

Towards a sociology of disease

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Abstract We argue for a sociology of health, illness, and disease. Under the influence of Talcott Parsons, the social study of health began as medical sociology and then morphed into sociology of health and illness, focusing largely on the social aspects of health-related topics. Social scientists have been reluctant to tackle disease in its physiological and biological manifestations. The result is an impoverishment of sociological analysis on at least three levels: social scientists have rarely made diseases central to their inquiries; they have been reluctant to include clinical endpoints in their analysis; and they have largely bracketed the normative purpose of health interventions. Consequently, social scientists tend to ignore what often matters most to patients and health care providers, and the social processes social scientists describe remain clinically unanchored. A sociology of disease explores the dialectic between social life and disease; aiming to examine whether and how social life matters for morbidity and mortality and vice versa. Drawing from specific advances in science and technology studies and social epidemiology, we point to ways that sociologists can participate as health researchers.

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Genesis of medical sociology

Every successful scientific discipline sooner or later develops an historical narrative of how it all started (Schlich 1995). For medical sociologists, the genesis of the social study of medicine originates in Talcott Parsons' (1951) theoretical account of the doctor-patient relationship (e.g. Gerhardt 1990, Williams 2005). In Chapter X of *The Social System*, Parsons conceptualised illness as a form of deviant behaviour with the physician as societal gatekeeper to restore patients to normal societal functioning. Parsons noted that both patient and physician performed specific role expectations to conquer disease. The actual genesis of medical sociology occurred early in Chapter X when Parsons justified the study of medicine for social scientists. Parsons first argued that health was functional for individuals and society:

A little reflection will show immediately that the problem of health is intimately involved in the functional prerequisites of the social system. (. . .) Certainly by almost any definition health is included in the functional needs of the individual member of the society so that from the point of view of functioning of the social system, too low a general level of health, too high an incidence of illness, is dysfunctional (Parsons 1951: 430).

Parsons then noted that health would already be of interest to social scientists if it was 'purely a "natural phenomenon,"' not involved in the motivational aspects of social action because then we would be interested in how people reacted to uncontrollable events. Health and illness, however, are sociologically interesting because social factors play a role at various stages of sickness and cure: 'In a variety of ways motivational factors accessible to analysis in action terms are involved in the etiology of many illnesses, and conversely, though without exact correspondence, many conditions are open to therapeutic influence through motivational channels' (Parsons 1951: 430). Here, Parsons rejects a narrow view of medicine condensed to pathophysiology:

At one time most medical opinion inclined to the 'reduction' of *all* illness to a physiological and biological level in both the sense that etiology was always to be found on that level, and that only through such channels was effective therapy possible. This is certainly not the predominant medical view today. If it ever becomes possible to remove the hyphen from the term 'psycho-somatic' and subsume all of 'medical science' under a single conceptual scheme, it can be regarded as certain that it will not be the conceptual scheme of the biological science of the early nineteenth and twentieth centuries. It is also certain that this conceptual scheme will prove applicable to a great deal of the range of social action in areas which extend well beyond what has conventionally been defined as the sphere of medical interests (1951: 431, *italics in original*).

In contrast to the exaggerated view that medicine is only about biology, Parsons distinguished a clear social or psychosocial (Lupton 1997) dimension that permeates every aspect of health maintenance and is open for social analysis. He anticipated that these social factors would play a crucial role in medicine of the future, although hedging on their specific importance. In fact, observers noted that while Parsons led the fight against psychological and biological reductionism in the 1930s (Camic 1989), he saw a place for translating biological pathology into 'psychogenic' processes (Gerhardt 1990: 345).

Combining the functional aspects of health services and the social aspects of the illness experience together, Parsons articulated the social study of medicine in the following terms:

Summing up, we may say that illness is a state of disturbance in the 'normal' functioning of the total human individual, including both the state of the organism as a biological system and of his personal and social adjustments. It is thus partly biologically and partly socially defined. Participation in the social system is always potentially relevant to the state of illness, to its etiology and to the conditions of successful therapy, as well as to other things (1951: 431).

Parsons envisaged a division of labour where social scientists would work along with biological scientists to tackle health problems. Although Parsons was more open to biology than many of his successors (Williams 2005), in effect, he articulated the sociological study of illness in contrast to biological disease. Consequently, social scientists have become mainly interested in the experience, culture, and social structuring of illnesses while bracketing the biological bedrock of disease (for an influential example, see Kleinman 1989: 4–6).

Parsons' contribution as a founding figure of medical sociology consisted of parcelling out a social realm of medicine while leaving biology, physiology, and pathology for others. Although next-generation medical sociologists strongly reacted against the functionalist underpinnings of Parsons' theorising (e.g. Freidson 1970b, Gallagher 1976), they settled in the conceptual niche of the social aspects of medicine and health. They sharpened

Parsons' observation that the medical encounter constitutes a 'mechanism of social control' (Parsons 1951: 477) and asked pointed questions about who benefits from such an authoritative arrangement (e.g. Freidson 1970a, Waitzkin 1979, Zola 1972). A survey of medical sociologists in the fifties showed that most US medical sociologists were already doing sociology *in* rather than *of* medicine, leading the author to warn that the sociology of medicine runs the risk of losing its professional identity if it engages too closely with medicine (Straus 1957). Professional identity construction depended on establishing the sociological value of medical sociology and downplaying the world of physiology and pathology. The editors of early editions of the *Handbook of Medical Sociology* asserted that, 'there are no reasons for the development of unique or special theories in medical sociology. Medical sociology, like all sociology, is concerned with social relationships and social processes, and its theoretical base must of necessity be that of general sociology'. (Freeman *et al.* 1972: 506, see also Freeman *et al.* 1963: 476 and 1979: 467). These editors took a stance against medical sociology evolving into an applied discipline, especially a social science subservient to clinical medicine.

