

## Review Article

### Sociology of diagnosis: a preliminary review

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**Abstract** Diagnoses are the classification tools of medicine, and are pivotal in the ways medicine exerts its role in society. Their sociological study is commonly subsumed under the rubrics of medicalisation, history of medicine and theory of disease. Diagnosis is, however, a powerful social tool, with unique features and impacts which deserve their own specific analysis. The process of diagnosis provides the framework within which medicine operates, punctuates the values which medicine espouses, and underlines the authoritative role of both medicine and the doctor. Diagnosis takes place at a salient juncture between illness and disease, patient and doctor, complaint and explanation. Despite calls for its establishment, almost two decades ago (Brown 1990), there is not yet a clear sociology of diagnosis. This paper argues that there should be, and, as a first step, draws together a number of threads of medical sociology that potentially contribute to this proposed sociology of diagnosis, including the place of diagnosis in the institution of medicine, the social framing of disease definitions, the means by which diagnosis confers authority to medicine, and how that authority is challenged. Through this preliminary review, I encourage sociology to consider the specific role of diagnosis in view of establishing a specific sub-disciplinary field.

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#### Introduction

Diagnoses are the classification tools of medicine. They do what Bowker and Starr (1999) refer to as 'work': segmenting and ordering corporeal states, valorising some, disregarding others, and in any case, exerting an important material force. A diagnosis is both the pre-existing set of categories agreed upon by the medical profession to designate a specific condition it considers pathological, and the process, or deliberate judgement, by which such a label is applied (Blaxter 1978). Diagnosis is integral to the system of medicine and the way it creates social order. It organises illness: identifying treatment options, predicting outcomes, and providing an explanatory framework. Diagnosis also serves an administrative purpose as it enables access to services and status, from insurance reimbursement to restricted-access medication, sick leave and support group membership and so on.

Being diagnosed gives permission to be ill. What was previously a complaint is now a disease. Light duty, rest, sick leave, and disability payments are authorised as the individual

becomes patient and (in some cases) pampered. Diagnosis provides what Parsons (1951) referred to as 'a claim for exemption'. The individual who is ill finds him/herself treated, rather than blamed, for imputed deviance (Freidson 1972). The diagnosis enables the social incorporation of the afflicted individual, with the allowance for, or tools to palliate and explain, what makes him or her different (deviant) from the norm.

Diagnosis also provides a cultural expression of what society is prepared to accept as normal and what it feels should be treated. Witchcraft, homosexuality and the tendency of slaves to abscond (drapetomania) have all been previously diagnosed as disease (Gevitz 2000, Mendelson 2003, Cartwright 1981 [1851]). There are similar contemporary examples such as erectile dysfunction, excited delirium and undoubtedly others which are likely to look as value-laden and as culturally fraught as witchcraft to future researchers, once time has elapsed and some historical distance is available. I will touch on these specific examples later.

Diagnosis guides medical care. It organises the clinical picture, determines intervention, and provides a framework for medical education. But diagnosis also defines professional medicine. The ability to construct a medical diagnosis from a complaint and physical or biological findings sets the doctor apart from the lay person and other professionals, confirming the medical practitioner's greater knowledge and status, as well as medicine's authority (Freidson 1972). Diagnosis also structures relationships within the profession, defining who should assume responsibility for particular disorders (Rosenberg 2002): this complaint to the general practitioner, that one to the immunologist, the haematologist or the rheumatologist.

On the one hand, diagnosis is interpretive and organisational (Balint 1964). It provides structure to a narrative of dysfunction, or a picture of disarray, and imposes official order, sorting out the real from the imagined, the valid from the feigned, the significant from the insignificant. On the other, diagnosis is an important site of contest and compromise, because it is a relational process with different parties confronting illness with different explanations, understandings, values and beliefs. The misfit between patient and medical explanatory models may result individually in unsatisfactory therapeutic values and goals (Kleinman *et al.* 1978), or collectively generate politicisation of illness, with social movements and disease advocacy groups battling for recognition, funding and other forms of support (Brown and Zavestoski 2004).

Brown (1990, 1995, 1987) is perhaps the only scholar to have made an explicit call for a sociology of diagnosis, arguing that understanding diagnosis provides an important insight into how we understand disease, health, illness and the forces which shape our knowledge and practices. However, the sociology of diagnosis does not have a clear identity or literature, hanging more on the coat tails of medicalisation, disease theory and history of disease. It's not that diagnosis has been excluded from medical sociology, it's simply that it has been well buried in these and other areas of focus, and whilst pivotal, it hasn't been clearly isolated from these interests. Extirpating diagnosis and revealing it for specific discussion provides an opportunity to study an array of topics from a different perspective: for example, patient-doctor interaction, medicalisation, illness experiences, health social movements and disease recognition.

This paper aims to display a range of works discussing diagnosis in order to encourage sociology to define and analyse the specific role of diagnosis in medical sociology. It is not the purpose of this paper to define the field, rather, to draw together a number of threads of medical sociology that potentially contribute to this proposed sociology of diagnosis.

In constructing a review of pertinent articles there is nonetheless a need to be selective, because the range of topics to consider is immense. Diagnosis is, as I have observed above, both a process and a label. As a process, it is the method of evaluating and adjudicating

the physical complaint. But diagnosis is also the actual category assigned to a constellation of complaints. For the purposes of this paper, I will restrict myself to categorisation, rather than process, which should be the topic of a future paper. In the introductory paragraphs, I have located the interest of this area of study in understanding how medical practice and authority are simultaneously exercised and challenged in contemporary Western settings. This is why I have selectively chosen to focus on such texts which help to elucidate the role of diagnosis in producing/reproducing medicine and its authority or challenges thereto. My review therefore focuses on the history of diagnosis: both how disease names came to be part of Western medicine, and how individual diseases emerge. It then explores how diagnostic labels both reinforce and contest medicine's authority.

The first part of this paper looks at medicine and its relationship to diagnosis. I consider how diseases are named by exploring the place of diagnostic labels in medical history. Diagnosis has not always played a central role in medicine, and I describe how nomenclature and classification came to be prominent in the practice of medicine. I use two individual disorders – post-traumatic stress disorder and Alzheimer's disease – as heuristics for demonstrating how the emergence of disease entities can be framed by, and in turn frame, social and cultural values. Further, I consider how medical authority and medicalisation both enable, and are enabled by, diagnosis.

In the second part of this paper, I investigate diagnostic tension. The illness-disease dichotomy is my starting point. I discuss the differentiation between these two terms in order to describe the challenges present in reconciling lay and medical perspectives on sickness. I investigate contested diagnoses, and the role of social activism in both the emergence of some disease labels, and the removal of others. And finally, I examine the promotion of diagnostic categories by non-medical agents. The conclusion reflects upon how the sociology of diagnosis has a contemporary and immediate relevance to health policy, practice and outcomes.

## Medicine and diagnosis

### *The naming of diseases*

Ancient Greek medicine, according to historian Ilza Veith (1981), did not have a medical terminology: 'So long as medical knowledge was restricted, a narrative descriptive style was used to evoke a picture of a disease, where nowadays one word, a simple disease name, would suffice'. The lack of nomenclature reflected a lack of systematic knowledge of the nature of disease, which, according to Fisher-Homberger, a number of 18<sup>th</sup> century physicians threw themselves at correcting. Thomas Sydenham, who many, including Foucault (1975), see as the father of classificatory medicine, sought 'the improvement of physick' (Sydenham 1742: iiv–iv) by classification. It provided the doctor with a tool to 'distinguish [a disease] from all other distempers' (1742: xvi). Sydenham followed a botanical model of classification, listing the characteristics of diseases as one might the petioles or the sepals of a flower. Fisher-Homberger (1970) explains that nosology served to further medicine as a science, providing a linguistic means to rein in its unintelligible and confused inconsistencies (1970: 401).

Not all doctors felt that disease was ontological, or a natural entity waiting to be named, as assumed by Sydenham and many of his followers. Broussais (1828) for example, vehemently opposed such a conceptualisation, and believed instead that organs transmitted stimuli from one part of the body to another, causing and propagating illness.

Regardless of the epistemological perspective which underpinned the various approaches to diagnosis, this classificatory project saw medicine shift its focus from individual symptoms

to groups and patterns of symptoms that doctors could reliably recognise. Clinical medicine, according to Foucault (1963), removed the symptom from its previously supreme position, seeing it instead as simply one element in a symptom cluster which would constitute the disease.

Historian Lester King (1954) describes historical disease construction as pattern recognition which takes on new and different forms as knowledge changes:

What one epoch calls a disease is, to a later period, only a symptom. A pattern has reasonable stability only when its criteria are sharp, its elements cohere, and its utility in clarifying experience remains high. Let these factors become blurred, and the erstwhile disease, as a well-defined and useful class, will melt away (1954: 202).

