

# The diffusion of diagnosis and its implications for the epistemology and ontology of disease

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## Abstract

Rather than confining the categories health and sickness to a biomedical conception of the biological organism, there is growing recognition of epistemological and ontological multiplicity in the realm of diagnosis and, indeed, in the very realm of disease itself. In short, the empirical manifestations of health and illness as well as the processes thought to cause them are now understood to assume a much wider variety of both biological and other forms. This essay considers the underlying epistemological and ontological opportunities and challenges of taking what we are calling this diffusion of diagnosis seriously. By diffusion we mean the movement from a concentrated understanding of diagnostic authority as confined to scientific biomedicine to a less concentrated appreciation of the diverse approaches to diagnosis throughout the world. We consider the extent to which, and the manner in which, we as sociologists of diagnosis might not only critique these various processes but perhaps also take them seriously in an ethnographic sense as locally produced, evaluated and legitimated forms of health care.

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**KEYWORDS**

epistemology of disease, medical pluralism, medical practice, ontology of disease

**INTRODUCTION**

The sociology of diagnosis explores such topics as the genealogy of our contemporary diagnostic categories, their uses in a wide variety of social contexts, the interests served by the formulation and operationalisation of particular diagnostic categories and related topics. It is fundamentally concerned to cast a critical eye upon topics pertaining to diagnosis and to properly place them in the socio-historical contexts within which they arise (cf., Blaxter, 1978; Brown, 1990; Jutel, 2011; Nissen & Risor, 2018; Smith-Morris, 2016). To a considerable extent the sociology of diagnosis builds on the influential medicalisation literature, and social constructionist literature more generally, to problematise uncritical endorsements of the diagnostic claims of biomedicine and to ethnographically appreciate the rich diversity of diagnostic systems and practices to be found in the world. Rather than confining the categories health and sickness to a biomedical conception of the biological organism in health and pathology there has been for some time a growing recognition of epistemological and ontological multiplicity in the realm of diagnosis and, indeed, in the very realm of disease itself.

In short, the empirical manifestations of health and illness as well as the processes thought to cause them are increasingly understood to assume a much wider variety of biological and other forms (cf., Weinberg, 2021). This essay contributes to the sociology of diagnosis by considering the epistemological and ontological opportunities and challenges of taking the diffusion of diagnosis seriously.<sup>1</sup> By diffusion of diagnosis we mean the various processes by which some of the diagnostic claims of biomedicine have come to be rivalled both within an often fractious biomedical research community and by alternative diagnostic systems and practices, including Ayurvedic medicine, traditional Chinese medicine, the 12 step recovery movement and many others. We use the concept of diffusion specifically to move beyond highlighting the growing multiplicity of recognised diagnostic systems and practices. We wish to also note a dispersal from a concentrated understanding of diagnostic authority as confined to scientific biomedicine to a less concentrated understanding of the intrinsically local practices of grounding and evaluating the world's various approaches to diagnosis. We consider the extent to which, and the specific manner in which, we might not only critique these diverse diagnostic processes but perhaps also sometimes critically appreciate them not in the biomedically orthodox sense of naming generic and ahistorical biomedical pathologies but rather as historically and culturally specific forms of locally evaluated and legitimated health care provision.

The impulse to radically critique modern medicine has deep roots in medical sociology (cf., Ilich, 1976) and remains ubiquitous. Eliot Freidson (1970) was among the first to interpret biomedical claims to possess an epistemologically privileged knowledge of disease as little more than efforts to legitimate medicine's social power. Practitioners of what Michael Bury (1986, p. 140) has called post-Freidsonian medical sociology—that is, symbolic interactionists, feminists, Foucauldians, ethnomethodologists, Marxists and other social constructionists—have elaborated extensively upon this theme. In stark contrast to earlier work, this research often questions the ontological validity of medical categories, suggesting many conditions understood as diseases or disabilities are in fact socially manufactured primarily for sociologically rather than biomedically

discoverable reasons (cf., Busfield, 2017; Conrad, 2007; Conrad & Schneider, 1992). Likewise, the social model of disabilities literature has also influentially highlighted the myriad social, rather than biomedical, challenges suffered by those with putative disabilities (cf., Oliver, 1990; Shakespeare, 2006).

