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Epistemic Privilege, Phenomenology and Symptomatology in Functional/Dissociative Seizures

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ABSTRACT
Much work on clinical testimony assumes that none can know better than the patient what they experience. We show that in certain contexts this assumption is unwarranted; clinician expertise encompasses disease *phenomenology*, to the extent that the clinician *may know better than the patient what the patient is experiencing or has experienced*. Conversations between clinicians and people with functional/dissociative seizures (FDS) show that initial phenomenological reports of FDS (what we call 'surface' phenomenology) are often inconsistent with more fine-grained descriptions produced after detailed inquiry ('reflective' phenomenology). Assuming the initial reports are made in good faith, this process involves the clinician *showing the patient something about their experience they did not already (explicitly) know*. Failure to engage in this reflective process can result in misdiagnosis and mistreatment. Thus, uncritical acceptance of patient testimony – an unwarranted credibility *excess* – may be as harmful as its unwarranted dismissal. We conclude that: the epistemically just clinician cannot rely on expertise in *le corps objectif* alone, they must also cultivate an understanding of *le corps propre* for the patients they encounter; and epistemic (in)justice cannot be considered solely something a clinician does to the patient. Instead, epistemic justice in the clinical encounter is an intrinsically collaborative process.

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Introduction

There is a commonplace narrative about knowledge exchange in the clinical encounter that goes something like this: a person (the 'patient') experiences a sensation or constellation of such sensations. They consider these sensations to be potentially suggestive of illness, by whatever means such judgments are made (Bernhardson et al. 2021; Hay 2008). They therefore seek medical attention through an encounter with a health professional (the 'clinician'). In this encounter, the patient reports their experience; the clinician pieces together these reports, combined with other bits of information gleaned from targeted questioning, potentially complemented by examination or investigations, to interpret patient reports in terms of a disease process (Leder 1990).

This story presents a fairly neat division of epistemic labour in the clinical encounter: the patient is taken to have the phenomenal knowledge of their illness experience while the clinician is taken to have the technical, medical expertise to interpret that illness experience in pathological terms. It is the patient's role to state what is happening and the clinician's

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role to explain why and discuss how it could be changed. Lauren Freeman describes this distinction in terms of the patient's epistemic *privilege*, arguing that patients 'have a unique epistemic route to facts about their bodies', compared with the clinician's epistemic *authority*, whereby the clinician 'has expert knowledge to interpret, explain, and if necessary, diagnose, and treat what a [patient] is feeling' (Freeman 2015, 48). According to this view of epistemic privilege, the phenomenology of illness is readily accessible to the patient, they know what they are experiencing and feeling, although they may struggle to articulate or communicate it to others (Carel 2016; Carel and James Kidd 2014).

This standard account of the epistemic division of labour between patients and clinicians forms the backdrop for many alleged cases of *epistemic injustice* in medicine: a failure to acknowledge patient epistemic privilege in illness experience leads to its description being unjustly disbelieved or dismissed (Freeman and Stewart 2024), assigned unduly low credence (Buchman, Ho, and Illes 2016; Sanati and Kyratsous 2015) or deemed irrelevant (Lakeman 2010). It may mean that knowledge claims derived from such privilege are barred from shaping the hermeneutical resources supporting clinicians' interpretations (Blease, Carel, and Geraghty 2017; Kidd and Carel 2017; Wardrope 2015). It might devalue the patient's interpretations of the significance of illness experience or deny them a role in informed self-management (Greenhalgh et al. 2015). Conversely, mistaken belief attributions nonetheless grounded in a clinician's appropriate epistemic authority may not be considered epistemic injustices (Goldstein 2022).

According to this story, a clinician may claim legitimate epistemic authority in the interpretation of illness experience – in the form of 'symptoms', the 'scraps of pages' from which a pathological 'plot' is formed (Leder 1990, 12–13) – but defining the symptoms themselves falls within the scope of the patient's epistemic privilege. It is often presumed that none can know better than the patient what the patient is experiencing – 'we … take each person to be the ultimate authority on his or her own sensations, feelings, and experiences' (Carel 2016, 46). It is this common presumption that we want to call into question. As such, we will argue that, in certain contexts, clinician expertise encompasses expertise in disease *phenomenology*, to the extent that, in some cases, the clinician *may know better than the patient what that patient is experiencing or has experienced*. Evidence for this argument can be found in one of the author's (Alistair Wardrope's) field of clinical practice, specifically by drawing on patients' reports of experiencing functional/dissociative seizures (FDS). This condition—involving paroxysmal episodes of altered bodily awareness and control, sometimes mistaken for epileptic seizures – is valuable for the analysis in this context given the extensive body of research devoted to understanding how patients with FDS talk about their experiences and how clinicians interpret it. This research demonstrates that initial phenomenological reports of FDS (what we are calling 'surface' phenomenology) are often inconsistent with the more fine-grained descriptions that can be produced with more detailed interrogation, guided by an expert clinician (what we are calling 'reflective' phenomenology). Assuming the patient's initial phenomenological reports are made in good faith, this process of interrogation involves the clinician *helping the patient come to see and understand aspects of their experience they otherwise would not (explicitly) see.*

If this is correct, then with some illness experiences (such as those which accompany FDS) patients' epistemic privilege must be qualified by clinicians' expertise in disease phenomenology. This makes adjudicating claims of epistemic injustice in the clinical encounter more complicated.[1] The clinician who disbelieves a patient's testimony regarding the phenomenology of illness may not always be dismissing their epistemic privilege in a way that is unjust but rather from their expertise identifying that the patient may need additional support in exploring, understanding and articulating their own experiences in more robust and reflective ways. Epistemic justice and injustice become not simply functions of the clinician's attitude toward the patient as a more or less credible informant but rather reflect dialogical features of the clinical interaction.