King's words reflect the fact that medicine is temporally situated, and makes its diagnoses on the basis of the technology and values available at a specific point in time. As an unidentified writer penned in the *British Medical Journal* in 1886, 'The imperfection of our medical vocabulary is not a matter for surprise. It is the measure and gauge of the imperfection of our medical knowledge, and only perfect knowledge admits of a perfect nomenclature' (Anon 1886: 1116). Rosenberg describes a range of technological innovations which served to present objective images of disease, such as the ECG, the X-ray and the manometer, and to 'operationalize' diseases, providing a deeper texture and substance to their description (Rosenberg 2002).

Diagnoses also emerge as individuals, professions or society dynamically modify the boundaries of what they consider respectively normal and problematic. Aronowitz (2001) argues that 'although biological and clinical factors have set boundaries for which symptoms might plausibly be linked in a disease concept, social influences have largely determined which symptom clusters have become diseases' (2001: 803). The status of homosexuality in the *Diagnostic and Statistical Manual of Mental Disorders (DSM)* is one useful example. Kirk and Kutchins (1992) expose the degree to which political battles and controversies shaped the taxonomic project of modern psychiatry, using the status of homosexuality in the view of American psychiatry as one example amongst others. During the preparation of the *DSM-III*, gay activists adamantly objected to homosexuality's then-categorisation as mental illness. They sought public acknowledgement of their position via disruptive protests at the American Psychiatric Association conventions. The cumulative effect of their collective action was compounded by media attention and the personal ambition of the chair of the committee appointed to oversee the *DSM* revision process and resulted in the removal of homosexuality as a diagnostic category.

Seeking agreement about what conditions should be awarded diagnostic status serves a range of practical purposes. Bowker and Star (1999) write that classification 'provide[s] a stabilizing force between the natural and the social worlds. [It holds] in place sets of arrangements that allow us to read the natural as stable and objective and the social as tightly linked to it' (1999: 87). Diagnostic classification satisfies a range of needs, from health data collection, to the determination of treatment protocols, public planning, and marketing strategy (Bowker and Star 1999). As a classification project, diagnosis captures and serves different ideologies. Hacking (2001) explains that 'the idea of nature has served as a way to disguise ideology, to appear to be perfectly neutral. No study of classification can escape the obligation to examine the roots of this idea . . . no study of the word "natural" can fail to touch on that other great ideological word, "real"' (2001: 7). Hacking's discussion points to the fact that classification is seeking out the picture of an object, a 'fixed target', which is true to nature.

The *International Classification of Diseases* (ICD) is the diagnostic inventory which underpins medical practice. Despite the range of uses which medicine makes of it today, its original purpose was to produce mortality statistics. Each revision of the ICD starts with a detailed historical exposé of its genesis and subsequent revisions, given the influence that the decisions taken at the time of each revision hold over its subsequent editions. Many of its contemporary categories are residual, hearkening back to historical ways of clinical practice: symptom-focused, ontological or anatomic-pathological medicine. Blaxter (1978) has written that contemporary diagnostic categories are best viewed 'as a museum of past and present concepts of the nature of disease' (1978: 10).

Blaxter (1978) also points out the complexity and fragmentation of diagnoses which reflect a similarly disjointed body of knowledge in medicine, a point which Bowker and Starr (1999) underline as well. A glance through the ICD, for example, reveals diagnoses assembled on the basis of cause, description, site or symptom, syndrome, variation from statistical norm (hyper and hypo this-or-that, under-or over-weight) and even treatability. She captures the fractured nature of diagnostic categories by quoting Kendall, who charmingly writes:

In fact the diseases we currently recognise are rather like the furniture in an old house, in which each generation has acquired a few nice pieces of its own but has never disposed of those inherited from its predecessors, so that amongst the inflatable plastic settees and glass coffee tables are still scattered a few old Tudor stools, Jacobean dressers and Regency commodes, and a great deal of Victoriana (Kendall in Blaxter 1978: 10).

This reference to the historicity of diagnostic categories provides a convenient introduction to the next section, in which I explore how specific diagnostic categories have emerged at particular junctures, stemming from political action, cultural context, and technological advancement.

#### *'New' diseases*

The emergence of specific diagnostic labels provides a heuristic to the student of diagnosis. The process by which particular conditions become first described in medical terms, and secondly incorporated as disease concepts, elucidates how social elements influence and frame diagnoses, and lead decision makers to view a diagnosis as validating a reality which is simply waiting to be discovered (Goode 1969), or which can be taken for granted (Scott 1990). This speaks to Hacking's comments on the intense interest in the classification of people. The focus is on 'a picture of an object to be searched out, the right classification, the classification that is true to nature, a fixed target if only we can get there' (Hacking 2001: 11).

Brown (1995) has described the stages of social construction of disease that are typically part of the disease discovery process. These include lay discovery, social movement, professional and organisational factors. The histories of individual diseases illustrate this social construction quite usefully.

Wilbur Scott's account of Post Traumatic Stress Disorder's incorporation into the DSM-III provides a detailed account of the considerable individual and collective effort required to obtain acknowledgement that the psychological distress of numerous Vietnam veterans was something different from the psychosis, cowardice, or malingering, to which it had previously been attributed (Scott 1990). The effort was political, involving negotiation, relationship management and persuasion. Scott recounts this as an example of how diagnosis brings conditions forward as 'always-already-there objects in the world' (1990: 295), via a

convincing display of objective evidence: 'a discovery of what was present but previously unseen' (1990: 295). The agents in this particular political process were cognisant of the fact that it did not suffice for the condition, as they saw it, to be a real-thing-in-the-world: those with control over classificatory processes needed to be brought to face the realness of the diagnosis by concerted and repeated efforts. Choosing how to speak of the disorder, with whom to discuss it, when to have said discussions and how to use collective action was instrumental in its inclusion in the DSM-III.

Scott's (1990) description brings to the fore each step in Brown's (1995) model of social discovery. Lay discovery by individual veterans, buttressed by the social movement of veteran organisations were pivotal in the acceptance of PTSD in the DSM-III. As Brown has written, it is to be expected in lay-led discovery that the promotion of this particular label is also reliant upon professional backing of the lay movement, which in this case, came from a variety of sources. These included the director of Manhattan State Hospital, psychiatrists Lifton and Shatan, and social worker Sarah Haley who played a pivotal role in reporting the traumatism of war veterans to the American Psychiatric Association's working group. Ultimately, institutional factors, that is to say, inclusion in the DSM, would solidify PTSD's disease status.

In contrast, Alzheimer's disease did not follow all of the stages that Brown (1995) has described – not that this is problematic. Brown has clearly stated that not all disease discovery follows all the stages, or necessarily in the same chronological order, as in his model. In the case of Alzheimer's disease, which was named in the early 20<sup>th</sup> century, professional factors come to the fore, and lay participation played a much later role; one which is notable more for the promotion, than for the creation of the diagnosis. The professional factors revolve both around scientific discovery (technology) and inter-professional relationships.

Two different neuropathological schools, respectively in Munich, where Alzheimer worked in Kraepelin's laboratory, and in Prague where Fischer worked under Pick, were involved in a range of discoveries which were to frame Alzheimer's disease (Amaducci *et al.* 1986). Previous medical literature described dementia in purely clinical terms and linked it with normal ageing. The introduction of new staining and autopsy results enabled Alzheimer and his colleagues to identify 'neurofibrillary tangles', whilst simultaneously, presumably using similar technology, Fischer described 'senile plaques'. Both lesions are considered characteristic of what we call Alzheimer's disease today. However, scientific rivalry between the schools at Munich and at Prague, and between Alzheimer and Fischer, resulted in a range of explanatory claims and descriptions for these disorders including Fischer's plaques, Fischer's presbyophenia and, of course, the now-assimilated Alzheimer's disease (Amaducci *et al.* 1986).

The nosological discussion was not resolved by technological advances, but by Kraepelin, the director of the department in which Alzheimer worked, a researcher whose own work was devoted to the classification of psychiatric disorders and disease categories. He assigned his junior's name to the diagnosis of presenile dementia. Amaducci (1986) surmises that this action was taken to consolidate the position of both Kraepelin's school and of his researcher, and comments that Kraepelin's reputation and authority were of primary importance in the creation and perpetuation of this particular diagnosis. It also would likely be safe to presume that Kraepelin's particular focus on taxonomy (see Kahn 1957) may have contributed to his interest and success in assigning the name to the condition.