Over time, medical sociology morphed into the sociology of health and illness (Bloom 2002, Conrad 2005b: 1). Social scientists considered medicine too restrictive as an indicator of the sociological interest in the health realm. 'Medical sociology' implied a discipline focused on the medical profession, hospitals, and the broader health service industry. Even more, it may have implied a discipline that uncritically worked within the value parameters and priorities set by clinicians. To rename medical sociology as the sociology of health and illness thus manifested a recognition that illness experiences spilt over into family, work, school, and other areas of life. In addition, social scientists were interested not only in how people's health improved but also in how they prevented health problems in the first place. Health care became one aspect of the social study of health and illness. Sociologists also became cognisant of the role of nurses and other allied health professionals in maintaining health.

The beginning of a scientific discipline is often marked by conscious discussion about what the field is about, but once the discipline receives momentum, assumptions of what qualifies as medical sociology are taken for granted. The social study of health and illness set upon an ambitious topic matter but explicitly excluded biology and disease as research foci. The point of this discussion paper is to argue that the genesis of medical sociology is not deterministic and that we may be the richer for studying disease in addition to illness and health. We aim to open a research space for the sociology of disease, not to replace the rich scholarship that sociologists have produced but to include fundamental research questions that now remain unformulated. Sociologists of disease are interested in the dialectic interaction between social life and specific diseases, aiming to broadly examine whether and how social life matters for morbidity and mortality and vice versa. Rather than viewing the broad field of health as a unique case of social organisation, social forces, or identity formation, the sociology of disease focuses on how social processes affect the severity or course of diseases and how, in turn, specific stages of disease affect social relationships, work, neighbourhood, or family life. Sociologists of disease, for example, like to know whether the extensive literature on medicalisation or biographical disruption matters for patients' health; how exactly neighbourhoods may affect asthma morbidity; or whether the biology of methamphetamine addiction affects treatment modalities. These research questions are concerned with explaining the pathways, processes, and mechanisms of the dynamic interplay between biological health and social life. This approach will require new skill sets and expertise, especially in the biology of disease. A sociology of disease may be of interest to clinicians but its greatest potential is strengthening the

theoretical engagement of the social sciences with biology (see *e.g.* Freese *et al.* 2003, Fremont and Bird 1999).

In order to ground our discussion and to avoid overgeneralisations, we will illustrate some of our points with a content analysis of the 10 most recent years of original articles published in *Sociology of Health and Illness* (1997–2006).¹ Our aim is not to criticise individual contributions or the journal's editorial decisions but to demonstrate the current marginal position of the sociology of disease and to make an argument for fostering the methodological tools and expertise to tackle social inquiries of disease.

Sociological blinders

While the focus on illness has allowed sociologists to claim a subject matter, a price was paid for the restriction of a sociological perspective and of ignoring the 'technical' or 'biological' aspects of health care. Sociologists often make a case for studying health and illness holistically rather than with a narrow focus on biological factors but an aversion to taking the 'disease' aspects of medicine into consideration results in gaping analytical holes. In effect, social scientists grant health professionals, many health researchers and, increasingly, epidemiologists the clinical facts, leaving themselves no choice either to accept clinical parameters at face value, tirelessly denounce the 'construction' of factual knowledges, or, more often, to ignore such factors. In addition, fundamental questions remain unasked: we may have established the stratification of longevity and health, but rarely explain how this longevity is socially achieved. We may know much about the effects of chronic illness on identity but fail to establish the health consequences of this identity formation. An observation of a decade ago still rings true, all too often 'the [social] investigator stood with his or her back to the heart of medicine and studied the "social phenomena" surrounding it' (Berg and Casper 1995: 397).

This ignored 'heart' of medicine consists of three crucial aspects that sociologists routinely bracket. First, social scientists rarely make specific diseases central to their inquiries. Instead, sociologists tend to study health conditions at an abstract level of conceptual aggregation, or, alternatively, focus on the multiple ambiguities of disease diagnosis. In everyday life, however, most patients and health professionals deal with specific diseases (Rosenberg 2003). Secondly, social scientists rarely include clinical markers of disease in their analyses. Specifically, we rarely find out how the processes that social scientists explore affect actual health outcomes. Thirdly, social scientists also tend to ignore the normative purpose of health interventions. An extensive literature analysing patient-doctor encounters, for example, documents studies more concerned with patient satisfaction than with the actual health outcomes (Heritage and Maynard 2006). Taken together, these omissions reflect a social science studying medicine pragmatically as a site of social action while ignoring what makes medicine medicine: its existential, ontological, and purposeful dimension of diminishing human and social suffering. In the next sections, we will explore these omissions in more detail and suggest solutions that refer to studying disease as it unfolds in collective life.

