The Tyranny of Diagnosis: Specific Entities and Individual Experience

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DIAGNOSIS HAS ALWAYS PLAYED A PIVOTAL ROLE IN medical practice, but in the past two centuries, that role has been reconfigured and has become more central as medicine—like Western society in general—has become increasingly technical, specialized, and bureaucratized. Disease explanations and clinical practices have incorporated, paralleled, and, in some measure, constituted these larger structural changes.

This modern history of diagnosis is inextricably related to disease specificity, to the notion that diseases can and should be thought of as entities existing outside the unique manifestations of illness in particular men and women. During the past century especially, diagnosis, prognosis, and treatment have been linked ever more tightly to specific, agreed-upon disease categories, in both concept and everyday practice. In fact, this essay might have been entitled "Diagnosis Mediates an Invisible Revolution: The Social and Intellectual Significance of Specific Disease Concepts." It would have been even more precise, if rather less arresting.

This title also would have the virtue of emphasizing both the importance and comparative novelty of 19th- and 20th-century conceptions of disease, ideas we have come to take so much for granted that they have become invisible. It would not be inappropriate, however, to compare

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the cultural impact of modern assumptions about the specific nature of disease with the effects of the Newtonian, Darwinian, or Freudian revolutions, "events" that have been long assimilated into the accepted canon of cultural visibility and the subject matter of history textbooks. Certainly this cultural impact is comparable to those conceptual shifts in terms of the ways in which ordinary men and women think about themselves and others. Everywhere we see specific disease concepts being used to manage deviance, rationalize health policies, plan health care, and structure specialty relationships within the medical profession. And I have not even mentioned the countless instances in which clinical interventions and expectations have altered the trajectory of individual lives.

My interest in the history—and historicity—of disease categories began more than a quarter century ago with two incidents fortuitously linked in time. One was my serving as a consultant to a large demographic project studying the causes of death in Philadelphia between 1880 and 1930. The principal investigator faced a methodological dilemma in her critical reading of manuscript death certificates: how were they to code diagnoses like "old age," "senile," or "marasmus" still common in 1880 but banished by 1930? In previous archival research, I had been struck by early 19th-century hospital case records in which either no diagnosis was recorded or general descriptive terms (*fever, fits, dropsy*) served as diagnosis. At about the same time (in the early 1970s) as this coding dilemma, the American Psychiatric Association was undergoing an embarrassingly public struggle over the revision of its *Diagnostic and Statistical Manual.* Most conspicuously, psychiatrists voted, argued, then voted again as they reconsidered the problematic category of homosexuality. Was this a disease or a choice? How could a legitimate disease—in most physician's minds, a biopathological phenomenon with a characteristic mechanism and a predictable course—be decided by a vote, especially one influenced by feverish lobbying and public demonstrations (see Bayer 1981; Grob 1991; Kirk and Kutchins 1992; Kutchins and Kirk 1997)?

What was particularly striking at the end of the 20th century was the variety of contexts in which we have become accustomed to seeing disease concepts being negotiated in public. On September 5, 1997, the *Philadelphia Daily News* reported that a school bus driver in rural Selinsgrove, Pennsylvania, felt, as he put it, like a woman trapped in a man's body and expressed himself by wearing women's clothing, a wig, and eyeliner while driving his bus to and from school. When anxious parents demanded that he be dismissed, the driver was perplexed: "I don't understand what all the fuss is about. I am diagnosed with gender identity disorder syndrome, and I am being treated."

Gender identity is only one such concept. Contested and widely discussed diagnostic categories such as attention deficit hyperactivity disorder or chronic fatigue syndrome—not to mention road rage, premenstrual syndrome, and addictions to gambling and sex—have become familiar subjects for public discussion. Physicians are not the only participants in such contentious debates. Not too long ago, to cite another sort of example, feminists challenged the Centers for Disease Control's prevailing definitions of AIDS as ignoring those opportunistic infections peculiar to women. And what are we to make of so-called risk factors such as elevated cholesterol levels or blood pressure or marginal bone densities in postmenopausal women? Are they statistically meaningful predictive indicators? Substantive factors in a multicausal etiology? Or diseases in themselves?

The social power—and, I should add, utility—inherent in naming diseases is routinely demonstrated in the administrative world of medicine as well as in the wider culture. For example, the Hospital of the University of Pennsylvania, reinvented not long ago as a component of a corporate health care system, boasted of having created 40 evidence-based and cost-containing practice guidelines for what its administrators described as "disease management," comprehensive and regularly updated protocols intended to codify and mandate the practitioner's adherence to formal diagnostic, treatment, prevention, and referral plans. One could cite many parallel instances. During the last two decades of the 20th century, planners managing America's disjointed health care system sought to control health care costs through a variety of bureaucratic schemes organized around such disease-oriented guidelines. Perhaps the most controversial were the diagnosis-related groups once enthusiastically endorsed as a tool for controlling the length of hospital stays. In each of these instances, the presumed existence of ontologically real and definitionally specific disease entities constituted a key organizing principle around which particular clinical decisions could rationally be made. The act of diagnosis structured practice, conferred social approval on particular sickness roles, and legitimated bureaucratic relationships. Not surprisingly, disease advocacy groups have flourished in the same social and intellectual context, all lobbying for social acceptance and research support. The Alliance of Genetic Support Groups, an umbrella organization, claims a membership of more than 250 such groups organized around genetic diseases alone.

