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# Naming and Framing: The Social Construction of Diagnosis and Illness\*

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*This paper examines the social construction of diagnosis and illness in several ways. First, I discuss the centrality of social construction in medical sociology. Next I discuss the major role of diagnosis in social construction, leading to the need for a sociology of diagnosis. I emphasize controversial and conflictual diagnoses, as a first step toward a more general sociology of diagnosis. Then I put forth a typology of social construction, involving four combinations based on whether a condition is generally accepted and whether a biomedical definition is applied. Next I detail a series of stages in the social construction of a condition. In that process, my primary concern is the initial social discovery, which is essentially a matter of diagnosis, with a secondary emphasis on illness experience. This is followed by stages of treatment and outcome, which recursively affect social construction. I conclude by noting the health policy implications of the social constructionist perspective.*

The social construction of diagnosis and illness is a central organizing theme in medical sociology. By studying how illness is socially constructed, we examine how social forces shape our understanding of and actions toward health, illness, and healing. We explore the effects of class, race, gender, language, technology, culture, the political economy, and institutional and professional structures and norms in shaping the knowledge base which produces our assumptions about the prevalence, incidence, treatment, and meaning of disease.

Despite the fact that the notion of social construction is such a common organizing theme, it is rarely defined in a systematic fashion, and has many meanings which are often divergent. This paper seeks to refine our understanding of the social construction of diagnosis and illness. It begins by examining the multiplicity of competing versions of social constructionism, and by pointing out the problems of relativism in the traditional approaches. I then put forth a new version of social constructionism, which synthesizes elements of symbolic interactionist and structural/political-economic approaches. Next I discuss the major role of diagnosis in social construction, leading to the need for a sociology of diagnosis. I emphasize controversial and conflictual diagnoses, as a first step toward a more general sociology of diagnosis. Following that I put forth a typology of social construction of diagnosis, involving four combinations based on whether a condition is generally accepted and whether a biomedical definition is applied. Next I detail a series of stages in the social construction of a condition. In that process, I turn attention to both the initial social discovery of the condition (essentially a matter of diagnosis) and illness experience. This is followed by examining stages of treatment and outcome, which recursively affect social construction. I conclude by noting the health policy implications of the social constructionist perspective.

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*Definitions and Disputes—Versions of Social Construction*

There are three main versions of social constructionism that apply to medical sociology. The first and most prominent draws on the work of Spector and Kitsuse (1977:75) and argues that social problems are the “activities of individuals or groups making assertions of grievances and claims with respect to some putative condition.” The Spector and Kitsuse perspective is not concerned with whether there is a real condition; the focus of interest is on the social definition. The early social constructionists were concerned with formulating a break with a positivist worldview that saw social facts, including social problems, as given and measurable entities. Using ethnomethodology, symbolic interactionism, and related approaches and theories, social problems scholars sought to uncover the hidden world of everyday interaction and definition-making.

As we see in a review of the debates over social constructionism (Miller and Holstein 1993a), there is an enormous range of interpretations to this approach, though some argue that the success of the original Spector and Kitsuse framework is the large legacy of work it has generated. This includes approaches based on the “micropolitics of trouble,” interest group competition for public resources, claims-making by the media, and work place constructions of meanings (Miller and Holstein 1993a).

Not surprisingly, much of the debate on social constructionism centers on the degree of “reality” in phenomena—are social problems objectively real, or are they created by purposive action by social labelers and problem finders? Best (1989) makes a distinction between “contextual constructionism” and “strict constructionism.” Contextual constructionism gives credence to the actual condition, though it does not put primary emphasis on the condition. Strict constructionism deals only with the claims made by social actors, not the putative condition itself. For the strict approach, even statistics purporting to provide evidence for prevalence of the condition are suspect, since such statistics are also a form of construction, and ought to receive no more credence than other claims. Woolgar and Pawluch (1985) argue that social constructionists actually do have a “realist” position, since they choose certain issues for their attention. These issues apparently have a constant reality, but only become important when the scholar chooses to analyze them. Hence, Woolgar and Pawluch tell us, there is a selective realism in constructionism.

Strict constructionists believe that constructionism challenges sociological realism and centers itself on the “assumption that social realities are accomplished through interactional and interpretive practices.” They somehow make the leap that such constructionism “cannot be subsumed within more general, realist theories of society” (Miller and Holstein 1993b). I cannot see why a solid sociological framework cannot argue for the centrality of structural/political-economic factors, while also posing an interpretive, reflexive approach.

This first version of social constructionism is the one most commonly employed by medical sociologists. Yet medical sociology has not elaborated much on this theoretical framework. The main debates about the nature of social constructionism occur within social problems theory, and have been applied more to social labeling of behaviors (e.g., child abuse, sexual relations) than to the types of questions and issues addressed by medical sociology. Social constructionism, as traditionally defined, can contribute to an understanding of how health and illness are rife with biased definitions and forms of social control; it can help us learn about experience of illness and clinical interaction. But traditional constructionism is limited, since it refuses to accept any elements of a structural perspective, in particular the notion that fundamental social structures of society play key roles in health and illness. These include the core stratification elements of race, class, and gender, as well as professional and institutional factors.

For example, much medical sociology in the social constructionist vein focuses on talk. This makes sense, given that symbolic interactionism emphasizes the human agency in people’s exchanges of meanings. Yet to focus on talk is a simplification of the larger meaning of interaction. In creating meanings and interpretations, people’s interaction also includes how they play out their social roles, and how they relate to professional and institutional structures where interaction takes place. Put otherwise, there must be a context for talk. Interestingly, a number of scholars who support a strong conversational analysis or discourse analysis

perspective actually do provide a contextualization, even if they still view the discourse as central (cf. Mishler 1984).

A second version of constructionism, based more on European postmodern theory, originates as early as Foucault's (1966) *Madness and Civilization*. The postmodern approach shares with the more American constructionism a critique of positivism. But postmodern approaches would be dissatisfied with other constructionist emphasis on given sets of social actors, groups, and institutions. Instead, postmodernist approaches would say that to even center on those sets of institutions and actors is a false reliance on existing structures. The postmodern alternative is to deconstruct language and symbols in order to show the creation of knowledge, and to explore the ever-changing, indeterminate 'realities' of the situation. Interestingly, this departs from the original approach of Foucault who, despite his emphasis on language and definition-making, based his analysis of asylum creation on the transition from feudalism to capitalism, migration, and the development of the psychiatric profession. Actually, some scholarship based on Foucault does take such a social approach. Armstrong (1983) looks at the social production of knowledge as a result of changes in social perceptions of space and time, including the proper location (home or institution) of medical care (Armstrong 1983).

