agency. All three—Temkin, Fleck, and Elias—were undeniably different, yet in some ways similar. Temkin was not a sociopolitically oriented epistemologist-cum-historical-sociologist of knowledge like Fleck, and he was a more cautiously traditional, high-culture oriented historian than Elias—but all three secular Jews sought to explore the interpenetration of socially situated ideas and value orientations in specific historical settings. Temkin’s article “Zur Geschichte von Moral und Syphilis” was published in 1927 in the *Archiv für Geschichte der Medizin* (19: 331–48), and appears in translation in *Double Face* (n. 2): “On the History of ‘Morality and Syphilis,’” pp. 472–84. See also Ludwik Fleck, *Genesis and Development of a Scientific Fact* (Chicago: University of Chicago Press, 1979); Norbert Elias, *The Civilizing Process: The Development of Manners, Changes in the Code of Conduct and Feeling in Early Modern Times* (translation of vol. 1, *The History of Manners*) (New York: Urizen Books, 1978).

12. Owsei Temkin, “Some Moral Implications of the Concept of Disease,” in idem, *On Second Thought and Other Essays in the History of Medicine and Science* (Baltimore: Johns Hopkins University Press, 2002), pp. 49–59, quotation on p. 56. There are many examples of disease symptomatology shaping society’s response to sufferers. Tuberculosis provides a conspicuous example: see, for example, René and Jean Dubos, *The White Plague: Tuberculosis, Man, and Society* (Boston: Little, Brown, 1952); Susan Sontag, *Illness as Metaphor* (New York: Farrar, Straus and Giroux, 1978). Temkin’s classic study of “epilepsy” provides another instance of an ailment whose arresting symptoms elicited powerful social responses: Owsei Temkin, *The Falling Sickness: A History of Epilepsy from the Greeks to the Beginnings of Modern Neurology* (Baltimore: Johns Hopkins Press, 1945; rev. ed., 1971).

Disease in Context

This situated approach to disease was so congenial to me as a student that it is only gradually and in retrospect that I have become aware that it is, in fact, a distinctive point of view. And because it is, I would like to be more self-conscious in specifying what seem to me three fundamental aspects of this contextual style of understanding disease.

First, we cannot discuss the *what* of disease without discussing the *when* and the *where*. Philosophers, paleopathologists, immunologists, clinicians seeking to "diagnose" illustrious figures in the past—all may have their own set of disciplinary priorities and perceptions, but for social scientists and most humanists disease is necessarily historical (as is medicine more generally), and the historian necessarily an ethnographer. Even those contemporary Western notions of disease specificity that seem to most of us somehow right and inevitable, so heuristically useful, so productive of insights into the body in health and disease are, of course, artifacts of a particular moment in time and of particular institutional and intellectual developments. They are, that is, socially constructed, like everything else in our culture—even if they have led incrementally to more circumstantial understandings of particular biopathological mechanisms and more efficacious clinical practices.¹³

A second assumption of what I have termed the contextual viewpoint lies in the way disease concepts function as elements in a communication system, as units of intelligibility. And that intelligibility lies at the heart of medicine as a functioning social institution. Communication implies a mutually comprehensible (or seemingly comprehensible) vocabulary; and disease categories and related notions of etiology and pathology are an important part of that vocabulary, allowing patient and practitioner to share a measure of understanding.¹⁴ During the past two centuries, such categories have become increasingly central to that shared understanding. In a classic and much cited-formulation, medicine has been seen as

13. The phrase "social construction" is thus little more than a polarizing slogan, more useful as mobilizing rhetoric than as analytic tool. "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" (Charles E. Rosenberg, "Framing Disease: Illness, Society, and History," in *idem, Explaining Epidemics and Other Studies in the History of Medicine* [Cambridge: Cambridge University Press, 1992], p. 306).

14. I use the word "seemingly" advisedly. The same word may have different meanings for the several actors in a clinical interaction—doctor and patient, man and woman, specialist and primary care physician—but still serve as a necessary structural element in making that system work as a system.

constituted by patient, disease, and physician. But it is, of course, not simply patient and physician as idealtypical social roles: both the terms "physician" and "patient" are abstractions, representing positions in a schematized social system. Historians and social scientists studying any *particular* social world, however, must consider not only doctor and patient, but the specific content of the actors' heads. Clinical experience and observations—"facts"—are imbued with meaning only when they are placed in "an understandable context," as Temkin put it, "analogous to words in a sentence."¹⁵ And that intelligibility is necessarily time- and place-specific.