Fox (1989) further maintains that the context of medicine at the time of these discoveries enabled the creation of this diagnosis. Alzheimer believed that the changes he saw in the brain tissue were due to more than just ageing. Fox writes: 'The elimination of the age

criterion was central because it contributed to the transformation of what had been generally considered “senility” into a specific disease with specific pathological characteristics and symptoms’ (1989: 59). Fox also describes lay social movements, including the push from family members of Alzheimer’s patients, which, from the mid-20<sup>th</sup> century, rallied behind the Alzheimer’s disease label to bring it forward in public consciousness, generate research interest and promote its diagnostic status, as well as its characterisation as a leading cause of death.

### *Diagnostic authority and medicalisation*

Medicine’s authority is embodied in diagnosis at the institutional and individual levels. We will discuss later how other organisations and interests promote medicine’s authority, above and beyond medicine itself. For the profession, diagnoses and their classificatory systems are an important collective arrangement which both defines and enables the promotion and influence of professional medicine. The authority of medicine, according to de Swaan (1989), resides in such professional accords about scientific medicine.

At an individual level, the ability to assign categorical status (diagnosis) also confers power on medicine and its agent, the doctor, as allocator of resources (De Swaan 1989). The diagnosis legitimises sickness. As discussed previously, when a doctor deems a patient’s condition to be medical, the latter receives previously unauthorised privileges such as permission to be absent from work, to have priority parking, to be insurable, to receive reimbursement for treatment or access to services. The doctor certifies the medical nature of the complaint, and ‘medical advice’ informs administrative and policy decisions.

Freidson’s (1972) work on professional dominance focuses on the important role of diagnosis in reinforcing medical authority. It is, he postulates, ‘the . . . foundation upon which the strength of a profession rests . . . which establishes and supports the profession’s claim to honor, income and power. Where illness is the ubiquitous label for deviance in an age, the profession that is custodian of the label is ascendant’ (1972: 244). He continues: diagnosis is the mission of the doctor, whose task is ‘to authoritatively label as illness what a complainant suspects to be illness, and also to label as illness what was not previously labelled at all, or what was labelled in some other fashion, under some other institution’s jurisdiction’ (1972: 261).

Authority in medicine comes from its ability to define and delimit behaviours, persons and conditions write, Conrad and Schneider (1980), but also from the organisation and structure of the medical profession. Medicine has an officially approved monopoly over the right to define health and to treat illness, which results in its high public esteem (Freidson 1972). The doctor, as the agent of medicine, is accorded a prominent position in the hierarchy of expertise, and a mandate to exercise his or her authority, over that of say, other health professionals, in addition to that over lay people (Freidson 1972).

The medical dominance articulated by Freidson is not however, immutable. In 1988, Light and Levine argued that the power of the medical profession was already in decline as evidenced by the introduction of malpractice lawsuits, profit-driven administration of physician performance, and cost-management strategies in medicine. More recent evidence of change in the status of doctors is present, according to Lupton (1997b), in increasing patient complaints, increasing use of alternative therapies, media portrayals of doctors, and lack of financial autonomy. Further, wider access to information has led to changes in the doctor-patient relationship, with patients more willing to challenge their doctor, dispute findings, or seek advice outside the doctor-patient relationship (Lupton 1997a). The authority to diagnose some medical conditions has also been expanded to include other professional categories. In New Zealand, for example, a chiropractor or physiotherapist

may diagnose certain conditions and grant access to Accident Compensation Corporation benefits and services.

This is not to say that medicine no longer has authority. The biomedical expertise of those trained to practise medicine still carries much weight (Lupton 1997a). The practice of medicine, as well as its authority, is socially-contingent, and is framed by broader socio-technological change (Nettleton 2004). Nettleton discusses this change, and speaks of the informatisation of medicine, where the body is seen as a system of information networks: the art of medicine gives way to evidence-based practice, the physical body defers to the CT scan, information once restricted to medicine is now available to the lay web-surfer, and the doctor-patient relationship becomes a meeting of experts. Medicine's jurisdiction is shifting, incorporating new agents and social forces in its contemporary context. The theory of medicalisation offers the explanatory framework to understand the changing yet persistent face of medical authority.

Zola coined the term medicalisation in 1968 (Zola 1983). Zola's work explores the historical and theoretical basis of the medicalisation of society, as well as its political consequences (Zola 1972). He looked at the impact of medical authority on the individual; patient resistance; notions of power; compliance and submission (Zola 1986); the distance between doctor and patient (Zola 1973); and the breaking down of 'distancing barriers' (Zola 1991). Diagnosis played an important role in medicalising, Zola (1972) contended. 'If anything can be shown in some way to affect the workings of the body and to a lesser extent the mind, then it can be labelled an "illness" itself or jurisdictionally "a medical problem"' (1972: 495), he wrote, and he marvelled at the increasing rate of clinical entities and disorders reported in surveys and studies.

Medicalisation and diagnosis are clearly closely linked, but they are just as clearly *not* synonymous terms. Medicalisation is a process, one which may be aided in its accomplishment by diagnosis as a classification tool. It may be that this close relationship is fundamentally the explanation for why a sociology of diagnosis has not had its own delineation: it has been enveloped in the folds of medicalisation.

This broader literature of medicalisation informs the sociology of diagnosis by the way in which it establishes the authoritative and pervasive position of medicine in Western society. Whilst Conrad's later definition points to the role of diagnosis in medicalisation, indicating the place of illness and disorders in the assertion of medicine's professional territory, medicalisation encompasses more than just diagnosis. Infant feeding and child rearing, for example, have been historically, and continue to be, medicalised as part of scientific motherhood (Apple 1995). Seeking medical advice for matters of infant health, using medical endorsement for child nutrition and educational products, and reading doctor-authored columns or books on childrearing, privileges medical authority over other forms of knowledge without any diagnosis or pathological condition. This is in contrast to, say, sadness, or sexual problems, both arguably non-medical in nature, but variably transformed by the diagnostic labels 'depression' and 'erectile dysfunction', both of which trigger an army of medicalised actions, therapies and processes. In these cases, it is the diagnosis which is a specific step in, and an enabling factor of, medicalisation.

Understanding medicalisation requires us to look at the preceding work of other social scientists who were concerned with medicine's authority in contemporary society, and its role in legitimising social concerns (Zola 1983). Prior to the emergence of the concept of medicalisation, Talcott Parsons (1951, 1958) and Eliot Freidson (1972) wrote about the roles of the various components of the social system. Freidson focused particularly on the professional role of the physician with regard to illness, whilst Parsons explored health and illness in terms of how they respectively affected participation in a social system. 'Health



and illness' he wrote 'are not only "conditions" or "states" of the human individual . . . they are also states evaluated and institutionally recognised in the culture and social structure of societies' (1972: 126).

Zola acknowledged that one of the means by which medicalisation functions is by affixing diagnostic labels to socially deviant behaviour. Conrad (1975, 1979, 1992) and Conrad with Schneider (1980) explore this in greater depth, noticeably in the book *Deviance and Medicalization: From Badness to Sickness*. They note the role of medicine in reform – medical crusaders attempting to influence public morality and behaviour – as well as the respect for medical advances. These authors propose a five stage model by which a deviant behaviour is medicalised through diagnoses: defining the behaviour as deviant; discovering the behaviour from within the medical community; making claims; challenging the existing designation to bring the behaviour to medical turf; and finally, institutionalising the behaviour via diagnosis.

A number of scholars focus on the myriad of social conditions receiving medical attention and diagnostic labels. John Rosecrance (1985) extends Conrad and Schneider's model to his work on compulsive gambling. Scholars have explored hyperactivity (Conrad 1975), alcoholism (Blaxter 1978), menstruation (Vertinsky 1994, Smith-Rosenberg and Rosenberg 1973), pregnancy (Barker 1998), sexuality (Tiefer 1996), obesity (Jutel 2008), andropause (Conrad 2007), adult ADHD (Conrad 1979) and even compulsive buying (Lee and Mysyk 2004) as examples of the transfer of life events, activities and ways of being to the auspices of medical care.

The expansion of diagnostic categories is not without risk and can have severe iatrogenic results. The concordant treatment which accompanies a diagnosis may expose an individual to undesirable, or unintended, secondary effects. The medicalisation of shyness which results in the diagnoses of Social Phobia, Social Anxiety Disorder and Avoidant Personality Disorder, as one example, encourages patients to request, and doctors to recommend, the use of pharmaceutical remedies, some of which have led to reports of devastating side-effects (Scott 2006). As we will note further along in this essay, this focus on diagnosis also provides a fertile ground for the commercial exploitation of patients and doctors alike.

The close relationship between medicalisation and diagnosis, as well as the strong sociological focus of the last few decades on medicalisation, may fundamentally explain why a sociology of diagnosis is yet to emerge. More attention to the actual role that diagnostic labels play in medicalisation is likely to provide further, fruitful insights into the processes medicalisation entails.