Turner's (1992) development of a sociology of the body also stems from Foucault. It is concerned with symbolism, in that most of the symbols and rituals in social structures are focused on actions regarding the body. Turner is mainly concerned with the embodied person as an agent of social action. This postmodern constructionism views the legacy of medical social control as specifically targeted at the body; control may be in terms of physical and emotional health, as well as by the moral cultures of self-beautification and self-maintenance.

There is a third constructionist approach, more related to the sociology of science. This viewpoint, most associated with Latour (1987), argues that the production of scientific facts is the result of mutually conceived actions by scientists in workaday life in the laboratory, combined with scientists' efforts to promote their work in public and official venues. This "science in action" perspective is worth noting, since a number of medical sociologists utilize elements of the sociology of science. This approach is useful for medical sociology in examining the work of professionals' discovery of disease and the development of medical technology, though it is less valuable when considering elements of lay discovery and of interaction between people/patients and the world of medicine.

So we have seen that there are many different opinions about what social constructionism means. Medical sociologists have frequently used this term in a very broad-stroke fashion. For example, Bury (1986) conceives of social constructionism as a broad umbrella, containing often contradictory elements that range from those who believe in a perfectly relativist standpoint to those using political-economic analyses. Bury's broad umbrella even includes some perspectives that ignore cultural features, something quite against the grain of any social constructionism.

### *A New Version of Social Construction*

The wide variety of definitions of social constructionism belies any claim that there is a unitary social constructionist theory or perspective. Hence, my approach is not bound by the traditional definitions of social constructionism. I would go further and claim that existing theoreticians of social constructionism cannot lay sole claim to the term, "social construction." A brief search of literature in medical sociology will reveal many articles and books with that term in their title, yet which do not explicitly follow the traditionalist approach, and in fact add a conflict, structural perspective.

I view social constructionism as a synthesis of symbolic interactionism and structuralist/political-economic approaches. Depending on the subject matter, one or the other of these two may predominate though, ultimately, we should be moving toward a greater synthesis of these two approaches. The symbolic interactionist/structural synthesis I propose is, in truth, hardly a new theoretical statement. In practice, this synthesis is widely found in much of medical sociology. Freidson's pathbreaking *Profession of Medicine* (1970) is the best example, with a

whole section of five chapters called "The Social Construction of Illness." Other leading medical sociologists have made similar linkages (Waitzkin 1989; Zola 1972), and much published work in the field does so also, even without specifically stating this. Even some of the postmodernist medical sociologists, who criticize conflict-oriented social structural approaches, wind up referring to the pervasive power of social institutions and structures. Turner's (1992) sociology of the body, for example, sees the importance of commodity production and advertising in the creation of socially constructed notions of proper bodies.

It is important from the outset to note that the *social construction of medical knowledge* is distinct from the *social construction of illness*; traditional constructionist writing has not generally taken this into account. The social construction of medical knowledge deals mainly with the origins of professional beliefs, and with diagnosis. It deals with the ways of knowing that are based on the dominant biomedical framework, contemporary moral and ethical views, the socialization of medical providers (especially physicians), the professional and institutional practices of the health care system, and the larger social structures of the society. Here, we are more concerned with diagnosis, and the structural approach predominates. Scholarship on the construction of medical knowledge includes social factors such as professional advancement (Freidson 1970; Wright and Treacher 1982), patriarchal attitudes (Scully 1980), and corporate and imperialist labor market needs (Walsh 1987; Brown 1979).

The social construction of illness deals mainly with the illness experience. It has to do with a more interactionist approach of experience at personal, dyadic, and group levels. Here we are concerned with the lay experience of illness, and the symbolic interactionist approach predominates (this is dealt with more extensively in a subsequent section). Of course the constructions of medical knowledge and illness are connected, in that people deal with their own and others' illnesses largely in accordance with the dominant social elements of medical knowledge.

Using the framework I have laid out, we may consider the social construction of a phenomenon to involve a multiplicity of social forces that combine to create and modify the phenomenon. Rather than a given biomedical fact, we have a set of understandings, relationships, and actions that are shaped by diverse kinds of knowledge, experience, and power relations, and that are constantly in flux. This social constructionist perspective looks at how the phenomenon was identified and acted upon. This involves the impact of the underlying social stratification system, and the roles of professionals, institutions, governments, media, pharmaceutical companies, patients, and people with illness and disabilities as well as their families. This process of social constructionist logic requires us to ask questions such as: Why did a condition get identified at a certain point in time? Why was action taken or not taken? Who benefits, or at least avoids trouble, by identification and action? How did the divergent perspectives on the phenomenon merge or clash? How does the person's experience of the illness affect the course of the disease, as well as the social outcome of the illness?

Using this social constructionist perspective, medical sociology can link together and make social sense of health and illness across three levels: the microlevel (such as self-awareness, individual action, and interpersonal communication), mesolevel (such as hospitals, medical education), and macrolevel (such as the nation's health status, the structure and political economy of the health care system, and national health policy). By analyzing these three levels of knowledge and action, we are better able to understand social policy consequences in the health care system.

My approach to a social constructionist perspective holds that we take a critical look at the world of medicine, but we do not view that world as an epiphenomenon. It is quite possible to believe that biomedical components are important, while still emphasizing social forces as well as people's interactive definition-making (Lock 1988). We are, after all, talking about phenomena which occur in people's bodies. If we do not take seriously this reality, our search for socially constructed definitions will be very shortsighted. I cannot see that an appreciation of actual conditions must automatically prevent us from grasping the social construction of the definition and treatment.

My scope is not to synthesize the voluminous literature on social construction. Indeed, since I believe that the social construction perspective is so central to medical sociology, such a synthesis would be beyond the scope of a bounded paper such as this.<sup>1</sup> Rather, I intend to develop theoretical and analytic tools for understanding and furthering this perspective.

One of my differences with much traditional social constructionism is that it fails to deal with aspects of social causation. Because traditional constructionism holds that there are no constituted, objective problems, it obviously believes that social causation is irrelevant. My viewpoint on this is that medical sociology loses its explanatory power if it denies social causation. The next section locates causation centrally within the bounds of social construction.

## SOCIAL CAUSATION AND SOCIAL CONSTRUCTION

The *social causation* of health status is actually a prerequisite, or at least a concurrent requirement for the perspective put forth here. One of the cardinal principles of the sociology of health and illness is that social factors are integral to health status. Causation encompasses three categories: (1) *underlying social causes*, such as social structural elements of the society (e.g., class, race, sex, military spending); (2) *proximate social causes*, such as neighborhood structure, migration, and environmental and work place hazards; and (3) *mediating social causes*, such as social supports, social networks, and marital and family status.