A third element in my contextual understanding of sickness is the assumption that individual disease concepts exist as social entities—in the form of linguistic and social practice, in ways complexly and not always directly related to a possible substrate in a specific biopathological mechanism.¹⁶ Disease has always been a social as well as a biological entity—though the components of that social entity have varied enormously over time. I refer to the diverse history of etiologic and therapeutic ideas and practices that range from traditional notions such as feeding a cold and starving a fever, or avoiding a sudden stoppage of perspiration, to the most technologically advanced of today's imaging techniques and evidence-based treatment protocols. The linkage of ideas and practices guaranteed, and guarantees, that disease concepts will have an impact on particular women and men. The historically tenacious practice of bloodletting reflected notions of balance, for example, often but not always explicitly humoral; today's treatment protocols reflect a very different sort of understanding of the body in health and disease, but they still link disease concept with therapeutic—and, in the contemporary world, bureaucratic—practice. In this sense, the patient always exists in tension with the aggregated case records of every previous patient, with the collective experience and agreed-upon medical certainties of his or her time and place. Modern imaging and laboratory tools only intensify the mutually constitutive nature of these relationships. We are our laboratory outputs and can in good measure be understood—

15. Temkin, "Introduction" (n. 5), p. 15.

16. I discuss the "social entity" approach at greater length in Charles E. Rosenberg, "Tyranny of Diagnosis: Specific Entities and Individual Experience," *Milbank Quart.*, 2002, 80: 237–60. Temkin's reference to the paradox posed by smallpox vaccination as practice in the absence of clinical smallpox as clinical reality indicates his awareness of this issue: Temkin, "Scientific Approach" (n. 3), p. 455. He was also aware that well-marked clinical syndromes might be neglected by clinicians because their cause had not been found and they seemed nonspecific: *ibid.*, p. 449.

read—only in terms of the way those outputs track onto an agreed-upon repertoire of disease templates. But let me add a word of clarification: That disease is a social entity, and thus socially constructed, means neither that it has no biological basis, nor that it is “unreal.” Social expectations and institutional practices are real indeed—as real, in their particular way, as the sufferer’s felt symptoms that elicit collective social and institutional responses.¹⁷

Disease Today

Though it may seem contradictory in terms of my emphasis on the social and historical specificity of disease entities, it is also true that each generation (and place) shares a characteristic framework for thinking about disease and the body generally—in Ludwik Fleck’s idiosyncratic terminology, a *Denkstil*. It was natural, for example, for a seventeenth-century Puritan to think of disease as the indicator of an individual or community’s spiritual status. It was equally natural, if seemingly paradoxical, for the same seventeenth-century Englishman to assume environmental—including astrological—second causes for the incidence of epidemic disease. Not surprisingly, we have our own cultural assumptions, ones we take so much for granted that they have become opaque.¹⁸ As I see it, there are four such fundamental—intricately linked, but separable—aspects of our generation’s particular *Denkstil* in conceptualizing disease.

First is the tightness and prominence of the specific disease entity as a coherent organizing concept (reified in the form of diagnostic, therapeutic, and bureaucratic practice). Most of our social and intraprofessional debates turn not on formal questions of epistemology and ontology, but on the contested legitimacy of *particular* diseases—and the practices that validate or fail to validate them. Controversy over disease definitions is in general a political, not a philosophical, problem. One thinks of problematic contemporary entities such as chronic fatigue syndrome, multiple chemical sensitivity, chronic Lyme disease, or Gulf War syndrome. Advocates for such problematic entities are often skepti-

17. It is significant that neither Michel Foucault nor Erving Goffman, often read as implicitly endorsing antiontological views, categorically rejected the idea that severe mental illness might have a biological substrate—though they did in their different ways articulate the time- and culture-specific character of disease concepts and social responses.

18. I do not mean to imply that a culture’s views of health and disease are monolithic and universally distributed and assimilated. Obviously differences in cohort, gender, class, region, race, and ethnicity imply differences in belief. Nevertheless, I think it is still useful to try to delineate certain widely distributed assumptions.

cal of medical authority, but rarely question the mechanism-based legitimacy of “their” disease, or of disease more generally. It is in fact precisely that status which they claim: the reductionist legitimacy based on the existence of an ultimate biopathologic basis for their elusive symptoms. They do not question the causal relationship; what they do question is the unwillingness (or inability) of the medical establishment to recognize, study, and elucidate the presumed mechanism. A variety of social critics have in the past two generations questioned this reductionist style of understanding and defining disease, but such skeptics have remained an oppositional minority. The great majority of our contemporaries, both lay and medical, assume the unambiguous identity—the reality—and heuristic value of specific, mechanism-based disease concepts.