One could provide scores of similar examples, but the moral is apparent. Specific disease categories are omnipresent at the beginning of the 21st century, playing substantive roles in a variety of contexts and interactions ranging from the definition and management of deviance to the disciplining of practitioners and the containment of hospital costs. The social uses of disease categories, however, are hardly limited to individual interactions between doctors and their patients or to the setting of research agendas and treatment plans. Philosophers and sociologists of knowledge have voiced an abundance of opinions regarding their epistemological and ontological status, but to the historian, disease entities have become indisputable social actors, real inasmuch as we have believed in them and acted individually and collectively on those beliefs.

Diagnosis is central to the definition and management of the social phenomenon that we call disease. It constitutes an indispensable point of articulation between the general and the particular, between agreed-upon knowledge and its application. It is a ritual that has always linked doctor and patient, the emotional and the cognitive, and, in doing so, has legitimated physicians' and the medical system's authority while facilitating particular clinical decisions and providing culturally agreed-upon meanings for individual experience. Not only a ritual, diagnosis is also a mode of communication and thus, necessarily, a mechanism structuring bureaucratic interactions. Although diagnosis has always been important in the history of clinical medicine, it became particularly significant in the late 20th century with the proliferation of chemical, imaging, and cytological techniques and the parallel conflation of diagnosis, prognosis, and treatment protocols (see Christakis 1997, 1999). Diagnosis labels, defines, and predicts and, in doing so, helps constitute and legitimate the reality that it discerns.

The Specificity Revolution

Many of the ways in which we think about disease seem novel. But assumptions about the existence of particular diseases have a long history. Laypersons and physicians have always used words to signify what seemed to constitute discrete disease experiences in their place and time. And such named disease pictures have always been important to practitioners of medicine. In the often-cited language of Knud Faber's classic (1923) history of nosography, the clinician "cannot live, cannot speak or act without the concept of morbid categories" (vii). A time- and place-specific repertoire of such agreed-upon disease categories has, in fact, always linked laypersons and medical practitioners and thus has served to legitimate and explain the physician's status and healing practice. Mastering a vocabulary of disease pictures and being able to distinguish among them have long been fundamental to the physician's role, as such knowledge underlies the socially indispensable tasks of diagnosis and prognosis and the rationalization of therapeutic practice.

"Every one must acknowledge the difficulty of distinguishing diseases," argued the influential Edinburgh teacher and practitioner William Cullen in his widely used late 18th-century textbook of nosology, "but in most cases, the possibility must also be allowed; for whoever denies this, may as well deny that there is such a thing as the medical art" (1800, ix). Disease categories have, that is, always linked knowledge and practice, necessary mechanisms for moving between the idiosyncratic and the generalizable, between art and science, between the subjective and the formally objective. And the physician's skills have, as Cullen implied, always turned on differentiating among available clinical pictures. In 1804 Thomas Trotter, a prominent British physician, similarly underlined this ever present reality. "The name and definition of a disease," he explained, "are perhaps of more importance than is generally thought. They are like a central point to which converging rays tend: they direct future inquirers how to compare facts, and become, as it were, the base on which accumulating knowledge is to be heaped" (3:467).

Ideas about disease have, in other words, been almost synonymous with the content of medicine as a set of explanatory concepts as well as bedside practices—in Trotter's words, "a base on which accumulating knowledge could be heaped," a mechanism that is for converting the uniqueness of experience and particular clinical interactions into a portable and collectively accessible form of data. But not all early 19th-century physicians believed that formal nosologies were worth constructing. "Whether a nosological arrangement, the fruit of modern pathology, is a hopeless expectation, remains yet to be seen," said John Robertson in 1827. "The degree to which diseases are modified by constitution, season, climate, and an infinite variety of accidental circumstances, renders it at least doubtful" (82–3).

In traditional medicine, disease concepts were focused on the individual sufferer. They were symptom oriented, fluid, idiosyncratic, labile, and prognosis oriented. Diseases were seen as points in time, transient moments during a process that could follow any one of a variety of possible trajectories. A common cold could become bronchitis, for example, and could then resolve without long-term consequences or could terminate, rapidly in a fatal pneumonia or slowly in chronic lung disease. A flux (or looseness of the bowels) could resolve itself without incident or could deteriorate into a fatal or debilitating dysentery. A humoral imbalance might manifest itself in the form of a fever or superficial lesions as the body tried to relieve itself of noxious matter though the skin. The body was always at risk, but a risk configured in idiosyncratic, physiological, multicausal, and contingent terms (Rosenberg 1977).

There were a few exceptions. By the beginning of the nineteenth century, epidemic diseases, such as yellow fever, and a number of other ailments, such as smallpox and venereal disease, were generally conceded to be contagious and thus were thought of somewhat differently. Epidemic outbreaks were explained, however, in terms of either a specific contagion or a peculiar configuration of environmental conditions, with patients' individual constitutions and lifestyles accounting for their differential susceptibility. For example, outbreaks of what in retrospect might be diagnosed as typhus fever were often associated with filthy, crowded, and badly ventilated circumstances, and thus a number of vernacular terms for such epidemics (jail fever, camp fever, famine fever, or ship fever) came into use.

These generally fluid and nonspecific ideas had changed fundamentally by the beginning of the 20th century. Recognizably modern notions of specific, mechanism-based ailments with characteristic clinical courses were a product of the 19th century. Pathological anatomy with its emphasis on localized lesions, physical diagnosis, the beginnings of chemical pathology, and studies of normal and abnormal physiological function all pointed toward the articulation of stable disease entities that could be—and were—imagined outside their embodiment in particular individuals and explained in terms of specific causal mechanisms within the sufferer's body.