There is no room to go into even the briefest of summaries of the literature on social causation.<sup>2</sup> But it is worth noting that some scholars might accept a wide variety of explanations of social causation of health and illness, yet not accept a social constructionist approach to understanding the person's experience of illness, the professional role in defining problems, and issues of service delivery. For example, they might readily agree that class, gender, and race affect the epidemiologic distribution of psychosis or cardiovascular disease, but might not consider relevant to a causal model that social actors and institutions affect the labeling, discovery, and treatment of those conditions. Because of this possibility, we need both social causation and social constructionist explanations to produce a complete medical sociological view.

Social construction begins with social discovery—the ways in which people, organizations, and institutions determine that there is a disease or condition. Other components of social constructions follow: the experience of illness; decisions regarding treatment; and social understandings of what constitutes outcomes. Later, since my intent is to propose a general model, I will present an outline of these stages of social construction. Within this, my primary focus will be on diagnosis, with a secondary focus on illness experience. These two areas are the most fertile locations for observing social construction. Illness experience has been more widely studied, and hence is a secondary focus here. Since diagnosis has been less developed, I now proceed with a general discussion of the logic of a sociology of diagnosis.

### *The Logic of a Sociology of Diagnosis*

Diagnosis is integral to the theory and practice of medicine. For social scientists the process of making the diagnosis is central to subsequent constructions of illness. Diagnosis represents the time and location where medical professionals and other parties determine the existence and legitimacy of a condition. Diagnosis is a matter of the “politics of definitions” (Conrad and Schneider 1992:22) whereby illness designations are created from social conflict. Diagnostic discovery is frequently laden with dispute, which provides a lens for viewing many of the social conflicts which revolve around issues of medicine and health.

Yet despite the frequent discussion of diagnostic concerns in medical sociological research on illness, scholars have not elaborated the common threads of diagnostic processes. We see many examinations of the social construction of a particular disease entity, with some attention paid to diagnostic issues. Indeed, a considerable body of work in medical sociology is concerned with lay/professional differences in disease and illness conception and experience and with the social construction of disease (cf. Freidson 1970; Schneider and Conrad 1981). That research directly touches on diagnostic issues, although they are not usually considered specifically as such. Most specific studies of diagnosis are in studies of psychiatry. While this can help us in developing a general view of diagnosis, it is not sufficient, largely since there are specifics about psychiatric diagnosis which are not completely generalizable. In particular,

there is more room in psychiatry for a high degree of interpretation and direct bias, which we see far less in medicine. For example, competing schools within psychiatry (e.g., psychoanalytic and biopsychiatric) hold tremendously divergent beliefs on the very existence of certain conditions. For another, there is considerable room for mental health professionals to engage in patient selection within one facility.

One reason for emphasizing diagnosis is found in a core assumption of medical sociology—the distinction between disease and illness (Schneider and Conrad 1981). *Disease* is a more biomedical phenomenon, though strongly affected by social forces. The distribution of disease and death differs on the basis of class, race, sex, ethnicity, education, and other social factors. The key issue here is how social position or social factors affect the production of disease. *Illness* reflects a more subjective phenomenon. The same social forces which affect the distribution of disease also lead to varying perceptions, conceptions, and experiences of health status. This explains why people differ in making their way to various providers and institutions to seek care. In particular, some people with the same symptoms or conditions as others choose widely disparate ways of dealing with those symptoms or conditions. These structurally different perceptions then cloud the treatment encounter.

For sociology, Blaxter (1978) tells us, diagnosis has two meanings—*process* and *category*. Process is the set of interactions which leads to the definition of the category and to its imposition in particular cases. This is the core of my discussion of social discovery. Category is the nosological location in medical knowledge where the diagnosis resides. This involves the often reified definitions of disease into which professionals and others fit their observations.

In both of Blaxter's types—process meaning and category meaning—diagnosis has various functions. For patients, diagnosis can provide personal, emotional control by way of knowing what is wrong. For medical professionals, diagnosis also provides control by mastering the knowledge of the problem at the individual care level. As well, diagnosis frequently determines the course of treatment, though treatment is also determined by many other factors. For both patient and professional, diagnosis can lead to a prognosis. Physicians also employ diagnosis as a vehicle for building the whole body of medical knowledge.

Diagnosis is central to the work of all medical professionals. Differential diagnosis is probably the most rewarded skill for medical students and doctors in training. As Balint (1957) discusses, physicians are confronted with what is often an "unorganized illness," an agglomeration of complaints and symptoms which may be unclear, unconnected, and mysterious. Their job is to understand and interpret that material in order to arrive at an "organized illness." In other cases, patients may present more clearcut material which requires less organizing work. Certainly much medical work consists of routine diagnoses of problems, many of which are not conflicted or political. I am less concerned with the routine, nonconflicted diagnoses of daily medical work. My focus primarily concerns the conflicted diagnoses because they offer a window into some of the most pressing issues of power in medical experience.

For socially powerful groups and institutions, diagnosis can be a tool for social control, such as the medical labeling of homosexuality as mental illness. Our conception of medicalization (Conrad 1992) involves social control at very routine levels of socialization, labeling of behavior, and prescriptions for medical intervention. Diagnosis is central to such social control, since *giving the name* has often been the starting point for social labelers. Diagnosis is a *language of medicine*, a crucial component of what Elliot Mishler (1984) calls the "voice of medicine," in contrast to the "voice of the life-world." Diagnosis locates the parameters of normality and abnormality, demarcates the professional and institutional boundaries of the social control and treatment system, and authorizes medicine to label and deal with people on behalf of the society at large. This labeling is often enough the legal basis for provision of health services, welfare benefits, unemployment certification, worker's compensation claims, and legal testimony (Zola 1972; Brown 1990).

Diagnostic categories are often fought out as turf battles between medicalizers and their opponents, as in alcoholism, drug abuse, and child abuse. For social groups which have been in subservient roles, diagnosis can give credence to conditions which may legitimate their suffering, as well as legitimize themselves. It offers them a tool for engaging in politically charged definitional settings. Black lung, environmental disease, and post-traumatic stress

disorder (PTSD) are good examples. Victims of violence and sexual abuse can benefit from a diagnosis, in this case PTSD, because it removes the blame from the victim, takes a social view of the problem, and opens the door for access to care and insurance coverage (Scott 1990).

Last, for sociologists and other scholars, diagnosis serves as a pathway into the history of medical knowledge and practice. We can also understand the relationship between medical knowledge and other forms of social knowledge and action. After all, Blaxter (1978:11) tells us, diagnosis is “a museum of past and present concepts of the nature of disease.” Taking that one step further than just concepts, I believe we can view diagnosis as also the *sociomedical archives* wherein we find the history of action by all levels of the health care system. These archival elements of diagnosis are found, for example, in succeeding revisions of the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM) or the International Classification of Diseases (ICD). They are also found in the textbooks of medicine. These archives also include the records of legislation, regulation, and litigation which have given names and meaning to conditions. Mass media and public beliefs also are found in these sociomedical archives, for those historically changing public understandings are important components of social action concerning diagnoses.