By insisting that the biomedical diagnosis of disease and disability are not innocent of social values, interests and influences, social constructionism radicalised the explanatory promise of medical sociology. More fundamentally, biology—once understood as the universal bedrock upon which the multitude of human cultures is built—has, with the advent of science and technology studies, been recast as diverse forms of socially orchestrated work accomplished across a range of historically evolving social institutions (cf., Fleck, 1979; Fujimura, 1992; Haraway, 1991; Mol, 2002). While indisputably invigorating for many medical sociologists, these initiatives made many others decidedly uncomfortable. Critics of social constructionism have contended that although there are certainly the odd cases of medical over-reach, surely it is absurd to suggest conditions like cancer, diabetes, or heart disease are ‘mere’ social constructions (cf., Bury, 1986; Shakespeare, 2006; Timmermans & Haas, 2008; Turner, 2004; Williams, 2006). Social constructionists have, of course, provided their rejoinders (cf., Atkinson, 1995; Nicolson & McLaughlin, 1987; Weinberg, 2014). But despite long labours at this particular coalface, the field of medical sociology remains demonstratively uncertain about how best to conceptualise the epistemology and ontology of disease, or the relationship between the two (cf., Weinberg, 2021).

These debates raise the challenge of reconciling the critical sociological eye to the immense evidence of biomedical and other successes in the realms of health care. As a critical medical sociologist and disability theorist diagnosed with multiple conditions, physical, neurological and psychological, the first author has had extensive personal experience navigating the interfaces among biomedical diagnoses, their critique and their value in facilitating people’s empowerment and the enhancement of the lives of people living with health problems. Without the many achievements of biomedically informed health care, he would be living at a considerably greater disadvantage than he now is. Equally though, the first author has ample personal experience of the marginalising, disempowering, dehumanising and demoralising ramifications of modern western medicine. In this he is very obviously not alone. The question we have sought to address in this essay, then, is the question of how to epistemologically and ontologically provide simultaneously for: (1) the manifest therapeutic achievements of biomedical and other approaches to diagnosis; (2) the manifest achievements of medical sociology in critiquing and socio-historically situating biomedical and other approaches to diagnosis, and (3) the embodied experience of health and illness and the local social conditions influencing those experiences that we believe should be at the centre of deliberations concerning therapeutic successes and failures. In our view, a consideration of the diffusion of diagnosis and diagnostic authority in and beyond biomedicine provides a particularly illuminating vehicle for addressing these matters effectively.

## SOME HISTORICAL BACKGROUND

The consolidation of epistemic power and the authority to diagnose in the institutions of biomedicine is often said to have begun with the emergence of the clinic in the eighteenth century (Foucault, 1973), to have become widely institutionalised in the nineteenth century (cf., Starr, 2017) and to have reached its zenith by the mid-twentieth century (cf., Freidson, 1970; Starr, 2017; Tremain, 2015). During this period, many assumed this consolidation would only accelerate and intensify with the expansion of ‘objective’ biomedical knowledge (cf., Parsons, 1951;

Scott-Fordsmand, 2021; Stegenga, 2017). However, beginning in the 1960s, the largely unrivalled ascendancy of biomedical approaches to diagnosis in the global west and north has been increasingly disrupted. Though by no means dethroning biomedicine, broad trends in the organisation of health care have conspired to elevate the diagnostic authority of a variety of non-biomedical health care providers including acupuncturists, chiropractors, clinical psychologists, social workers, practitioners of a wide range of alternative or complementary medicines and, last but not least, recipients of health care services themselves (cf., Jutel, 2011). As can be vividly seen in organisations like the 12 step recovery movement, these trends have sometimes even blurred the distinction between service providers and service receivers in general, and between diagnostician and diagnosed in particular (cf., Thornton & Lucas, 2011).

Not only are some patients growing more proactive in their relationships with mainstream biomedical health care providers but they are increasingly organising both online and offline into assorted mutual help and support groups that both lobby for more and better health care services and often provide therapeutic services themselves (cf., Barker, 2008; Brown & Zavestoski, 2005; Lupton, 1997; Maslen & Lupton, 2018; Nettleton, 2004). While some of these groups self-consciously refrain from trespassing on the traditionally biomedical province of diagnosis, many clearly do not (Weinberg, 2005, 2013). These developments are putting increasing pressure on researchers to forsake the image of the sovereign biomedical diagnostician unearthing the biological bedrock underlying our various forms of unwellness and to appreciate not only the diversity and proliferation of both biomedical and other sorts of diagnostic systems and practices but also the intrinsically collective manner in which diagnoses are often actually rendered (cf., Atkinson, 1995; Jutel, 2011; Mairs, 1996; Schneider & Conrad, 1985). In short, the empirical manifestations of health and illness as well as the processes thought to cause them are now understood to assume a much wider variety of both biological and other forms. The epistemological authority to render locally legitimate forms of diagnosis has been diffusing now for several decades. This is widely recognised. However, what has not been given nearly as much attention are the consequences of this diffusion for our understanding of the epistemology and ontology of disease. If we are to abandon a myopic, exclusively and ahistorical biomedical epistemology and ontology of diagnosis with what shall we replace it?