## Diagnostic tension

Brown (2008) has written that defining diseases is often like a turf war: individuals and groups with different interests scramble to establish the authenticity of their claims or of their expertise. These tensions can be present between lay person and medical representative, intra- and inter-professional groups, policy makers and doctors, doctors and administrators and so on. In the section that follows, I describe areas of tension in diagnosis: the illness-disease distinction, the contested diagnosis and non-medical agents of medicalisation.

### *Illness-disease distinction*

The distinction between illness and disease is important to the sociology of diagnosis. This differentiation was not made clear in earlier sociological texts. Freidson (1972), for example, used the terms interchangeably. Today, however, the distinction contains important

conceptual differences that frame discussions of diagnosis. Kleinman, Eisenberg and Good (1978) wrote about illness as the personal experience of sickness, shaped by culture and influential for health outcomes. Illness problems are those which result from undesirable changes in social or personal function. How an individual perceives these problems, explains or labels them and seeks remedy, originates from a cultural context, and in turn influences the response to, or decision to access, medical services. In any case, as Locker (1981) points out, to consider oneself ill is to presume a biological cause for a disvalued state of being.

Disease, in contrast, is framed by the biological, rather than the personal. Western medicine considers disease a biological or psychophysiological dysfunction or maladaptation (Kleinman *et al.* 1978). Disease is diagnosed, illness is not; rather, it is presented to a clinician as *presumed* disease. The transformation from illness to disease takes place via the intermediary of the doctor and the diagnosis.

Someone who feels unwell describes their sense of disorder, and recounts what ails them, constructing a narrative which describes and contextualises their complaint; this description does not in itself constitute a diagnosis. This is what Balint (1964) refers to as the patient 'proposing' one or many illnesses in an attempt to find one upon which patient and doctor will concur. Diagnosis is the medical reading of these symptoms: interpreting and organising them according to models and patterns recognised by the profession. Leder (1990) describes this process as a 'clinical hermeneutic' or interpretive project. The individual initiates an encounter with the doctor to obtain an explanatory position from which to approach the illness.

While not all illnesses can be diagnosed, their narratives are the starting point for diagnosis. Note that there is more than one narrative: both the patient's and the doctor's stories juxtapose and merge for a diagnosis to materialise. The patient's stories, emerging from his or her own experience, culture, and consideration of the role of the doctor are transformed into medical accounts upon their telling. The doctor interrogates, interprets and retells the story, establishing the 'plot' and a diagnostic organisation (Hunter 1991). In Leder's model, the patient has already determined that the explanation for his or her discomfort is medical in nature, and that it is a doctor (rather than a different social authority, say a rabbi or a lawyer) who will confer meaning to the narrative. Illness is the story which results when an individual sees the interpretation in terms of health and medicine. Alternatively, diagnosis is the story of medicine, told in the language of disease. 'In the narrow biological terms of the biomedical model', says Kleinman (1988), 'this means that disease is reconfigured *only* as an alteration in biological structure or functioning' (1988: 5–6).

Arthur Frank (1995) claims that a social expectation of being ill is not just seeking care, it is 'a narrative surrender' in which the patient's story is relinquished to the doctor's, told through diagnosis, and 'the one against which others are ultimately judged true or false, useful or not' (1995: 5–6). Kleinman maintains that doctors are taught to be sceptical of patients' narratives about illness, a view shared by Foucault (1963), who wrote that clinical medicine sought to silence the patient's story unequivocally. 'In order to know the truth of the pathology, the doctor must abstract the patient . . . who, by trying to show things, ends up concealing them' (1963: 8, my translation).

The diagnosis thus confers legitimacy on illness, yet does not necessarily align with the patient's narrative for a number of reasons, not the least of which is the position from which the stories are recounted. Illness narratives 'reveal what life is like for the narrator . . . [including] the practical consequences of managing symptoms, reduced mobility and so on. In telling their story, individuals also reveal, or indeed may assert, their self and social

identity' (Nettleton *et al.* 2004: 49). Medical narratives come from an institutional position, which presumes the absence of the lived experience. It is the objectivity of scientific classification (in this case, the diagnosis) which confers authority on the label. Diagnosis is the fulcrum of the medical narrative. The judgement that this infers, as Frank has asserted above, may deny the self and social identity that the story of illness embodies.

Frank (1995) refers to illness as the experience of living through disease. It begins, he writes 'when popular experience is overtaken by technical expertise, including complex organisations of treatment. Folk no longer go to bed and die, cared for by family members . . . [they] go to paid professionals who reinterpret their pains as symptoms, using a specialised language that is unfamiliar and overwhelming' (1995: 5).

Hunter (1991) encapsulates this disconnection between the languages of disease and illness when she writes that the 'transformed and medicalised narrative may be alien to the patient: strange depersonalised, un-lived and unlivable. Returned to the patient in this alien form the medical narrative is all but unrecognizable as a version of the patient's story – and all but useless as an explanation of the patient's experience' (1991: 13). This occurs when the medical model takes inadequate account of the illness problems, how the patient has actually lived, explained and accounted for her dysfunction, and is unable to incorporate this in its own narrative via the diagnostic label.

Medical and individual narratives can also align, and in so doing, provide positive outcomes. Lillrank (2003) reports the stories of women who suffered from chronic back pain. Finally receiving a diagnosis was a relief to these women; their illness was validated – not imagined – despite the fact that the name referred to a chronic, and potentially disabling condition.

An individual narrative of disease is not, however, independent of the *regime* associated with a diagnosis, proposes Klawiter (2004). A disease regime consists of the cultural, spatial and historical practices associated with a diagnosis and goes beyond the circumstances of the individual and the physiological nature of her illness. Klawiter demonstrates how the narrative of one individual altered over time as a result of different conditions in which she experienced the same diagnosis. The agendas, identities, social relations, policies and emotional vocabularies embodied in different 'regimes of practice' transformed public discourses and other forms of cultural production around breast cancer, and in turn transformed the personal narrative of this particular woman.

The diagnostic process is engaged upon with a positive end in mind, although, as above, positive does not necessarily imply a welcome pathology. As Engelhardt (1992) writes:

One invests labor in making a diagnosis not simply in order to know truly, but because one would hope to be able to avoid or mitigate some unpleasant state of affairs. In the case of prognosis, one wants at least to be able to plan for likely unpleasant future developments (1992: 73).

When the patient's account and the doctor's interpretation of symptoms enable the discovery of pathology, the treatment, or correction of the biological abnormality, ideally results in the restoration of good health, or at the least, enables a sense of where the road ahead may lead.

Winston Chong (2001) points out another positive outcome of diagnosis. Diagnosis may also confer collective identity on patients, removing them from the isolation of their suffering and providing them with new potential networks of support. In turn, this collective identity has political potential to shape, and in some cases challenge, professional authority, political imperatives, and social identity (Brown and Zavestoski 2004). The social health

movement is driven in part by what these authors refer to as ‘embodied health movements’: groups constructed around particular diagnostic labels, illnesses, conditions, or by the perception of vulnerability to the same.

The collective identity may be virtual. A growing number of internet communities are diagnosis-focused. Web pages play a part in the social health movement: using the web to gather individuals around both existing and emerging diseases. Dumit (2006) explains that internet communities offer a means of survival for sufferers of medically unexplained symptoms. They provide an alternative support structure when the absence of diagnosis impugns the medical legitimacy of the individual’s complaint. These communities ‘create their own separate and distinct medical culture, a culture that gives primary importance to the role of subjective experience’ (Goldstein 2004: 127). An example of a virtual community serving to create an alternative culture are pro-anorexia sites that seek to redefine anorexia nervosa outside medical discourse, instead casting it as a sanctuary, a ‘place where control and purity [can] be found’ (Fox *et al.* 2005: 958). Conversely, internet communities are also launched by health providers who have identified web pages as a site at which patients can be transformed from consumers into a ‘community of practice’ with potentially improved health outcomes (Winkelman and Choo 2003).

In any case, the question of identity which both diagnosis and its absence help to consolidate has an important role to play in understanding the social context of health, illness and disease. Klawiter’s (1999) description of three distinct cultures which developed around breast cancer – and the varying needs of its sufferers – highlights different conceptions of the diagnosis which framed cultures of action. The discourses she described were as divergent as the ahistoric biological cancer for which medicine is salutatory for breast cancer as the product and source of profit of a predatory cancer industry.