## THEORETICAL AND ANALYTICAL MODELS

I present here two ways to understand theoretically and analytically social construction processes. The first is a more theoretical approach that deals with diagnosis. It is a typology of conditions and definitions that locates commonalities across four categories of social construction. This model is useful for a “rough cut” that provides broad categories for the social construction of disease. This allows us to better refine our concepts of social constructionism. With this in hand we then must trace the development of the construction. For this, the second—a more analytical and procedural approach—follows from the first. It is a stages model, which is more useful in examining the chronology of social construction, beginning with social discovery. It helps us to identify the range of social actors involved in disease discovery and illness experience, and provides a framework for future case studies.

### *A Typology of Conditions and Definitions*

Social construction involves a real or putative *condition* and a *biomedical definition*. The condition is the disease, disability, or physical state. It is generally either *accepted* or *not accepted* as a biomedical entity. The biomedical definition is the presence or absence of a specific identification of the condition on the part of medical science. The biomedical definition is either *applied* or *not applied*. The *definitional setting* is the way that these two elements interact, and the way in which the social construction of a condition is shaped. The following typology illustrates this.<sup>3</sup>

In Cell 1, we have *routinely defined conditions* which are usually *accepted*, and for which biomedical definitions are *applied*. These constitute probably the vast majority of situations. Diagnoses here are typically less conflictual than others, and are not the main focus of this analysis. Nevertheless, there may be significant bargaining between patient and provider over the giving of a diagnosis. Recalling Balint’s (1957) notion of the “unorganized illness” being “organized” by the doctor, we can picture situations where a person may on the one hand desire or, on the other hand, fear or resist a diagnosis that may have a large impact on him or her. When a cold is redefined as a flu, or sniffles as allergy, there may be social benefits for the patient, such as exemption from social responsibilities. When what begins as an acute injury is defined as a more serious and long-term disability, the person may face activity limitation, job loss, and stigma.

Since these Cell 1 types are the vast majority of conditions, and since they tend to be the least conflictual, the social construction is more centered on the illness experience than on the



FIGURE 1. Typology of Conditions and Definitions

	Condition generally accepted	Condition not generally accepted, or condition is questionable
Biomedical definition applied	<div>1</div> <div>Routinely Defined Conditions</div> <div>(infectious diseases, chronic diseases, injuries)</div>	<div>2</div> <div>Medicalized Definitions</div> <div>(late luteal phase dysphoric disorder, chronic fatigue syndrome, chronic pain syndrome)</div>
Biomedical definition not applied, or there is conflict on making a definition	<div>3</div> <div>Contested Definitions</div> <div>(occupational diseases, environmentally induced diseases, multiple chemical sensitivity)</div>	<div>4</div> <div>Potentially Medicalized Definitions</div> <div>(genetic predispositions to diseases)</div>

diagnosis. Hence, despite the clarity of the biomedical definition and diagnosis, much of people's experience of these conditions involves adjustment and adaptation in non-medical realms. The social construction of treatment is also relevant: choices are made about caregiving on the basis of local medical cultures, race, class, gender, insurance status, and other social variables (illness experience and treatment issues are discussed in more detail in the later section on stages of social construction).

In Cell 2, there are *medicalized definitions*, cases where the condition is generally *not accepted* and/or is widely considered to be non-medical, yet a biomedical definition is *applied*. Often, the labeling processes by which these diagnoses are made represent forms of social control. Sometimes these medicalized definitions are mainly a feature of professional expansionism, as with late luteal phase dysphoric disorder (LLPDD, the psychiatrized definition of premenstrual syndrome) and chemical dependency. In the case of LLPDD, psychiatry enforces gender norms by pathologizing normal functioning. With chemical dependency, medicine replaces or collaborates with the criminal justice system.

In other cases, labeling is not a form of social control, but is sought by people as a way to legitimate their condition. For instance, a diagnosis of chronic fatigue syndrome may be helpful in excusing absence from, or poor performance in, work or school. Chronic pain also may require similar legitimization. Here, there is a congruence with professional and institutional expansion; pain clinics have grown rapidly, treating what professionals often believe to be somaticized manifestations of psychological problems. Legitimation does not necessarily

require secondary gain; it may be important for people's self-esteem to legitimate their complaints in their own and others' eyes.

Cell 3 includes *contested definitions*, situations where there are generally *accepted* conditions, but no widely *applied* medical definition. Diseases caused by environmental and occupational exposures are a prime example of this. For example, many people complain of cancers, rashes, respiratory problems, immune system dysfunction, and cardiac problems which they believe may be caused by a local contamination source. Medical and governmental authorities, however, are often unable and/or unwilling to recognize these conditions as syndromes or diseases attributable to contamination. This has occurred in numerous community and work-place toxic exposures, leading to a large social movement of toxic waste activists, and to considerable epidemiological research confirming these environmental health effects. It has also occurred in military settings such as the Persian Gulf War, where early complaints of rashes, muscle and joint pain, headaches, and respiratory problems were initially disparaged; following considerable veterans' organizing and public discussion, Congress held hearings to push the military to study the phenomenon. Official and scientific opposition to these toxic effects is based on opposition to lay involvement in science and medicine, resistance to new etiological pathways, rigid criteria concerning sample sizes, a preference for false negatives over false positives, and fear of the political and economic consequences of recognizing the source (typically corporate and military) of contamination (Brown 1992).

Cell 4 contains *potentially medicalized definitions*, what we might consider a 'latent' class of phenomena which are not *accepted* medical conditions and to which medical definitions have *not been applied*, yet might be in the future. Because there are so many bodily differences, there are endless possibilities for potential medicalization. The best current example is genetic screening, which increasingly locates characteristics which are not necessarily pathological, but are "predispositions" to future conditions. These include predisposition to diseases, based on known or estimated genetic ratios, including Huntington's Disease, various cancers, and hemophilia. When we talk about potential medicalization, we are talking here about the genes, not the actual diseases which might develop. Sometimes these are calculated on family genotypes, but often they are determined only on population-based estimates of predispositions, such as genetic markers for increased risk of cancer. Hence data that may appear statistically sound in terms of large populations are used to clinically label individuals. These screening approaches wind up defining as pathology the genetic makeup, rather than the disease that may arise. For some professionals, predispositions are not *yet* conditions, while for others, predispositions will *never* become conditions. Genetic *differences* exist, but only certain parties decide that these are in fact *defects*, and therefore that they should be treated in certain ways, such as excluding people who have them from particular jobs and from insurance coverage (Nelkin and Tancredi 1989; Draper 1991). Such insurance exclusion has indeed become well-known as national discussions of health reform bring more such cases to light. Work-place exclusion policies are often carried out as 'blaming-the-victim' responses which target individuals rather than work-place hazards.