Ignoring disease

The first omission consists of sociologists' refusal to grant ontological status to diseases as clinical entities. Largely due to weak and strong forms of social constructivism (for a review, see Hacking 1999, Williams 2006), sociologists are reluctant to attribute ontological value to conditions that appear 'natural' to clinicians and patients. Sociology's 'biophobia'

(Freese *et al.* 2003: 234) includes the deeply held concern that a strong recognition of the role of biological and genetic factors in health implies the automatic devaluation of social factors, and leads to politically suspect forms of determinism. Thus, social scientists are more likely to point out the genetic and biological 'fabrication' (Fox 1999) of conditions. They tend to focus more on how diagnostic categories emerge, evolve, and are phenomenologically experienced in particular health contexts rather than in taking the diagnosis as a starting point and seeing how various people address health problems. Some social scientists explicitly acknowledge the materiality of the body as a biological 'restriction' to be integrated with more social perceptions. The sociology of disability, for example, aims to acknowledge biological impairment as a correction to the now prevalent social model of disability (Mulvaney 2000, Shakespeare and Erickson 2000, Thomas 2002). Researchers interested in sex and gender differences also realise that valuing gender at the expense of sex haunts social theories (Yanagisako and Collier 1990). Yet, these timid steps – replete with qualifiers and reassurances (see Williams 2006) – leave biology and disease as a tightly closed 'black box' (see Bury 1997: 199–200). As Latour (1987) pointed out, selective scepticism leads to an asymmetrical situation in which sociological concepts have a privileged ontological status but medical categories are up for construction and debate.

The literature reflects four general barriers to medical sociologists' engagement with diseases. First, most medical sociologists do not study specific diseases as biological diseases but they may study general medical sociological themes such as clinical interactions, professions, social organisations, health discourses, social control, medicalisation, etc. Secondly, those who research specific diseases regularly do so outside any clinical context. Thirdly, when studying patients or clinicians managing specific disease conditions, sociologists tend to generalise to non-disease-specific medical sociology themes. Finally, medical sociologists' understanding of the biological basis of disease is limited (see next section).

These tendencies can easily be found in the contributions to *Sociology of Health and Illness*. Between 1997 and 2006, 21 per cent of original articles (82 out of 387 articles) published in *SHI* involved a specific disease category, meaning that the overwhelming majority did not deal with diseases.² The most written-about diseases were HIV (16 articles) and various cancers (14 articles), stroke (6 articles), heart disease (5 articles), and depression (4 articles), followed by anorexia, asthma, and chronic back pain (3 articles). These figures do not necessarily mean that the authors paid attention to disease as a biological phenomenon because they included every possible topic related to disease such as, for example, the media representation or historical development of a disease classification. If we further limit the articles to those dealing with disease as a health issue for patients and/or clinicians, the pool shrinks to 16 per cent (60 out of 387).

The majority of these remaining articles contain an ontological gestalt switch where sociologists turn data about specific diseases into medical sociology concepts. The best example of this transmutation is in the articles on chronic illness experiences. Without exception, the literature on chronic illness depends on specific disease populations but they are then extrapolated to the vague notion of chronic illness. Thus, May *et al.* (2004) reanalyse studies of menorrhagia, depression, unexplained medical symptoms, and back pain as generic chronic illness. These authors argue that 'biomedical reductionism is ultimately impossible' (2004: 151) because of the mixture of pathology with social and psychological factors. Yet, they fail to engage with the biomedical substance of the conditions and treat the vague notion of medically unexplained symptoms as equivalent to a firmly established mental health condition such as depression. Similarly, Gregory (2005) conceptualises interviews of coronary heart disease and coeliac disease patients as chronic illness, and Higginbottom (2006) turns narratives of high blood pressure into chronic

illness experiences. Why is the experience of high blood pressure patients not sociologically relevant, but framing these same patients as nondescript chronically ill opens up analytical possibilities? In other studies, patients with anorexia, HIV, autism, Alzheimer's disease and other diseases contribute to medical sociological mainstays such as stigma, biographical disruption, narrative reconstructions, masculinity, risk, patient-clinician relationship, uncertainty, illness trajectories, embodiment, and sick roles. Specific diseases and sociological interests correlate: the same diseases lend themselves to exploration of recurring sociological themes. Similarly, in quantitative mental health social research, sociologists tend to study a specific disorder but then generalise to a broad range of mental health outcomes without differentiating between, for example, major depression and substance abuse (Aneshensel 2005).

The advantage of this ontological gestalt switch is that it allows medical sociologists to discover social patterns in experiences that cut across many conditions and these writings have established a rich literature on the social experience of illness (e.g. Pierret 2003). The price paid for conceptual amalgamation is an important loss of specificity. Most clinicians and patients remain unconvinced that patients with Alzheimer's disease, diabetes, HIV, depression, and hypertension can be lumped together in the melting pot of chronic illness. Investigating hypertension not as a generic illness but as a specific disease forces the social scientist to take specific changes in physiology into consideration, such as the trade-off between controlling blood pressure with an ACE inhibitor and causing impotency (Abraham 1993). In addition, when taking disease seriously, it becomes clear that sociologically relevant physiological differences exist in clinical entities such as hypertension. As Williams (2000) pointed out, social scientists may be attuned to social diversity but not to physiological diversity or disease-specific differences.

