

The Social Construction of Illness: Key Insights and Policy Implications

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Peter Conrad¹ and Kristin K. Barker²

Abstract

The social construction of illness is a major research perspective in medical sociology. This article traces the roots of this perspective and presents three overarching constructionist findings. First, some illnesses are particularly embedded with cultural meaning—which is not directly derived from the nature of the condition—that shapes how society responds to those afflicted and influences the experience of that illness. Second, all illnesses are socially constructed at the experiential level, based on how individuals come to understand and live with their illness. Third, medical knowledge about illness and disease is not necessarily given by nature but is constructed and developed by claims-makers and interested parties. We address central policy implications of each of these findings and discuss fruitful directions for policy-relevant research in a social constructionist tradition. Social constructionism provides an important counterpoint to medicine's largely deterministic approaches to disease and illness, and it can help us broaden policy deliberations and decisions.

Keywords

social construction, illness, medical knowledge, health policy

In the last 50 years, the social construction of illness has become a major research area in the subfield of medical sociology, and it has made significant contributions to our understanding of the social dimensions of illness. In this article we briefly trace the roots of a social constructionist approach to illness, and we present some of the key findings of social constructionism organized under three themes: the cultural meaning of illness, the illness experience as socially constructed, and medical knowledge as socially constructed. In addition, we address central policy implications of these findings and fruitful directions for policy-relevant research in a social constructionist tradition.

Social constructionism is a conceptual framework that emphasizes the cultural and historical aspects of phenomena widely thought to be exclusively natural. The emphasis is on how meanings of phenomena do not necessarily inhere in the phenomena themselves but develop through interaction in a social context. Put another way, social constructionism examines how individuals and

groups contribute to producing perceived social reality and knowledge (Berger and Luckman 1966). A social constructionist approach to illness is rooted in the widely recognized conceptual distinction between disease (the biological condition) and illness (the social meaning of the condition) (Eisenberg 1977). Although there are criticisms and limitations of this distinction (Timmermans and Haas 2008),¹ it is nevertheless an exceedingly useful conceptual tool. In contrast to the medical model, which assumes that diseases are universal and invariant to time or place, social constructionists emphasize how the meaning and experience of illness is shaped by cultural and social systems. In

¹Brandeis University

²Oregon State University

Corresponding Author:

Peter Conrad, Department of Sociology, Brandeis University, Waltham, MA 02454–9110
E-mail: Conrad@brandeis.edu

short, illness is not simply present in nature, waiting to be discovered by scientists or physicians. As Gusfield (1967) notes, "Illness is a social designation, by no means given in the nature of medical fact" (p. 180). There are, of course, biophysiological bodily conditions or naturally occurring events, but these aren't ipso facto illnesses. Neither are they ipso facto diseases. The *disease* side of the disease/illness conceptual distinction is also ripe for social constructionist analysis, insofar as what gets labeled a disease or qualifies as biological is often socially negotiated.

THE ORIGINS OF SOCIAL CONSTRUCTIONISM

There are multiple intellectual roots of a social constructionist approach to illness.

Some of the basic building blocks are evident in the writings of early sociological thinkers (e.g., Emile Durkheim, Karl Mannheim, and W. I. Thomas), but we will start the story in the 1960s with the more direct predecessors of, and early contributors to, the social construction of illness.

One of the most important intellectual foundations of the social construction of illness is social problems theory and research from the 1960s and 1970s. Distancing themselves from positivist interpretations, scholars in this tradition asserted that what comes to be identified as deviant behavior or a social problem is not "given," but rather is conferred within a particular social context and in response to successful "claims-making" and "moral entrepreneurialism" by social groups (Becker 1963; Gusfield 1967, 1975; Spector and Kitsuse 1977). These scholars also emphasized the intentional use of these categories for the purpose of social control (i.e., defining and enforcing how particular people ought to behave). The basic tenets of this framework have been readily applied to illness. Specifically, medical sociologists point to the contingent processes by which certain behaviors and experiences come to be defined as medical conditions, and the way those definitions can function as a type of social control (Conrad and Schneider 1992; Zola 1972).

Symbolic interactionism and phenomenology—two popular and overlapping intellectual trends in sociology in the 1960s—also significantly contributed to a social constructionist approach to illness. Erving Goffman's (1961, 1963) early work helped to shape the symbolic interactionist tradition. Through his conceptualization of the "moral

career," Goffman spoke to the social experiences of patienthood, as distinct from any biological condition that may (or may not) launch such a career. According to Goffman and other symbolic interactionists, individuals actively participate in the construction of their own social worlds, including the construction of selfhood, via ongoing social interaction (Blumer 1969). The key tenets of symbolic interactionism effectively lent themselves to a detailed exploration of illness as experienced within the context of daily social interactions, which in turn alter the performance of self (Charmaz 1991; Glaser and Strauss 1965). In a related fashion, phenomenological tenets (Berger and Luckmann 1966; Schutz 1967) were appropriated by medical sociologists to showcase how individuals make sense of their illness, how they cope with physical and social restrictions, and how they deflect self-erosion in the face of those restrictions (Bury 1982).

