Epistemic Injustice and Illness Bibliography

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   a. Chronic fatigue syndrome or myalgic encephalomyelitis (CFS/ME) remains a controversial illness category. This paper surveys the state of knowledge and attitudes about this illness and proposes that epistemic concerns about the testimonial credibility of patients can be articulated using Miranda Fricker's concept of epistemic injustice. While there is consensus within mainstream medical guidelines that there is no known cause of CFS/ME, there is continued debate about how best to conceive of CFS/ME, including disagreement about how to interpret clinical studies of treatments. Against this background, robust qualitative and quantitative research from a range of countries has found that many doctors (and medical students) display uncertainty about whether CFS/ME is real, which may result in delays in diagnosis and treatment for patients. Strikingly, qualitative research evinces that patients with CFS/ME often experience suspicion by healthcare professionals, and many patients vocally oppose the effectiveness, and the conceptualisation, of their illness as psychologically treatable. We address the intersection of these issues and healthcare ethics, and claim that this state of affairs can be explained as a case of epistemic injustice (2007). We find evidence that healthcare consultations are fora where patients with CFS/ME may be particularly vulnerable to epistemic injustice. We argue that the (often unintentional) marginalisation of many patients is a professional failure that may lead to further ethical and practical consequences both for progressive research into CFS/ME, and for ethical care and delivery of current treatments among individuals suffering from this debilitating illness.

   a. How do we listen to children? How do we decide whether we believe a story relayed to us by a child? We don't often reflect on our listening practices, which can rely on unrecognised presuppositions. This issue is particularly important when listening to patients: how do we decide what level of credibility to assign to testimonies and interpretations offered by children? We suggest that a philosophical framework can encourage reflection on this important, yet neglected, topic.

   a. In this paper we argue that ill persons can experience epistemic injustice in the sense articulated by Miranda Fricker (2007). Ill persons can suffer testimonial injustice through the presumptive attribution of characteristics like cognitive unreliability and emotional instability that downgrade the credibility of their testimonies. Ill persons can also suffer hermeneutical injustice because many aspects of the experience of illness are difficult to understand and communicate and this often owes to gaps in collective hermeneutical resources. We then argue that epistemic injustice arises in part
owing to the epistemic privilege enjoyed by the practitioners and institutions of contemporary healthcare services – the former owing to their training, expertise, and third-person psychology, and the latter owing to their implicit privileging of certain styles of articulating and evidencing testimonies in ways that marginalise ill persons. We suggest that a phenomenological toolkit may be part of an effort to ameliorate epistemic injustice. Keywords epistemic injustice, illness, patient experience, phenomenology, patient toolkit

   a. This chapter explores the relation of epistemic injustice to medicine and healthcare as they arise from epistemic asymmetries and differential power relations. Healthcare systems rely on complex structures of epistemic norms and expectations, both implicit and explicit, that create knowledge asymmetries—for instance, privileging the knowledge derived from medical training and theory, rather than that potentially rooted in patient experience, which effectively limiting epistemic authority to healthcare practitioners

   a. People who endure mental and emotional distress experience a plethora of negative experiences beyond the effects of the symptoms themselves. For centuries, the designation of labels of difference; that is, those which transgress approved social norms, have affected the lived experiences of those individuals, and more widely in structuring responses, engagements with, and attitudes between society and the individual. Understanding the creation of tainted identities, particularly of those with experience of mental and emotional distress have been well rehearsed in the sociological literature of the second half of the twentieth century. Central to much of this analysis has been to understand the nature of the manufacture of deviant identities, how they are sustained and the impact of these identities on those who experience them. This paper explores the experience of those with mental and emotional distress as a victim of crime. The interconnectedness of matters of identity created though the application of a diagnosis of illness/disorder is addressed as is the crisis of criminal victimisation. This is achieved via an exploration of contemporary concerns surrounding victims of crime with experience of mental and emotional distress, including the (further) loss of voice and agency when interfacing with agencies of the State.