Much of this conceptual change had taken place by the 1860s and thus antedated the germ theory of disease, which is so often credited with transforming both lay and professional notions of disease as entity. Bright's disease provides an illuminating case in point. It was perhaps the first doctor's disease—not only named for a physician in the 1820s but also understood and configured in terms of chemical pathology (albumen appearing in heated urine) and postmortem findings (the visual appearance of abnormal kidneys) as much as with the patient's felt experience and verbal narrative.[1] Thus a shift in ideas of pathology was already under way by the mid-19th century. Now disease was equated with specificity and specificity with mechanism, all the while decoupling this increasingly ontological conception from idiosyncrasies of place and person. In this sense, the several versions of the idea, articulated in the 1860s and 1870s, that wound infection and communicable disease were caused by living organisms—what has come in retrospect to be called the germ theory—only intensified and documented a way of thinking about disease already widely assimilated (if not consistently applied).

These new ideas obviously became a telling argument for the assumption that disease could be understood as existing in some sense outside the body. Perhaps more fundamentally, germ theories constituted a powerful argument for a reductionist, mechanism-oriented way of thinking about the body and its felt malfunctions. These theories communicated metaphorically the more abstract notion of disease entity as ideal type abstracted from its particular manifestations. A legitimate disease had both a characteristic clinical course and a mechanism, in other words, a natural history that—from both the physician's and the patient's perspective—formed a narrative. The act of diagnosis inevitably placed the patient at a point on the trajectory of that ineluctable narrative. Ubiquitous modifying terms such as *atypical* or *complications* only underscored the unspoken centrality of such ideal-typical disease models—and the need for secondary elaborations that would make these concepts more flexible and thus viable clinically.

The second half of the 19th century saw the initiation of a trend toward the clinical use of what contemporaries sometimes called "instruments of precision" in the study of disease. One thinks of the thermometer, of blood and urine chemistry and microscopy, and by the 1920s, the blood pressure cuff, the EKG and EEG, and x-ray were all available in well-equipped hospitals. And all promised to provide ways of describing disease that could be built into tight, seemingly objective pictures, useful in diagnosing and monitoring particular cases yet capable of being generalized into larger understandings. It was not only that temperature could "neither be feigned nor falsified"—as a well-known advocate of the thermometer argued—but also that its results could be expressed in standard units. Thus the patterned regularity of temperature readings might "aid in the discovery of the laws regulating the course of certain diseases" (Wunderlich and Seguin 1871, vii). Similarly, pH readings or red cell counts seemed to provide objective ways of helping characterize an ailment's essential character; aggregated, they promised ever more precise understandings of disease as entity.

Disease could now be operationally understood and described. It was measured in units, represented in the visible form of curves or continuous tracings, and taught to successive generations of medical students. Advocates of scientific medicine a century ago did not, of course, think that each of these measures could do more than reflect one characteristic of a particular disease entity. Each individual curve or tracing could in this sense be likened to the particular findings of the blind men who in the well-known fable were asked to describe an elephant. One said it was rather like a snake, another like a tree trunk, and the third—who grasped a tusk rather than the trunk or a leg—likened it to a scimitar. At the beginning of the 21st century, some of us might construe this epistemological parable as an argument for the contingent and situated quality of medical knowledge. But to most observers a century ago (and a good many physicians today), the blind men's varied findings were in sum proof of the existence of elephants. That is, in a circumstantial way, the gradual deployment of an ever increasing array of seemingly objective tools worked to establish the texture and corporeality as well as the essential unity of disease entities.

The very possibility of modern epidemiology is in some measure dependent on the acceptance of standardized disease categories as employed in aggregate morbidity and mortality statistics and in hospital and government statistics. In the programmatic words of the pioneer vital statistician William Farr in 1837, a uniform nosological nomenclature "is of as much importance in this department of inquiry as weights and measures in the physical sciences" (Farr 1843, app. p. 6; see also Eyler 1979; Porter 1995). Disease entities were seemingly objective units in which regional difference, social policy, and etiological variables could be weighed. Standard nosological tables seemed to be a necessary tool for helping transcend the subjective, the local, and the idiosyncratic in clinical practice, that is, for implementing what by the late 19th century had come to be called the scientific aspect of medicine. Without an agreed-upon vocabulary of disease, for example, the hospital's wards could not contribute to the medical profession's collective task of accumulating valid clinical knowledge.

In addition to their gradual embodiment in the form of accumulated data, agreed-upon disease categories constituted a language that linked physician and patient, especially in the hospital's increasingly bureaucratic context.

By the end of the late 19th century, the acute care–oriented hospital had already become a key factor in nurturing an administratively standardized and specific disease-oriented way of thinking about sickness. Disease categories played a fundamental role in the hospital's internal order, and the hospital's increasing centrality, served to make diagnosis among a repertoire of specific disease entities indispensable to inpatient medicine and thus the texture of patient experience. That intellectual centrality was intensified and, to a degree, embodied in the beginnings of specialism and the growing significance of the general hospital in delivering care to all classes in society. Moreover, much of the era's systematic clinical investigation was performed in hospitals. Codified in formal classification systems, disease entities became useful tools as these promising institutions sought to at once impose a rational internal order and project an image of efficacy and science. Although in retrospect the late 19th- and early 20th-century hospital might seem almost bereft of technology, it had already identified itself as an institution devoted to clinical science, increasingly defined and legitimated by its technological capacities. And as I shall argue, those growing capacities were indispensable in providing operational texture to disease as social entity (Rosenberg 1987).