Eliot Freidson's (1970) paradigm-shifting book, *Profession of Medicine*, also laid important groundwork for the social construction of illness approach. In the latter part of the book, in a section titled "The Social Construction of Illness," Freidson (1970) explains how illnesses have consequences *independent* from any biological effects:

[W]hen a physician diagnoses a human's condition as illness, he [*sic*] changes the man's [*sic*] behavior by diagnosis; a social state is added to a biophysiological state by assigning the meaning of illness to disease. It is in this sense that the physicians creates illness . . . and that illness is . . . analytically and empirically distinct from mere disease. (p. 223)

Not only did Freidson (1970) explicitly recognize the real and tangible social consequences of an illness label, but he also urged sociologists to address "how signs or symptoms get to be labeled or diagnosed as an illness in the first place" (p. 212). By arguing that illness and disease, like deviance, are social constructions (i.e., they are evaluative categories based on social ideas about what is *not* "acceptable" or "desirable"), Freidson foreshadowed the subsequent sociological study of medical categories and knowledge.

The writings of Michel Foucault (1977) and work in the Foucauldian tradition, albeit in a different vein, also emphasized the scrutiny of medical knowledge, and, in so doing, contributed significantly to a social construction of illness approach. Foucault regarded knowledge as a form

of power. Specifically, he argued that expert knowledge about human “normality” and “abnormality,” which is not objective or naturally given, is the principal form of power in modern societies: hence, his oft quoted expression, “knowledge/power.” Foucault stressed how medical discourse constructs knowledge about the body, including disease. As Bryan Turner (1995) notes, “We can no longer regard diseases as natural events in the world which occur outside the language in which they are described. A disease entity is the product of medical discourses” (p. 11). In turn, medical discourse can influence people’s behaviors, impact their subjective experiences of embodiment, shape their identities, and legitimate medical interventions (Foucault 1975, 1977). Accordingly, Foucault-inspired scholars deconstruct medical knowledge (i.e., provide a detailed analysis of medical discourse) to reveal its embedded meanings, normalizing tendencies, and relationship to embodiment and identity (Barker 1998; Lupton 1997; Rose 2006).

This is by no means an exhaustive account of the intellectual strands that lead up to, and continue to inform, a social constructionist approach to illness. Moreover, these strands are not mutually exclusive. Many medical sociologists draw on various aspects of these different traditions. As we proceed, we consider the social construction of illness approach as something of an amalgam. Although this minimizes important differences between various types of social constructionism, it can be justified in that they all share an eschewal of a strictly positivist conception of illness as the mere embodiment of disease. The approach foregrounds how illness is shaped by social interactions, shared cultural traditions, shifting frameworks of knowledge, and relations of power.

KEY FINDINGS OF SOCIAL CONSTRUCTIONISM

Cultural Meanings of Illness

Illnesses have both biomedical and experiential dimensions. Although often unnoticed or taken for granted, certain illnesses have particular social or cultural meanings attributed to them. These meanings adhere to the illness and may have independent consequences on patients and health care. Cultural analysts point out that illnesses also may have metaphorical connotations. Susan Sontag (1978), for example, argued that negative metaphorical meanings of cancer, as evil or repressive,

are common in our society and significantly impact those afflicted with the disease. Similarly, Barry et al. (2009) examined how obesity metaphors, such as “obesity as sinful” (gluttony), affect individuals’ support for different public policies aimed at reducing obesity.

While sociologists have rarely focused on the metaphorical connotations of illness, they have examined the impact of other cultural meanings embedded in illness. In this regard, all illnesses are not the same. For instance, some illnesses are stigmatized, and others are not; some are contested, and others are not; and some are considered disabilities, while others are not. What is important about these distinctions is that they exist for social rather than purely biological reasons. As we will see, sociologists are keenly interested in examining these distinctions because they bring into sharp relief the cultural landscape that ordinarily eludes us; or, as the anthropologist Ralph Linton (1936) once quipped, “The last thing fish would notice is water.” But more than mere sociological curiosities, these cultural meanings have an impact on the way the illness is experienced, how the illness is depicted, the social response to the illness, and what policies are created concerning the illness.

Here, one key line of sociological research is that which considers the cultural meaning of stigmatized illnesses. Drawing on the work of Goffman, Gussow and Tracy (1968) were the first to distinguish “stigmatized illness” as a category using the case of leprosy. Subsequent researchers examined the construction and impact of a number of stigmatized illnesses, including mental illness, epilepsy, cancer, HIV/AIDS, and sexually transmitted diseases (STDs). These researchers have identified how some illnesses become stigmatized, the impacts of stigma, the ways individuals and collectivities manage stigma, and how illness stigma can change over time. For example, research has shown, in the case of epilepsy, that it can be more difficult for sufferers to manage the stigma than the seizures (Schneider and Conrad 1983; Scambler 1989). In the case of HIV/AIDS, other research has shown how stigma limits access to treatment and affects relationships and identity (Epstein 1996; Weitz 1990). The lesson from a constructionist standpoint is that there is nothing inherent about a condition that makes it stigmatizing; rather, it is the social response to the condition and some of its manifestations, or the type of individuals who suffer from it, that make a condition stigmatized (Conrad 1987).