Inadequate understanding of patient illness, disease frameworks or cultural context by either party prevents therapeutic alliance and shared ownership of the explanatory narrative. The ownership of the narrative is at the heart of tension between patients and doctors, Hunter (1991) maintains. Ownership, she argues, revolves around the language used, the assignment of authorship, and prioritisation of one version over another. In a medical re-telling, the illness becomes diagnosis, the person patient, and ‘professional values are transferred from the practitioner to the “case”’ (Kleinman 1988: 131).

In contrast, in some instances, medicine relinquishes willingly, and perhaps surprisingly, ownership of the diagnosis to the patient. For example, a sub-classification of migraine in the ICD is ‘intractable migraine, *so-stated*’ (italics mine). For this diagnosis to exist, the patient must speak (Bowker and Star 1999). Medicine’s occasional willingness to shift ownership depending on the condition, write Bowker and Star, is not evidence, of oppression, rather of what kind of a tool the ICD is: ‘what work it does, and whose voice appears in its unfolding narrative’ (1999: 84).

### Contest

Hadler (1996), in his discussion of fibromyalgia, describes diagnosis in confrontational terms: it is a battle in which a submissive patient agrees to participate only because of a tiny sliver of residual trust in the doctor-patient relationship resulting from generations of reverence. He underlines the vulnerability of the patient, the potentially flawed process of diagnosis, the inability of the profession to accept its limitations, and the imperfection of science. Hadler undoubtedly overstates many cases. But he does punctuate the degree to which contest or dispute is always potentially present in the diagnostic process, particularly, as he notes here, in the case of the disability determination (which unsurprisingly entails the allocation of resources) of someone with a disputed diagnosis.

Contest is accentuated by the latent dichotomy between illness and disease, the unequal power relationship between the patient and doctor, and the need for medical diagnosis for access to other services. Contest is present, notably in emerging illnesses such as Hadler's above example of fibromyalgia, and assumes a particularly acute form when the absence of diagnosis denies the patient access to the sick role, and, more importantly, to institutional recognition of suffering. Many have written of the distress of patients who do not receive a diagnosis for their complaint. This distress typically focuses on disorder, confusion, fear of being stigmatised by a psychogenic explanation and denial of services (Dumit 2006, Nettleton 2006, Malterud 2001, 2005).

Dumit (2006) describes how conflict is shaped both in- and outside of the patient doctor relationship. Clinicians are directed in their practice by the impositions of the health maintenance organisation, the employer and the insurer; bureaucracy determines who can provide care, and for what ailments. These organisations join in symbolic domination over the individual patient. But the key point, as Dumit makes clear in this paper and others, is 'the intense interplay between diagnosis and legitimacy: without a diagnosis and other forms of acceptance into the medical system, sufferers are at risk of being denied social recognition of their very suffering and accused of simply faking it' (2006: 578).

Contested diagnoses are typically those that cannot currently be explained by medicine or have explanations which are in dispute (Brown and Zavestoski 2004). The contest focuses on debate around whether they are primarily social, psychiatric or biological in nature (Dumit 2006). These are illnesses that are 'are not defined in terms of organic pathology, but on the base of their symptoms' (Nettleton *et al.* 2004). As I have discovered in my own work in progress, the literature dealing with medically unexplained symptoms predominantly assembles these enigmatic symptoms discursively as synonymous with somatising ailments and psychogenic in origin. The term 'medically unexplained symptoms' is used interchangeably with psychiatric diagnostic terms such as somatoform disorder, somatising, functional somatic syndrome, or other related terms implying an illness of psychogenic or sociogenic origin. Yet, the absence of the objective finding is prevalent in many debilitating disorders such as chronic fatigue syndrome, lower back pain, occupation overuse syndrome, and others. Nettleton (2006) also demonstrates that the difficulties of living with the uncertainty of non-diagnosis, and of defending the legitimacy of their complaints results in significant distress and dissatisfaction with the medical encounter and profession.

Conflict may also arise conversely, when diagnosis achieves non-clinical ends, and stymies the rights of the patient, who does not believe him or herself to be ill. A powerful example of this is political psychiatry, where dissent is treated as mental illness. Robin Munro (2002) quotes a Chinese textbook which develops the notion of 'political mania' as a form of paranoid psychosis:

Those afflicted do avid research into politics and put forward a whole set of original theories of their own, which they then try to peddle by every means possible . . . such people are sometimes viewed [by others] as being political dissidents (Sifa Jingshen Yixue Jianding Zixun Jieda, in Munro 2002).

A less sinister example of the state's utilisation of diagnosis is captured in the simple naming of foetal death; miscarriage, spontaneous abortion, and still-birth give access to different privileges and liabilities according to the label applied. An almost-arbitrary gestational limit determines whether a death certificate is issued, a burial permitted, a death benefit awarded, or charges pressed (Jutel 2006).

Another diagnosis which may go counter to the patient experience is the contemporary diagnosis of obesity. Many patients and advocacy groups refute that obesity is a disease and maintain that the medicalisation of obesity is evidence of size discrimination rather than of biophysical dysfunction (Gard and Wright 2005, Campos *et al.* 2006a, 2006b). Both individual and collective action in the case of other disputed diagnoses has resulted in reconsideration in some cases, and removal, in others, of the disease label.

The women's health movement has both advocated for, and succeeded to a certain extent in, the demedicalisation of some aspects of female biology, including menstruation and childbirth. Whilst childbirth is still generally medically managed in the West, there has been a move towards its demedicalisation. In New Zealand, for example, current policy enables midwives to be lead maternity carers and 78.1 per cent of New Zealand women registered with a midwife rather than a general practitioner or obstetrician to manage their pregnancy (New Zealand Health Information Service 2006).

Routine screening is another source of potentially disputed diagnoses. Screening seeks to find evidence of disease in a patient who is presenting for what may be unrelated, and possibly not even clinical, reasons. Whilst there has been a rise in screening as part of health assessment, there is significant debate about its putative benefits. Black (2000) has written that detecting subclinical conditions which would have otherwise gone to the grave with the patient (while not being the cause of death) can result in anxiety, unnecessary treatment, complications and even actual death. Screening for disease is practised with religious fervour, according to Howard Brody (2006), but not always with the acquiescence of the patient. This reflects what Armstrong (1995) casts as 'surveillance' medicine: a perception of human existence which sees everyone as normal, but no-one as truly healthy. Disease potential thus drives a focus on multiple and interrelated risk factors and continual monitoring.

The disease potential is a salient means of social control and is amplified by the ever-expanding technical access to new screening tools. The potential to detect genetic predispositions for disease, for example, may result in a range of actions including discriminatory hiring and insurance practices, selective abortion and stigmatisation of carriers (Wertz 1992, Raz and Vizner 2008). Screening programmes, such as the Dor Yeshorim premarital genetic testing programme for potential spouses in ultra-orthodox Jewish communities, results in the reinforcement of stigma of potential spouses who are presumed genetic carriers (Raz and Vizner 2008).

### *Engines of diagnosis*

Whilst medicine holds the power to diagnose, many other agents hold the ability to promote particular diagnoses, if not to create them. Conrad (2005, 2007) has made reference to 'engines of medicalisation' which maintain or cultivate a medical locus for the management of banal life activities. These include biotechnologies, consumers and managed care. These engines bolster the flagging authority of medicine in the face of declining trust in the doctor. Conrad's concern is with medicalisation, and I have argued above that this focus is more general than on diagnosis alone. Whilst there is not the space to expand upon each of these drivers in the context of this essay, I will focus predominantly on the example of the pharmaceutical and related industries, whose interests are specifically served by the creation or maintenance of specific diagnoses.

In 1992, Payer introduced the term 'disease monger' and identified a medical-industrial complex which, she argued, had a great interest in promoting the notion that the greater population is either already sick or at risk of so becoming. Her focus was on the abuse of diagnosis as a mechanism for advancing political, social and commercial interests. She

identified a range of agents who stood to benefit from the proliferation of diagnostic labels – creating a need for their products and services – including medical researchers, medical writers, health educators/promoters, the pharmaceutical and diagnostics industry, doctors, lawyers, hospitals, the courts, and insurance companies (Payer 1992).

There has since been wide-ranging critical discussion of the clinical and economic contexts of disease mongering (Moynihan and Cassels 2005, Payer 1992, Moynihan *et al.* 2002, Moncrieff *et al.* 2005, Tiefer 2006, Wolinsky 2005, Healy 2006, Dear and Webb 2007), with an array of definitions. Payer (1992) described mongering as ‘big business trying to convince essentially well people that they are sick, or slightly sick people that they are very ill’. Moynihan and colleagues (2002) refer to ‘widening the boundaries of treatable illness in order to expand markets for those who sell and deliver treatments’. However, to date, sociologists have paid scant attention to the pharmaceutical industry, in great part because of the discipline’s focus on the experience of illness, the secretive nature of the industry, the inadequate scientific-technical knowledge of many sociologists, and the threat of legal challenge emanating from the pharmaceutical companies (Busfield 2006, Abraham 2007).<sup>1</sup>

From within a sociology of diagnosis, however, it is useful to explore, and indeed theorise, the phenomenon referred to as disease mongering by its critics, as diagnostic labels are at the fulcrum of its activities. To understand the way that diagnoses are promoted by non-medical sources requires reflection which includes, but goes beyond, the pharmaceutical industry, and notably includes other industries as well as the context in which diagnosis currently takes place.