A second characteristic of contemporary styles of thinking about disease lies in the extraordinary value we place on such concepts. I use “value” here in two senses. One refers to the importance of disease categories—and diagnosis—in shaping individual identity, in legitimating suffering and the sick role’s prerogatives. A second kind of value (not entirely unrelated) is the functional importance of disease categories in their relationship to the administration and management of health care. Disease, I must repeat, does not exist in the domains of clinical and bureaucratic practice as a general quality or experience: without a specific diagnosis it remains largely invisible—unreadable—to the world of clinical medicine. In the words of a cynical (if familiar) aphorism: “If it can’t be coded, it doesn’t exist.” The needs of bureaucratic systems and the rationalizing trend within medical therapeutics align the acceptance of clearly bounded diseases with the need for discrete categories to at once initiate and legitimate behaviors (in the everyday forms of diagnostic and treatment protocols, admission decisions, and—at least in the United States—formulae for reimbursement). In this sense, disease categories serve as integrating mechanisms, facilitating countless micro-decisions and thus linking different parts of the health-care system in a way that seems both necessary and proper. Some years ago, to put this point in different terms, I compared a nosological table to the Rosetta Stone, as translation mechanisms—the latter making languages mutually intelligible, the former translating individual experience into administratively readable units.¹⁹ Bureaucratic needs, that is, imply a bias toward the creation of seemingly discrete disease categories. The controversial yet seemingly ineluctable elaboration of the American Psychiatric Association’s DSM categories in the last two generations provides a striking example of this phenomenon: even clinicians skeptical of the

19. Rosenberg, “Framing Disease” (n. 13), p. 316.

ontological status of these categories have found it necessary to employ them; they are simply too useful.

Which suggests the third, closely related—in some ways indistinguishable—theme. This is what I would call the bureaucratization of disease. I refer to a long-term trend exemplified, for example, by the evolution of hospital records from discursive narratives, to conventional ledger formats, to printed forms, to filing systems, and finally to electronic versions. I refer similarly to the treatment rules of evidence-based medicine, reflecting and incorporating the results of randomized clinical trials and consensus conferences. This tendency obviously relates to the vexed contemporary question of ensuring optimum clinical efficacy at reasonable cost, but reflects at the same time a more general trend—in the direction of centrally managed uniformity in the provision of diagnostic and therapeutic services. Such trends long antedate contemporary managed care schemes. And insofar as these bureaucratic procedures are instituted, they not only utilize specific disease entities, but in a measure come to constitute those entities. In some ways (and certainly the bureaucratic) all disease as conceived, managed, and experienced is iatrogenic—if that peculiar term is broadened to include not just medicine in the form of clinical interactions, but the health system in all of its aspects. For disease includes diagnostic procedures, standardized treatments, and agreed-upon clinical trajectories that increasingly subsume diagnosis and prognosis.²⁰ And it should include as well institutional responses that shape both professional and patient lives. I refer to a variety of organizational adaptations ranging from specialized treatment sites—cancer or diabetes centers, for example—to medical subspecialties and disease-oriented advocacy groups.

Negotiating Boundaries

All of which implies the fourth characteristic of contemporary thinking about disease: that is, the omnipresence of conflict and negotiation at

20. In the contemporary United States especially, it is clear that one of the characteristics of disease concepts—in their manifestation as social entities—is their intensification and diffusion through commodification. It is true that the term “commodification” is used so loosely by contemporary scholars and social critics that it lacks specificity. On the other hand, in the narrow sense of describing the effects of the linked research and marketing strategies of pharmaceutical companies, for example, the term seems entirely appropriate. But the linkage of such policies with public sector regulation and professional and business strategies is so complex and multidimensional that it is hard to disaggregate the commodification of disease from bureaucracy and its functional needs, and from market behavior generally.

the boundaries of particular ills. Such conflict is a logical consequence of the very power and persuasiveness of specific disease categories; the value of disease implies equity—and equity, conflict. In a medical world dominated by the idealtype of disease as specific and mechanism-based, the stakes of diagnosis are high. Boundary-setting is inevitably excluding as well as incorporating, and the conferring of a particular diagnosis can be legitimating or stigmatizing. Individual and family hopes as well as treatment plans can turn on the “accuracy” of particular diagnoses. Let me suggest four aspects of boundary management so as to illustrate the pervasive dimensions of this phenomenon.