A first step towards answering this question is to more explicitly and precisely scrutinise the diverse ways in which this diffusion has been occurring. The diffusion of diagnosis manifests in a wide variety of ways: the focus of diagnostic discourses and the set of diagnostic practices employed both within and beyond clinical settings are expanding. The International Classification of Diseases (ICD) and the International Classification of Functioning, Disability and Health both issued by the World Health Organization have grown larger to include a wider range of diagnoses (Smart, 2015). This has also been true of successive volumes of the Diagnostic and Statistical Manual of Mental Disorders (DSM) issued by the American Psychiatric Association (cf., Suris et al., 2016). Diagnoses are being increasingly finely delineated: for example, the conditions once formally construed within the DSM through the binary couplet autism disorder and Asperger's syndrome have been reconfigured within the more broadly differentiated and fine grained diagnostic discourse of autism spectrum disorder (cf., Eyal et al., 2010). These processes have also been facilitated by the proliferation of diagnostic nosologies and discussion groups online (cf., Jutel, 2011; Maslen & Lupton, 2018). Such trends are often noted in more expansive critiques of putative over-medicalisation (cf., Conrad, 2007; van Dijk et al., 2016) and suspicion of newer diagnostic categories and discourses (cf., Horwitz & Wakefield, 2007; Stegenga, 2017). However, it is our argument that these critiques of overdiagnosis must be supplemented with a more refined epistemological and ontological appreciation of the local practices according

to which diagnostic systems and practices are evaluated as legitimate or illegitimate under the diverse ethnographic conditions under which this work actually gets done.

Central to the debate regarding the pros and cons of diagnostic diffusion has been the power dynamic exhibited in the relation between lay and expert knowledge of health and illness (cf., Prior, 2003). This dynamic can be traced back to a distinction originally put forward by Aristotle between experiential knowledge and what he called craft. Indeed, Aristotle's distinction has figured centrally in recently influential arguments on diagnosis to be found in disability scholarship and activism (cf., Shakespeare, 2015). Within this model, expertise is characteristic of craft rather than of experience. Craft here means institutionally systematised and sanctioned knowledge acquired through education. Craftspeople are said to be wiser than experienced people on the supposition that wisdom follows from formal knowledge rather than experience. This is because craftspeople are said to know causes, whereas experienced people do not (cf., Aristotle, 2016). Lindsay Prior (2003) in his widely cited discussion of lay expertise makes precisely this form of argument as do many others (Jutel, 2011). The very term 'patient' also reflects this Aristotelian conception. Institutionally trained and legitimised experts are by these lights the agents in the clinical encounter, while those experiencing disruptions to their lives are patients—that is, passive beings acted upon by medical experts. In recent decades this model of knowledge and expertise has been widely challenged by those who argue for a more ethnographically informed epistemological and ontological pluralism or an appreciation of 'situated knowledges' (cf., Haraway, 1991; Longino, 2002; Rouse, 1993, 2002; Weinberg, 2014).

## EPISTEMOLOGICAL AND ONTOLOGICAL PLURALISM IN DIAGNOSIS

Two forms of this epistemological and ontological pluralism are of particular interest to the current discussion. The first is what might be referred to as cross-cultural pluralism. This form of pluralism involves: (1) a recognition that different cultures often embrace very different epistemologies and ontologies of diagnosis and indeed (2) a recognition of the practical integration or hybridisation of knowledges from across cultures. This occurs through translations between diagnostic systems, syntheses of discourses and practices, and critical dialogue between practitioners acting on the basis of differing epistemologies and ontologies (Kleinman, 1978; Watson-Gegeo & Gegeo, 2011). Examples of such cross-cultural epistemological and ontological pluralism in action include the use of acupuncture in the treatment of addiction (Meng, 2019; Meng & Lenhard, 2022) and the use of ayahuasca ritual ceremonies as a form of treatment for post-traumatic stress disorder (Nielson & Megler, 2014). There are many more.

The second form of epistemological and ontological pluralism highlights the virtues of experiential knowledge. It does so by asserting that there are certain insights provided by experiential knowledge that no formal knowledge refined and systematised by formal education can achieve. In one form, this kind of epistemological and ontological pluralism can be found in the direct privileging of the personal knowledge of individual patients with regard to their conditions over what formal diagnostic frameworks would highlight (cf., Carel, 2016; Jutel, 2011). In another form, this kind of epistemic and ontological pluralism can be seen in feminist standpoint theory and the traditions influenced by it. Standpoint theorists have argued that the social structural position of women in society yields a distinctively authoritative understanding not only of the specific forms of suffering and injustice that women must endure but also of the broader structural dynamics that yield those forms of suffering and injustice. A formally trained biologist

herself, Donna Haraway (1991) took standpoint theory beyond the scope of feminist theory to argue all knowledge, including biological knowledge, is 'situated' or emergent and sustained from within specific social contexts. This perspective argues that our socio-historical differences may be sources of objectivity as well as bias, and that knowledge need not take a totalising or universalistic form. Standpoint theorists instead defend pluralistic and situated understandings of knowledge and objectivity while at the same time assiduously avoiding descent into a full-blown and wholly uncritical cultural relativism.