The field of science studies used to be in a situation similar to sociology of health and illness today (see Bartley 1990). Early scholars of the science field discussed the social organisation of modern science through occupational stratification, national cultures in science, and so forth. But they did not address the actual content of science. Then, in the early eighties, social scientists from a variety of theoretical backgrounds conducted a series of ethnographies looking exactly at how scientists established the veracity of their findings (Knorr-Cetina 1981, Latour and Woolgar 1979, Lynch 1982). They found that the credibility of knowledge claims does not depend on innate rational qualities; rather, science-studies scholars asserted, rationality is itself an outcome of the process of knowledge production and is *specific* to the science at hand. Thus, scientific practice produces the kinds of objects scientists deal with: geology is different from, for example, the study of electromagnetic fields with each discipline developing its own criteria of evaluation, instrumental expertise, means of arguing their case, and methodological sensitivities. The task of the science-studies scholar was to follow specific science in action: investigating how disparate epistemic elements are transformed into discipline dependent factual knowledge (Latour 1987).

Some science-studies scholars have applied this approach to health care. In her book *The Body Multiple*, empirical philosopher Annemarie Mol explored atherosclerosis of the leg vessels in one hospital (Mol 2002). She thus focused on a disease rather than an illness experience. Mol showed that atherosclerosis had multiple meanings depending on which medical specialty worked on the leg vessels. Not one clinician completely captured the meaning of atherosclerosis but each discipline satisfied a different purpose. This diversity, according to Mol, did not lead to fragmentation; she explored how the family of resemblance of atherosclerosis as practised in the different niches of the clinic produced only partially overlapping similarities. Rather, atherosclerosis became a rallying point that

co-ordinated different people, objects, and actions. Mol thus tackled disease as a clinical entity while critically questioning clinicians' notions of this disease. Her methodological strategy consisted of looking how a disease category is acted upon and, in turn, facilitates action. Rather than worrying whether atherosclerosis is real, she was satisfied with the observation that atherosclerosis *is*; the disease existed and she investigated what its existence consisted of. Ironically, Mol's project offers a generalisable sociological approach to take the situated specificity of disease seriously.

As pioneered by science-studies scholars, one sociological approach to investigate diseases is to focus on practices and observe how diagnostic categories facilitate particular actions (for a review, see Timmermans 2007: 23–31, Pickering 1992). Practice refers here to the actual contingent, situated process of performing tasks, doing work together, and transforming something into something different. An analysis of practice concerns who does what, when, where, and with what consequences. By following clinicians and patients around, we can map the ways specific diseases foreshadow trajectories that are simultaneously deeply clinical, social, therapeutic, iatrogenic, political, and bureaucratic. Biology is no longer the invisible canvas for social action but both biology and social arrangements are continuously recreated as intertwined entities, often quite literally as in Adriana Petryna's (2002) exploration of biological citizenship in the aftermath of the Chernobyl nuclear disaster. Rather than contributing to a sociology of chronic illness, such a disease-centered approach allows us to contribute to a sociology of diabetes, asthma, or whatever disease we investigate.

Clinical endpoints

Social scientists rarely examine the health effects of their own conceptual innovations because they fail to include health outcome measures and biomarkers. A popular theme in the sociology of health and illness is medicalisation (Clarke *et al.* 2003, Conrad 1992, 2005a, Lupton 1999). While there is some conceptual confusion about medicalisation's precise point of reference, most commonly the term is used to denote the process by which social problems are turned into medical issues (Conrad 1992). Labelling fidgety children hyperactive and then treating them with Ritalin is an example. Sociologists have noticed medicalisation everywhere but especially in women's health, at the beginning and end of life, and, most recently, in the field of wellbeing and enhancement. What does it exactly mean when social problems are medicalised for new patient populations? What are the various health effects of medicalisation? Mostly, we do not know because social scientists only exceptionally investigate those health effects. In fact, they explicitly sidestep the question whether a disease is 'real' or not (Conrad 2007: 3–4). More generally, sociologists are unable to answer questions about the clinical efficacy of social processes because social analysis of health and illness rarely includes biomeasurements of clinical endpoints. This is unfortunate because clinical endpoints are often commonly available, and including them would add a bottom-line health dimension to a sociological analysis, linking social processes to the physiological workings of our bodies and minds (Scheper-Hughes and Lock 1987, Shostak 2003).