In visualizing early 20th-century diagnostic practice, one thinks immediately of a hospital-based technology—of machines and microscopes, test tubes and reagents, autoclaves and petri dishes. But nothing illustrates these gradual yet inexorable changes with more circumstantiality than the mundane case record. By the middle of the 19th century, the linking of an emphasis on disease nomenclature, hospital practice, and the use of uniform forms for recording clinical data was, as an ideal, well established in academic medical circles (see Lyons 1861). By the end of the century, printed forms for recording case records had gradually become standard. Such forms provided blanks for recording the diagnosis, though with little space ordinarily left for a summary of the patient's account of his or her sickness. These uniform case records also included lines for recording the results of blood and urine work and the findings of physical diagnosis. By the 1880s and 1890s, temperature curves were routine components of case records in teaching hospitals, and by the 1920s, tracings from EKGs were often added. Well before the computer emerged to streamline the management of clinical data, the chart at the head of the patient's bed and the hospital's annually aggregated morbidity statistics promised in their different ways to control and rationalize both individual care and the institution's internal order. Diseases were accumulating the flesh of circumstantiality, both biological and bureaucratic. They were becoming social as well as conceptual entities.

By the end of the century, the greater coherence and cultural centrality of disease entities were manifested in another, ironic, way. I am referring to their use in the understanding and ordering of behavior. Conspicuous examples of ills such as neurasthenia, hysteria, sexual psychopathy, alcoholism, and homosexuality have already become familiar subject matter for historians. Although they were controversial a century ago—as many of them still are—the cultural work performed by such medicalized categories illustrates the power and pervasiveness of disease entities, no matter how hypothetical, in providing seemingly value-free frameworks for thinking about the normal and the deviant.

As striking as their persistence over time is the way in which such problematic diagnoses were routinely justified in terms of a material mechanism. Without such a mechanism, they could hardly have been advanced as legitimate ills. Here I am referring to the various entities contested during the past century and a half, putative ailments ranging from railroad spine and soldier's heart to shellshock and posttraumatic stress disorder, from neurasthenia to chronic fatigue syndrome. That such diagnoses and their lineal descendants remain contested at the beginning of the 21st century is—from this essay's point of view—evidence for the persistent cultural centrality of the mechanism-defined disease entity as an explanatory category as much as for the moral and political resonance of these particular would-be ills.

The organization of sickness into discrete categories was consistent as well with the bureaucratic imperative, not only in hospital management, but also in a variety of contexts ranging from life and health insurance to epidemiological and related public health and policy debates. It was not an accident that the 1890s saw agreement on an international classification of causes of death as well as an increasing demand for consistent and comprehensive morbidity statistics.

Disease pictures had already been built into textbooks of medicine; soon they would be sharpened and made even more central under the explicit banner of differential diagnosis. (The origins of the term *differential diagnosis* are obscure. Although it had been used earlier, it is often associated with the didactic efforts of Richard Cabot in the early 20th century.) The adjective *differential* assumes *differentiation* among discrete alternatives, and thus it legitimates—and prospectively creates—disease entities as social realities, whatever the evidentiary basis for their existence. "By the differential method," Philadelphia teacher John H. Musser wrote unself-consciously in 1894, "the diagnosis of one of a few possible diseases must be made" (19). Instructing medical students in nosological grammars was an important de facto step in the creation and increasing clinical salience of specific disease entities, as such entities constituted conceptual building blocks around which successive generations of medical students—soon-to-be practitioners—would organize their therapeutic and diagnostic practice. Even earlier in the 19th century, the stethoscope and physical diagnosis had promised academic physicians an objective path to understanding the course of particular ills during life. At the beginning of the 20th century, the clinical-pathological conference provided another institutional and pedagogical ritual. It also underscored the ultimate meaningfulness of discrete disease entities and the social centrality of their diagnosis by focusing on the connection between clinical signs during life and postmortem appearances. In addition, the clinical-pathological conference exemplified and, in part, constituted the dominant role of the hospital in medical education while structuring the relationship between pathology and clinical medicine (Maulitz 1980). To recapitulate, by the end of the 19th century, a vocabulary of named disease pictures had already become a widespread and largely unquestioned component of Western medicine.

And diagnosis of such ills was becoming inexorably and increasingly dependent on tools and techniques derived from the laboratory. This linkage among procedures, machines, and diagnosis seemed to the majority of physicians both desirable and inevitable, for disease could now be defined in increasingly objective terms. It is hardly surprising that as early as the first decade of the 20th century, critics were beginning to express a kind of oppositional disquietude, the fear that a brash and burgeoning scientific medicine meant treating diseases and not people, that it meant excessive dependence on the laboratory's tools and findings, that it meant a glorification of the specialist at the expense of the generalist, and that it denigrated the physician's holistic and intuitive clinical skills (see Lawrence 1985; Lawrence and Weisz 1998).

Disease as Social Entity

All these trends unfolded steadily—if not dramatically—throughout the 20th century. The narrative that constituted and described each disease became tighter, more procedure oriented and rule defined. In the United States, insurance reimbursement reified and intensified this tendency. The logic of clinical epidemiology and randomized clinical trials has also turned historically on the ordering of data in terms of entities, as does much of what has come to be called evidence-based medicine. The disease entity as concept had, in other words, steadily accumulated the texture of bureaucratic and biological circumstantiality.