Haraway's approach is certainly culturally relativist if by relativist we mean that assessments of epistemic success and failure must inevitably be made with recourse either to implicit or explicit standards of epistemic value that are themselves historically and culturally specific and contingent. However, this brand of relativism brings about none of the consequences critics have traditionally assumed. It does not foreclose on the possibility of systematically comparing the epistemic value of competing accounts or on the possibility of critically constructive dialogue across lines of cultural, disciplinary, or theoretical difference. Indeed, far from depriving us of the tools necessary for fostering critical and constructive dialogue, a turn from putatively universal biomedical standards of epistemological authority to a systematic ethnographic scrutiny of the local standards undergirding specific diagnostic practices and debates is actually the only realistic means by which we might find those tools (Weinberg, 2014).

Nancy Mairs (1996) has elaborated on Haraway's conception of situated knowledge to theorise what she calls 'sitpoint' knowledge as an extension of standpoint theory more appropriate to disability theory. Beyond the mere deconstruction of the ableistic connotations of *standpoint* theory, Mairs' elaboration posits that situated knowledges stem not only from aspects of one's social structural positions but also the specificities of one's corporeality or embodiment (see also Leder, 1990). Mairs' analysis includes the idea that sitpoint knowledge emerges from an often complex combination of social structural and embodied or otherwise intrapersonal influences. However, her work squarely foregrounds the experiential knowledge of disability. The theoretical specification of sitpoint knowledge is particularly applicable to understanding the experiences of those personally engaged in and with practices of diagnosis.

Much ethnographic research has shown that many experienced conditions are not well captured by the diagnostic devices of biomedicine. Examples include fibromyalgia, chronic fatigue syndrome and borderline personality disorder (cf., Whynacht, 2018). Though such conditions are often formally acknowledged in the mainstream medical literature (cf., Bellato et al., 2012; Bradley et al., 2005), perceived deficiencies of biomedical diagnostic procedures have led to epistemic contestation between patients and biomedical experts, particularly in clinical settings (Jutel, 2011). More generally, the diffusion of diagnosis has drastically increased the frequency and intensity of such contestation, as patients have grown increasingly confident in their own understandings of their conditions and have come to resist the privileging of biomedical knowledge over their own experiential knowledge (Shakespeare, 2015).

Beyond the details of people's biographies, standpoint theory, including Mairs' work, is fundamentally concerned with the collectively orchestrated production of situated knowledges within communities of practice—sharing stories, modes of communication, struggles, and other aspects of experience. Friedner and Kusters (2015) conceptualised communities of those with related conditions and/or diagnoses as distinctly epistemically productive. Examples of such communities include organised groups comprised of people with deafness, cancers, or addictions. The diagnostic practices emergent from these communities constitute some of the most vivid examples of the diffusion of diagnosis. In an ethnographic study of a state-sponsored residential therapeutic community in California dedicated to the treatment of mental health problems, Weinberg (2013)



showed one kind of diagnostic practice that can emerge from experiential knowledge. This case, among many others, invites us to reconceptualise diagnosis as a type of collective action, and as an ongoing project. Weinberg (2013, p. 68) discovered that ‘the lion’s share of therapeutic work was done in and as the collective life of the community. Rather than being confined to a technical procedure, or a generic formally specified set of diagnostic categories and criteria for their application, diagnosis at Canyon House was usually orchestrated collectively as a process of identifying one another’s “issues”, or patterns of dysfunctional behaviour, in and through the mundane details of living together as a community’.

This collective diagnostic action combined experiential knowledge with formally institutionalised biomedical knowledge. It is worth quoting from that paper at length:

There was...a priority placed on holistic and individualised efforts to foster tenable community living over psychiatric improvement more narrowly conceived. There also was a priority placed on client empowerment (both in dictating what in their lives merited clinical attention and in contributing to the recovery of their peers) over deference to the clinical judgements of bio-psychiatrists. Despite these priorities however, clinical work at Canyon House remained unequivocally cast as a form of treatment for discrete mental illnesses. If funding agencies had not seen Canyon House to be providing credible and effective mental health care to people suffering from genuine mental illnesses, there would have been no possibility of garnering public funding for it. As a result of this fusion of a very broad, democratically orchestrated and individualised focus on fostering tenability with the resolute insistence that this work was a proven form of clinical treatment for mental illnesses, mental illnesses came to be viewed at Canyon House as diseases that 1) take a wide variety of forms depending on the personal characteristics and circumstances of those said to suffer from them, and 2) exert their influences in a variety of idiosyncratic ways but always so as to strain the tenability of a resident’s membership in either the program’s therapeutic community or their communities at large.