   a. Epistemic injustice is a harm done to a person in their capacity as an epistemic subject (a knower, a reasoner, a questioner) by undermining her capacity to engage in epistemic practices such as giving knowledge to others (testifying) or making sense of one’s experiences (interpreting). It has been argued that those who suffer from medical conditions are more vulnerable to epistemic injustice than the healthy. This paper claims that people with mental disorders are even more vulnerable to epistemic injustice than those with somatic illnesses. Two kinds of contributory factors for epistemic injustice in psychiatric patients are outlined: global and specific. Some
suggestions are made to counteract the effects of these contributory factors, for instance we suggest that physicians should participate in groups where the subjective experience of patients is explored, and learn to become more aware of their own unconscious prejudices towards psychiatric patients.

   a. In this essay, I argue that certain injustices faced by mentally disabled persons are epistemic injustices by drawing upon epistemic injustice literature, especially as it is developed by Miranda Fricker. First, I explain the terminology and arguments developed by Fricker, Gaile Pohlhaus, Jr., and Kristie Dotson that are useful in theorizing epistemic injustices against mentally disabled people. Second, I consider some specific cases of epistemic injustice to which mentally disabled persons are subject. Third, I turn to a discussion of severely mentally disabled persons who, because they are unable to share information or develop interpretations of shared social experiences, may fall outside Fricker’s discussion of epistemic injustice. Fourth and finally, following arguments given by Kristie Dotson and Christopher Hookway, I define and explain a type of epistemic injustice: intimate hermeneutical injustice that I believe supplements other discussions of epistemic injustice.

   a. In her book, *Transformative Experience*, [L.A.] Paul endorses an ideal of authenticity: as well as being rational, she says, our choices should make sense to us from our own ‘first personal points of view’. I argue for some important connections between social power and ideals of authenticity, with a particular focus on the connections between ideals of authenticity and hermeneutic injustice.

   a. This paper demonstrates how the problematic kinds of epistemic power that physicians have can diminish the epistemic privilege that pregnant women have over their bodies and can put them in a state of epistemic powerlessness. This result, I argue, constitutes an epistemic injustice for many pregnant women. A reconsideration of how we understand and care for pregnant women and of the physician-patient relationship can provide us with a valuable context and starting point for helping to alleviate the knowledge/power problems that are symptomatic of the current system and structure of medicine. I suggest that we can begin to confront this kind of injustice if medicine adopts a more phenomenological understanding of bodies and if physicians and patients – in this case, pregnant women – become what I call ‘epistemic peers’.

This chapter is about narrative approaches to end-of-life wishes. Following an initial discussion of last wishes and plans as affected by cultural differences, pain, and the biochemistry of advanced disease, the chapter covers three main areas. First, it provides a general flavour of the narrative dimensions of illness and care through key themes from the literature on illness narratives. Second, it turns to definitions and distinctions that have been drawn between the terms ‘narrative’ and ‘story’, focusing upon speech act theory as one approach to understanding the complex relationships between what is said, its meaning, and effects. Finally, the chapter draw upon ideas from the palliative care concept of ‘total pain’ to highlight the limits of empathic understanding in situations of suffering and the importance of recognizing how narrative research with dying people can affect the researcher.

   
a. Part one contains chapters exploring the core concepts of epistemic injustice. Part five contains chapters with applied case studies of epistemic injustice in medicine and healthcare (by Carel and Kidd) and mental illness (Tasia Scrutton). Several other chapters will be of interest to those interested in epistemic injustice and illness—for instance, there are chapters on intersectionality, Foucault, and so on.

   
a. This paper analyses the phenomenon of epistemic injustice within contemporary healthcare. We begin by detailing the persistent complaints patients make about their testimonial frustration and hermeneutical marginalization, and the negative impact this has on their care. We offer an epistemic analysis of this problem using Miranda Fricker’s account of epistemic injustice. We detail two types of epistemic injustice, testimonial and hermeneutical, and identify the negative stereotypes and structural features of modern healthcare practices that generate them. We claim that these stereotypes and structural features render ill persons especially vulnerable to these two types of epistemic injustice. We end by proposing five avenues for further work on epistemic injustice in healthcare.