The key factors are obvious. One is technology, medicine's increasing ability to interrogate and even alter the trajectory of particular disease pictures. In the 20th century, both therapeutic innovation and a growing diagnostic capacity have defined and legitimated disease concepts as they have empowered medical practitioners and reconfigured lay expectations of medicine. Such innovations have even altered the ecology and manifestations of disease: after antibiotics, bacterial pneumonias were in some real sense not the same entities, and diabetes after insulin therapy, pernicious anemia after liver extracts, chronic kidney disease after dialysis, and heart disease after angioplasty all became new diseases, given shape, texture, and often a greater degree of predictability through the agency of medicine even when they could not be definitively cured.

Particular ills have often been given a definitional specificity through the specificity of their response to therapeutics. Pernicious anemia, for example, was defined in the 1920s as the part of the spectrum of anemias that responded to liver extracts (see Wailoo 1997). The role of lithium in defining and legitimating bipolar disorder provides a familiar parallel example, as does the role of quinine in differentiating malaria from other recurrent fevers. It should be remembered that the predictability of a response to a particular agent implies the specificity of the pathological mechanism and hence its epistemological legitimacy. This circular—and self-fulfilling—tightness of fit has historically provided evidence for the hard, sharply bounded, and mechanism-legitimated definition of disease entities. It is instructive as well as ironic that contemporary forms for ordering clinical tests often specify a presumed diagnosis, prospectively justifying the laboratory expenditure.

The increasing dominance of the 20th-century hospital as a site for research, education, and the delivery of care was a second key factor in the social embodiment of disease. By the end of the 19th century, the hospital had—as I have already suggested—emerged as a dynamic site for the delivery of urban health care and for the development of elite medical careers (Rosenberg 1987; Stevens 1989; see also Sturdy and Cooter 1998).The growth of clinical pathology, imaging, and other diagnostic tools have not only helped centralize care in the hospital; they have also helped operationalize and embody disease entities. Late 20th-century imaging, immunological, and cytological procedures provide even more precise assurances that clinical medicine can base diagnoses on an understanding of the body's fundamental mechanisms and not simply the externally observable or patient-reported signs and symptoms of disease. Disease entities became more plausible, more sharply defined, and more frequently the framework and rationale for predetermined therapeutic interventions. Once articulated, these entities have helped order the relationships among machines, experts, caregivers, and patients in the hospital, creating a structure of seemingly objective priorities and practices. They have provided a language as well, enabling and structuring communication among different sectors of the health care system: to what service would a patient be assigned; what sequence of tests or procedures was most appropriate; and, in America at least, what procedures would be reimbursed.

Bureaucratic structures and practices constituted a third key aspect of the 20th-century embodiment of disease entities. Moreover, bureaucracy has become increasingly dependent on the deployment of numbers and categories; thus data management provides another kind of tissue in a late 20th-century disease's social body. Advocates of the computer in the clinic have worked eagerly to digitize, rationalize, and ultimately help link diagnosis, prognosis, and therapeutics, intensifying a tendency already well under way before the computer era (see Berg 1997). Randomized clinical trials, consensus conferences, and the coding conventions of nosological tables—as exemplified in the *Diagnostic and Statistical Manual* of the American Psychiatric Association—all create socially agreed-upon parameters of disease (see Marks 1997; Matthews 1995). So too does the way in which laboratory findings are often expressed in numbers, stages, and thresholds. Moreover, the bureaucratic need for numbers that legitimate and trigger a sequence of additional diagnostic, therapeutic, and administrative actions obscures the very constructedness of those numbers. The fact that such numbers are routinely generated by seemingly objective, highly technical tools and procedures works to endorse their plausibility and meaningfulness. Ironically, the very negotiated quality of the numerical values that define ailments and specify their treatments creates a reciprocal social rigidity as numbers become the measure and legitimation of presumed things. Participants in the health care system are well aware of the pitfalls (not the least of which is a loss of autonomy) inherent in the use of such operationalized definitions, but they remain nevertheless in thrall to the need for seemingly objective measures through which to manage disease both therapeutically and administratively.

The use of ideal-typical disease pictures creates experience as well as conceptualizing and recording it. The power of specific disease entities rests not in their Platonic—abstract—quality, but in their ability to acquire social texture and circumstantiality, to structure and legitimate practice patterns, to shape institutional decisions, and to determine the treatment of particular patients. We see disease entities given social life in the use of treatment protocols in research and cure; we see it in the use of what has come to be called evidence-based medicine; we see it embedded in expert software and elaborate treatment guidelines. Protocols are powerfully constraining even as physicians concede their frequent arbitrariness in particular clinical situations.

Medical knowledge is consistently articulated around disease pictures. They not only help make experience machine readable, they help create that experience. Disease categories connect aggregate statistical data and practice. As we have seen, they link and conflate diagnosis, prognosis, and treatment; they are ghosts in the health system's software. But perhaps ghosts are an imprecise metaphor, for systems of disease classification are very real and quite intractable technologies, linguistic tools that allow the machines and institutions of government and health care to function. Disease entities are social realities, actors in complex and multidimensional negotiations that configure and reconfigure the lives of real men and women. Just as disease can be created by ideological and cultural constraints in traditional societies—as generations of anthropologists have reminded us—so contemporary medicine and bureaucracy have constructed disease entities as socially real actors through laboratory tests, pathology-defining thresholds, statistically derived risk factors, and other artifacts of a seemingly value-free biomedical scientific enterprise.