Even nongenetic predispositions can fit into this potentially medicalized category. In the case of a predisposition to clinical hypertension, there is an arbitrary cutoff point of a certain blood pressure. For many people this pressure might never become clinical hypertension. By locating blood tests to show a worker's higher susceptibility to lead poisoning, the company excludes the person rather than cleaning up the work-place environment. Whether the initial impetus is work-place or insurance exclusion, the person then has a medical record establishing them as having a certain medical condition.

Not all diagnoses will fit neatly into a single cell. Indeed, the ongoing social construction of diagnosis and illness means that there will be complexity and change. Sometimes the history of a condition and definition moves it from one cell to another. For instance, asbestos causes mesothelioma, but early attempts to make this case were challenged by many medical professionals and institutions. Hence, the particular relationship between asbestos and mesothelioma was denied, even though those who did so might believe in other etiologies for the disease. It was originally a contested definition in Cell 3. But a definitional shift occurred, mainly due to social activism, and finally this particular relationship was widely accepted, making it a Cell 1 type of routinely defined condition.<sup>4</sup> Homosexuality was a Cell 2

medicalized type for psychiatry until activist pressure convinced the American Psychiatric Association to delete homosexuality as a mental disorder.

Similarly, there are diagnoses which at a single point in time will fall into one cell for one group, and another cell for another. For example, late luteal phase dysphoric disorder (LLPDD) is a medicalized type (Cell 2) for psychiatry, since a non-psychiatric condition is labeled psychiatric. For gynecology, and for many women's health organizations, however, there is no LLPDD entity, but only a normal gynecological event, making it a routine type (Cell 1) (see Figert 1993).

The above points on the changing nature of constructions inform us that the typology alone is insufficient, since it locates the type of the construction without necessarily tracing its development. Whether a construction remains as one type or changes, we need to study the developmental components of that construction. That is the intent of the following scheme.

### *Stages of Social Construction of Disease*

Finding the common elements in the process of the social discovery of disease can help identify the relative importance of various social forces across different disease discovery processes. Another advantage is that this stages model helps others to conduct new investigations. These stages typically occur chronologically, although not all cases will follow the precise order, nor will they necessarily go through all the stages.

There are some similarities between my model and Conrad and Schneider's (1992) "sequential model" of the medicalization of deviance. Conrad and Schneider argue that labelers first make a definition of behavior as deviance, prior to the existence of a medical definition. Second, medical professionals go "prospecting," wherein they float the medical definition for debate. In the third stage of claims-making, both medical and non-medical parties engage in further delineating the problem as medical. Fourth comes legitimacy, usually through an appeal to state authority in legislatures and courtrooms. Finally, an institutionalization stage occurs when the definition is rooted firmly within the official world. This sequential model is useful, but it specifically applies to medicalized definitions, for which it offers a rich framework. It would not, however, be applicable to contested definitions, such as those of toxic waste-induced diseases.

#### *I. Identification and Diagnosis—The Social Discovery of Disease*

*Lay initiation.* Stemming from a critique of the biomedical model, medical sociology understands that laypeople are often central to the discovery of diseases and conditions. People are often most aware, via direct experience, of problems which might not routinely come to medical attention.

The social construction of "conflictual" diseases involves lay (and usually a subsequent social movement) initiation of the discovery process. "Conflictual" diseases are those, such as toxic waste-induced diseases and iatrogenic effects of contraceptive technology, in which lay discovery conflicts with biomedical and other societal authority. Not all conflictual diagnoses are lay-initiated. For instance, pediatricians and other physicians introduced hyperactivity as a condition, leading to considerable conflict both within and outside of medicine (Conrad 1975). But lay-initiated definitions are extremely likely to be conflictual by virtue of the lay source of discovery.

The social construction of disease also involves the ways in which 'nonconflictual' diseases are discovered and/or defined. Very occasionally, lay discovery is central to 'nonconflictual' diseases, as with Lyme Disease. This neurological disorder with potentially severe outcomes is transmitted via deer ticks. Residents of Southern New England pioneered its detection, and their efforts led to more specific diagnostic categorization, public health warnings, and research in epidemiology and treatment.

But usually 'nonconflictual' conditions are those where people are not trying to convince the world of medicine and the relevant social institutions of their reality. For such diseases and

conditions (typically Cell 1 types, according to the earlier typology), there is no dispute over the discovery of the disease because both laypeople and professionals already accept it as a medical condition; the social construction is a construction of the illness experience. For example, Schneider and Conrad (1981) contrast sociological typologies of epilepsy (e.g., pragmatic, secret, and unadjusted adaptation) with biomedical ones (e.g., grand mal, petit mal). These divergent typologies reflect different social positions of doctors and patients, as well as the fact that the patient is experiencing personal and social effects on his or her life, while the physician is dealing with a concrete biomedical entity. (The role of illness experience in social construction is more fully discussed in a later section.)

On their own, lay discoveries may not succeed. Even if lay efforts are the initiators, sympathetic professionals (doctors, epidemiologists) and institutions (medical societies and philanthropies) are usually needed for successful claim-making. Frequently social movements are needed to propel such professional and institutional action.

*Social movements.* Social movements are central to many discovery processes. Lay discovery typically predates a social movement, though once a sufficient number of individuals recognize and act on a disease, they may form activist organizations to press their claims. These movements have mainly been in women's health, environmental health, occupational safety and health, civil rights, and disability rights/independent living. Some movements seek government and medical recognition of unrecognized or underrecognized diseases such as black lung, sickle-cell anemia, and post-traumatic stress disorder. The disability rights movement has had a great impact on the conceptualization of many chronic diseases and conditions. Other movements seek to affirm the knowledge of yet-unknown etiological factors in already recognized diseases such as the relationship between diethylstilbestrol (DES) and cervical cancer (Bell 1986). Some movements work to overturn medicalized definitions such as homosexuality and LLPDD as mental illnesses (Kirk and Kutchins 1992; Figert 1993). Others act to affirm knowledge of as yet unrecognized effects and side-effects of medications and technologies, as with organizing around silicon breast implants. In some cases, prior formation of social movements makes it easier for newly discovered diseases to be identified and pursued. For instance, once a women's health movement exists, it is more likely to deal rapidly with new problems, such as breast implants.

*Professional factors.* Professional factors can include discovery as well as resistance to discovery. Medical science makes routine and extraordinary discoveries, as with pediatric radiology and child abuse (Pfohl 1977), although these discoveries do not always come to broad public light or become standard practice. Frequently, media or social movement action is needed to catalyze knowledge and skills that might otherwise be lost or less widely disseminated. We also know that general social conditions can delay routine discovery. A current example is the way that anti-choice movements and federal policy (under Reagan and Bush) suppressed valuable research and treatment uses of fetal tissue and of the drug RU486.