   
a. Delusions are one of the most elusive concepts in psychiatry. There have been several theories on the nature and definition of delusions. Jaspers described them as entailing a total transformation of reality and considered primary delusions as un-understandable. When it comes to clinical practice, psychiatrists resort to criteria of falsity, incorrigibility, conviction and being out of keeping with the person’s culture. All these criteria have been subject to various criticisms, some of which will be discussed in the paper. We will use the concept of epistemic injustice to explore the role of stereotypes and prejudice in the identification of delusions. We will discuss cases where patients are suffering from testimonial injustice by virtue of having a mental disorder that is so often associated with attributions of irrationality, bizarreness and incomprehensibility. Two vignettes will be presented to show that this is often the case in clinical practice. We will discuss relevant issues
around the epistemology of the delusions. We think that in order to challenge the testimonial injustice, there needs to be an awareness of its possibility and thus recognition of the role of certain stereotypes in assessing these mental states. Challenging the stigma against mentally ill and adopting a holistic view of delusions can help tackle the prejudice that pre-empt the testimonial injustice.

   a. Miranda Fricker’s concept of epistemic injustice has been quite a novel idea in epistemology. The application of the concept in the context of mental health is less explored. Here, we aim to apply the concept of epistemic injustice in attributing responsibility to patients with borderline personality disorder. We will focus on patients suffering from borderline personality disorder. We provide a case vignette to show a tendency in the professionals in holding these patients responsible for their action when it can be argued otherwise. We argue that prejudice against the patient with borderline personality disorder where the person is seen as manipulative plays a significant role in the process of epistemic injustice. The suggested manipulative nature of patients with borderline personality disorder leads to professionals to ascribe agency and knowledge where it is not due.


   a. The process of medicalization has been analyzed in the medical humanities with disapprobation, with much emphasis placed on its ability to reinforce existing social power structures to ill effect. While true, this is an incomplete picture of medicalization. I argue that medicalization can both reinforce and disrupt existing social hierarchies within the clinic and outside of it, to ill or good effect. We must attend to how this takes place locally and globally lest we misunderstand how medicalization mediates power and justice. I provide concrete examples of how this occurs by considering dysesthesia ethiopsis, autism, chronic fatigue syndrome, depression, and HIV/AIDS.

17. Reiheld, Alison, ‘What you don’t know can hurt you: Epistemic injustice and conceptually impoverished health promotion’, talk given at the IAB World Congress of Bioethics, 13 June 2016.
   a. This paper considers a particular kind of wrong within medicine and health promotion: epistemic injustice and its harms. My case study is obesity conceived of as a public health concern. However, the analytic framework I deploy may prove useful in ethically assessing many health promotion campaigns. Individuals—both doctors and patients—are often provided with an impoverished set of conceptual tools for making sense of health and health behaviors, a set of tools that can lead to inappropriate individualization of responsibility and to unproductive attitudes towards health and which behaviors are health promoting. This is the case with obesity. Public health campaigns and clinical care of obese persons rely on a family of simplistic
reductions. The first reduction is that body size correlates reliably with health: witness the use of Body Mass Index (BMI) to diagnose obesity, and the medicalization of obesity as not just a risk condition but a disease in its own right. In June of 2013, the American Medical Association’s House of Delegates endorsed the notion of obesity as a disease defined primarily by BMI, joining the World Health Organization (WHO), U.S. Food and Drug Administration (FDA), and the U.S. National Institutes of Health (NIH). In the International Classification of Diseases (ICD-10), cases of obesity which are not caused by metabolic disorders or pharmaceuticals are classified as ‘hyperalimentation’: overeating. This brings us to the second reduction in the conceptual toolkit available to doctors and patients: that obesity is caused by over-eating, and weight gain/loss is a simple calories-in-calories-out equation. This etiology shows up in public health campaigns, in the clinical recommendation that patients eat better and get more exercise, and in the widespread use of dieting in Western culture. By focusing on body size as a measure of health, and on calories-in-calories-out as both an explanation and a treatment for obesity, these two reductions create a third: the locus of responsibility for obesity falls upon the individual rather than on systemic features contributing to ill health. Consider, in the U.S., Michelle Obama’s ‘Let’s Move!’ campaign which takes little or no account of factors in the built environment which make it dangerous to exercise in many neighborhoods due to crime or traffic and which place residential areas often quite distant from workplaces and necessary errands, thus disincentivizing foot travel. ‘Let’s Move!’ explicitly aims to ‘solve’ the epidemic of childhood obesity within a generation. While it includes discussion of healthy foods in schools—an environmental factor—it also explicitly address ‘healthy moms’ and ‘healthy families’ thereby placing responsibility for health disproportionately onto women and individual family units, much as the framing of obesity places individual responsibility onto fat adults generally. A fourth form of reductivism is well-documented in physician diagnosis of fat patients’ ills as originating in fatness, such that fat patients with joint pain will be met with directions to lose weight rather than, say, a consideration of rheumatoid arthritis or a recommendation for physical therapy. This contributes to misdiagnosis and undertreatment. By providing clinicians, patients, and the general public with reductive frameworks, public health campaigns foster several forms of epistemic injustice. The first of these is hermeneutic injustice. As described by Miranda Fricker, this occurs when a knower is harmed because she lacks the toolset to make sense of her lived experience. It may be that, while both doctors and patients can be impoverished, power relations mean that only patients truly suffer injustice from insufficient toolsets. This is especially the case with dominant frameworks about obesity which foster a calories-in-calories-out reductivism, leading to widespread failure of weight loss regimes, and to damaging assertions of individual responsibility. Interwoven with this is unjustified skepticism about patient testimony that contradicts simplistic conceptual frameworks. So entrenched are these reductions that physicians who see that patients have not lost weight often presume they have been non-compliant, and that fat patients who claim to eat well and exercise must be lying. Indeed, adjectives American doctors most associate with fatness include ‘noncompliant’ and ‘lazy’. Fricker calls this form of epistemic injustice
these physician-patient interactions. Only once we both perceive and understand these interactions as unjust can we repair the physician-patient relationship and deliver better patient care for members of stigmatized groups.