The ability to promote diagnoses is facilitated by the diffusion of information through e-escaped medicine as described by Nettleton above. In this context, control over medical information shifts from doctor to a variety of other loci with manifold motivations (in the case of the industry, commercial). The patient becomes ‘consumer’, but not only in the commercial sense of the word. A proliferation of information and media sites are available to for ingestion: direct-to-consumer advertising; on-line self-screening tests; patient advocacy organisations; and disease awareness campaigns. Many of these are covertly, if not overtly propped up by the industry standing to gain from expanding the number of individuals under a particular diagnostic umbrella (Herxheimer 2003).

Leonore Tiefer (2006) argues that it was a convergence of pharmaceutical companies, urologists closely associated with this industry, and media-savvy sex therapists operating within the for-profit sector, which resulted in the creation and promotion of a diagnosis of ‘female sexual dysfunction’. The acute interest in women’s sexuality, she maintains, is linked to uncritical definitions of what constitutes normal female sexuality. It is also part of the industry’s desire to expand the market for drugs like Viagra by promoting erectile dysfunction more widely than justified (Lexchin 2006).

Commercial interests have an important stake in highlighting overweight as a medical diagnosis, rather than a statistical deviation from normative weight. These interests go beyond the pharmaceutical industry. Fitness centres – part of a \$15 billion per annum industry in the US (US Census Bureau 2004) – in addition to the pharmaceutical and weight-loss industries, and even some practising physicians, rely heavily upon promoting public belief in overweight-as-disease. Identifying obesity as a disease against which gym-goers can battle, reminding them of the ever-present ‘threat’ of disease with body mass index charts, scales for self-monitoring and doomsday publications about the risks of corpulence, are important marketing tools: both of the diagnosis of obesity, and of vigilant exercise; the first justifying the second.

As Campos and colleagues (2006a) have pointed out, many of the leading researchers in obesity research, including those who set the criteria to determine what constitutes obesity,

have an economic interest in defining overweight as widely as possible, either by their partnership with the pharmaceutical industry or by their own private weight-loss clinics. Their preoccupation with overweight as disease defies evidence of: lower mortality associated with overweight (BMI 25–29) than with normal weight (BMI 18.5–24.9) (Romero-Corral *et al.* 2006); health benefits of subcutaneous fat on hips and thighs (Nevill *et al.* 2006); and an increase in non-cancer mortality after weight loss (Nilsson *et al.* 2002).

Commercial influences are not the only non-medical forces to have an interest in promoting particular diagnoses. The diagnosis of ‘excited delirium’ has surfaced in coroners’ courts as explanation for deaths in custody following physical restraint, even though the criteria for such ‘deliria’ are far from established (Milliken 1998). Attributing these unexpected deaths to disease rather than to excessive force concords comfortably with the presumed ethical behaviour of the police and the role one would hope to see them play in the community.

Ivan Illich (1976) wrote that ‘disease always intensifies stress, defines incapacity, imposes inactivity, and focuses apprehension on non-recovery, on uncertainty, and on one’s dependence upon future medical findings’. He continues:

Once a society organizes for a preventative disease-hunt, it gives epidemic proportions to diagnosis. This ultimate triumph of therapeutic culture turns the independence of the average healthy person into an intolerable form of deviance (1976: 104).

Good (1969) writes in a similar tone, pointing out that ‘by devising a linguistic category with specific connotations, one is designing the armaments for a battle; by having it accepted and used, one has scored a major victory’ (1969: 89). Bowker and Starr (1999) explain the power of the diagnosis through its classificatory functions: the diagnosis, as classification, does the work of ‘making it appear that science describes nature (and nature alone) and that politics is about social power (and social power alone)’ (1999: 46). In any case, however, the work of the diagnosis is often invisible, ‘erased by [its] naturalization into the routines of life’ concealing conflict and multiplicity beneath layers of obscure representation (1999: 47).

## Conclusion

Most readers of this journal will have, at some point, gone to see the doctor to ‘find out what’s wrong’. Some will go with trepidation, wondering if they’re wasting the doctor’s time – ‘It’s probably nothing’ – while others will leave with even more unease than when they went in – ‘If nothing’s wrong with me, why do I feel this way?’. Yet a third group will leave a consultation with a clear sense of what is amiss, instructions about treatment, and with some luck, an anticipation of when and how the ailment will be resolved. Diagnosis structures the reality of individuals, as it clarifies and sometimes explains what they experience. Interactions in the doctor’s rooms are strongly framed by what it means both to be a patient and a doctor. Subservience to medical authority is both reassuring and problematic. Good patients show signs of ‘compliance’ and ‘adherence’ to doctor’s orders. Informed self-advocates work hard with, and sometimes against, the doctor, probing and questioning why their complaint is or isn’t considered medical, and protesting if a psychogenic cause is proposed: less physical, less real.

In a contemporary world where information abounds, the diagnostic relationship between patient and doctor is different. Patients may, at odds with Balint’s description,



propose a diagnosis, rather than an ailment, when they consult. Or, they may circumvent the doctor altogether. They calculate their BMI, take depression self-tests, or use medical terminology to describe their idiosyncrasies and those of their friends. 'Are you sure you don't have ADD?' they might quiz. Lay people are changing the shape of what diagnosis means in practice.

The 'modern' patient is the ideal: an informed 'consumer' who can sit on an equal platform with the doctor as a result of now-open access to information previously restricted to doctors. The idealised clinical encounter is a co-operative interaction which brings patient and doctor together in a kind of hand-shake agreement about what ails the former and what the latter can do in response. It is not always so simple, particularly as the encounter is about far more, as Hunter (1991) points out, than a simple classification of our malady; focusing on the diagnosis draws attention away from the care of the person who is ill. Furthermore, the profession's acknowledgements of its limitations and as well as of the myriad of social influences on its classificatory practices, needs attention from within.

Exploring the social forces which influence the clinical process of diagnosis provides a greater understanding of both the fluidity and the fallibility of the diagnosis. Diagnoses do not exist ontologically. They are concepts which bind the biological, the technological, the social, the political and the lived. Thomas Laqueur wrote that 'Believing is Seeing'. Despite the advent of autopsy and a presumed clear vision of the ways in which structures were connected, Renaissance anatomists still depicted the vagina as inside-out penis, and menstrual flow as transformed into breast milk during lactation (Laqueur 1990). Diagnosis similarly, captures what the medical institution currently believes to be the 'Way Things Are'. Suffice it to say, the world of facts is not detachable from an a priori conceptual framework.

Sociology of diagnosis is an important avenue for understanding not only lay experience of illness and lay-professional discord as we have discussed above, but also patient compliance, disease control, public health, health education and many other aspects of health and illness. Kleinman and his colleagues' claims of thirty years ago hold strong today: understanding social science is necessary to deal competently with essential, nonbiomedical, aspects of clinical practice. They maintain that medicine is both a biological and a social science (Kleinman *et al.* 1978). Focusing on both social and biological aspects assists clinicians to treat patients as well as diseases, a sometimes neglected feature of contemporary medical practice (see Leder 1990, Goldstein 2007). Understanding the social frames within which diagnoses are generated, and grasping the impact of the label, is clinically powerful. As Aronowitz (2001) cautions: there is an 'essential continuity between persons who have symptoms that have been given a name and disease-like status and persons whose suffering remains unnamed and unrecognized' (2001: 808).

Sociology of diagnosis has a salient role to play in understanding health, illness and disease – unpacking and identifying the play of interests which enter into discussions of what priorities should be set, and what goals attained. Diagnosis defines the field of medicine and its professional reach, serves as the nexus in which the clinical encounter takes place, arbitrates normality and difference, organises a patient's illness, and determines how resources are allocated. In this review I have, with a broad brush, covered a range of considerations which contribute to a sociology of diagnosis: the place of naming in medicine, and the tensions naming can engender. But there is more work to be done. A rich collection of structures, agents and actions enter into the diagnostic arena and deserve consideration. Identifying, analysing and understanding these and their connections will ultimately contribute to a better understanding of medicine's role and how it achieves it, as well as the relationship of medicine to culture and society.