(Weinberg, 2013, p. 75)

Clearly, Canyon House was not an orthodox biomedical treatment programme. However, the programme can be understood as at least a kind of extension of the institutions of biomedicine insofar as it was specifically state mandated and funded to enact projects of healing from genuine mental illnesses. Therefore, while the programme cannot be viewed as ‘clinical’ in the strict Foucauldian sense of an institution in which patients are treated as docile objects (Scott-Fordsmand, 2021) of authoritative biomedical consideration, it should nonetheless be understood as a state sponsored, medically authorised mental health care programme. The diffusion of diagnosis, however, has expanded the scope of diagnostic practice even further. The setting Weinberg studied is one formed for the explicit purpose of therapeutically engaging with mental disease. However, the diffusion of diagnosis has in fact reached a threshold of breadth in which forms of diagnostic practice that could be considered rigorous and disciplined by standards rooted in Mairs’ sitpoint knowledge are now focused less on the identification of disease or disability and more on situated identifications of personal growth. Analysing such examples is therefore useful to mapping out the scope of the diffusion of diagnosis more fully.

A valuable case in point can be found in the uses made by people with disabilities of sci-fi fantasy culture. The participation of people with disabilities in various forms of sci-fi fantasy culture, that is, the culture of science fiction and fantasy literature fandom, video game fandom

and science fiction and fantasy role play, has been well documented (cf., Anderson, 2019; McGonigal, 2015; Pearce, 2009). Barth (2022) shows how distinct forms of identity work that respond to the biographical disruption of disease and diagnosis occur as integral facets of such participation. Just as Weinberg describes in Canyon House, this form of diagnostic practice can be understood as a form of collective action. Unlike Canyon House, however, the diagnostic identity work that Barth describes did not involve mutual observation over a long period of time, and also does not involve any direct participation by formal medical actors. Instead, in this sci-fi fantasy context Barth illuminates ways in which playful (Pearce, 2009) worldmaking practices (Goodman, 1978; Kleinman, 1978) that evoke the fantastic permit a kind of intense, concentrated, radically pluralistic exchange of insights concerning even the most profound and particular nuances of diagnosed conditions and their effects on lived experience. In particular, these exchanges occurred in the context of meetups, where people have the opportunity to articulate their conditions and evoke diagnostic labels in ways that would probably be considered dubious in settings where formal biomedical hegemony holds sway. For instance, consider the following radically alternative understanding of their diagnosis of Dissociative Identity Disorder (DID) offered by one of Barth's research subjects:

Artemis explained that they were a member of a hive, which they further explain is the term they employ to identify their total selves within their conditionality of Dissociative Identity Disorder (DID). In a conversation held with them ... they provided an explanation of that conditionality. ... Artemis shared: "... You have memories sometimes of experiencing trauma in certain ways, and seeing someone in your life or more often in some form of media who you just feel in your gut, who wouldn't be powerless in the face of the trauma you're experiencing. Either because they wouldn't be vulnerable to it, or because they would be able to get away from the trauma or fight it, overcome it, defeat it, protect against it, and then the thought of wanting to be that way just gets interjected into every other thought you're thinking".

(Barth, 2022, p. 15)

Following this line of thought, they reconceptualised their diagnosed condition of DID as a label for what they view as a valid coping strategy in response to severe trauma rather than a disease in need of curative treatment. Another person describes the role of sci-fi fantasy culture in the process of reaching an autism diagnosis:

For my entire childhood, everybody just thought of me as obsessive. My parents used to accuse me constantly of being scared of the world, becoming fixated on the world and structures of fantasy characters like the ones at this convention as a way of coping with my anxiety. I hate the word 'obsession'—it has become such a pejorative. It means stuck, spinning around an imaginary world like a broken record, and that's the thing, this place where we are, this group, this convention, is that hidden world, we're all here. They'd call all of us obsessed, and this, this is real and I only figured that out once I read that article and figured out that that was what was going on inside my mind, that was how I was able to get on the right medication and start using the right therapy.

(Barth, 2022, p. 16)

Examples like these illuminate a pronounced contrast between diagnostic practice in formally institutionalised medical contexts and diagnostic practice based on personal experience and



dialogue in more epistemically and ontologically pluralistic contexts, such as those emergent in sci-fi fantasy culture. Another person explicitly discussed this contrast when she said:

...In the medical world, they're just making sure you're taking care. They're saying, 'Okay, this is what you're dealing with. This is how we're gonna treat it.' And it's not. It's not. And it's a 'I'm taking care of this as a doctor' way, rather than, at the con[vention], it's, 'I feel what you're feeling. I get what you're feeling.' More of an empathy way...