Professional expansionism and moral entrepreneurship are more often the subject matter of medical sociology than is routine professional discovery. Obstetricians have used prenatal diagnosis to increase the detection of conditions which are then labeled dangerous, and hence lead to obstetrical interventions (Rothman 1989). Psychiatry enlarged its sphere to include gynecological conditions via LLPDD (Figert 1993). Children's diagnoses are especially on the rise, including the amorphous category of learning disabilities. In an era of deinstitutionalization, children's admissions to psychiatric facilities are rapidly increasing.

There is also an intraprofessional variant of moral entrepreneurship; for example, expansionist changes in DSM diagnoses have been due to the triumph of biopsychiatry over psychoanalysis and community psychiatry (Brown 1990; Kirk and Kutchins 1992). More broadly, the saturation of the biomedical model leaves physicians and their allies in government less able to perceive health and illness through the lay lens (Freidson 1970). They are therefore more likely to view routine social and bodily phenomena as pathological entities. This tendency to medicalize most likely increases with the level of specialization.

Resistance to discovery is also common, especially with regard to syndromes and diseases which are iatrogenic effects. Psychiatry was extremely reluctant to recognize tardive dyskinesia, a movement disorder stemming from neuroleptic drugs. Despite clear and early warnings in the psychiatric literature, practitioners and their professional association found it

hard to recognize a disease which called into question their most effective treatment (Brown and Funk 1986).

*Organizational and institutional factors.* Organizational and institutional factors also determine the type and amount of conditions discovered. We see self-perpetuation and institutional moral entrepreneurship, as when alcohol treatment facilities locate more cases of alcoholism, or when an expanding mental health system locates more mentally ill people. Sometimes this is merely expanding the pool of people who already have the condition; other times it involves new, less severe conditions that are viewed as needing treatment. There are also boundary disputes—such as arguments about the homeless mentally ill—between mental health and social welfare sectors. Here, mental health professionals diminish the extent of mental illness in order to reduce their responsibility, while the social service sector assumes a greater amount of mental illness, in order to get the mental health sector to take more responsibility (Snow, Baker, and Anderson 1986).

There are, in addition to professional resistance to discovery, organizational and institutional resistance to discovery. AIDS is perhaps the best-known example, where the scientific discovery of the disease and its etiology were held up due to both professionals and institutions and organizations, largely because of stigma, stereotypes, and judgmental attitudes toward gay men. The professional's social location has much to do with the construction of disease. Occupational physicians working for unions will be likely to diagnose diseases as caused by occupational hazards, while corporate physicians will be more likely either not to recognize the disease, or to attribute it to personal habits (Walsh 1987). Thus, coal company physicians claimed that black lung (silicosis) was really asthma and emphysema brought on by tobacco smoking (Smith 1987).

## *II. Experience of Illness*

Once there has been some form of discovery, the continuing forms in which people experience illness contribute to an ever-changing construction. Medical sociology counters a singular biomedical worldview with a social view that sees the interaction of biological and social factors. People may have the same disease, yet experience it quite differently. For example, the existence of a cardiac condition might lead one person to severely restrict their physical activity, even if that were not necessary. Another person, however, might actively reorient their dietary habits and figure out a healthy physical exercise regimen.

These differences might arise from individual personality. For example, Kleinman (1988:91) found that for chronic pain sufferers, pain is a symbol and a metaphor for their life situation, as with one person for whom "The stiff neck is a kind of symbol, an icon of what I need to become: tough, stiff-necked."

Differences in perception of health problems often stem from race, class, sex, ethnic, and national differences, as noted in the now-classic report by Zola (1973) on patient help-seeking in three clinics. He found differences, not based on physiology, among Italian, Irish Catholic, and Anglo-Saxon Protestants in the experience of illness and the ways that complaints were presented to doctors.

More generally, differences in illness experience stem from broader social perceptions and interactions, such as interpersonal crises, perceived interference with social or personal relations, social support from family and friends, sanctioning on the part of another family member, perceived interference with work or physical activity, and temporalizing (time-bound perceptions of symptoms) (Zola 1966). People feel and act on symptoms in many non-medical ways. For instance, what may seem an illogical form of noncompliance with doctor's orders may be a well-thought-out plan to avoid medical and social "side-effects" which might impair personal work life (Conrad 1985). This perspective may be especially useful for chronic diseases which have become our predominant health problems, and for which medical knowledge often lacks successful interventions.

People bring entirely different worldviews to their illnesses, especially in the ways they frame an etiology. In looking at rheumatoid arthritis sufferers, Williams (1984) found that one imputed a political and economic causality; another located etiology in a nest of social

relationships and psychological makeup; another used a spiritual explanation. Each of these people produced a coherent self-analysis for their own narrative, thus providing a way to repair the rupture which chronic disease caused in their relationship with the world.

This is very similar to Kleinman's (1988:6) amplification of the distinction between disease and illness. He adds other forms of social experience. One is *sickness*, by which he means "the understanding of a disorder in its generic sense across a population in relation to macrosocial forces," by which he means economic, political, and institutional. Kleinman also adds *explanation and emotion*, which is "the struggle of sick persons, their families, and practitioners to fashion serviceable explanations of the various aspects of illness and treatment" (Kleinman 1988:43).

In light of the above, it is understandable that people do not always experience disease as illness. Conversely, not all experienced illness is the result of a particular disease. Some people manage to avoid active symptoms, or to attribute them to other sources, or to accommodate to them. At the other side of the equation, certain people experience symptoms that are not traceable to a known cause, and some spend much time fearing they will catch any number of diseases. A large number of visits to doctors are for very minor symptoms. Varying estimates tell us that between 20 and 30 percent of visits to primary doctors are for psychological attention. Not surprisingly, primary care doctors, rather than psychiatrists, account for the bulk of psychiatric drug prescriptions.

Chronic illness forces people to come to new terms with the experience of time and change in their relation to past, present, and future (Freund and McGuire 1991:155). When experienced as overwhelming, unpredictable, and uncontrollable, chronic illness often causes damage to the self since sufferers cannot plan their life. This damage to the self causes a redefinition of illness experience (Charmaz 1991). Sufferers lose much, if not all, of their independence. They are often undermined in their reciprocity in relations, putting them under further strain (Freund and McGuire 1991:156). These core concerns force people to formulate an understanding of their personal biography and to make a "narrative reconstruction" (Williams 1984).

For people with stigmatizing illness, much of the illness experience is wrapped up in avoiding public awareness. This is often the case with disfiguring and sexually transmitted diseases, which bear a high degree of moral judgment. Epilepsy is one such case, where sufferers attempt to avoid seizures that may give away what for many is a secret (Schneider and Conrad 1981). People with AIDS spend much time hiding their illness, its symptoms, and the medications, though after a certain course of the disease it becomes impossible to continue hiding it (Weitz 1991).