Epistemic Injustice, Epistemic Privilege, and the Distinction Between Surface and Reflective Phenomenology

Discussion of epistemic injustice has exploded in the past decade and a half following the publication of Miranda Fricker's influential book, *Epistemic Injustice: Power and the Ethics of Knowing* (M. Fricker 2007). For the sake of brevity, we will not provide extensive exegesis of the many concepts and applications of this rich literature.[2] Instead, we will focus primarily on the concepts of *testimonial injustice* (M. Fricker 2007; Wanderer 2017) and *hermeneutical injustice* (M. Fricker 2007; Medina 2017), which Fricker describes as different forms that epistemic injustice can take. For our purposes, and in brief, testimonial injustice (TI) concerns how we respond to the testimonial reports of others, in ways that are shaped and influenced by background social facts and features of the testifier's identity. TI is perpetrated when, through prejudicial dismissal of another's ability to reliably provide knowledge, we do not let their testimony sufficiently influence our own beliefs in a way that systematically disadvantages that person (M. Fricker 2007, 27). This could be through affording insufficient credibility to a speaker's testimony, attributing an insufficient degree of relevance to a speaker's testimony (Hookway 2010), acting toward a speaker in ways that compromise their ability to provide reliable testimony (e.g. manipulation or coercion) (Lackey 2022) or testimony at all (e.g. testimonial smothering) (Dotson 2011). Hermeneutical injustice (HI) concerns instead the ways in which the conceptual resources that allow us to understand and share our experiences are constructed. Processes of oppression and marginalisation exclude some groups from equal participation in the construction of these shared conceptual resources, with the result that aspects of their experience are obscured from collective understanding in a harmful fashion. This may take the form of an absence of resources necessary to articulate some phenomenon (e.g. lacking the concept of 'postnatal depression' to interpret low mood, anhedonia and emotional distance after birth) or the presence of resources that harmfully distort the phenomenon in question (e.g. a concept of homosexuality that treats it as a mental illness).

Much of the literature on epistemic injustice in healthcare focuses on a specific form of devaluing, namely, dismissal of the essentially first-personal experience of illness. This is often parsed in terms of the phenomenological distinctions between the objective (*Körper, corps objectif)* and lived (*Leib, corps propre*) bodies (Carel 2016; Freeman 2015; Kidd and Carel 2017), with medicine prioritising the material body as an object of scientific investigation over the embodied subject experiencing illness. Anita Ho describes an 'inter-method hierarchy' that assigns lexical priority to information interpretable in terms of physiological or clinical descriptions of phenomena over other forms of understanding illness (Buchman, Ho, and Goldberg 2017, 33; Ho 2011, 115). Even prominent clinical researchers have described low status assigned to patient experiences as a key bias of evidence-based medicine (Greenhalgh et al. 2015, 4).[3]

Lauren Freeman claims that this prioritisation reflects a systematic devaluing of patient expertise,[4] namely, the expertise that comes from the *epistemic privilege* of the patient:

> [Patients] have *epistemic privilege* over their bodies insofar as only they have first-personal, immediate access to their bodily sensations, and on the basis of this access, only they can refer to their sensations and give testimony as evidence in support of claims about their bodily states. (Freeman 2015, 47)

Freeman's proposal echoes Havi Carel's assertion that 'we . . . take each person to be the ultimate authority on his or her own sensations, feelings, and experiences' (Carel 2016, 46). The hypothesis of epistemic privilege – implicitly or explicitly – is invoked in many of the published accounts of TI in healthcare. These arguments all identify situations in which patient testimony is apparently disbelieved or dismissed in ways that prove apparently detrimental to the patient. Epistemic privilege is then invoked to claim that this dismissal is necessarily unwarranted since claims of epistemic privilege entail that patients have unique access to the knowledge of concern; as such, the clinician has no warranted grounds on which to dismiss it.[5]

There is, however, a subtle distinction between Freeman's and Carel's conceptualisations that will become important here. Freeman's epistemic privilege focuses on 'first personal, *immediate* access to . . . bodily sensations', while Carel assigns the patient the '*ultimate* authority on his or her own sensations' (our emphases). Freeman's claim that patients have 'immediate' access to bodily sensations implies that the experience of illness is readily accessible to the patient and *only* the patient. Carel's 'ultimate' authority thesis, on the other hand, holds that the patient gets the final say on whether a given description of illness experience accurately captures their own understanding and experience of it but allows that it might be the case that significant exploration and epistemic work (potentially involving another party) may need to be done in order to arrive at that description.

This difference becomes practically relevant when we consider that the immediately accessible experience of illness – what we are calling 'surface' phenomenology – may not always be the most complete or accurate description of what a patient is experiencing. Perceptual awareness is not always dichotomous but can permit gradations, such that there is a fuzziness regarding what we do or do not consciously experience (Jimenez, Antonio Hinojosa, and Montoro 2020). Determining the content of that experience is not trivial, distorted as it may be by direction of attention, emotional appraisals or prior expectations (Petitmengin 2006; Van den Bergh et al. 2017; Wardrope and Reuber 2022). Beyond this, experience is often not solely individual; it is shared with others, or else constructively and iteratively interpreted through dialogue with others (Hay 2008). The upshot is that we do not always have clear, immediate and perfect access to or ability to understand and articulate our experiences. Our impressions and recollections of our experiences can be influenced by a great many things.