(Barth, 2022, p. 16)

This description resonates with Mairs' assertion that experiential synergies enable feats of empathy, which are perhaps impossible where those synergies do not exist. The diffusion of diagnosis to forms such as those described here can therefore be seen as having enabled the use of knowledge resulting from such empathy in diagnostic processes that would have been difficult to imagine if diagnostic practice remained confined within orthodox biomedicine. A parable well-known in the 12 step recovery movement also illustrates the point. It speaks of a man trapped in a pit continuously yelling for someone to throw him a rope. Eventually his cries for help result in another man jumping down into the pit with him. He asks the man 'Why didn't you just throw me a rope? Now we're both trapped'. To which the man replies, 'No we're not. I've been in this pit before and I know a way out'. This parable speaks to another ubiquitous way in which empathetic knowledge can be a genuinely therapeutic resource. The rope is here cast as a kind of technical but impersonal resource of the kind provided by orthodox biomedicine whereas the help actually offered is less obviously technical and much more obviously empathetic. Likewise, diagnosis is here to be understood less in terms of martialling generic institutionally authorised diagnostic categories and more in terms of empathetically identifying the particular therapeutic challenges faced by particular people (cf., Weinberg, 2022). It is, in other words, a matter of effectively saying, 'I can see the nature of the trouble you're up against'.

But even in more formal contexts, this diffusive expansion of the scope of therapeutically authoritative judgement has begun to invite a reframing of diagnosis as not only concerned with dysfunction, disorder, disease, deficiency, damage and disability but also with talent, ability, and proficiency. Hackmann et al. (2019) undertook the first study of organised formal engagement with diagnosed populations in the authorship of a diagnostic compendium, specifically, the ICD. Their findings demonstrate the inclusion of sitpoint epistemologies that, among other things, highlight facets of positive empowerment. For example, with regard to a diagnosis like autism, there are the widely recognised positive associations with certain kinds of savantism (Straus, 2014). Even more common are the positive associations with dyslexia (von Károlyi et al., 2003). Regardless of the rarity or diversity of posited positive facets of experienced diagnosed conditions, these kinds of practices nonetheless help us to better understand the diffusion of diagnosis more fully than would an exclusive focus on disability.

Hackmann et al.'s (2019, p. 9) suggestions for promoting accountability to this more expansive range of possible diagnostic meaning can be understood as a call to more actively encourage multidirectionality of communication in response to the diffusion of diagnosis:

One future direction is to coproduce with service users, carers and clinicians shared summaries of the diagnostic features and related phenomena for collaborative use by clinicians and service users. This could offer a shared language that captures additional aspects of lived experience, avoids medical terminology, provides lay

understanding of the operational features and enriches these features with the underlying felt-experience...this could encourage a reciprocal and collaborative diagnostic process and sharing of power between clinicians and service users. There is evidence that this facilitates rapport and engagement, and may support recovery. Coproduced shared summaries could also allow greater elaboration of contextually situated lived and felt-experience and the local language and idioms used to describe MH phenomena. These shared summaries could also be used for public engagement, health education and clinical training.

(Hackmann et al., 2019, p. 9)

Despite its promise of greater inclusion and empathy, an analysis of the diffusion of diagnosis cannot neglect to acknowledge potential problems and risks. Too often the growth of pluralism is celebrated rather uncritically as simply the expansion of tolerance and/or respect for the other and the genuine risks involved are sometimes overlooked or downplayed. But particularly in would be therapeutic contexts these risks are numerous and often complex, as when they involve articulating reasonably rigorous standards by which to combine attention to liberal principles of patient autonomy and self-determination with a simultaneous recognition of people's disabilities and genuine needs for special assistance and care (cf., Redley & Weinberg, 2007). If the diffusion of diagnostic practice is not subject to regulation with respect to such standards, this can lead to profound lapses from adequate care—that is, neglect or incompetent treatment of genuinely harmful conditions. For example, an uncritical epistemological pluralism has often been seen to foster anti-vaxer beliefs (Raffini & Penalva-Verdú, 2022). Further rhetorics advocating epistemic pluralism are often invoked to legitimise harmful pseudo-scientific treatment practices, intensifying the risk of predatory, fraudulent and exploitative money-making schemes offering 'miracle cures'. For example, Solomon (2018) describes a kind of abuse of epistemic pluralism taking place in scientifically fraudulent stem cell clinics promising supposed miracle cures for a wide variety of conditions, many of which have never been empirically studied, let alone validated.