   a. The first part of this chapter looks at epistemic injustices that can take place in the context of psychiatric diagnosis and treatment. I argue people diagnosed with mental illnesses are often stereotyped in such a way as to deflate their credibility, and that the authoritative and even exclusive status accorded to third-person, medical perspectives on experiences of mental illness leads to hermeneutical marginalization and silencing. The second part of the chapter takes as its starting-point the idea that epistemic injustice can be countered by a recognition of the ways in which the marginalized person is in fact epistemically privileged. I argue that recognizing the ways in which people diagnosed with mental illnesses have access to distinctive and/or unique forms of knowledge can correct our testimonial sensibilities and provide us with new hermeneutical resources, and is therefore a route to epistemic justice. I explore ways in which this might be the case in relation to experiences of mental illness, focusing on two kinds of knowledge: knowledge of what the experience is like, and knowledge of what is good for the person. I conclude with some implications for clinical practice and more general ethical behaviour.

   a. Many critics of medicalization (the process by which phenomena become candidates for medical definition, explanation and treatment) express concern that the process privileges individualised, biologically-grounded interpretations of medicalized phenomena, inhibiting understanding and communication of aspects of those phenomena that are less relevant to their biomedical modelling. I suggest that this line of critique views medicalization as a hermeneutical injustice – a form of epistemic injustice that prevents people having the hermeneutical resources available to interpret and communicate significant areas of their experience. Interpreting the critiques in this fashion shows they frequently fail because they: neglect the ways in which medicalization may not obscure, but rather illuminate, individuals’ experiences; and neglect the testimony of those experiencing first-hand medicalized problems, thus may be guilty of perpetrating testimonial injustice. However, I suggest that such arguments are valuable insofar as they highlight the unwarranted epistemic privilege frequently afforded to medical institutions and medicalized models of phenomena, and a consequent need for greater epistemic humility on the part of health workers and researchers.

   a. Many of the most vociferous critiques of medicalisation present the process as an instance of hermeneutical injustice - a form of epistemic injustice that prevents people having the hermeneutical resources available to interpret and communicate significant areas of their experience. In this paper, I propose to
consider this line of argument in relation to the medicalisation of ‘medically unexplained symptoms’ (MUS), persistent physical complaints for which no consistent organic pathology can be demonstrated. Examination of clinical encounters between health workers and patients with MUS, I argue, demonstrates that understanding the epistemic consequences of medicalisation requires more nuance than is often displayed in the hermeneutical injustice critique.