Allowing for this, the general argument for TI in healthcare contexts becomes more complex. Epistemic privilege alone does not grant that disbelief in patients' experiential testimony is always unwarranted, since they may be reporting partial or incomplete surface phenomenology only. The next section presents a case of this in practice.

The Phenomenology of Functional/Dissociative Seizures

Functional/dissociative seizures (FDS) are episodes of altered subjective experience, involuntary movements and reduced self-control, modelled as arising from (possibly heterogeneous) neuropsychological network dysfunction (Stoyan et al. 2019). They often superficially resemble – and are frequently misdiagnosed as – epileptic seizures. Neurologists – who manage both FDS and epilepsy – thus frequently face the problem of deciding whether a person's experience is more likely explained by one or the other condition. However, both these disorders are paroxysmal; it is rarely the case that the clinician can witness the patient having a seizure or that the patient can describe them while the episode is ongoing. Outside the seizures themselves, examination and investigation findings often have little to add in telling the difference between these conditions.

The patient's seizure experience (and their testimonial reporting about it) therefore becomes of paramount importance in differentiating between these two diagnoses. There is a wealth of data reporting not just *what* people with epilepsy and FDS say about their seizures but *how* they say it (Bianchi et al. 2018; Erba et al. 2017; Giussani et al. 2020; Reuber et al. 2009, 2016; Schwabe et al. 2008). From this research – and associated work on seizure neurophenomenology (Petitmengin, Baulac, and Navarro 2006) – it is evident that *the experience of seizures is not always easily accessible to the person who experiences them*. We highlight two key features of FDS phenomenology here and sketch how expertise in FDS may be employed clinically in responding to patient testimony in each case.

Ictal Consciousness in FDS[6]

One of the hallmarks of FDS – and many forms of epileptic seizure – is a phase of reduced self-control, awareness and responsiveness, or what is called a 'gap' (Schwabe et al. 2008, 63–65). Most commonly, this takes the form of a 'blackout' – a period of complete absence of conscious awareness. Typically, patients with FDS will describe this gap as complete, encompassing the whole seizure, and struggle to embed it within their peri-ictal experience; by contrast, those with epilepsy will more frequently be able to identify the extent to which they have preserved awareness of different ictal experiences, delineate the 'boundary' of the unaware period and try to interpolate, e.g. from witness reports, what happens during the 'gap' itself (Schwabe et al. 2008). The surface phenomenology of FDS is thus barren – to the patient, it seems that there is not 'something it is like' to be in a seizure.

These reports, however, conflict with phenomenological accounts produced by other means. When provided with forced-choice questions regarding the level (self-perception of a degree of ictal awareness and responsiveness) and content (specific phenomenal characteristics) of ictal consciousness, patients with FDS actually report *greater* ictal consciousness than those with epilepsy (Ali et al. 2010; Cavanna et al. 2012). Focussed attention on ictal experience surfaces aspects of ictal phenomenology in FDS that are not immediately apparent to the patient; they are able to recall, to some extent, 'what it is like' to be within an episode previously described only as a 'gap'. This is puzzling, of course, given the previous inability to recall or describe the experience, given the lack of conscious experience while the episode is ongoing.

Volition and Agency

FDS are perceived as unwilled events; characteristically the patient will describe attacks as happening without their doing anything to bring them on and with no sense of agency over their occurring (Schwabe et al. 2008). In contrast, those with epilepsy will often attempt to identify things they can do that may alter seizure progression or experience (Reuber et al. 2009). However, this perceived absolute passivity is in tension with other aspects of seizure experience reports. Patients with FDS tend to describe their seizures in more active terms (like a space or place they go into) than those with epilepsy (who more commonly describe the seizure as an external agent coming over them) (Plug, Sharrack, and Reuber 2009; Schwabe et al. 2008). Witnesses to FDS often identify a degree of purposeful interaction with others while someone is experiencing FDS (Wardrope et al. 2018).

This tension becomes more apparent with sustained clinician support in exploring the phenomenology of agency in FDS. With careful, fine-grained discussion, patients with FDS often report that they *are* able to identify some features of the attack over which they feel a degree of agency, whether in identifying things that might abort or delay the attack or conversely bring it on (often with a view to 'getting it over with') (Jon and Carson 2013). Identifying these features – and relating them to underlying neuropsychological networks (e.g. autonomic arousal – 'fight/flight/freeze' responses) can help patients to better understand the disorder and can guide therapeutic intervention (Rockliffe-Fidler and Willis 2019). Again, these cases demonstrate a dissonance between the surface phenomenology of FDS that patients initially report versus that disclosed in the detailed, supportive exploration of its experience.