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## Note

- 1 Since this manuscript was submitted, a special issue of *Sociology of Health and Illness*, 'Pharmaceuticals and society: critical discourses and debates' (Volume 30 Issue 6, September 2008), reviewed a number of important debates in this area.

## References

- Abraham, J. (2007) Building on sociological understandings of the pharmaceutical industry or reinventing the wheel? Response to Joan Busfield's 'Pills, power, people', *Sociology*, 41, 4, 727–36.
- Amaducci, L.A., Rocca, W.A. and Schoenberg, B.S. (1986) Origin of the distinction between Alzheimer's disease and senile dementia: how history can clarify nosology, *Neurology*, 36, 11, 1497–9.
- Anon (1886) The nomenclature of medicine, *British Medical Journal*, 1, 1328, 1115–6.
- Apple, R.D. (1995) Constructing mothers: scientific motherhood in the nineteenth and twentieth centuries, *Social History of Medicine*, 8, 2, 161–78.
- Armstrong, D. (1995) The rise of surveillance medicine, *Sociology of Health and Illness*, 17, 3, 393–404.
- Aronowitz, R. (2001) When do symptoms become a disease? *Annals of Internal Medicine*, 134, 9 part 2, 803–8.
- Balint, M. (1964) *The Doctor, his Patient and the Illness*. Kent, England: Pitman Medical.
- Barker, K.K. (1998) A ship upon a stormy sea: the medicalization of pregnancy, *Social Science and Medicine*, 47, 8, 1067–76.
- Black, W.C. (2000) Overdiagnosis: an underrecognized cause of confusion and harm in cancer screening, *Journal of the National Cancer Institute*, 92, 16, 1280–2.
- Blaxter, M. (1978) Diagnosis as category and process: the case of alcoholism, *Social Science and Medicine*, 12, 9–17.
- Bowker, G.C. and Star, S.L. (1999) *Sorting Things Out: Classification and its Consequences*. Cambridge, MA: MIT Press.
- Brody, H. (2006) Informed refusal, *Virtual Mentor*, 8, 1, 24–9.
- Broussais, F.J.V. (1828) *De l'irritation et de la folie, ouvrage dans lequel les rapports du physique et du moral sont établis sur les bases de la médecine physiologique*. Paris: Delaunay.
- Brown, P. (1987) Diagnostic conflict and contradiction in psychiatry, *Journal of Health and Social Behavior*, 28, 1, 37–50.
- Brown, P. (1990) The name game: toward a sociology of diagnosis, *The Journal of Mind and Behaviour*, 11, 3–4, 385[139]–406[160].
- Brown, P. (1995) Naming and framing: the social construction of diagnosis and illness, *Journal of Health and Social Behavior*, Health Module, 34–52.
- Brown, P. (2008) Naming and framing: the social construction of diagnosis and illness. In Brown, P. (ed.) *Perspectives in Medical Sociology*. Long Grove, Ill: Waveland Press.

- Brown, P. and Zavestoski, S. (2004) Social movements in health: an introduction, *Sociology of Health and Illness*, 26, 6, 679–94.
- Busfield, J. (2006) Pills, power, people: sociological understandings of the pharmaceutical industry, *Sociology*, 40, 2, 297–314.
- Campos, P., Saguy, A., Ernsberger, P., Oliver, E. and Gaesser, G. (2006a) The epidemiology of overweight and obesity: public health crisis or moral panic? *International Journal of Epidemiology*, 35, 1, 55–60.
- Campos, P., Saguy, A., Ernsberger, P., Oliver, E. and Gaesser, G. (2006b) Response: lifestyle not weight should be the primary target, *International Journal of Epidemiology*, 35, 1, 81–2.
- Cartwright, S. (1981 [1851]) Report of the diseases and physical peculiarities of the negro race. In Caplan, A., Englehardt, H.T. and McCartney, J. (eds) *Concepts of Health and Disease*. Reading, MA: Addison-Wesley Publishing Company.
- Chiong, W. (2001) Diagnosing and defining disease, *JAMA*, 285, 1, 89–90.
- Conrad, P. (1975) The discovery of hyperkinesis: notes on the medicalization of deviant behavior, *Social Problems*, 23, 1, 12–21.
- Conrad, P. (1979) Types of medical social control, *Sociology of Health and Illness*, 1, 1, 1–11.
- Conrad, P. (1992) Medicalization and social control, *Annual Review of Sociology*, 18, 209–32.
- Conrad, P. (2005) The shifting engines of medicalization, *Journal of Health and Social Behavior*, 46, 1, 3–14.
- Conrad, P. (2007) *The Medicalization of Society: On the Transformation of Human Conditions into Treatable Disorders*. Baltimore: Johns Hopkins University Press.
- Conrad, P. and Schneider, J., W. (1980) *Deviance and Medicalization: From Badness to Sicknes*. St. Louis, MO: The C.V. Mosby Company.
- De Swaan, A. (1989) The reluctant imperialism of the medical profession, *Social Science and Medicine*, 28, 11, 1165–70.
- Dear, J.W. and Webb, D.J. (2007) Disease mongering: a challenge for everyone involved in healthcare, *British Journal of Clinical Pharmacology*, 64, 2, 122–4.
- Dumit, J. (2006) Illnesses you have to fight to get: facts as forces in uncertain, emergent illnesses, *Social Science and Medicine*, 62, 3, 577–90.
- Engelhardt, H.T. (1992) The body as a field of meaning: implications for the ethics of diagnosis. In Peset, J.L. and Gracia, D. (eds) *The Ethics of Diagnosis*. Netherlands: Springer.
- Fischer-Homberge, E. (1970) Eighteenth-century nosology and its survivors, *Medical History*, 14, 397–403.
- Foucault, M. (1963) *Naissance de la clinique*. Paris: Presses Universitaires de France.
- Foucault, M. (1975) *Surveiller et punir: naissance de la prison*. Paris: Gallimard.
- Fox, N., Ward, K. and O'Rourke, A. (2005) Pro-anorexia, weight-loss drugs and the internet: an 'anti-recovery' explanatory model of anorexia, *Sociology of Health and Illness*, 27, 7, 944–71.
- Fox, P. (1989) From senility to Alzheimer's Disease: the rise of the Alzheimer's Disease Movement, *The Milbank Quarterly*, 67, 1, 58–102.
- Frank, A. W. (1995) *The Wounded Storyteller: Body, Illness and Ethics*. Chicago: University of Chicago Press.
- Freidson, E. (1972) *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York: Dodd, Mead and Company.
- Gard, M. and Wright, J. (2005) *The Obesity Epidemic: Science, Morality and Ideology*. Milton Park, UK: Routledge.
- Gevitz, N. (2000) 'The Devil hath laughed at the physicians': witchcraft and medical practice in seventeenth-century New England, *Journal of the History of Medicine*, 55, 1, 5–36.
- Goldstein, A. (2007) Medicine's flight from interpretation: when a cough is simply a cough, *Clinical Ethics*, 2, 1, 15–18.
- Goldstein, D.E. (2004) Communities of suffering and the internet. In Packard, R.M., Brown, P.J., Berkelman, R.L. and Frumkin, H. (eds) *Emerging Illnesses and Society: Negotiating the Public Health Agenda*. Baltimore: The Johns Hopkins University Press.