One kind of conflict turns on the issue of subjectivity and objectivity. Who owns disease, and what counts as evidence? Are a patient’s “subjective” pain and disability to be discounted when they seem to have no discernible physical basis? or because they seem so trivial and nonthreatening that they fit into neither the nosologies nor the time and value priorities of the medical profession? I refer to the enormous clinical burden of such ills as headache, insomnia, chronic back pain, irritable bowels. Are they intractable and idiosyncratic conditions of life? or symptoms of “actual” diseases? Issues of authority as well as epistemology—and social policy—are raised by all such questions. And issues of authority have numerous aspects—it is not just the individual’s perception of illness as opposed to the licensed practitioner’s diagnosis of disease. The conflicts include differences among the similarly “objective” claims of specialties and subspecialties. Who is to manage back pain? control invasive cardiac diagnostic technologies? There are many such instances of conflicted intraprofessional authority, as well as recurring conflicts between regularly credentialed practitioners and the claims of alternative healers. One can cite as well the long-standing conflicts between medicine and the law—between doctors and lawyers—in regard to behaviors that might be regarded either as sinful and blameworthy or, on the contrary, as the products of a disease process and thus to a degree excusable.²¹

This implies a second kind of endemic boundary conflict, which reflects the difficulties of defining and responding to ailments whose manifestations are primarily or exclusively behavioral or emotional. Controversies surrounding the proper categorization of behavior and emotion are in fact far more pervasive than one would think from the comparatively small number of such instances that surface in the civil and criminal courts. Depression, compulsions, manic moods all represent

21. Obviously, malpractice, disability, and product liability cases represent other areas of civil contestation in which the definition and etiology of disease are debated.

behaviors that shade from what might be called normally distributed variants through what might seem to be incapacitating pathologies. But where does one draw the line? When does depression, either chronic and long-term or situational, shade into what many of us casually call clinical depression?²² And why is it important to have language—in the term “clinical depression”—that demarcates disease as opposed to one end of an emotional spectrum? Even when the term “clinical depression” is so obviously circular? To ask such questions is to underline the tenacious social utility of such verbal stratagems. The awarding of diagnoses is one way of managing individual pain and social deviance, yet one that will remain endlessly contested at both the individual and social system levels.

And the diagnoses will remain contested because of another—closely linked—aspect of boundary tensions: that is, the existence of an implicit yet socially meaningful boundary between agency and the guilt-reducing randomness of somatic illness. How much are we responsible for our own pain and suffering? In an era of chronic disease, such questions remain unsettling. How do we allocate blamelessness? How do we weigh the moral burden of contributory negligence by the smoker or imprudent eater? Were AIDS victims morally responsible for their medical plight, or the victims of a random virus? These are both individual and policy issues—and the often-contested boundaries of “legitimate” disease become rhetorical tools in the public sphere as well as coloring social and familial attitudes toward particular individuals. Courts of law have been the site, of course, for a very special history of debates over the relationship(s) among disease, cognition, self-control, and moral acuity. Did a disease process impair the individual’s ability to understand the difference between wrong and right and to control impulses in accordance with such social norms? Did a particular disease process undermine an individual’s cognitive ability such that he or she could not write a valid will or enter into a valid contract? To mention these issues is to underline how far we are from consensus. Every contested will or claim of criminal responsibility reenacts in microcosm these complex and contentious issues.

A fourth aspect of boundary work grows out of the slippery slopes created by what one might call technocreep—by our growing technical capacity and dependence on the laboratory to elicit evidence of previously invisible pathologies. Many of our increasingly pervasive and powerful diagnostic tools create new ways of thinking about disease, new

22. It is significant that most lay people would explain the difference in terms of “brain chemistry”—underlining the legitimating power of mechanism-based disease models.

outputs whose determinations can be read as proxies for disease states. One thinks of silent heart attacks, of elevated cholesterol levels and hypertension. (“Obesity,” although it is far from invisible, provides another sort of example of the ill-defined boundary between risk as predictor and disease entity.) All these protodiseases have in common their ordinarily symptomless quality and their dependence on newly shifting diagnostic criteria. And all pose public policy, therapeutic, and preventive dilemmas. In an era of chronic disease, our technical capacities have helped ensure the increasing pervasiveness of risk factor analysis—which constitutes another context in which the boundaries of disease become porous, while de facto disease categories proliferate. That slippery slope embedded in the notion of risk adds another kind of socially pervasive boundary negotiation.²³ When does risk as statistical likelihood become disease as social entity? That it does so can hardly be denied. Whether proxy or indicator, an elevated blood pressure, for example, creates a new social entity in the guise of “hypertension.” Genetic diagnosis and counseling promises to dramatically extend this sphere of immanent illness. It is also an occasion for negotiation by many actors: specialists and subspecialists, pharmaceutical companies, clinical epidemiologists, laboratories with differing capacities. All such controversies individually and collectively illuminate the complex process through which disease is socially articulated, defined, and managed. In this sense many ailments are at least in some measure what I have termed iatrogenated—created, that is, by the ideas, practices, and personnel of medicine. Certainly such symptomless ills as are diagnosed in the laboratory or imaging suite are, quite literally, created by medical technology, personnel, and clinical practices.