Paradoxes of Disease Specificity

This way of thinking about disease—the vision of abstracted disease entities as ever more precise mirrors of nature—has become extraordinarily pervasive, yet in its very explanatory power, it has posed a variety of intractable social dilemmas, problems that in fact underline the cultural centrality and ubiquitousness of contemporary disease concepts.[2]

As I have already suggested, one such problem is implicit in the way in which we use disease categories to perform the cultural work of enforcing norms and defining deviance. A second dilemma grows out of the difficulty inherent in fitting idiosyncratic human beings into constructed and constricting ideal-typical patterns, patterns necessarily abstract yet, in individual terms, paradoxically concrete. A third problem lies in medicine's growing capacity to create protodisease and disease states that shape everyday medical practice and thus individual lives. Fourth is what might be described as the bureaucratic imperative, the way in which the creation of nosological tables, guidelines, protocols, and other seemingly objective and practice-defining administrative mechanisms constitutes in aggregate an infrastructure mediating between and among government and the private sector, practitioners and patients, specialists and generalists, and—in the United States—insurers and providers. That infrastructure is as much a part of the experience of sickness as diagnosis or clinical management is; they are in fact indistinguishable.

Since the mid-19th century, putative disease entities have been called on to do a variety of cultural tasks, most conspicuously to naturalize and legitimate conceptions of difference and deviance. I am referring, of course, to an assortment of problematic ailments ranging from attention deficit disorder to homosexuality and alcoholism. Not surprisingly, such entities remain controversial because their diagnosis turns on underlying conceptions of normal behavior as well as individual responsibility and professional jurisdiction. We have become accustomed to the public and often-contentious negotiations surrounding these and other problematic disease categories—with individuals, advocacy groups, and medical specialty associations all participating. Equally predictable is the way in which successive generations of physicians have advanced somatic mechanisms to legitimate and explain such ills.

The history of forensic psychiatry in the past century and a half reflects, for example, successive iterations of the notion that free agency could be inhibited by some biopathological process—such as moral insanity in the mid-19th century and a variety of successor diagnoses later—that overrode an offender's ability to have chosen the right and rejected the wrong. Insofar as the supposedly pathological behaviors can be construed as the consequence of a somatically based—and thus deterministic—mechanism, such entities necessarily undermine traditional notions of agency and thus engender legal as well as ideological conflict.

I have described a recurring paradox: the unavoidable use of reductionist means to achieve cultural and behavioral—necessarily holistic, multidimensional, and contingent—ends. Sociologists have described one aspect of this history as the medicalization of deviance. One can hardly disagree. But what they have generally failed to emphasize is this very paradox: the consistent use of determinist, mechanism-oriented explanatory strategies to define, to stigmatize, and to de-stigmatize. In this sense, one can trace a direct line of intellectual descent from such 19th-century formulations as George Beard's neurasthenia (a constitutional nervous weakness that could manifest itself in a variety of ways) or Cesare Lombroso's degeneracy (an evolutionary atavism) to late 20th-century notions of the genetic determinism of criminality, homosexuality, or even dyslexia, depression, and risk taking (see Pick 1989). The ways in which such speculative entities serve as vehicles for articulating cultural norms have, in fact, become a cliché in contemporary historical writing. But the persistent framing and reframing of such entities in terms of somatic mechanisms are as striking as the failure of such formulations to compel general and lasting assent. What has remained consistent in the last century and a half is the form of such norm-defining and enforcing sanctions: the creation of hypothetical, mechanism-based disease entities and the role of credentialed experts in attesting to the validity or illegitimacy of such ills. Even when we cannot agree on an underlying biological mechanism, we find ourselves debating the existence and legitimacy of scores of problematic ailments. For many participants, the diagnosis constitutes a kind of social equity, although others may regard the same designation as a form of stigmatization. Contemporary discussions of chronic fatigue syndrome and chronic Lyme disease constitute a particularly egregious example (Aronowitz 1998; see also Johnson 1996).

A somewhat different set of dilemmas turns on the difficulty inherent in adjusting the individual to the general and the abstract. How is a particular case of tuberculosis or lupus, for example, related to the textbook's description or a treatment protocol's prescriptions? Agreed-upon disease pictures are configured in contemporary medicine around aggregated clinical findings—readings, values, thresholds—whereas therapeutic practice is increasingly and similarly dependent on tests of statistical significance. Yet men and women come in an infinite variety, a spectrum rather than a set of discrete points along that spectrum. An instance of cancer exists, for example, along such a continuous spectrum; the staging that describes and prescribes treatment protocols is no more than a convenience, if perhaps an indispensable one. In this sense, the clinician can be seen as a kind of interface manager, shaping the intersection between the individual patient and a collectively and cumulatively agreed-upon picture of a particular disease and its optimal treatment.

Within this managerial context, the practitioner's role is inevitably compromised and ambiguous. On the one hand, the physician's status is enhanced by serving as an access provider to the knowledge and techniques organized around disease categories. Yet at the same time, the physician is necessarily constrained by the very circumstantiality of that generalized knowledge, by the increasing tightness of diagnostic and treatment guidelines (and, in the United States in recent years, by the mixture of malpractice angst and managed care that impinge ever more powerfully on autonomy in clinical choice). Although this pattern of practice is described and justified as "ensuring quality," in the terminology of contemporary health administration, slippage, frustration, communication failure, and unmet expectations are inevitable. How, for example, does one explain a prognosis framed in aggregate probabilities to a particular patient and his or her family? When every patient constitutes an *N* of one? How does one ensure clinical flexibility and an appropriate measure of practitioner autonomy in such a system? How does one manage death—which is not precisely a disease—when demands for technological ingenuity and activism are almost synonymous with public expectations of a scientific medicine?