The last 10 years of *SHI* sociologists have sampled disease populations largely through pragmatic organisational means *e.g.* interviewing patients in a prostate cancer support group (Olliffe 2006) or through self-reports (Burr and Chapman 2004). In most instances, any person with a disease is interchangeable with anybody else. Thus, while sociologists may be attentive to differences in ethnicity, gender, communication styles, or social capital, disease is disease. Any stroke is equivalent to any other stroke. Severity, stages, or symptoms do not seem to matter. Thus, in an article about masculinity and prostate cancer, the

authors discuss in the introduction how this cancer is subdivided into stages of severity, but do not provide this stage-based information in their description of respondents or analyse their data in light of severity of disease (Chapple and Ziebland 2002). An imaginative study that discussed how social and organisational aspects of health care delivery may hinder people's recovery from stroke did not provide any measurements of the actual physiological effects of 'system induced setbacks', which would have undoubtedly strengthened the author's main point (Hart 2001). In another study about concordance and patient-centred care, the authors evaluate two case-studies of patients with back pain for how their caregivers were able to negotiate common understandings (Ong and Hoper 2006). The patients, however, have not only different experiences with care providers but are also not compatible with regard to their chronic back pain. One patient fell off a horse four years ago while the second patient received treatment for bowel cancer, is partly wheelchair bound, and has a family history of rheumatoid arthritis. Couldn't any differences between patient-doctor encounters be explained by the very different disease history of these patients? Here and in other contributions, disregarding an alternative explanation grounded in the biology of disease may undermine any explanation drawn from an exclusive focus on illness narratives.

The field of proximate bioindicators is vast, increasingly specialised, often ambiguous, and quickly expanding (Freese *et al.* 2003), but sociologists do not need an exhaustive engagement with physiology to come up with the more interesting and valuable data points. People treated for high cholesterol are often acutely aware of their overall lipid profile; health care providers teach diabetic patients to monitor their glucose levels and provide them with A1c measures at regular visits; asthma patients often chart their spirometer output; HIV patients know their T-cell counts. It is thus often quite easy to obtain such measures during social science research, either by asking respondents about their latest values, by consulting medical records, or by taking such measures. The use of biomarkers can be equivalent, for example, to the use of validated scales to measure depression (Nazroo *et al.* 1998).

These data can then be employed to admit patients to a sociological study and to generate biologically more homogeneous samples. The idea is here not to regard biomedical pathology as a determinant of the social experience but as a group of characteristics that set the parameters of social interaction. A study that unwittingly mixes conversations between oncologists and patients with different stages of cancer will inevitably find very different kinds of data and be unable to tease out the role of the severity of the disease. A study controlling for severity or explicitly comparing cancer stages will be able to address this critical alternative explanation. Most of us would take the news of stage 1 cancer much better than if we were told that a biopsy showed stage 3 colon cancer. And even if the patient is equally devastated by the finding of any kind of cancer, the physician, aware of various treatment modalities, will approach the interaction quite differently and try to bring different points across. The severity of the disease will help anchor the interaction.

As an illustration of how sociologists would benefit from studying disease outcomes and collect and analyse the proximate biomarkers of disease in their research we present the case of type-2 diabetes. Recent estimates suggest that diabetes affects at least 18 million American adults (approximately 8.3 per cent of the population aged 20 and over) with the large majority of these being type-2 cases (Geiss *et al.* 2006); in the UK 1.8 million people have been diagnosed with diabetes (Department of Health 2005). Diabetes remains a leading cause of death and a major source of morbidity. From a clinical standpoint, the physiology of diabetes is relatively well understood. As a metabolic disorder, diabetes is characterised by elevated blood glucose (hyperglycemia) resulting from the dysregulation of glucose due to a combination of lack of insulin production, insulin insensitivity, or insulin

resistance. Type-2 diabetes is associated with obesity, in particular the concentration of adipose tissues around the abdomen. Clinicians encourage weight loss and management through physical activity and diet. The standard treatment for those whose bodies do not naturally produce enough insulin is the injection of exogenous insulin. Diabetes requires monitoring blood glucose level (often multiple times daily) and controlling intake of carbohydrates based on standards developed by the clinical community.

A clinical description does a rather poor job of describing the causal processes by which individuals ultimately come to be diabetic. Nor does it adequately describe why large differences in prevalence rates exist between social groups. Or why some diabetics fare much better than others. At the microlevel, the risk of diabetes incidence is strongly patterned along sociodemographic characteristics and there are large disparities in risk by level of income, educational attainment, and across racial-ethnic groups (Maty *et al.* 2005). While some of these differences can be explained by group patterns of diet and physical activity, these lifestyle and behavioural factors do not fully explain health disparities. In addition, such an approach often implicitly ignores the ways in which such lifestyle and behavioural factors are themselves products of the social environment. The increased risk associated with such individual-level social characteristics is structured by larger social forces, such as patterns of consumption, residential and commercial development, and public policy. For example, governmental subsidies of corn have expanded consumption of high fructose corn syrup (HFCS) and other foods of high energy but lacking nutritional value (Haley *et al.* 2005), a finding of relevance to the emerging field of nutritional epigenetics that links exposure of generations of food intake to expression of genes. Per capita HFCS consumption is currently 10 times higher than it was in the 1970s (Haley *et al.* 2005). Obesity and diabetes also results from the way we have structured the cities and neighbourhoods in which we live and work to discourage walking and other forms of physical activity (Institute of Medicine 2005) as well as the way scientific news is disseminated (Saguy and Almeling 2008). Therefore, to understand the sequelae of causality involved in diabetes, its epidemiology, and the population health implications of the recent substantial rise in obesity requires a sociological perspective focused on the role of social institutions and other aspects of social structure.