Studies of the lay experience of illness stem from a "bottom-up" approach in sociology, which places people in the center stage, as active knowers. For many, this is based on Blumer's (1969) three basic premises: (1) people act on the basis of meanings that things have for them; (2) meanings derive from social interaction; and (3) meanings are modified by their interpretations in practice. Yet even this core symbolic interactionism is dependent on social structures, since the social interaction that provides the fabric for the generation of meanings is an interaction defined largely by the dominant structures of the society. In the case of health, these include professionalism and medical institutional structure, in addition to class, race, gender, and family structure.

The lay experience of illness cannot be completely separated from elements of clinical interaction, even though there is no space here to take up this larger concern. Briefly, we know that people's understandings of illness are shaped in large part by health providers, and that the dynamic interaction between patient and provider leads to conflicted and/or negotiated diagnosis and treatment. Professionalism, gender roles, and class and race differences are the chief forces that shape such interaction.

For one example, an increasingly biological trend in psychiatry has convinced more people that mental illness is a purely biological phenomenon without social etiology or social exacerbation. This has led many self-help groups and family and friends' associations to renounce previous critical stances by patients' rights organizations and innovative professionals in favor of purely biological explanations. This leads many people to accept a more mechanistic and positivist approach in which they rely solely on drug treatment and eschew

collective responses (Kovel 1988; Mirowsky and Ross 1989). This is a situation where a larger social construction alters the personal experience of illness for some people.

The experience of illness is often inextricably tied up with structural issues. For example, we may look at obstetrical reforms (presence of fathers at birth, birthing suites, midwives, vaginal birth after caesarean) as stemming from women's experience of illness as a lay phenomenon rather than a medical one. Ultimately, these lay experiences led to changes in health care delivery due to the women's health movement. In a sense, we can view the women's health movement as a *sociopolitical form of illness experience*. Rather than being merely individual experiences of illness, or even collections of individual experiences, these lay experiences are collective social constructions and productions of reality.

Another example of sociopolitical forms of illness experience can be seen in community response to toxic waste contamination. Here we have a situation where disease exists for a long time before it is recognized. Lay people recognize symptoms that they attribute to toxic contamination, and they notice disease clusters which they push health providers and public health officials to investigate (Brown 1992).

### III. Treatment

At first glance, it may seem hard to place treatment in the context of social construction of disease, since treatment appears to be a subsequent phase. Yet treatment is a logical sequel. In constructing their definition of an illness, people also construct what they consider appropriate ways to treat it. In the previous section on illness experience, we saw that people's choices for care are not based solely on medical criteria, but on other criteria such as family responsibilities, perceived stigma, and interference with work. Indeed, social constructionist approaches to what medicine terms "compliance" have given us a firm basis for viewing choice of care as an integral part of illness experience (Conrad 1985).

Our growing awareness of the importance of self-care is further evidence for this connection. People interpret and respond to conditions based on their social and economic circumstances, personal biographies, health beliefs, self-concepts, and through reinterpreting present, past, and expected future symptoms and illness (Haug, Wykle, and Namazi 1989). In choosing self-care, either alone or in combination with professional care, people define and structure the future of their illness experience (Dill et al. 1994). That illness experience is further shaped by the informal caregivers and social networks who play roles in self-care.

On a more political level, there are many occasions where a condition is diagnosed, yet there is discretion about whether it is treated. That discretion is often a matter of how the condition is socially constructed. The infamous Tuskegee syphilis experiment is perhaps the most overt example—Blacks were viewed as inferior and as material for human experimentation, hence it was possible for physicians, the Public Health Service, and major foundations to intentionally withhold life-saving treatment (Jones 1981).

If unethical treatment seems a matter of the past, it is noteworthy that medical researchers today still condone their past actions. In 1993, the Department of Energy, along with some involved hospitals and state health and mental health departments, made public that for decades radioactive experimentation had been conducted on unwilling and incompetent populations such as prisoners and retarded patients. Quite shockingly, several leading experimenters affirmed in 1993 and 1994 that they found nothing wrong with such practices because those practices conformed to acceptable science of the era, and that the work contributed to human knowledge (Allen 1993). The social construction here, however, must include the cold war attitude that radiation was a powerful weapon for all purposes, and the attitude of technological imperative that supported objectionable research even if there were expected side effects.

Even if such egregious actions no longer occur, political decisions are still made on other levels, where people and institutions make choices about allocating services to those in need. For instance, despite enormous knowledge of the prevalence of lead poisoning, poor and minority children most at risk are very underserved (Berney 1993). This produces both a greater epidemic of lead poisoning and a more politicized construction of lead hazards.

Indeed, there is frequently politicization of disease as a result of social allocation of

treatment, research, and prevention. Recent increases in breast cancer, for instance, have led many to view the increase as a result of environmental toxins, and also to fault government agencies and the health care system for failing to take the epidemic seriously enough (Arditti 1993). Public and social movement perspectives on the social nature of disease, and on acceptable treatment, may determine actual treatment. AIDS activism, for instance, has led to greater reliance on community-based treatment, and to lay constructions of acceptable drug trials.

The availability of treatment can further medicalize the professional framing of a normal process. For instance, the presence of synthetic estrogens helped push physicians to medicalize menopause as an estrogen deficiency disease (McCrea 1983). Medical technology in the form of fetal monitoring has led to increased 'discovery' of fetal distress, leading to dramatic increases in caesarean sections.

#### *IV. Outcome*

Organizational factors often determine belief in success, and hence in allocation of services. Roth's (1963) study of TB patients is a good example of how staff construct a view whereby certain patients wind up eligible for accelerated treatment and then for release. In part, patients had to urge staff to see that they were ready to move on to the next stage, despite an absence of clear, standardized clinical criteria.

Social factors influence outcome in many ways. The WHO schizophrenia study found better recovery from schizophrenia in less developed countries. Richard Warner (1985) found that there is better recovery from schizophrenia in times of labor shortage. And the Vermont Longitudinal Study learned that there was better recovery from schizophrenia when psychosocial preparation was used before release (Harding et al. 1987). These findings all indicate a high degree of social action in the determination of outcome. For the WHO study and from Warner's research, we can understand macrostructural factors as central. From the Vermont study, we know that professional and institutional expectations are important. In the absence of positive expectations, though, the socially constructed belief about schizophrenia is that it is far more unremitting than it is in fact. A more positive belief concerning outcome would alter the way in which both organized psychiatry and the general public view schizophrenia. As well, when clinicians and administrators become aware of these outcome studies and use them to formulate policy, they contribute to a revised (and more optimistic) social construction of schizophrenia.