Finally, I have not even mentioned the much-discussed moral and policy implications of an acute-care and mechanism-oriented clinical medicine that assigns a comparatively low priority to the multicausal, to the social, ecological, public policy, and quality of life perspectives. Western medicine's historical focus on specific disease entities and the management of acute illness is obviously an integral aspect and product of this fundamental worldview—and thus policy—reality. This is another area of maladjustment or difficulty of fit, not, from this perspective, the fit between the individual patient and the generalized disease picture, but between a reductionist, mechanism-centered understanding of disease and a collective strategy for defining and maximizing health. This pattern of episodic care structured around specific entities seems particularly problematic, moreover, in an age of chronic illness when men and women do in fact die of old age.

Another dilemma growing out of the emphasis on disease specificity turns on our increasing ability to create and modify disease entities, what one might call the iatrogenesis of nosology. One significant aspect of this technology-dependent process is the invention of protodiseases, for example, elevated blood pressure or cholesterol levels, or low bone densities in postmenopausal women. Once articulated and disseminated in practice and the culture generally, these conditions become emotional and clinical realities, occupying a position somewhere between warning signal and pathology. Our expanding armamentarium of cytological, biochemical, physiological function, and imaging tests create screening and treatment options and thus new and altered diseases. Prostate cancer, for example, has been changed as a social and clinical reality by the availability of new screening options, as has breast cancer by mammography. Genetic testing has already created new diseases—carrier states in Huntington's chorea or Tay-Sachs, for example—and promises to shape a multiplicity of such immanent ailments. Breast cancer figures prominently in this prognostic context as well.[3]

The bureaucratic management of disease creates another kind of dilemma. Nosological categories play an indispensable administrative role. Although that role constitutes a fundamental part of the ailment's social identity, in one of its aspects, disease *is* its bureaucratic management. Can one imagine 20th-century medicine and society without a rationalizing and organizing vocabulary of disease entities? Such nosologies constitute a tool for arranging compromises among a variety of interested actors—let us say patients, drug companies, competing specialties, insurers, researchers, and patients—as well as a tool for the day-to-day administration of such compromises. In this functional sense, modern society might be thought of as demanding the creation of diseases as social entities; they help legitimate the society's values and status system and also provide an instrument for the system's day-to-day management.

In this sense, a repertoire of disease categories becomes a mediating interface between and among parts of the system. Once articulated, such bureaucratic categories cannot help but exert a variety of substantive effects on individuals and institutional relationships. Because most somatic disease categories seem in themselves value neutral, for example, and thus legitimate care, there seems something wrong in not treating the sick when an efficacious technology is available and mandated by a particular diagnosis. Thus a poor or homeless person becomes visible to the health care system when diagnosed with an acute ailment but then returns to invisibility once that episode has been managed. It is almost as though the disease, not its victim, justifies treatment. Thus the employment of seemingly objective disease categories obscures the conflicted relationships among medicine's moral, technical, and market identities.

Linkage is the key concept here, the way in which bureaucracy, market, cultural identity, and other factors all can interact around the creation of an agreed-upon disease threshold. One can cite scores of instances illustrating this proliferating phenomenon. In 1999, for example, the National Institutes of Health broadened its definition of overweight, conceptualizing their new categories in terms of a body mass index. "Until last year, men were overweight if their body mass index was 27.3 or higher; for women, the cut-off was 27.8. Today anyone with a body mass index of 25 or over is overweight by Government standards. And a new category, obese, has been added for those whose index is 30 or above." With, as the *New York Times* (May 2, 1999) put it, "excess body fat increasingly being viewed as a disease," the drug industry could now market a "pharmacological fix." Pharmaceutical firms could now hope for an expanded market for diet drugs, legitimated as insurance reimbursement by their status as "disease treatment." Somewhat more recently, to cite a parallel example, the Food and Drug Administration announced that it had approved an already much-prescribed antidepressant, Zoloft, for use in treating posttraumatic stress syndrome in women (*Philadelphia Inquirer*, December 6, 1999). The drug could now be advertised for this use and, presumably, its costs covered by insurers.

The Social Function of Diagnosis

All these problems illustrate the central role of diagnosis itself. Perhaps most fundamentally, the act of diagnosis links the individual to the social system; it is necessarily a spectacle as well as a bureaucratic event. Diagnosis remains a ritual of disclosure: a curtain is pulled aside, and uncertainty is replaced—for better or worse—by a structured narrative. Think of the moment when the patient and his or her family are shown revelatory x-rays or printouts, when the physician pronounces a diagnosis that can allay or intensify fear. Even though contemporary diagnosis is ordinarily a collective, cumulative, and contingent process, it is significant that most of us think of it as a discrete act taking place at a particular moment in time. Both physician and patient are hostage to this age-old ritual. There is an instructive irony in the way in which nosological tables can effectively reshape the lives of particular men and women, even when the physician bestowing a particular diagnosis is aware of how arbitrary that determination may be.