Contested illnesses are a category of disorders that, by definition, have a very particular cultural meaning. These are illnesses where sufferers claim to have a specific disease that many physicians do not recognize or acknowledge as distinctly medical. Contested illnesses, including chronic fatigue syndrome, fibromyalgia syndrome, irritable bowel syndrome, and multiple chemical sensitivity are medically suspect because they are not associated with any known physical abnormality. These illnesses showcase the tension between lay and medical knowledge with respect to the cultural legitimization of symptoms and suffering. In the words of one researcher, these are “illness[es] you have to fight to get” (Dumit 2006). Physicians, the public, and sometimes even sufferers themselves question the authenticity of the symptoms and the mental stability of the sufferer. In sum, contested illness sufferers are burdened by the cultural meaning of a medically invisible condition in an era of high-tech biomedicine (Barker 2005; Brown 2007; Kroll-Smith and Floyd 1997). In fact, this becomes one of the most important characteristics of these illnesses, affecting access to a diagnosis and health care, the response of others to one’s problem, and the very identity of the sufferer.

Research describing the social construction of disability also provides a powerful example of the cultural meaning of certain conditions. The roots of this approach are found in Goffman’s (1963) *Stigma*, wherein he highlights the social meaning physical impairment comes to acquire via social interactions. Specifically, Goffman claims that the social meaning of impairment does not emanate from the impairment itself, but from the fabric of everyday life. The social model of disability, grounded on social constructionist tenets, conceptually distinguishes impairment (i.e., the attribute) from disability (i.e., the social experience and meaning of impairment). Because the attributes that are deemed disabilities, and the very meaning of being disabled, vary across time and space, disability cannot be reduced to a mere biological problem located in an individual’s body (Barnes, Mercer, and Shakespeare 1999). In its most basic form, this distinction suggests that the body has an impairment (e.g., loss of limb) while society creates the disability (Oliver 1996). Rather than a “personal tragedy” that should be fixed to conform to medically determined standards of “normality” (Zola 1982), disability becomes politicized. New questions then emerge. What obstacles limit the opportunities for individuals with impairments? How can those obstacles be altered or removed?

Policy Implications of the Cultural Meaning of Illness

As we have noted, certain illnesses come to have cultural meanings that are not reducible to biology, and these cultural meanings further burden the afflicted. At a general level, insights from this line of research suggest a shift in emphasis away from an exclusive focus on biomedically fixing individuals and toward changing the social and cultural context that gives particular illnesses their negative meaning.

For example, there are policy implications of both stigmatized illness and contested illness. Stigmatized illness can make an illness much more difficult to treat and manage. For example, if an illness such as epilepsy or HIV/AIDS has a powerful stigma, it can make people less likely to seek treatment for fear of being mistreated by health care providers and publicly associated with a tainted condition. Obese women report avoiding routine gynecological exams, despite having higher rates of gynecological cancers than non-obese women, because of the stigma of obesity and the corresponding negative attitudes of health care professionals toward overweight people (Amy, Aalborg, Lyons, and Keranen 2006). Therefore, an effective policy based on early cancer screening must overcome this barrier.

In the case of contested illnesses, the fact that sufferers’ symptoms are not readily associated with a discernable biomedical abnormality often makes it difficult for them to have their symptoms acknowledged or treated, and often raises suspicions that their problems are “all in their heads.” Some physicians refuse to treat patients diagnosed with contested illnesses, and some insurance companies will not reimburse for such treatment. On the other hand, patients’ desires for a medical diagnosis as confirmation that their symptoms are “real” often lead to excessive demand for unnecessary and costly diagnostic procedures. Faced with this situation, health organizations may find that giving patients a contested illness diagnosis and providing them with inexpensive palliatives is the most effective means of cost containment. Consequently, there are real concerns that these diagnoses are being overused to manage difficult and potentially expensive patients (Barker 2005). This may be one factor behind the growing prevalence of contested illnesses. Another may be the rise and spread of Internet support groups as alternative arenas for legitimating such illnesses. Despite the widespread use of these diagnoses, sufferers of

contested illnesses only infrequently receive disability benefits, even when they meet the stated criteria regarding the inability to do "usual and customary work." Funds for medical research to find solutions for the putative problems that underlie contested illnesses are also scarce relative to the number of individuals afflicted. In each of these areas, effective medical practice and policy are likely to be enhanced by a greater appreciation of the behavioral consequences of cultural meanings that grant legitimacy to the symptoms of some sufferers and not to those of others.