Further, just as the limits of collective sitpoint knowledge must be acknowledged, especially those related to diagnosis, the limits of personal or autobiographical knowledge must also be acknowledged. As we have seen, self-knowledge has distinct potencies with respect to diagnosis and health care. However, this can be taken too far. For example, if someone comes to feel they have some form of ocular visual impairment, when they actually have a cortical visual impairment, their self-knowledge (potentially reinforced by collectively generated, socially constructed sitpoint knowledge concerning ocular impairment) could be hazardous. It could lead them to employ ineffective methods of compensation, seek the wrong kinds of pedagogical or occupational accommodations, and the wrong kinds of therapeutic treatment. Whether formally in the contexts of biomedical institutions or otherwise, it is imperative that diagnosticians engage the processes of epistemic sensemaking *critically* and with due regard for its risks. An ethnographic articulation of how such standards of evaluation emerge and are applied in specific empirical contexts presents a very promising path forward.

The ethnographic contexts of diagnostic diffusion discussed above all exhibited their own distinctive approaches to the situated evaluation of epistemic legitimacy and illegitimacy and were plainly not vulnerable to a charge of uncritical pluralism or unbridled relativism. Likewise, Watson-Gegeo and Gegeo (2011) explicitly describe ways in which epistemological and ontological pluralism with respect to diagnosis can and often does acknowledge limitations of indigenous knowledge without necessarily subordinating it to biomedical knowledge. They describe how their research subjects who enacted indigenous diagnostic practices also respected

the prospective relevance of formal biomedical knowledge especially where safety is a paramount concern. In his specification of diagnosis as collective action, Weinberg (2013) maintains that formal biomedical knowledge and formally trained biomedical actors remained an important, if not dominant, part of the diagnostic melange at Canyon House. The maintenance of epistemic standards is even evident in the radically non-biomedical setting studied by Barth (2022). Even as Barth describes the wide range of epistemic positions permitted, indeed actively fostered, by the playful nature of the sci-fi fantasy cultural context, he describes how the very recognition of its roots in play pervades the consciousness of most participants. Barth argues this awareness ensures that these forms of diagnostic processes are not treated as either subordinate to biomedical knowledge nor as a warrant for the rejection of biomedical advice, but much more conscientiously as a rich, valuable supplement to biomedical knowledge and advice, though importantly an often subversive one. For their part, Hackmann et al. (2019) insist on persisting in the use of diagnostic compendia like the ICD in medical practice, despite its frequent failure to resonate with many facets of their research subjects' lived experience. Each of these examples of diagnostic diffusion exhibit an adherence to locally legitimate epistemic standards as well as an openness to alternatives without thereby descending into an uncritical celebration of epistemological and ontological pluralism for its own sake.

## CONCLUDING REMARKS

We have argued that there is presently a tension in medical sociology between, on the one hand, taking biomedical diagnoses seriously as ahistorical and epistemologically sovereign identifiers of objective, or ontologically real, biomedical pathologies and, on the other hand, a social constructionism that highlights historical specificity, provisionality and the economic, political and cultural forms of power that govern diagnostic practice. Orthodox biomedical invocations of a biological bedrock undergirding all human health and disease categorically privilege biomedicine and reduce alternatives to it to an at best second rate epistemological status and often to the status of quackery (Cant & Sharma, 1999). In this way, Ayurvedic medicine, traditional Chinese medicine, the 12 step recovery movement and other well-established approaches to diagnosis tend to be summarily dismissed on the all too ethnocentric grounds that they do not square with our own current biomedical understandings.

Needless to say, this orthodoxy systematically forecloses from the outset on our capacity to understand and evaluate the therapeutic efficacy of these approaches on their own terms and with respect to the specific standards of judgement by which these systems and practices are ontologically grounded and epistemologically evaluated locally. Equally, however, substituting for biomedical orthodoxy a sociological regard for what Conrad (2005) has called the engines of medicalisation, while usefully foregrounding some of the important social causes of diagnostic practice, tends also to background specifically therapeutic considerations and attention to the standards of judgement by which these considerations are ontologically grounded and epistemologically evaluated locally. Too often this results in a tendency to emphasise the illegitimacy of diagnostic practices, over-medicalisation, or what Payer (1992) once called 'disease mongering' and an underemphasis of the diversity of ways in which therapeutic efficacy is fostered and critically evaluated locally. In place of the antinomy between biomedical orthodoxy and social constructionism we have therefore recommended an ethnographic regard for the standards of practice by which critical judgements are made as to therapeutic efficacy locally both by biomedical practitioners and other diagnosticians. As we have argued, this by no means entails

an uncritical celebration of diagnostic pluralism for its own sake. Rather than remaining content with an uncritical or radically relativist tolerance of ethnographic differences in diagnostic practice, we have emphasised the possibility of critical dialogue between diagnostic systems and hybrid approaches to diagnostic and therapeutic work.