Disease pictures are formally objective narratives that provide meaning as well as underline social hierarchies. We ordinarily expect a diagnostic determination and subsequent communication as part of the clinical interaction; even its absence shapes our expectations and becomes part of a necessarily altered narrative. Such diagnoses need not be optimistic to be socially efficacious. In our largely secular society, sometimes meaning can be reduced to the admission that we do not yet know the mechanism, that medicine cannot intervene in certain predetermined illness trajectories, that some disorders remain mortal. Anxiety and mystery can be ordered, if not precisely allayed.

Diagnosis remains both a bureaucratic and an emotional necessity—for records, for reimbursements, and for the coordination of complex intraprofessional and institutional relationships. Vocabularies of disease entities are a necessary aspect of the contemporary world and are not easily disaggregated from the technical capabilities that the great majority of us have come to expect from medicine. When America's political and medical spokespersons boast of enjoying the world's best health care, they are implicitly referring to the capacity to intervene in the trajectory of disease, to alter a worst-case scenario.

Our understanding of the biopathological aspects of disease and the technologies available to manage and understand them are a part of reality as much as are our clogged arteries or dysfunctional kidneys. It is in this sense that I employ the phrase *tyranny of diagnosis.* I might just as well have used the term *indispensability.* Diagnosis is a cognitively and emotionally necessary ritual connecting medical ideas and personnel to the men and women who are its clients. Such linkages between the collective and the uniquely individual are necessary in every society, and in ours the role of medicine is central to such negotiated perceptions and identities. The system of disease categories and diagnosis is both a metaphor for our society and a microcosm of it. Diagnosis is a substantive element in this system, a key to the repertoire of passwords that provide access to the institutional software that manages contemporary medicine. It helps makes experience machine readable.

In the act of diagnosis, the patient is necessarily objectified and recreated into a structure of linked pathological concepts and institutionalized social power. Once diagnosed, that bureaucratic and technically alienated disease-defined self now exists in bureaucratic space, a *simulacrum* thriving in a nurturing environment of aggregated data, software, bureaucratic procedures, and seemingly objective treatment plans. The power of the bureaucratized diagnostic function is, as I have suggested, exemplified in the willingness of physicians to employ the constraining—yet empowering—categories of such nosologies even when they remain skeptical of their validity. The routine use by clinicians of the American Psychiatric Association's *Diagnostic and Statistical Manual* and its often arbitrary categories remains a powerful example of this phenomenon. Equally revealing is the spectacle of individual sufferers and disease interest groups demanding the attribution of particular disease identities, of which chronic fatigue syndrome is a particularly visible example.

Elements of this argument have become familiar in the past generation. They are manifestations of a more general antireductionist critique widely articulated and elaborated since the beginning of the 20th century. Such criticisms have in fact become a cliché. A wary skepticism of the laboratory, of the impersonal acute care hospital, and of a dehumanizing specialism has had a history as long as the 20th century itself. It has in fact become fashionable among humanistic and social science–oriented commentators to dwell on the distinction between illness and disease, between the patient's felt experience and the constructions placed on that experience by the world of medicine (see Kleinman 1988). And this distinction is certainly valuable for the purposes of analysis. But in practice, sickness is, of course, a mutually constitutive and interactive merging of the two; we are not simply victimized, alienated, and objectified in the act of diagnosis. Disease categories provide both meaning and a tool for managing the elusive relationships that link the individual and the collective, for assimilating the incoherence and arbitrariness of human experience to the larger system of institutions, relationships, and meanings in which we all exist as social beings.

Thus specific disease entities can be understood as holistic and integrative in a social system sense, just as they can be fragmenting and alienating in terms of an individual's relationship to that larger society.

We are never illness or disease but, rather, always their sum in the world of day-to-day experience. Illness and disease are not closed systems but mutually constitutive and continuously interacting worlds. In the patient's case, it is always experience as well; we are always in contact with our own worlds of physical and emotional pain and experience—and thus identity—that cannot be reduced to the external zone of intersection between society and the men and women who constitute it. Identity relates to individual consciousness as well as social location. Pain, sickness, and death help make that particular aspect of experienced identity unavoidable and, at some level, ultimately inaccessible to medicine's changing understandings of disease and tools for managing it.

ENDNOTES

1. The term *Bright's disease* is now obsolete and does not correspond to today's diagnostic terminology. It was, however, used as recently as the mid-20th century and reflects a contemporary understanding of renal pathology (Peitzman 1981, 1992).
2. It is not my intent to either question or defend the pragmatic usefulness or epistemological status of disease entities by placing them in this contingent historical framework. Rather, I am trying to address a different problem: understanding that framework. Perhaps most important, I do not want to impugn their provisional value in increasing the understanding of the body in health and disease. Efforts to contextualize the enterprises of science and medicine are often construed as relativist and delegitimating. But I would suggest that such defensive reactions are created by polarized ideological positions, not by the demands of logic. To historicize and contextualize our changing understandings of disease is not the same as impugning their ontological basis—or implying that all contingent positions occupy a necessarily arbitrary relationship to the natural world. I have made related arguments elsewhere: "Disease and Social Order in America: Perceptions and Expectations" and "Framing Disease: Illness, Society, and History" (both in Rosenberg 1992).
3. For example, the contemporary debates over the efficacy of screening mammography for breast cancer underscores the complexity and multidimensionality of such issues. Social expectations and economic imperatives, as well as rapidly changing technology and our still imperfect understanding of the ailments' natural history, all interact to configure a particular, time-specific screening reality. Changes in any of these component elements imply change in the aggregate.

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