The policy insights derived from the social construction of disability approach are myriad. Passed in 1990, the Americans with Disabilities Act (ADA) affirms the essence of social constructionist claims—namely, an individual's impairment need not be disabling when society makes reasonable accommodations, such as ramps to allow wheelchair access into buildings. Although a symbolic civil rights victory for individuals living with disabilities, the legal limitations of the ADA are well known (Acemoglu and Angrist 2001; Lee 2001). Moreover, the ADA primarily addresses workplace discrimination and issues of public access, which, although important, do not represent a fundamental shift in the cultural meaning of disability. The social constructionist perspective helps make sense of many other policy debates, including the opposition of many members of the deaf community to cochlear implants. For example, while parents of deaf children hope the implant will make their children as normal as possible by giving them at least some ability to hear, the deaf community contends that deafness is not a medical defect but a cultural identity with its own language and that implants undermine that identity (Dolnick 1993). Social constructionist tenets also help explain why some disability rights advocates part ways with other progressives on policies concerning death with dignity and prenatal genetic screening and selection. The disability rights movement often opposes the cultural messages behind these policies and procedures—namely, that it's better to be dead (or not born at all) than disabled.

Illness Experience as Socially Constructed

Another key insight of constructionism is that the illness experience is socially constructed. This assertion is grounded in the strong pragmatist underpinnings of symbolic interactionism and phenomenology, which suggest that reality does not just exist out there in the world waiting to be

discovered, but rather is created by individuals who act in and toward their world. Applied to illness, people enact their illness and endow it with meaning. They are not merely passive entities to whom things are done (be it by a disease or by doctors and treatments). This is the general starting point for a number of important lines of sociological research, all highlighting the everyday and subjective experience of illness.

In the 1960s, sociologists began to study the patient's perspective of illness (e.g., Glaser and Strauss 1965; Goffman 1961). Strauss and his colleagues (Strauss and Glaser 1975), however, were among the first to recognize that the patient experience is not the same as the illness experience; after all, people with illnesses spend very little time in the patient role. This important step laid a foundation for a more developed approach to the experience of illness. Building on this tradition, Conrad (1987) elaborated the approach:

[A] sociology of illness experience must consider people's everyday lives living with and in spite of illness. It needs to be based on systematically collected and analyzed data from a sufficient number and variety of people with an illness. Such a perspective necessarily focuses on the meaning of illness, the social organization of the sufferer's world, and strategies used in adaptation. (pp. 4–5)

This research is usually based on in-depth interviews, focusing on the subjective illness experience and creating an "insider's" view. Such a perspective is well positioned to examine how individuals construct and manage their illness, and with what consequences. The research of Charmaz (1991) is a well-developed example. Charmaz describes how the worlds of some individuals shrink when they are immersed in the day-to-day aspects of managing a chronic illness. They become increasingly cut off from the routines of conventional life—unable to work, spend time with family, socialize with friends, or move about freely. Thus, the foundation on which a sense of self is based can be lost, there is nothing to look forward to, and nothing to do; time is experienced as unchanging (Charmaz 1991).

There are also a number of studies that closely examine the experience of specific illnesses such as HIV/AIDS (Klitzman and Beyer 2003; Weitz 1990), diabetes (Peyrot, McMurry, and Hedges 1987), asthma (Snadden and Brown 1992), and fibromyalgia (Barker 2005). Schneider and Conrad (1983), for example, provide a detailed account of

the experiences of individuals with epilepsy, including the ins and outs of when, and to whom, they reveal or conceal information about their illness. From getting a driver's license and negotiating intimate relationships, to going on a job interview or being on the lookout for "safe places" to have seizures, individuals with epilepsy try to maintain self-control, skirt embarrassment and discrimination, and avoid becoming the object of a public crisis. Whether focusing on chronic illness in general, or on a specific chronic illness, these are the types of rich details that emerge from research into the illness experience.

This research also describes how people struggle to make sense of their illness and reclaim a sense of self. People endeavor to endow their illness with meaning within the context of their personal and social relationships, employment status, health insurance coverage, religious and cultural beliefs, and the like. Individuals may abate an erosion of self by engaging in identity reconstruction. Said differently, when illness becomes a "biographical disruption," individuals recast themselves in terms of new and unexpected plot developments (Bury 1982). Chronic illness can prompt a re-evaluation of one's former life and identity, and, in some cases, the creation of a new illness identity (e.g., cancer survivor). Finally, medical sociologists have documented how laypeople sometimes create and join illness-based social movements, generate lay knowledge about their own medical conditions, and forge new communities based on illness identities (Banks and Prior 2001; Brown et al. 2004; Kroll-Smith and Floyd 1997). Millions of American women, for example, identify as breast cancer survivors and activists in the fight against breast cancer. They exchange information about their treatment options, participate in national fundraising events, and mobilize in support of relevant policies and initiatives (Klawiter 2008; Radin 2006). In sum, individuals actively shape the parameters of their illness and the meaning of selfhood in relationship to those parameters.