Diabetes would appear to be a prototypical case in which to illuminate the social milieu connecting the difficulties of individuals (disease pathology) to larger social problems (the rise in obesity, social disparities in health). Clinical investigations of diabetes are fundamentally limited because they do not address the socially constructed patterns of consumption, lifestyle, and behaviours in which its manifestation in individuals and its great variation between social groups is embedded. Similarly, the traditional sociological study of diabetes as an experiential phenomenon provides little insight into material processes by which the social world comes to be embodied. Disparities in diabetes can only be understood through a sociology that includes the study of disease and its proximate biopathways and that integrates the study of human wellbeing as simultaneously both a biological and social phenomena.

In the case of diabetes, like other health conditions, there are several advantages to collecting proximate biomarkers. First, it is critical to understanding social inequalities in health to be able to map out the pathways by which the social world comes to be embodied within the biological (Adler and Stewart 1999, Krieger 2001). How are larger macrosocial processes linked with various psychobiological processes to generate health disparities (Berkman *et al.* 2000: 143)? While the root causes of type-2 diabetes are to a large degree social, ultimately the disease manifests itself in discreet physiological processes, which can be measured in the body.

Secondly, from a methodological perspective a large proportion of diabetes cases are undiagnosed. Estimates suggest that as much as 29 per cent of diabetes cases in the US are undiagnosed (Geiss *et al.* 2006) and an estimated 1 million people in the UK remain undiagnosed (Department of Health 2005). The use of biomarkers would provide for more objective, valid, and reliable measurement of diabetes. This is especially important in research on socioeconomic and racial/ethnic disparities in health, as the groups at greater underlying risk of the disease are significantly less likely to have a regular health care provider and thus to have had a clinician diagnosis of their condition. Using biomarkers thus bypasses the limitations of relying on physician diagnosis or self-reports.

The collection of biomarkers may also provide unique insights into the nexus between the larger structural factors that predispose individuals and communities to risk, the more proximate behavioural and lifestyle pathways, the role of access to and utilisation of diagnostic and therapeutic services in the management of the disease and the minimisation of co-morbid externalities, as well as how individual and social factors both promote and prevent disease management. The purpose is not to reduce diabetes to a biological entity but to bring the same critical sociological lens aimed at clinical efficacy to 'social efficacy' (Rosenberg 2007). Which parts of our social world do we value and measure in disease, and what aspects of social life are valuable in disease management?

Unlike other biophysiological indicators such as blood pressure or salivary cortisol, which can be collected with minimally invasive procedures, biomarkers for diabetes usually involve collecting blood. However, depending on the specific aims of the study there are different types of diabetes biomarkers with varying degrees of intrusiveness. The least invasive is through the measure of glycosylated haemoglobin, a measure of glucose circulating in the blood. Multiple measurements over a period of weeks and months provide information on the overall level of glucose in the blood. Glycosylated haemoglobin is collected with a small drop of blood from a finger prick and read by a small electronic device. Diabetics have long used this method to monitor their blood sugar levels and the technology is increasingly compact, sophisticated, and inexpensive. Glycosylated haemoglobin would be best used for studying known diabetes cases. For example, how social factors influence compliance with disease management regimes. A fasting glucose test is more complicated and involves the individual fasting for a period of time (usually over night) and then having blood drawn. A final method of detecting diabetes is through the use of a glucose tolerance test. This involves an overnight fast and then the administration of a standard dose of sugar. Blood is then drawn two hours later to determine the degree of glucose intolerance.

It is important to note that biomarkers are not a panacea for social science research (see the exchange between Gersten 2008a, 2008b, Loucks *et al.* 2008 and McDade 2008). These indicators may be difficult to measure and their proximity to disease may not be well understood. Most physiologists take biological specimens under strict experimental conditions that are difficult to replicate in the field. Cortisol levels are popular because they can be extracted from saliva or urine samples but heterogeneity remains a big problem. Similar to other measures in social science research, these data also have limitations on interpretation of causality.

We provide an abbreviated example taken from a study of patient-doctor interactions in an urban clinic that demonstrates the analytical potential of including biomarkers in a sociological study.³

Dr. Mitchell's next patient is an elderly Argentinian woman with her daughter. The physician is very concerned because he has known this patient for four years and her

type-2 diabetes has been well under control. She used to be one of his better patients but she has not visited him in six months and her A1c value has skyrocketed to 16% where it used to be around 8% and ideally is less than 7% for adults with diabetes. The A1c test provides an average blood glucose level over the past 2–3 months and is considered more accurate than daily blood sugar measurements.

The physician questions mother and daughter and is able to slowly piece together a possible explanation for this sudden deterioration. Very reluctantly and after much prompting, the mother reveals that after her husband died, she moved in with her only son. She does not get along with her daughter-in-law and is not allowed in the kitchen. She has to eat what her daughter-in-law prepares for her and her daughter-in-law refuses to take her dietary needs into account. Although she is both stressed and depressed by the domestic situation, she does not want to complain because she is afraid that this will cause trouble with her son. Her daughter is taken aback by the tensions. The physician emphasizes that the mother's life is at stake and that something needs to be done. With both women in tears, the daughter invites her mother to live with her. The mother is not sure that she wants to move but seems to realize the seriousness of the situation.