The Last Boundary

A final boundary subsumes all these areas of contestation and ambiguity, yet implies certain more general questions. I refer to the (meta)boundary between the individual man or woman—where his or her skin ends—and the world(s) of culture, of ideas, of language, of conceptual categories, and of social relationships outside that skin. It is a boundary brutally concrete, yet elusively labile and continuously negotiated. In this sense,

23. For a more detailed discussion, see Charles E. Rosenberg, “Banishing Risk: Or, the More Things Change the More They Remain the Same,” *Perspect. Biol. & Med.*, 1995, 39: 28–42; reprinted in somewhat different form as “Banishing Risk: Continuity and Change in the Moral Management of Disease,” in *Morality and Health*, ed. Allan M. Brandt and Paul Rozin (New York: Routledge, 1997), pp. 35–52.

disease categories represent a microcosm of and metaphor for the constricting social world. And that relationship embodies a characteristic modern irony: the intelligibility that comes with disease categories and their heuristic—scientific and therapeutic—value comes at the cost of objectification. To have one's felt ailment made tangible through diagnosis is necessarily alienating; it is to become—literally—another, a being created by the collective history and practices of medicine specifically, and of society generally. It underlines as well the centrality of the boundary work that defines the individual in his or her particular social world. Consciousness—for want of a less problematic term—mediates the relationship between the individual as biological system (the individuality inside the skin) and the individual as actor in a social/cultural system. And the negotiations at that boundary between the individual and society are at no time more problematic and intense—more definingly individual—than at moments of pain, sickness, impending death. Though disease categories are in one dimension abstract they have, as we have seen, real-world consequences for particular men and women in terms of clinical treatment, of quality of life, perhaps even of life chances.

In some ways this is the best and worst of times in medicine. We are beset by fantasies of control and of being controlled—visions of a long and pain-free life, of cloning, of organ replacement, of gene therapy and genetically individualized therapeutics—and haunted by a dystopian universe of lives prolonged in pain and incapacity by machines and the relentless dictates of treatment protocols. And it is not only in the extreme environment of the ICU that patients and their families feel such alienation: in everyday practice, patients complain of being reduced to their diagnosis, of the insensitive demands of software, of the dehumanizing objectification built into the rationalizing notions of quality control, of evidence-based medicine, of centrally administered treatment protocols. Many clinicians articulate similar criticisms from their particular perspective. They fear becoming mere devices, mediating nodes in a bureaucratized, rationalized, and disease-based medicine. It is a fear that has increased steadily since the first decades of the twentieth century, when reformers already warned of a trend toward treating diseases and not particular men and women. In the West's bureaucratic and technology-dependent environment it is ironic that in some ways pain and sickness remain a final and inaccessible citadel of human idiosyncrasy. We are shaped by our diagnoses, but we are not reduced to them. The relationship between ourselves and our diagnoses illuminates and in part constitutes the negotiated texture of individuality itself as boundary phenomenon; and it is in fact such boundary work that in some measure defines identity.

Medicine, as Owsei Temkin both argued and demonstrated, is a particularly revealing site for the study and contemplation of such fundamental aspects of the human condition.²⁴ "Modern physics," he explained on one occasion, "boastfully or plaintively speaks of the meaningless universe. But there is no meaningless universe in medicine. Human beings are not satisfied with viewing health and disease as matters of mere chance separable from their lives."²⁵ Nor are we blank slates on which technological systems inscribe uniform meanings. Medicine will always remain a moral as well as a technical enterprise, reflecting individual needs and cultural as well as laboratory values.

24. "Medicine," he explained, "is not only a science and an art; it is also a mode of looking at man with compassionate objectivity." Temkin, "Introduction" (n. 5), p. 37.

25. Owsei Temkin, "An Historical Analysis of the Concept of Infection," in idem, *Double Face of Janus*, pp. 456–71, on p. 471.