This line of research brings to the fore aspects of illness that the tools of medicine are unable to reveal. A constructionist approach takes the subjective experience of illness seriously, examining the personal and social meanings of illness, and exploring how illness is managed in the social contexts that sufferers inhabit. This research has given us a detailed and intimate view of the suffering that illness often represents, but it has also shown us that agency and resistance are key to the

illness experience. Even in illness individuals are not passive: "the self is more than its body and much more than an illness" (Charmaz 1991:258).

Policy Implications of Illness Experience as Socially Constructed

The key research findings concerning the social construction of the illness experience have a number of critical policy implications. First, some of these findings shed a new light on clinical perspectives and policies toward issues such as "noncompliance" (Conrad 1985; Peyrot et al. 1987) and the impact of the subjective perspective on interactions with medical professionals and care-givers (Waitzkin 1991). The focus on the meanings of medications in the context of a patient's everyday life, rather than on compliance with doctors' orders, allows the clinical policy focus to shift from "compliance" to context-centered strategies to improve the effective implementation of medical regimens. By giving voice to the sufferers' perspective, the experience of illness approach can lead to important clinical reforms. Take the case of pain management. Despite its vast technical arsenal, medicine is simply unable to see or measure pain. For this reason, physicians have often trivialized the pain of patients who lack a visible injury to account for their suffering. More aggressive pain management may be mandated, however, once we take seriously and develop appropriate means of evaluating the vivid accounts of chronic pain sufferers. The current interest in narrative medicine is in large part predicated on the work of sociologists and others who were among the first to listen to illness stories (Frank 1995). As a window into subjective experience, illness narratives are now used as a means of bringing the *person* back into medicine, both as an end in itself and for potential therapeutic benefits. Again, chronic pain is illustrative: When it comes to affirming the humanity of the sufferer and authenticating the existence of pain, patient narratives are a tool for overcoming the limitations of high-tech medicine (Kleinman 1988).

There are also policy and clinical implications associated with the constructionist findings regarding lay knowledge and illness identities. With the expansion of the Internet, laypeople are becoming more actively involved in producing and consuming knowledge about their own health conditions; they are also increasingly likely to create and embrace new illness identities. Some medical

sociologists suggest that lay ways of knowing may supplement medical knowledge and positively influence health outcomes (Brown 1992; Kroll-Smith and Floyd 1997). Illness identities might also contribute to improved well-being insofar as they represent a form of self-empowerment (Popay and Williams 1996). However, there are also reasons to be concerned that lay knowledge and illness identities may negatively impact doctor–patient relationships and health outcomes and contribute to the expansion of medicalization (Fox, Ward, and O'Rourke 2005; Hardey 1999). For better or worse, lay and experiential knowledge will increasingly come into conflict with and challenge professional knowledge. This is all the more assured given orthodox medicine's mixed record of therapeutic efficacy in the face of many chronic illnesses. Coming to terms with these lay-medical conflicts and the movements they engender will create major policy challenges.

Medical Knowledge as Socially Constructed

Eliot Freidson (1970) was probably the first medical sociologist to articulate how medical knowledge is socially constructed. Over the years, social scientists have taken several different paths in the study of the social construction of medical knowledge.

One major line of research exposes how medical knowledge sometimes reflects and reproduces existing forms of social inequality. Rather than being value-neutral, some medical knowledge, implicitly or explicitly, shores up the interests of those groups in power. Upon close inspection, some medical ideas have been shown to support gender, class, and racial-ethnic inequality. For the sake of illustration, we present some important feminist contributions to this undertaking.

Feminists have found the social construction of illness approach to be a particularly potent analytic device. This affinity is likely the result of the strong constructionist tendency within feminist theory more generally. The starting point for most (but not all) feminist theory is the conceptual distinction between gender and sex. Feminists claim that gender is a social construction, by which they mean that our ideas about gender (i.e., norms and standards concerning femininity and masculinity) are not predetermined by our biological sex differences. Therefore, our ideas about gender and the social practices that they institutionalize are alterable.

A number of feminist scholars have shown how gender meaning is inscribed onto women's bodies and minds through past and present medical

discourse and practice, and, in turn, functions to naturalize gender inequality (Clarke 1998; Ehrenreich and English 1978; Lorber 1997). For example, embedded within medical knowledge about pregnancy, premenstrual syndrome (PMS), childbirth, and menopause, one finds clear ideas about women's "proper" (i.e., subordinate) place in society, as well as moral assumptions about women's sexuality and femininity more generally. In the early twentieth century, pregnant women were advised against driving an automobile or dancing, on grounds that these activities threatened the health of their unborn child. Today, pregnant women are endlessly warned about the risks of drinking alcohol (Armstrong 2003). In both periods, the medical advice reflects marked cultural anxieties about women's sexual and social freedoms; and, in both periods, when pregnant women follow the prescribed medical advice, they enact the dominant cultural ideals of femininity. Medical knowledge about PMS provides another interesting case. Precisely because some of the symptoms of PMS (e.g., frustration, aggression, anger) defy norms about how women ought to behave, they become *prima facie* evidence of a disorder (Markens 1996). Thus, not only can medical ideas result in the social control of women's behavior, but they also contribute to our cultural beliefs concerning the existence of unalterable differences between men and women. These beliefs, in turn, can be used to justify gender inequality within intimate relationships, families, institutions, and society.