- Goode, E. (1969) Marijuana and the politics of reality, *Journal of Health and Social Behavior*, 10, 2, 83–94.
- Hacking, I. (2001) Inaugural lecture: Chair of Philosophy and History of Scientific Concepts at the Collège de France, 16 January 2001, *Economy and Society*, 31, 1, 1–14.
- Hadler, N.M. (1996) If you have to prove you are ill, you can't get well. The object lesson of fibromyalgia, *Spine*, 21, 20, 2397–2400.
- Healy, D. (2006) The latest mania: selling Bipolar Disorder, *PLoS Medicine*, 3, 4, e185.
- Herxheimer, A. (2003) Relationships between the pharmaceutical industry and patients' organisations, *British Medical Journal*, 326, 1208–10.
- Hunter, K.M. (1991) *Doctors' Stories*. Princeton, NJ: Princeton University Press.
- Jutel, A. (2006) What's in a Name? Death before birth, *Perspectives in Biology and Medicine*, 49, 3, 425–34.
- Jutel, A. (2008) Doctor's Orders: Diagnosis, Medicalisation and the Exploitation of Anti-Fat Stigma. In Wright, J. and Harwood, V. (eds) *Biopolitics and the 'obesity epidemic': governing bodies*. London: Routledge.
- Kahn, E. (1957) The Life and Work of Emil Kraepelin, *Public Health Reports*, 72, 7, 527–74.
- King, L.S. (1954) What is disease?, *Philosophy of Science*, 21, 3, 193–203.
- Kirk, S.A. and Kutchins, H. (1992) *The Selling of DSM: The Rhetoric of Science in Psychiatry*. New York: Aldine de Gruyter.
- Klawiter, M. (1999) Racing for the cure, walking women, and toxic touring: mapping cultures of action within the Bay Area terrain of breast cancer, *Social Problems*, 46, 1, 104–26.
- Klawiter, M. (2004) Breast cancer in two regimes: the impact of social movements on illness experience, *Sociology of Health and Illness*, 26, 6, 845–74.
- Kleinman, A. (1988) *The Illness Narratives: Suffering, Healing, and the Human Condition*. New York: Basic Books, Inc.
- Kleinman, A., Eisenberg, L. and Good, B. (1978) Culture, illness, and care: clinical lessons from anthropologic and cross-cultural research, *Annals of Internal Medicine*, 88, 2, 251–8.
- Laqueur, T. (1990) *Making Sex: Body and Gender from the Greeks to Freud*. Cambridge, MA: Harvard University Press.
- Leder, D. (1990) Clinical interpretation: the hermeneutics of medicine, *Theoretical Medicine*, 11, 9–24.
- Lee, S. and Mysyk, A. (2004) The medicalization of compulsive buying, *Social Science and Medicine*, 58, 9, 1709–18.
- Lexchin, J. (2006) Bigger and better: how Pfizer redefined erectile dysfunction, *PLoS Medicine*, 3, 4, e132.
- Light, D. and Levine, S. (1988) The changing character of the medical profession: a theoretical overview, *The Milbank Quarterly*, 66, 10–32.
- Lillrank, A. (2003) Back pain and the resolution of diagnostic uncertainty in illness narratives, *Social Science and Medicine*, 57, 6, 1045–54.
- Locker, D. (1981) *Symptoms and Illness: The Cognitive Organization of Disorder*. London: Tavistock Publications.
- Lupton, D. (1997a) Consumerism, reflexivity and the medical encounter, *Social Science and Medicine*, 45, 3, 373–81.
- Lupton, D. (1997b) Doctors on the medical profession, *Sociology of Health and Illness*, 19, 4, 480–97.
- Malterud, K. (2001) [Subjective symptoms without objective findings – a challenge for theory and practice of general medicine], *Ugeskr Laeger*, 163, 48, 6729–34.
- Malterud, K. (2005) Humiliation instead of care? *Lancet*, 9488, 785–6.
- Mendelson, G. (2003) Homosexuality and psychiatric nosology, *Australian and New Zealand Journal of Psychiatry*, 37, 6, 678–83.
- Milliken, D. (1998) Death by Restraint, *Canadian Medical Association Journal*, 158, 12, 1611–2.
- Moncrieff, J., Hopker, S. and Thomas, P. (2005) Psychiatry and the pharmaceutical industry: who pays the piper? *Psychiatric Bulletin*, 29, 84–5.
- Moynihan, R. and Cassels, A. (2005) *Selling Sickness: How Drug Companies are Turning Us All Into Patients*. Sydney: Allen and Unwin.

- Moynihan, R., Heath, I. and Henry, D. (2002) Selling sickness: the pharmaceutical industry and disease mongering, *British Medical Journal*, 324, 886–91.
- Munro, R.J. (2002) Political psychiatry in post-Mao China and its origins in the cultural revolution, *Journal of the American Academy of Psychiatry and the Law*, 30, 1, 97–106.
- Nettleton, S. (2004) The emergence of e-scaped medicine, *Sociology*, 38, 4, 661–79.
- Nettleton, S. (2006) 'I just want permission to be ill': towards a sociology of medically unexplained symptoms, *Social Science and Medicine*, 62, 5, 1167–78.
- Nettleton, S., O'Malley, L., Watt, I. and Duffey, P. (2004) Enigmatic illness: narratives of patients who live with medically unexplained symptoms, *Social Theory and Health*, 2, 47–66.
- Nevill, A.M., Stewart, A.D., Olds, T. and Holder, R. (2006) Relationship between adiposity and body size reveals limitations of BMI, *American Journal of Physical Anthropology*, 129, 151–6.
- New Zealand Health Information Service (2006) Report on Maternity. Wellington: NZ, Ministry of Health.
- Nilsson, P.M., Nilsson, J.A., Hedblad, B., Berglund, G. and Lindgarde, F. (2002) The enigma of increased non-cancer mortality after weight loss in healthy men who are overweight or obese, *Journal of Internal Medicine*, 252, 1, 70–8.
- Parsons, T. (1951) Illness and the role of the physician: a sociological perspective, *American Journal of Orthopsychiatry*, 21, 452–60.
- Parsons, T. (1958) Definitions of health and illness in the light of American values and social structure. In Jaco, E.G. (ed.) *Patients, Physicians and Illness: behavioral science and medicine*. Glencoe, IL: The Free Press.
- Payer, L. (1992) *Disease-Mongers: How Doctors, Drug Companies, and Insurers Are Making You Feel Sick*. New York: John Wiley and Sons, Inc.
- Raz, A.E. and Vizner, Y. (2008) Carrier matching and collective socialization in community genetics: Dor Yeshorim and the reinforcement of stigma, *Social Science and Medicine*, 67, 9, 1361–9.
- Romero-Corral, A., Montori, V.M., Somers, V., K., Korinek, J., Thomas, R.J., Allison, T.G., Mookadam, F. and Lopez-Jimenez, F. (2006) Association of bodyweight with total mortality and with cardiovascular events in coronary artery disease: a systematic review of cohort studies, *Lancet*, 368, 666–78.
- Rosecrance, J. (1985) Compulsive Gambling and the Medicalization of Deviance, *Social Problems*, 32, 3, 275–84.
- Rosenberg, C. E. (2002) The tyranny of diagnosis: specific entities and individual experience, *The Milbank Quarterly*, 80, 2, 237–60.
- Scott, S. (2006) The medicalisation of shyness: from social misfits to social fitness, *Sociology of Health and Illness*, 28, 2, 133–53.
- Scott, W., J. (1990) PTSD in DSM-III: a case in the politics of diagnosis and disease, *Social Problems*, 37, 3, 294–310.
- Smith-Rosenberg, C. and Rosenberg, C. (1973) The female animal: medical and biological views of woman and her role in nineteenth-century America, *The Journal of American History*, 60, 2, 332–56.
- Sydenham, T. (1742) *The entire works of Dr Thomas Sydenham, newly made English from the originals: . . . To which are added, explanatory and practical notes, from the best medicinal writers*. By John Swan, M.D. London: printed for Edward Cave.
- Tiefer, L. (1996) The medicalization of sexuality: conceptual, normative, and professional issues, *Annual Review of Sex Research*, 7, 252–82.
- Tiefer, L. (2006) Female sexual dysfunction: a case study of disease mongering and activist resistance, *PLoS Medicine*, 3, 4, e178.
- US Census Bureau (2004) Amusement, Gambling and Recreation Industries 2002. Washington DC: US Census Bureau.
- Veith, I. (1981) Historical reflections on the changing concepts of disease. *Concepts of Health and Disease: Interdisciplinary Perspectives*. Reading, MA: Addison-Wesley Publishing Company.
- Vertinsky, P.A. (1994) *The Eternally Wounded Woman: Women, Doctors, and Exercise in the Late Nineteenth Century*. University of Illinois Press.

- Wertz, D.C. (1992) Ethical and legal implications of the new genetics: issues for discussion, *Social Science and Medicine*, 35, 4, 495–505.
- Winkelman, W.J. and Choo, C.W. (2003) Provider-sponsored virtual communities for chronic patients: improving health outcomes through organizational patient-centred knowledge management, *Health Expectations*, 6, 4, 352–8.
- Wolinsky, H. (2005) Disease mongering and drug marketing, *European Molecular Biology Organization* 6, 7, 612–4.
- Zola, I.K. (1972) Medicine as an institution of social control, *Sociological Review*, 20, 487–504.
- Zola, I.K. (1973) Pathways to the doctor – from person to patient, *Social Science and Medicine*, 7, 9, 677–89.
- Zola, I.K. (1983) *Socio-Medical Inquiries: Recollections, Reflections, and Reconsiderations*. Philadelphia: Temple University Press.
- Zola, I.K. (1986) *Illness Behaviour: A Political Analysis*. In McHugh, S. and Vallis, T.M. (eds) *Illness Behaviour: A Multi-disciplinary Model*. New York: Plenum Press.
- Zola, I.K. (1991) Bringing our bodies and ourselves back in: reflections on a past, present, and future ‘medical sociology’, *Journal of Health and Social Behavior*, 32, 1, 1–16.