Even the personal experience of illness can affect outcome. One example is the growing literature which shows that elderly people's self-assessment of health predicts mortality, after controlling for presence of health problems, disability, and biological risk factors (Idler and Kasl 1991). I believe we can view this phenomenon of health self-assessment as a form of illness experience, in which people hold more positive views of the self.

There is a more aggregate experience of illness as well. Community integration can occur in occupational and environmental health, where activists reframe a situation, turn it into a social problem, and thereby strengthen community ties. Such community integration can also aid victims of toxic waste sites by allowing them to see their problem as social and more broadly shared (Brown and Mikkelsen 1990). This is generally the case with social movements in health care—they provide an avenue for reinterpreting personal problems as social ones, thus redefining the very conceptualization of the illnesses at stake.

The preceding two sections on treatment and outcome have been briefer than the section on identification and diagnosis. As mentioned earlier, I am placing my main emphasis on the identification/discovery process and the experience of illness. Further, as those sections showed, treatment and outcome often operate as feedback loops to revise the original social construction.

#### SOCIAL POLICY IMPLICATIONS

There are many ways that understanding the social construction of illness has contributed and will continue to contribute to health policy. Medical sociology has long shown the importance



of lay understanding and action. At the clinical level, sociological study of illness experience has uncovered a vast array of fears, expectations, folk beliefs, self-care concepts, and relational issues. Many forward-looking clinicians have used this knowledge to provide more patient-centered care through understanding the interpersonal significance of the clinical interaction (Balint 1957) and by eliciting a "patient explanatory model" of illness (Kleinman 1988). The wealth of past contributions by social science researchers as well as clinical applications developed by joint medical/social science teams should be used to increase support for sociological participation in medical settings, as well as for research grant support.

Such sociological participation can play a useful role in medical education, through using social science approaches to illness experience in courses and clerkships. It would be best to integrate these concerns in regular courses and clerkships, rather than to segregate this material in electives that may be less central in medical training. Postgraduate education should also include training in social science approaches, specifically tailored to the specialty training. Medical professionals can employ these social science perspectives to elicit a more comprehensive picture of their patients' history, including their lay belief systems and self-care practices. Physicians might be encouraged to engage in research projects in collaboration with social scientists at their hospital or at the affiliated university, in which they might actually test the efficacy of more patient-centered approaches.

At broader social levels, lay constructions at the group level have shaped changes in the health care system. For example, women's health activists have long found considerable research and advocacy support from sociologists in their efforts to break down patriarchal attitudes and practices, and to institute woman-centered alternatives (Ruzek 1978). When we look at occupational illnesses and toxic waste-induced diseases, we see the importance of relying on lay detection through "popular epidemiology" (Brown 1992). In these and related areas, sociologists contribute both their analytic capacities and their skills at speaking with laypeople in health settings and communities. These abilities should be more widely tapped for health policy and planning. We should encourage federal health agencies and private health foundations to solicit requests for proposals from social scientists and from social scientist/clinician teams to investigate the contributions of such lay awareness.

Sociologists have been in the forefront of those who show that health and illness are often more affected by political, economic, and cultural factors than by biomedical ones. With AIDS, we know that bias against homosexuals played an important role in delaying recognition. Stemming from this knowledge, the implications for prevention and treatment are that we need social action to combat stigma and bias, that the work of gay health activists is an essential element in the campaign to eradicate AIDS, and that scientists and physicians need to be more aware of the social medicine components of this disease. Sociologists need to find more ways to connect to such social medicine approaches, both to foster them and to provide useful evaluation.

Sociologists need to emphasize the importance of social movements in the health care system. Movements and activists in the areas of AIDS, women's health, occupational health, and environmental health have been integral in several ways: (1) They have shown how to obtain more resources for the prevention and treatment of already recognized diseases (e.g., sickle cell anemia, AIDS); (2) They have pioneered the development of education and prevention efforts used by both laypeople and the medical sector; and (3) They have been major players in getting legislation for disease recognition, prevention, and treatment. Here, too, sociologists need to find ways to demonstrate to the medical and health policy communities the importance of social movements, including their importance in evaluation studies.

Because the sociological approach to the social construction of health and illness examines how socioeconomic factors cause and exacerbate disease, we can use our scholarship to design research to demonstrate that improvements in non-medical sectors such as housing, income supports, and education improve health status. We should also press for more intersectoral policies that seek to improve health status by improving those non-medical areas.

Medical sociology has pioneered the study of how chronic conditions and disabilities have become viewed as part of daily life, rather than as abnormalities. This has contributed to the disability rights movement and to the growing public acceptance of that movement's goals

(Zola 1982; Fine and Asch 1988). Sociological study of disability has sharpened our focus on the normality of symptoms, adjustments to a condition, chronicity, impact of the built/social environment on living with a condition, social/cultural changes as major impediments and/or gains, and the centrality of the body (Zola 1982). By emphasizing the significance of social movements, sociologists can show how collective action shapes social definitions of disease and disability and how social movements in health are often at the cutting edge of new approaches which later become more acceptable to the mainstream health care system. This can help policymakers appreciate such movements rather than seeing them as necessarily threatening.

Sociologists have contributed to understanding chronic illness by examining a wider and different range of issues than do official policymakers. Strauss and Corbin (1988:4–17) argue that policy toward chronic illness has largely been geared toward elderly people and terminally ill people, while largely ignoring chronically ill people's psychosocial needs, their needs for home care, their active work in the self-management of illness, and their self-care practices. Strauss and Corbin argue that chronic illness has a "trajectory" in which the acute phases are organized by medical professionals, yet without a recognition of the prior and subsequent stages of non-acute, nonprofessional care. This includes putting more attention on the role of informal caregivers and social networks in self-care. Sociologists, as part of the group of "policy thinkers," can demonstrate the importance of those alternative conceptions of the needs of chronic illness sufferers.

It will be important to think strategically about what impact our research can have, both in terms of choosing topics and in developing strategies for dissemination. In particular, sociologists need to devise ways to get their findings and their research skills in this area to those in the medical world, without losing their critical independent thinking. The social construction perspective has developed extensively in recent years. It offers much promise for building a firmer theoretical foundation, for conducting better research, and for influencing health policy. We owe it to ourselves to make good on this potential.

## NOTES

1. For those interested in more details on the literature of social construction, see Freidson (1970) and Freund and McGuire (1991). Anthologies by Lock and Gordon (1988), Brown (1989), and Conrad and Kern (1993) include many case studies of social construction.
2. See Link and Phelan's article in this issue for a discussion of the social causation of disease.
3. Peter Conrad was particularly helpful in thinking through this typology.
4. Interestingly enough, despite the voluminous evidence of this link, the eminent epidemiologist Richard Doll (1992) has recently tried to minimize the connection between asbestos and mesothelioma.

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