The research of medical sociologists in the subfield of science studies also reveals how medical knowledge is conditioned by the social context in which it is developed. Specifically, these scholars explain that what qualifies as biological disease or biomedical evidence is often socially negotiated and interpreted (Joyce 2008; Timmermans 2007). Steven Epstein's work is exemplary of this type of research. In a recent book Epstein (2007) analyzes the emergence, beginning in the mid-1980s, of a new paradigm of biomedical research that proactively included individuals from underrepresented social groups (e.g., women and racial and ethnic minorities) in clinical studies, with an eye toward understanding the differences between groups with respect to disease processes and treatment outcomes. Even as this new paradigm offers potential tools for addressing nagging questions about health disparities—e.g., why do black women with breast cancer have higher mortality rates than their white counterparts?—it has the consequence of reifying

the categories of race and gender as biological realities. But, by showcasing how a number of different interest groups and institutional players (e.g., feminist activists, advocates for racial and minority groups, and various cadres of bureaucrats) pushed for this new research paradigm, Epstein explains how the knowledge it produces about race and gender are in part the outcome of social and political conflicts and negotiations, as opposed to essential truths found in nature. In an earlier book, Epstein (1996) similarly underscored the politics of knowledge by demonstrating how the science regarding the cause and treatment of HIV/AIDS is best understood as an amalgam that was constructed and contested by different constituencies (e.g., scientists, doctors, drug companies, patients, and activists) rather than the outcome of "pure" science.

Also under the general theme of the social construction of medical knowledge is the influential work on medicalization. Medicalization occurs when human problems or experiences become defined as medical problems, usually in terms of illnesses, diseases, or syndromes. In general, sociologists who study medicalization emphasize the processes by which a particular diagnosis is developed, becomes accepted as medically valid, and gets used to define and treat patients' problems. Sociologists have described many different types of problems and experiences that have come to be defined and treated medically. Early studies focused on the medicalization of deviance, including madness, drug and alcohol problems, and homosexual behavior (Conrad and Schneider 1992). Over the years, sociologists have shown that women's natural reproductive functions (e.g., pregnancy, childbirth, menstruation) are routinely medicalized (Barker 1998; Riessman 1983; Riska 2003). For example, Prempro, a widely prescribed hormone replacement drug, is just the latest in the ongoing effort to medically "treat" menopausal "symptoms," despite the fact that changes associated with menopause are a common and ordinary aspect of women's reproductive lives.

In recent years sociologists have focused on the medicalization of ordinary life events, risk, and "proto illnesses," as well as individuals' perceived shortcomings and their desire for enhancements, e.g., improved sexual performance (Conrad 2007). Likewise, the engines of medicalization have expanded beyond medical professionals, social movements, and organizations to biotechnology, consumers, and the insurance industry. There is increasing evidence that commercial aspects of

medicine, especially the pharmaceutical industry, are increasingly important in the shaping and disseminating of medical knowledge to promote their products. There are now important case studies on female sexual dysfunction (Hartley 2006), menopause (Bell 1990), mild depression (Horwitz and Wakefield 2007), sleep disorders (Williams 2005), and many other problems. The case of erectile dysfunction is telling (Loe 2004). In the late 1990s male impotence was renamed "erectile dysfunction" (ED), and in 1998 the FDA approved Viagra for its treatment. The drug was intended for older men with chronic erectile problems and for ED associated with prostate cancer, diabetes, and other medical conditions. Pfizer, the drug manufacturer, soon began promoting the drug to a much larger audience. Using television commercials featuring virile and relatively young professional athletes, Pfizer presented Viagra as benefiting any man, regardless of age. When newer competitor drugs such as Cialis and Levitra came on the scene they were widely advertised as not only treating ED, but as useful for anyone who worried about or wanted to enhance their (or their partner's) sexual experience (e.g., "Cialis is ready when you are"). Both the boundaries of the ED diagnosis and the markets for ED drugs expanded enormously (Conrad 2007).

Policy Implications of Medical Knowledge as Socially Constructed

A number of policy implications are derived from the key findings concerning the social construction of medical knowledge. By acknowledging that medical knowledge about disease and illness is constructed by socially situated claims-makers and other interested parties, we can bring greater critical awareness to the policy-making process. After all, any policy response to a problem is determined by how the problem is defined or framed in the first place. For example, how do we approach the problem of health disparities between racial and ethnic groups? When the solution is to mandate that federally funded clinical studies include individuals from underrepresented subgroups, we inadvertently cast the problem as rooted in biological differences between racial and ethnic groups and downplay the role of socially structured inequalities (Epstein 2007).