Clinical Description of FDS (Hetero)Phenomenology

How do considerations such as these influence testimonial exchange in the clinical encounter between clinician and patient with FDS? A naïve reading of epistemic privilege would hold that the clinician ought to uncritically accept the testimony (or lack thereof) of the patient with FDS regarding its surface phenomenology. This would leave the clinician accepting that a patient experiences their seizures as a subjectively-barren 'gap' over which they have no agency. To accept this, however, would in fact be to assign an unwarranted *excess* of credibility to the patient's initial testimony in a way that could directly harm the patient – by failure to arrive at the correct diagnosis or identify components of the seizure experience that might be a target for therapeutic intervention.[7]

The epistemically just clinician, therefore, does not simply accept the patient's testimony at face value in such cases. She accepts initial testimony as a starting point for reconstructing seizure phenomenology. She will then interrogate this in greater detail alongside the patient. This could involve asking for clarification on what precisely the patient means when they use certain terms to describe their experience. They might 'open up' different phenomenal possibilities (e.g. of having some kind of phenomenal experience during a 'blackout') or challenge the patient's initial description (e.g. reviewing the possibility of intentional influence on the course of the seizure) (Plug and Reuber 2009). The clinician's efforts here will be guided by their initial interpretations of the patient's presentation. This will be shaped by the surface phenomenology but also a range of other considerations (from their medical background to the way they discuss their experiences). The patient can use the clinician's prompts to reflect on their experience, deriving a more nuanced, reflective account of their seizure phenomenology. This is a very different understanding of the epistemic division of labour in the clinical encounter from the standard narrative sketched in the introduction, in this case, the clinician's expertise is used to elucidate not just *why* the patient is ill but also something important about the content of the illness experience itself.[8] Rather than epistemically virtuous practice being simply a matter of responsiveness on the part of the clinician to the testimony of the patient, it is revealed as an interactive and iterative process through which patient and clinician together can create a shared space of knowledge. Moreover, through this process the epistemic agency of the patient is respected and ultimately enhanced.

This form of clinical exchange shows the importance of the distinction drawn between Freeman's epistemic privilege thesis and Carel's ultimate authority thesis. The FDS patient is not epistemically privileged in the sense of having immediate access to the phenomenology of FDS. Indeed, initially, the clinician in some respects knows more about the phenomenology than the patient. The patient does, however, get the last word on what they did or did not experience. The clinician can create the space for the patient to acknowledge or express certain experiences that may not have been readily apparent at first. They cannot, however, adjudicate in the end as to whether those experiences do in fact apply to the patient.

Alternative Explanations of the Distinction Between Surface and Reflective Phenomenology of FDS

We demonstrated above that patients with FDS initially report surface seizure phenomenology that is later contradicted by accounts resulting from the more detailed inquiry. We take this as evidence that seizure phenomenology is not always immediately accessible and may require additional reflective interrogation and consideration. This process may require clinician expertise to support. There are, however, alternative explanations for these differences between surface and reflective phenomenological reports. We consider three of these here and their implications for questions of TI in clinical encounters.

Stigma, the Unspeakable, and Conscious Deception

The first and simplest explanation for the apparent tension between the patient's initial surface phenomenological reports and their later refined phenomenological reports is that the patient's awareness of seizure phenomenology has not actually changed at all; rather, what has changed is their willingness to report it. There are several potential reasons a patient with FDS may not wish to disclose, or even consider, all aspects of their seizure experience.

Firstly, if somewhat paradoxically, these initial reports might comprise part of their work to be seen as *more* credible. Patients with FDS frequently report that their experiences are dismissed as being 'made up' or 'put on' (Markus, Rawlings, and Schachter 2018). Communication strategies that emphasise lack of consciousness or volition may also be seen as intentional deception to ensure that their true complaints are taken more seriously. This would be in keeping with the strategies adopted by some patients with functional disorders, who describe the work they put in to make their external presentation map to their internal experience (Werner and Malterud 2003).

Secondly, FDS remains a *stigmatised* condition (Annandale, Vilyte, and Pretorius 2022), and there are strong phenomenological and aetiological associations between the experience of FDS and feelings of shame (Reuber et al. 2022). The experience of shame is one of being exposed to the judgment of another. When shame is experienced, avoidance or withdrawal – rather than subjecting oneself to further judgment – is the habitual affective and behavioural response (Dolezal 2022). This presents a strong motivation to avoid open disclosure of illness phenomenology where stigma and shame are likely to be evoked.

Lastly, it is hypothesised that an important mechanism underlying the altered behaviour and sense of control in FDS is *dissociation*, or disruption in integration and continuity of perceptual, emotional, interoceptive and other processes of bodily awareness and control (Roberts and Reuber 2014). Part of the challenge for the patient with FDS in relating seizure phenomenology may then be to create an integrated whole out of dissociated parts, and the same neuropsychological mechanisms opposing this in FDS would oppose its phenomenological recreation.

There are several reasons to prefer the previously given explanation to these ones. Our proposed explanation does not imply the patient's conscious deception, an implication which can reinforce negative stereotypes about and perceptions of patients as (intentionally or unintentionally) dishonest or deceptive. Moreover, it is known that patients with related disorders (such as epilepsy) also struggle to clearly and effectively describe their illness experiences (Devinsky et al. 1991; Petitmengin, Baulac, and Navarro 2006; Schwabe et al. 2008). This gives reason to believe that a distinction between surface and reflective phenomenology is at play more generally.