This interaction provides an example for how social scientists can employ biomarkers to anchor and elicit data about how social relationships may affect health and how, in turn, actions taken based on biomeasures may lead to new social, in this case family, arrangements.

Some sociologists already have joined epidemiologists and psychologists. To explore the biosocial effects of chronic stress due to a lifetime exposure to disorder and violence in racially segregated neighbourhoods Douglas Massey (2004) argued in a state-of-the-discipline article for a large multi-racial dataset that contains biomarkers as well as more typical sociological variables. Massey here draws from clinical research showing that repeated triggering of the allostatic response through chronic exposure to stressful events may lead to hypertension and atherosclerosis, obesity, and to an increase in the disease of diabetes. Allostatic load also compromises the immune system and cognitive functioning. Massey's project is to show that African Americans living in stressful, violent segregated neighbourhoods have higher allostatic loads. He acknowledges that 'in the past, many social scientists have shunned biologically grounded explanation of racial gaps for fear of legitimising racist theories or our fear of being labelled a racist; but an appreciation of the biosocial mechanisms by which racial differentials are produced turns these fears on their heads' (Massey 2004: 22).

Norms

The third omission in sociological writings on health can be called the normative *raison d'être* of health: the primary purpose for medical encounters and preventive measures. This is the goal of relieving human suffering, preventing ill health in populations, curing diseases, addressing symptoms, monitoring bodily signs, rendering weary bodies comfortable, caring for deeply felt problems such as a drop in mobility and decreased cognition, or addressing striking reminders of one's mortality. The lack of interest in normativity may be traced back to the decline of functionalism and its replacement with a critical social constructivism. Parsons and Merton distinguished universal values that organise Western societies and their institutions. For example, Merton (1957) presumed that modern science was united by the shared norms of universalism, communality, disinterestedness, and organised scepticism. Taken together, these four institutional imperatives shaped a

communication system aimed at true, reliable knowledge. These norms became easy targets of social researchers who found that when one observed scientists at work, they embraced many conflicting values (Mulkay 1979). Similarly, in the social study of health and illness critical sociologists questioned Parsons' universalistic role expectations (Freidson 1970b).

Social scientists influenced by various kinds of social constructivism replaced the shared norms of science with the one norm of organised scepticism towards medical authorities. We can find many examples in the last 10 years of *SHI*. In interviews with providers about the drug cocktail that turned HIV from a death sentence into a manageable chronic illness, social scientists are only able to document a long litany of negative consequences and social side-effects. Ignoring the astounding therapeutic benefits for HIV patients, this article simply notes that HIV drugs 'produce new biological phenomena, most evidently "resistant" virus and iatrogenic disease' (Rosengarten *et al.* 2004: 592). Although a study of chronic back pain highlighted concordance as a mutual negotiation process between clinicians and patient, the only relevant outcome was whether the patient had been heard. We do not find out whether concordance leads to better patient outcomes, even though this was a key-rationale for the study (Ong and Hoper 2006: 204). A study of stroke survivors asymmetrically assesses therapeutic setbacks produced by the health care system without assessing how this system also helped some patients (Hart 2001). While some contributions do acknowledge the therapeutic aims of health care (Clark 2001, Lester and Tritter 2005, Lutfey 2005), such scepticism toward the purported goals of health interventions has been fuelled by influential writings that showed that most of the expansion of life expectancy and reduction of morbidity during the first part of the 20th century was incidental to medical care but due to self-care or public-health measures (Dubos 1959, Illich 1976, McKeown 1976, McKinlay and McKinlay 1977). The real engines of health progress were population-based, public health interventions.

The reluctance to engage with the purpose of medical interventions is unfortunate because in the last decades many conditions that may previously have led to a premature death or severe disability have actually improved through medical interventions: never before in history have clinicians been able to do so much for their patients (Kaufman 1993, Rosenberg 2007). Sociologists interested in professions note that when Freidson published his treatise on the dominance of the medical professions, the situation actually started changing and health care professionals started losing power due to the actions of countervailing forces (Light 2000). Similarly, sociologists' scepticism toward the effectiveness of medical interventions may reflect past times. In 1972, Freeman, Levine, and Reeder predicted that 'scientific and technical developments in medicine have reached the point where marked reductions in mortality and, to a lesser extent perhaps, morbidity are unlikely to be brought about by further biological and pharmacological discoveries'. Instead, they saw a much greater role for the 'importance of the social component' (Freeman *et al.* 1972: 504). With hindsight, they were wrong.