Likewise, when we define alcoholism as a disease, the dominant approach is to treat the individual alcoholic, rather than examine the social

factors contributing to alcohol abuse or the role of the alcohol industry in alcohol promotion. When medical perspectives increasingly define obesity as an illness (rather than a risk factor for diseases such as diabetes, cardiovascular disease, etc.), policies focus on solutions such as gastric bypass surgeries, rather than examining the role of product promotion by the food industry or the availability of healthy foods in neighborhoods with high rates of obesity.² Warnings about the risks of fetal alcohol syndrome effectively blame individual women and deflect attention away from the well-established links among class, race, and birth outcomes (Armstrong 2003). Framing anger in women as evidence of the disease PMS, to be treated with antidepressants, trivializes the impact of gender inequality on women's daily lives. And when difficulties in children's attention and behavior get defined as attention deficit hyperactivity disorder (ADHD), school policies increasingly encourage the use of medication and special accommodations for learning disabled students; yet these responses fail to address the social and nonmedical causes of children's classroom inattention or agitation, such as increasing class size or the termination of physical education programs (Conrad 1975).

In each case, and many others, the process by which human problems become medicalized in the first place is largely ignored in creating policy toward these issues. A social constructionist approach provides a means of understanding how such problems come to be defined in medical terms and how this translates into public policy (see Gusfield 1981). As the above examples attest, medicalized constructions can also be strongly evaluative (i.e., they suggest how people *ought* to behave) and result in policies that authorize social control.

For sociologists, one of the most troubling results of medicalization is that it encourages medical solutions while ignoring or downplaying the social context of complicated problems (Lantz, Uchtenstein, and Pollack 2007). It seems that we have a social predilection toward treating human problems as individual or clinical—whether it be obesity, substance abuse, learning difficulties, aging, or alcoholism—rather than addressing the underlying causes for complex social problems and human suffering. We are quick to see individualized medical interventions as logically consistent responses to our troubles (see Conrad and Schneider 1992). However, medicalization research forces us to recognize both the origin and limitation of clinical and medical accounts. In so doing, we can be

more skeptical of quick, medicalized fixes for what are really complex, multifaceted social problems.

Finally, medicalization itself raises concerns about the possibility of meaningful health care reform. Creating an ever larger jurisdiction of medical problems that are subject to potential insurance or public reimbursement may be a serious impediment to providing comprehensive and universal health care coverage. What is comprehensive coverage in the context of the successful commercialization of “elective” medicine, as in the case of cosmetic surgery or anti-aging medicine? Is it possible to provide universal coverage given our cultural predisposition for “a pill for every ill,” amplified by the pharmaceutical industry's promotion of an “ill for every pill” (Mintzes 2002:909)? Are there any limits to what can be medicalized, or are all human problems and variations in socially desirable characteristics fodder for medical diagnoses and treatments? In sum, the fiscal costs of run-away medicalization may significantly impede any effort to reform health care (Conrad, Mackie, and Mehrotra, 2010).

DIRECTIONS FOR THE FUTURE

We identify several important directions for future social constructionist research in medical sociology.

One intriguing direction for future research is to build on recent studies that examine the impact of the Internet on the illness experience (Barker 2008; Conrad and Stults 2010; Pitts 2004). For decades sociologists have shown illness to be a privatizing experience, and that, in comparison to other forms of social deviance, there were almost no illness subcultures. The Internet—with interactive Web sites, bulletin boards, and social network sites such as Facebook—is changing that. With thousands of Web sites and user groups dedicated to just about any illness imaginable, illness is becoming an increasingly public experience. This is leading not only to the creation of illness subcultures, but also to illness-based social movements, lay demands for medicalization or demedicalization (Conrad and Stults 2010), new avenues for sharing information and experiences, and the expanding influence of lay knowledge about illness. Thirty years ago few sufferers of an illness or disorder knew others with the same ailment; with the Internet this is becoming increasingly unlikely, and the consequences of this are grist for the sociological mill. Sociologists are well positioned to examine how Internet forums affect

participants' construction of illness identities and the impact on their illness experience. Beyond just the role of the Internet, future social constructionist researchers will need to track the rising influence of laypeople and lay knowledge about illness, the institution of medicine, and the nature of health care. As laypeople become more involved in collective illness behavior, including generating lay knowledge, and ever-more active consumers of medical care, what will be the impact on the meaning of illness, the delivery of services, and the role and influence of the medical profession? Laypeople can use the Internet to create and gather new medical knowledge and, with or without the Internet, organize to promote their own claims about sources and treatments of illness (Brown 2007). Compared to 50 years ago, physicians have experienced a relative decline in professional authority. Both reflecting and reinforcing this trend, laypeople with illness have a greater voice, and there is also greater recognition of that voice. The policy implications related to this shift are an important area of future research.