It is worth noting, however, that when it comes to questions of TI in the clinical encounter, the clinician's scepticism about patients' automatic epistemic privilege is still warranted in this situation. While they may not know *more* than the patient about the patient's seizure phenomenology, nonetheless their expertise in seizure phenomenology entitles them to question the patient's initial assertion of e.g. complete lack of conscious awareness, and then by exploring this further to reconstruct a more detailed phenomenological account. It is precisely because of the clinician's technical, medical expertise that they know there could be more to uncover about the patient's illness experience and seizure phenomenology than they initially reported or were even in a position to report. The clinician can then use this initial scepticism about the surface phenomenology to help the patient engage in reflective phenomenology, thereby working together to move the epistemic exploration into more productive terrain.

Furthermore, this alternative explanation would also support our contention that epistemic justice is an interactive and collaborative process. The clinician needs to cultivate an environment in which the patient feels comfortable openly sharing their experience and does not feel the need to engage in conscious deception. The patient needs to trust the clinician in sharing more accurate testimony. We discuss the role of trust in our conception of EI in the clinical encounter in more detail later.

Extracted Testimony and Agential Testimonial Injustice

A second possibility is that the modified testimony of the patient with FDS does not provide a 'reflective' phenomenological account at all but an *extracted* one. That is, the later accounts of FDS phenomenology represent manipulated testimony that circumvents the patient's epistemic agency. The inconsistencies between initial and subsequent phenomenological accounts can be accounted for by the clinician's altering the decision space within which the patient chooses how to describe their experience – for example, by artificially restricting the range of possible experiences that could be narrated or by making pragmatic considerations other than the accurate articulation of experience, which can come to dominate what the speaker 'chooses' to report (Lackey 2022).[9]

Jennifer Lackey describes how such processes can take place in the extraction of eyewitness testimony in criminal contexts. Eyewitnesses' accounts can be *manipulated* (e.g. by selecting people in a line-up such that only one plausibly fits with their previous descriptions) or *coerced* (e.g. threatening legal action against the witness, such that considerations of self-preservation dominate over truth-telling). These sorts of manipulation and coercion present an epistemic injustice because they invite people to act ostensibly as epistemic agents, but they are not being treated as informants at all. Instead, the testimony sought from them is predetermined – the manipulator is not interested in what knowledge they may putatively share, as they already know what claim they want it to support. They therefore deliberately manipulate the conditions of knowledge exchange to amplify epistemic weaknesses (in the case of manipulation) or to make non-epistemic ends more salient (in the case of coercion). In each instance, the speaker's epistemic agency is undermined.

It is at least plausible that the clinician's influence could exert a similar effect on the patient. Indeed, there is some suggestion from qualitative accounts of patients with other functional disorders that they modify their self-expression in order not to jeopardise a relationship with the clinician (Werner and Malterud 2003). It is thus at least possible that the patient amends their account of seizure experience to what they think the clinician 'wants to hear'. If this does indeed occur, it would represent a case of what Jennifer Lackey calls 'agential' testimonial injustice (Lackey 2022, 704ff); the patient's epistemic agency is undermined by compromising their ability to give testimony, not through disbelief, but rather influencing their epistemic agency such that accurate testimony is either no longer possible or is no longer a rational choice for the patient.

Though it might initially seem plausible that something similar is happening in clinical discussions with FDS patients, the disanalogy with the kinds of criminal justice cases that Lackey describes is that in the context of providing care to FDS patients, there is less of an obvious incentive for the clinician to manipulate the patient's testimony than for, say, the police officer or lawyer to influence the testimony of the eyewitness. It is not immediately clear how such extracted testimony would serve any useful clinical role or work in the interest of the clinician. Therefore, while we acknowledge this possibility, we do not take it to be the most plausible explanation of what is happening here. A more plausible explanation is the one we propose: the FDS patient really is experiencing an inability to immediately and accurately characterize some aspect of the illness experience and seizure phenomenology and the clinician helps guide and aid the essential exploration that helps the patient become better equipped to do so.

The Third Order of the Body

A last possible explanation – one which we think should be taken more seriously – also involves the clinician shaping the patient's testimony through the clinical encounter but in a less deliberately manipulative fashion than the extractive scenario described above. When the patient relays to the clinician their account of their illness experience, the clinician interprets that experience in terms they can render intelligible; not only does this produce a particular transformation of the experiential account (from 'sensation' to 'symptom') – the fact of having their experience interpreted in those terms may have a feedback effect, shaping the patient's own interpretation of their experience through the lens of those terms and concepts (Wardrope and Reuber 2022, 406–408).

Havi Carel describes this process in terms of Sartre's 'three orders of the body': the patient has their initial illness experience – of the 'body-for-me', the clinician interprets this experience in pathophysiological terms, the 'body-for-the-Other', but this alters the patient's relationship to their own body and experience – the clinician's lens shapes the patient's own, producing the 'body-as-seen-by-the-Other' (Carel 2016, 52–53; Sartre 1978, 357). This is not malicious or intentionally manipulative or coercive. Rather, this is the result of both parties trying to interpret the experience in the ways they know how or in the ways they have been trained to. When exposed to these framings, they can influence how the patient comes to understand and relate to their bodies and experiences, as language and concepts influence how we see and understand ourselves and our experiences.