Health economists and other social scientists, notably David Cutler (2004) (but see also Bunker *et al.* (1995), Skinner *et al.* 2006) persuasively argue that many of the latest gains in life expectancy can be attributed to pharmaceutical and surgical interventions. Infant mortality rates, for example, have been declining over most of the 20th century in the United States. Most of the decline in the first half of that century can be attributed to public health interventions and indeed the CDC lauded its fight against infant mortality as one of the major public health achievements (Centers for Disease Control 1999). In the second part of the 20th century, however, the action shifted from public health to medicine. A large proportion of the most recent decline can be attributed to the widespread use of surfactant

therapy in neonatal intensive care units (Frisbie *et al.* 2004, Malloy and Freeman 2000). This and other gains in previously fatal diseases do not mean that medical care is problem free. In contrast, the US infant mortality rate remains much higher than in other developed countries and racial disparities persist. Access to care is uneven, Americans pay much more than other countries for similar services, and the quality of care differs widely among geographical areas.

The point for sociologists is not to legitimise the authority of health care providers or to extol therapeutic successes. A critical appraisal of these powers is necessary but such an analysis should take the overall health purpose of interventions into consideration. What is accomplished with a subtle analysis of power differences without also demonstrating how these power differences matter in the management of disease, health, and wellbeing? Although the Chicago school of sociology of work did not focus on the normative dimension of work, it offers a general orientation of studying how norms are achieved in practice (Hughes 1971 (1945)). Medicine and public health aim to contribute to better health in myriad ways that are both local and shared across settings. Norms may often contradict each other. As, for example, the lack of honoured advance directives at the end-of-life show, health professionals have trouble following a patient's wishes when they believe that the patient can be saved with intubation and resuscitative measures (SUPPORT Principal Investigators 1995). Patients and relatives often change their minds about previously considered firm limits of care (Mairs 1997). Professionals and patients rally around common goals but then their actions show a shift in priorities. When embodied and put into practice, norms might clash, diverge, shift, or coexist in contradiction, collaboration, or tension. Norms highlight the important question of what the multiple purposes are of health care interventions.

Discussion

In the past half-century, sociologists of health and illness have argued for an expansion of social factors in health but have ignored the diseases that form the basis of much of the interventions. Sociologists have explored various social processes and interactional sequences occurring in medical sectors but have rarely examined the health effects of these social phenomena. Finally, sociologists tend to disregard the purported norms of the health field. The result of these three omissions is a rich literature with a tremendous blind spot: what is health care about?

Parsons' overall project was to create a meta-theory of complex social systems. His analysis of doctor-patient relationships set the sociology of health and illness on a course of sociology first and health second. Yet, we do not need to be captives of our history. A sociology of disease does not aim to replace the rich sociological work on illness, health, and medicine but to ask fundamental questions about the dynamic relationship between social life and morbidity. A sociology of disease takes up many of the themes examined in the sociology of health and illness but refocuses them toward an examination of their health effects. This reorientation requires expertise to incorporate explicit disease-related endpoints and to follow their evolution over time. While such an approach may find inspiration in some of the work of social epidemiology, the point is not necessarily to unreflectively produce collective or individual social risk factors of health. In fact, the goal may be to develop more comprehensive evaluation criteria of health and to account for the dynamic relationship between health and social life. A sociology of disease also does not need to work within the conceptual and normative parameters set by biomedicine, although it may

want to examine the assumption that health care is negligible in population health. Rather, the sociological focus of a sociology of disease relates to a broad theoretical understanding of the multiple mechanisms, processes, and pathways in which collective life affects disease and vice versa (Pescosolido 2006).

One counterargument is that sociologists may lose their critical role in engaging heads-on with clinical facts. The examples of science studies and social epidemiology show that this does not need to be the case. After sciences-studies scholars turned from sociology to science to sociology of scientific knowledge, they showed that, to use Latour's felicitous phrase, science is politics by other means. Consequently, they examined how social factors and scientific outcomes were intertwined to such an extent that to separate the two became increasingly difficult: not only did science depend on social factors but science helped create particular societies. Using this approach, social scientists critically interrogated scientific controversies (e.g. Hess 1998, Richard 1991). Similarly, the political and policy implications of social epidemiologists' analysis of the social gradient of health are not only highly critical and controversial but also influential in some policy circles (e.g. Kawachi *et al.* 1997, Wilkerson 1999).

A second fear is that a sociology of disease might loosen the links between medical sociology and the broader discipline of sociology. In contrast, medical sociology's engagement with mainstream sociology has developed its own specialty literature, and an intellectual engagement with biology may put medical sociology back to the foreground of sociological theorising. With demographers, network sociologists and others attempting to include biomarkers in databases, medical sociologists could become the experts in how to appropriately use these new variables. Why shouldn't training in the sociology of health, illness, and disease include expertise in physiology and anatomy? Why shouldn't qualitative sociologists become experts in bio-measurements? In addition, these variables will call for more knowledge in the intermeshing of social and biological pathways, calling for a revision of existing sociological theories (Bone 2005, Freese *et al.* 2003). Indeed, the final rationale for extending towards disease is the tremendous upside for sociological theorising about the fascinating interstices of embodied social life.

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Notes

- 1 We excluded editorials, comments and replies, and book reviews. We included review articles and special issues.
- 2 The classification of articles dealing with disease inevitably involved some judgment calls since there exists no clear nomenclature of diseases, and sociologists often write about peripheral disease conditions. We aimed to code the articles in a contextual manner, looking for how the authors referred to medical conditions as diseases or even potential diseases.
- 3 This example comes from an unpublished study of one of the authors.

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