Medicalization studies will continue to be an important area of research in the social constructionist tradition. As the United States moves toward health care reform and the potential of universal (or at least expanded) health insurance, how will medicalization impact what is covered, and how will what is covered impact medicalization? How will the rise of commercialized medicine and biomedical enhancements (e.g., genetics and drugs) impact our medical costs, and what role will the forces toward medicalization play in this area? For example, will health insurance cover infertility treatments, genetic interventions for "addictions," gastric bypass surgeries, and biomedical enhancements such as human growth hormone for short stature or so-called smart drugs (stimulant medications) for students and intellectual workers? Of course, unbridled medicalization is just one more reason health care reform is so difficult to achieve, but health care reform may, in fact, be one of the few countervailing forces to what otherwise seems to be an ever-increasing trend toward medicalization. Perhaps the problem of medicalization can help us as a society to realize that our resources are limited, even if the promises made by the commercial biomedical industry are seemingly boundless. In other words, the processes of medicalization are of considerable importance in the health care debate, and sociologists are in a good position to study those processes and inform the debate.

CONCLUSIONS

In this article we have touched on several different ways medical sociologists have utilized a social constructionist approach for studying illness over the last 50 years. We have highlighted the key findings of three lines of research and pointed to some policy implications of each. First, some illnesses are particularly embedded with cultural meaning—which is not directly derived from the nature of the condition—that shapes how society responds to those afflicted and influences the experience of that illness. Second, all illnesses are socially constructed at the experiential level based on how individuals come to understand their illness, forge their identity, and live with and in spite of their illness. Third, as feminist, science studies, and medicalization analysts have demonstrated, medical knowledge about disease is not necessarily objectively given in nature; rather, it is constructed and developed by claims-makers and interested parties who frequently have a strong evaluative agenda. These findings do not invalidate scientific and medical perspectives, but rather demonstrate that diseases and illnesses are as much social products as medical-scientific ones.

These findings, although sociologically significant in their own right, have a number of policy implications. Some of these have already been adopted, but others have yet to find their way into the policy arena. By revealing the social contingencies of illness at the individual, institutional, and societal levels, a social constructionist approach provides an invaluable conceptual wedge for policy formulation. It brings our attention to contingent spaces where some form of action (or inaction) can fundamentally alter subsequent events. A constructionist approach reminds us that how a problem is defined affects how (or even if) society responds to the problem, and how the experiences of individuals are influenced by the definition and response to their problem. As such, social constructionism provides a counter to medicine's deterministic logic in ways that can broaden and enrich policy deliberations and decisions. To that end, we must routinely ask ourselves, "What is the *definition* of the problem upon which this policy is based, how was it developed, and what are the consequences of adopting this definition?" Without these theoretically important questions to guide us in decision-making, we will likely make serious errors in the implementation of future health reforms and health-related policy initiatives

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NOTES

1. Our task in this article is to highlight the most significant findings and policy implications of social constructionism. As such, we do not showcase the criticisms of social constructionism. We do, however, acknowledge that there are important critiques. Among the principal charges: social constructionism explicitly or implicitly denies the existence of the natural world, and it trips over or ignores questions concerning whether some ideas are better representations of the world than others. Ian Hacking (1999) also alleges that social constructionism inevitably reproduces a false binary between things that are *real* (and therefore have an entirely biophysical basis) and things that are *socially constructed* (and therefore have no biophysical basis whatsoever). As a result, Hacking contends, social constructionism fails to consider the possibility that something can be *both* real and socially constructed. However, sociologists have often supported this *both/and* view. For example, they suggest that the social forces constructing the definition and treatment of illness are themselves real phenomena that can be studied empirically (Brown 1995; Freidson 1970). Moreover, what is judged to be biological often rests on social dynamics and processes (Joyce 2008; Timmermans 2007). Following Freidson (1970), we do not think it is sociology's job to adjudicate between what is "really" a disease or illness and what is "socially constructed." Indeed, like Hacking we consider this to be a false binary. From a social constructionist perspective, the point is to investigate how something comes to be defined as a "disease" or "illness" in the first place. Sociologists can further study the extant and changing cultural meanings that may inhere in a disease or illness while remaining agnostic about the "underlying" biological condition. In any given case, it is the viability of the *idea* of disease or illness itself (rather than its validity, *per se*) that is of greatest interest to sociologists.
2. Even the latter, more sociological approach misses the mark if being overweight merely represents part of the normal variation among humans, and, by itself, doesn't produce poor health.

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Bios

Peter Conrad is Harry Coplan Professor of Social Sciences at Brandeis University. His most recent book is *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders* (Johns Hopkins University Press, 2007).

Kristin K. Barker is associate professor of sociology at Oregon State University. She is the author of *The Fibromyalgia Story: Medical Authority and Women's Worlds of Pain* (Temple University Press, 2005).