This kind of process poses a slightly different explanation for our conflicting accounts of FDS phenomenology than those encountered above. In this case, the patient's initial (surface) account is not mistaken, nor does it reflect any conscious deception; the second account is not a warped, extracted testimony. Rather the first and second accounts provide different interpretations drawn from and shaped by different perspectives – the latter one in which the patient's interpretation of their own experience is in part seen and interpreted through the eyes of the clinician.[10]

How, then, are we to adjudicate the epistemically responsible position for the clinician to take on the patient's testimony in this situation? Though we cannot provide a perfectly complete answer here, we want to argue that one plausible possibility might come from the acknowledgment that the process of interpretation – of experience, as any other information – is always *perspectival*, presupposing certain interests, assumptions and objectives. If the account of FDS phenomenology produced by refraction through the clinician's lens is better equipped to serve the ends of the clinical encounter – accurate diagnosis, prognosis and management, let us say – then to that extent the clinician's initial credence or judgement of relevance in the initial surface phenomenological report is warranted. The role such (re) interpretation plays in accurate diagnosis (and the greater diagnostic accuracy of expert clinicians who engage in such processes than generalists who may not) suggests this may be the case. In this case, then, creating the space for patients to engage in practices of reflective phenomenology, guided by expert clinicians and their perspectives on the disease phenomenology, can be a matter of increasing health and epistemic justice alike. It is therefore the appropriate thing to do, epistemically and medically speaking.

Towards Epistemic Peerhood in the Phenomenology of Illness

If the above is correct, then patients do not always and necessarily have immediate or complete privileged access to their own illness experiences.[11] In their encounter with the patient, a clinician seeks to assemble from all the information at their disposal – the patient's given story, but also the ways in which they tell it, details of their background, their physical presentation – an interpretation of their experience that can most effectively serve the ends of the clinical encounter. Sometimes there may be dissonance within that assembled interpretation – one reason for which may be that the patient's initial phenomenological account differs from that which can be obtained with targeted, reflective exploration. Part of the clinician's expertise comes from their experience of hearing 'what it is like' to have certain illnesses and to use this 'heterophenomenological' expertise to help patients elucidate and articulate the phenomenology of their own condition.

This has implications for the important project of understanding, illuminating and addressing epistemic injustice in healthcare. It is not always sufficient just to say that clinician expertise lies with the *corps objectif*, the patient's lies with the *corps propre*; sometimes the patient's subjective account is the most important evidence a clinician has to guide their diagnosis. Furthermore, cases like FDS show that clinicians have to be interested in phenomenology proper; it is precisely through identifying the intersubjectively shared aspects of experience across certain conditions that the clinician can work from the surface phenomenological account to the reflective one.

Lastly, the necessity for that kind of facilitated guiding in certain occasions shows that recognition of the patient's epistemic privilege cannot be operationalised simply by accepting their testimony regarding their illness experience full stop; sometimes that testimony does need to be probed or challenged in order to better serve the goals of the clinical encounter and to best support the patient's full epistemic agency.

Understanding the conditions that support such practice requires a more nuanced understanding of the epistemic positions of patient and clinician in the clinical encounter and the contributions of both (alongside structuring factors) to the dynamics of clinical communication and knowledge exchange. In her work on the phenomenology of pregnancy and clinical experiences of pregnant people, Lauren Freeman proposes that confronting epistemic injustice in the clinic requires establishing what she calls *epistemic peerhood* between clinician and patient. She writes,

> One cannot become epistemic peers with an object (*Körper*). One can, however, become epistemic peers with a living body, a person who exists in the world, whose claims to knowledge are deemed credible, taken seriously, and engaged within a supportive, open, dialogic, and comfortable environment. (Freeman 2015, 61)

While her argument focuses on the tendency to privilege the reports of investigative technologies over first-person accounts, her descriptions of the dynamics of clinical interactions are perhaps more revealing as to the barriers to achieving this state:

> [P]atients in clinical encounters often feel intimidated, rushed, and uncomfortable to engage in dialogue and to voice their questions and concerns. Due to the asymmetry of power, patients tend to feel vulnerable and afraid that if they do voice their concerns, they will be dismissed. (Freeman 2015, 61)

If the epistemic and broader clinical conditions do not exist such that the patient feels supported and empowered to openly and honestly share their experiences, the clinician and patient alike are prevented from establishing the kind of dialogue that would permit clinically relevant interrogation of the patient's experience. How, then, might these epistemic and clinical conditions be improved, such that patients are more likely to feel comfortable sharing their experiences and trusting that they will be taken seriously when they do so?

A fuller answer to this question lies beyond the scope of this paper; here we offer only some starting places and suggested directions for future work. This work could look at the individual, interpersonal and structural features that inhibit robust epistemic peerhood in the clinical encounter.

One example of a possible individual-level change follows from the recognition that clinicians need to be aware of the limitations of their own perspectives even as they interrogate those of their patients. The virtue of epistemic humility – a 'willingness to recognise the limits of one's knowledge and appreciate others' intellectual strengths' (Porter and Schumann 2018, 140) – is often suggested as a remedy here (Buchman, Ho, and Goldberg 2017; Ho 2011; Lakeman 2010; Wardrope and Reuber 2022). Empowering clinicians to acknowledge the limitations of their own perspectives – whether that be the fallibility of third-personal investigative methods (e.g. discussing how medical investigations only give a partial and fallible picture of a person's condition) or the endemic uncertainty in medical decision-making – may allow them to begin cultivating this virtue. When patients perceive this epistemic humility in their clinicians, they might be more comfortable speaking up and also acknowledging their own limitations, confusions and concerns.[12]

On the interpersonal level, we need to better understand and enact the conversational norms that allow for more effective construction of a shared understanding of illness. Doing so requires acknowledging that the interpretation of human experience for the purposes of the clinical encounter is something clinicians and patients do together – *a joint act* (E. Fricker 2021). The clinical interpretation of patient experience requires not just identification of the appropriate attitudes of each party to the epistemic capacities of the other but also coordination of their objectives in that interpretation – in other words, what are we trying to understand this *for*? When shared goals can be identified and mutually endorsed, clinicians and patients are in a better position to work cooperatively toward those goals.