Our position here is entirely in line with the incisive arguments put forth in this regard by philosopher of science Joseph Rouse. For example, building on Foucault's critique of the widespread tendency in western political theory to conceive of power as sovereignty, Rouse (2005) notes an unfortunately analogous tendency in much mainstream western epistemology to cast epistemology in the exaggerated imagery of sovereignty. Foucault insisted attention be given to the multitude of micro-political struggles that yield sovereigns as 'terminal forms' (Foucault, 1978, p. 92), and serve as the historically specific networks within which sovereignty is either sustained or falters. In short, for Foucault, actually existing power is never as universally honoured, uncontested or absolute as western political theorists of power have sometimes seemed to suggest. Similarly, Rouse argues that the western epistemological tradition has too often cast the epistemologist as a kind of monarch, magisterially positioned entirely above the fray and from which s/he is uniquely disposed to legitimately adjudicate the disputes of those over whom s/he rules. But as Rouse (1993, p. 17) argues:

The turn to non-sovereign epistemological dynamics does not replace argument or a concern for truth with power and domination, even while insisting that argument and claims to knowledge are never politically innocent. The contested circulation of opposing knowledges, which cannot be consistently combined into a unitary framework of propositions, is a struggle for truth. Truth matters. Precisely because it matters, truth is often fiercely contested. And if we cannot stand outside that contest to assess it from a neutral standpoint, this does not mean that all claims to truth can be put forward on an equal basis. Knowledge claims are historically, socially and materially situated in contexts which govern what can be intelligibly and seriously asserted, and how much or what kind of argument is necessary to support it. But such epistemic contexts are always in flux; their boundaries and configurations are continually challenged and partially reconstructed, as epistemic alignments shift.

It is precisely in embracing what Rouse here calls 'non-sovereign epistemological dynamics', that we make a case for what we have called epistemological humility in understanding the diffusion of diagnosis. We have used the concept diffusion of diagnosis precisely to highlight that the growing recognition of a profusion of locally legitimate diagnostic systems and practices throws into question how we might, without recourse to a putatively primordial biological bedrock to human health and pathology (or what Rouse might call an epistemologically sovereign orientation to biomedicine), ontologically ground and epistemologically evaluate these systems and practices. The concept of diffusion has been chosen as an organising principle for our argument because above and beyond highlighting the multiplicity of recognised diagnostic systems and practices it also highlights that these diverse practices, by exhibiting thriving alternatives to biomedical orthodoxy, inherently foster a move from an epistemologically sovereign understanding of biomedicine to a more ethnographically informed appreciation for non-sovereign epistemological dynamics in the realms of diagnostics and therapy. Importantly, our approach also facilitates more inclusive, mutually attentive and mutually respectful dialogue among health care providers, patients, health care movements and academics by explicitly acknowledging that none of us has an a priori sovereign entitlement to epistemological authority. To the extent our claims

to epistemological (or ontological) authority are honoured they must continue to be successfully defended across the many different epistemological and ontological contexts within which these matters are adjudicated in any particular case.

By meticulously unpacking and clearly articulating the kinds of situated, emergent principles and standards observable in examples like the ones discussed in this essay, it is possible to navigate between, on the one hand, the Scylla of an Aristotelian exaltation of craft and formal training over experiential and situated knowledges and, on the other hand, the Charybdis of an unregulated, uncritical and profoundly hazardous embrace of infinite epistemological and ontological diversity. This kind of ethnographic attention to locally honoured critical standards and practices of diagnosis will no doubt require its own pluralism and will no doubt evolve. The lines between empowering and disempowering, practical and impractical, warrantably therapeutic and unwarrantably risky or dangerous forms of diagnosis and treatment are multiple and will continue to shift in response to a range of variables. Hence, we would like to conclude by contending that the continued ethnographic exploration of local techniques for evaluating diagnostic validity and therapeutic efficacy should become a core component of how we understand and implement the sociology of diagnosis.

### AUTHOR CONTRIBUTIONS

**Yishai Barth:** Conceptualisation; data curation; investigation; writing—original draft; writing—review and editing. **Darin Weinberg:** Conceptualisation; data curation; investigation; writing—original draft; writing—review and editing.

### DATA AVAILABILITY STATEMENT

Data sharing is not applicable to this article as no new data were created or analyzed in this study.

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### ENDNOTE

<sup>1</sup> For those unfamiliar with the terms epistemological and ontological, they refer to the branches of philosophy concerned, respectively, with what we know and how we know it, epistemology, and what exists or is there to be known in the first place, or ontology. Because it is our view that answers to ontological questions must inevitably implicate epistemological considerations, we write of the epistemological and ontological opportunities and challenges of taking the diffusion of diagnosis seriously in close proximity. Our argument is that reasonably determining what is ontologically real cannot be divorced from our particular epistemological techniques of knowledge acquisition and evaluation.

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**How to cite this article:** Barth, Y., & Weinberg, D. (2023). The diffusion of diagnosis and its implications for the epistemology and ontology of disease. *Sociology of Health & Illness*, 1–16. <https://doi.org/10.1111/1467-9566.13720>