Once the goals are in place and mutually endorsed, it is also important that barriers to trust and cooperation are minimized. Without trust in patients, clinicians will dismiss their testimony. Without trust in clinicians, patients will be unwilling or unable to share their experiences or concerns (Buchman, Ho, and Goldberg 2017; Ho 2011). To build trust, we have to understand what barriers exist to the perception of trustworthiness, to help clinicians and patients alike align trust with trustworthiness (O'Neill 2020). This will require taking stock of the kinds of historical and ongoing injustices that can lead patients to distrust healthcare institutions and practitioners (e.g. historical exploitation and ongoing instances of bias, stereotyping and microaggressions (see Freeman and Stewart 2024). When we know what kinds of interpersonal problems are likely to produce or exacerbate distrust, we know what kinds of barriers stand in the way of effective communication and cooperation. These, then, must be minimized (or more ideally, eliminated).

Finally, structurally speaking, we must attend to the social and institutional forces that may constrain both clinician and patient from successfully engaging in these processes. If there is an 'inter-method hierarchy' (Ho 2011) between first- and third-personal sources of clinical information or descriptions of illness experience, then we should ask whether that is a function of what clinicians do or how clinical knowledge is expropriated for non-medical purposes (Szmukler 2014; Wardrope 2015). Or if, as a result of top-down time and resource pressures imposed on clinicians, patients feel too rushed to meaningfully engage in dialogue, we need to attend to the structural changes that can ensure that clinicians have the appropriate time and resources to enact more productive dialogues during the clinical encounter, allowing patients to have the adequate time and attention required for their needs to be heard, understood and met. Addressing the structural factors that impose limitations on clinical dialogue will be crucial for fostering effective relationships of epistemic peerhood between clinicians and patients. More conceptually, healthcare interactions are structured by certain conceptions of health, disease and illness, that may represent 'overworked tools' (Szmukler 2014) that do not necessarily address the most important problems people are confronting. Resisting the biomedical scientism that insists medical descriptions of illness contain all that is relevant to understanding illness might help to promote the epistemic peerhood of patients and others who can contribute different and more robust understandings of illness phenomena (Kidd 2018; Wardrope 2017).

Conclusion

A naïve view of the relative epistemic positions of patients and clinicians in the clinical encounter assumes that the patient (alone) provides the first-personal illness experience and the clinician (alone) provides the third-personal expertise to interpret the patient's account. The case study of testimonial exchange in FDS, however, demonstrates that the clinician may also need to bring skills in elucidating the phenomenology of illness itself to support subsequent clinical discovery and understanding and that epistemically virtuous practice requires active collaboration between patient and clinician. While the patient has the ultimate authority regarding what they have or have not experienced, the clinician should not always accept initial reports of surface phenomenology unquestioningly.

This makes clearer the demands of testimonial justice in the clinical encounter – in particular, the hard, collaborative work required to achieve it. Uncritical acceptance of patient testimony regarding surface phenomenology – an unwarranted credibility *excess* – may in some cases, such as FDS, end up being as harmful as its unwarranted dismissal. Epistemically just clinical practice cannot be reached by quick fixes. If this case study does demonstrate anything regarding what such practice might look like, it is that the clinician cannot rely on expertise in *le corps objectif* alone; they must cultivate an understanding also of *le corps propre* for the patients they encounter – perhaps, even, more of an understanding than the patients themselves first have. And they have no means of achieving this other than by listening to their patients – with humility, though never uncritically. Instead, clinicians and patients must work together to arrive, collaboratively, at the best phenomenological and clinical understanding, that is, they must become epistemic peers. To understand better how to enable clinicians and patients to achieve robust epistemic peerhood will require interrogating the individual, interpersonal and structural features of epistemically just clinical knowledge exchange.

Notes

1. In this paper we do not explore in depth the rare, but nonetheless important, situations in which the patient consciously feigns symptoms such as in factitious disorder (i.e. 'Munchausen's syndrome'). However, the possibility of such conscious deception on the part of the patient (however rare such cases may be) further complicates the epistemic position of the clinician and highlights the shortcomings of a position of automatic and unqualified acceptance of patient testimony.
2. The underpinning concepts are explored extensively in Kidd, Medina, and Pohlhaus (2017). Ian James Kidd maintains a bibliography of work on epistemic injustice in health and illness (Kidd 2021).
3. The conventional 'hierarchy of evidence' in evidence-based medicine positions the 'case report' (summary of an individual patient experience) at the lowest rung in the hierarchy and cautions against the clinical application of 'anecdotal' evidence. In the context for which this hierarchy was initially developed – assessing the likely efficacy and effectiveness of a given treatment on an otherwise-unspecified patient with a given condition – this status is epistemically warranted. It is difficult to know how one person will respond to a given treatment purely on the basis of what happened to another entirely different person after they were given that treatment. Moreover, the case report is subject to many biases that are typically mitigated by forms of evidence higher in the hierarchy, such as randomised controlled trials. However, 'evidence-based medicine' as a social movement can misapply this hierarchy to questions where it is less well suited (e.g. how living with a particular condition in a particular social context affects an individual patient). This expropriation of critical appraisal heuristics can assign inappropriately low status to patient testimony.
4. We use the term 'expertise' here to denote the intimate experiential knowledge and understanding that patients have of experiencing or living with a particular condition. 'expertise' is increasingly the preferred term in clinical and biomedical research contexts, where there is an increasing recognition and promotion of the role of patient 'experts by experience'. However, we acknowledge that this sense of 'expertise' differs in important ways from that in which it connotes a system of qualification or accreditation and is associated with certain social licences – a sense which more accurately reflects the position of clinicians and health professionals.
5. Our discussion here assumes that 'patients', as a broad group, can be the subject of epistemic injustice. Carel and James Kidd (2014) have argued that, given their positions of lesser power vis-à-vis their clinicians and their state of heightened vulnerability, patients count as marginalized in the context of medicine and can thereby be on the receiving end of epistemic injustice in that context. Freeman and Stewart (2024) have argued that to properly understand experiences of epistemic injustice, we must consider the intersectional identities of patients and how various aspects of patient identity – race, gender, sexual orientation, etc. – will influence the likelihood that patients will be dis/believed, which are over and above the general vulnerabilities and power differentials inherent in clinician-patient interactions. We flag this to acknowledge that dismissals of patient testimony can be influenced by many things, e.g. racial and gendered stereotypes, which can exacerbate the injustice and the related harm.
6. 'Ictal' is the adjectival form of the term 'ictus', meaning a sudden attack (from the Latin term for blow, stroke or seizure). It is used medically to describe any paroxysmal event – most commonly in the context of seizures, but also e.g. syncope (fainting) or strokes. 'Peri-ictal' refers to the period around the event.
7. Though most of the epistemic injustice literature has focused on unfair credibility deflations and deficits, Jennifer Lackey (2022) has compellingly argued that, in some contexts, affording too much credibility to a speaker can also be harmful and damaging (e.g. Lackey focuses on the credibility excesses that occur in cases of soliciting false confessions in the criminal justice context). Similarly here, to afford an FDS patient too much credibility would be a way of undermining their full epistemic agency.
8. Note: something similar might happen in cases of sexual assault victims/survivors or those with PTSD, who report having 'blacked out' for some or all of the traumatic event or who otherwise experience disorientation in the aftermath of trauma (Harbin 2016). In such cases, as with the case of FDS, guiding a patient in uncovering and making sense of the content of their experiences (e.g. what happened and how it felt) can be essential for healing and can be a way to support and enhance one's epistemic agency in the aftermath of trauma. This is another avenue for exploration and another instance that supports our main thesis: at times, testimonial reports will need to be explored and guided by a caring expert professional in order to allow the patient to make the most possible sense of their experiences, where some of the content of that experience might not be immediately accessible to them. Taking on this collaborative epistemic work ultimately enhances the patient or client's epistemic agency as opposed to undermining it.
9. This is in some ways similar to how Kristie Dotson (2011) describes the phenomenon of 'testimonial smothering' as a form of coerced self-silencing. Here too, the worry is that while the testimony or the silence appears 'chosen' by the speaker, they are not chosen freely or without undue influence imposed by relevant features of the background environment.
10. It is worth noting that this (re)interpretation of one's self-understanding through the lens of dominant medical paradigms and clinical frames can, in some cases, be harmful. For example, dominant medical understandings of sex and gender often presuppose or take for granted the sex binary, which can limit conceptual understandings

of trans and non-binary patients' experiences. Often, such patients have the dominant understanding imposed on them even when it does not map onto their lived experiences of gender. A clear example of this is the reliance on the 'wrong body' narrative of trans experience, which fits for some but not all trans and non-binary people's subjective experience. When this narrative is imposed, the result can be that it encourages people to see and understand themselves through that frame of understanding, which can in very important ways alter their self-understanding (in ways that are inauthentic, and at times, harmful). Moreover, the dominance of these interpretative frames often compels people to conform their reports to fit the dominant narrative, e.g. to access medical resources (e.g. gender affirming care), which might only become accessible if one is able to speak to their experiences in a way that the clinician is likely to understand and accept, e.g. in a way that is in line with their interpretative resources.

11. Note the qualifications here: we hope to show that this kind of case illustrates that patients do not always and necessarily have immediate and infallible epistemic privilege because there are some cases, such as FDS, where that privilege is mediated or limited by features of the illness experience (e.g. loss of conscious awareness). This is not to rule out that patients in other contexts very well could (and likely do) have this kind of epistemic privilege. Part of the work of epistemic justice in healthcare will be to figure out when this is (and isn't) likely to be the case and to support patients by guiding their inquiry and reflection when necessary. Moreover, such cases as FDS highlight that a simple, binary and oppositional account of 'privilege' is unlikely to be flexible enough to allow for the nuances of differing epistemic positions needing acknowledgement to construct an epistemically just clinical encounter.
12. While some authors are sceptical of the possibility of individual virtues like epistemic humility to address epistemic injustice (Sherman 2016), there is evidence that (an operationalised definition of) epistemic humility is associated with precisely the ameliorative interactional features required here, such as a reduced myside bias and increased tendency to expose oneself to opposing perspectives (Porter et al. 2022).

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