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<https://doi.org/10.1057/s41599-021-00918-3>

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Epistemic injustice in the age of evidence-based practice: The case of fibromyalgia

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The aim of this paper is to analyze epistemic interactions in healthcare practices. In clinical encounters, participants exchange and interpret knowledge. Patients suffering from fibromyalgia often report that healthcare professionals do not take their testimonies and interpretations seriously. Such experiences will be explored using the concept of epistemic injustice. Epistemic injustice is wrong done to someone in their capacity as a knower. In healthcare settings, epistemic injustice occurs when patients experience an unjustified discrediting as unreliable informants of their own illness experiences. First, we will argue that patients' epistemic marginalization can be reframed as an epistemological problem. There is a gap between patients' lived experience of illness and professionals' conceptualization of illness as disease. This gap leads to two distinct conceptualizations, possibly causing harm to patients' capacity as first-hand knowers. Second, we will analyze epistemic injustice in light of the dominant model of knowledge translation in medicine and healthcare, namely evidence-based practice (EBP). EBP intends to diminish the gap between scientific knowledge and clinical practice. EBP prioritizes knowledge obtained through clinical research over other forms of clinical knowledge and has the potential for harmful epistemic devaluation of patients' stories.

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Introduction

In this paper, we present analyses of knowledge translation and consider the interactions between patients and healthcare professionals. More specifically, we show the testimonial injustice experienced by patients suffering from fibromyalgia. Clinical encounters are typically communicative in which knowledge is exchanged and translated among participants who interpret the evidence of illness. Patients suffering from fibromyalgia frequently report that healthcare professionals are suspicious of their knowledge claims (Werner and Malterud, 2003; Undeland and Malterud, 2007; Briones-Vozmediano et al., 2013; Eik Grape et al., 2015, 2017). Practitioners might doubt, ignore, or consider patients' arguments irrelevant in treatment and care. Patients' negative experiences, moreover, are related to some fundamental epistemic issues. Marginalizing patients' testimonies detract their status as knowers. In the pioneering book *Epistemic Injustice* (2007), Miranda Fricker analyzed the (un)ethical aspects of everyday epistemic practices. Epistemic injustice refers to unfair treatment that relate to knowledge, understanding, and participation in communicate practices. Fricker's notion of epistemic injustice will be used as an interpretative framework in the analysis of patients' experiences reported in multiple studies published in scientific journals over the last two decades.

The aim is twofold: first, we argue for the relevance of Fricker's theory of epistemic injustice to patients suffering from fibromyalgia, a low prestige disease. Second, we explore the epistemic barriers involved in legitimizing patients' knowledge and illness experiences in treatment and care. The epistemic imbalances between patients and professionals will be related to the prevalent conceptualization of illness as disease, as well as the dominant model of knowledge translation in medicine and healthcare, namely evidence-based practice (EBP).

Fibromyalgia—medical expert descriptions

The American College of Rheumatology gives the following description of fibromyalgia: it is a complex and, in most cases, chronic, condition with a set of signs and symptoms. The most common symptom is muscular pain all over the body, often combined with tenderness and severe fatigue. In addition, the patient might suffer from sleep problems, problems with memory, and symptoms of depression or anxiety. Fibromyalgia interferes with daily functioning and is often accompanied by distress. There is no test to detect fibromyalgia; the disease is diagnosed based on the patient's self-report of symptoms. However, lab tests or X-rays are often recommended to rule out other health problems (American College of Rheumatology, 2019).

Multiple types of treatments are often recommended, including both drug-based and non-drug-based treatments. Mindfulness-based stress reduction has been shown to improve symptoms, as has cognitive behavioral therapy, which increases a person's understanding of how cognitive and behavioral patterns affect pain and other symptoms. Other complementary and alternative therapies, such as acupuncture, chiropractic, and massage therapy, are sometimes recommended to alleviate fibromyalgia symptoms (American College of Rheumatology, 2019). There are some controversies related to the diagnosis. For instance, some prominent rheumatologists argue that fibromyalgia is a mind/brain disease and not a musculoskeletal disease (Bernstein, 2016).

Patients' illness experiences

Many of the illness experiences of patients with fibromyalgia share similar features (Briones-Vozmediano et al., 2013; Mengshoel and Grape, 2017; Eik Grape et al., 2017). Their illness narratives generally start with pain that does not resolve as

expected, followed by many visits to different healthcare personnel, who request various tests to rule out other pathologies, mainly rheumatological or psychiatric disorders. Various treatment options are tried, and patients report that the disease might take years to be diagnosed, during which patients experience several symptoms.

A frequent complain among patients is lack of understanding and support from professionals (Hadler, 2003; Briones-Vozmediano et al., 2013). Werner and Malterud (2003) documented that women with chronic muscular pain such as fibromyalgia report negative experiences during clinical encounters. Their illness was questioned and judged to be imaginary; reports about their condition marginalized during examinations or different psychiatric labels were used to explain and thus dismiss the symptoms of fibromyalgia. Hence, patients find fibromyalgia symptoms to be a double burden; they affect the patient's life situation, and at the same time, the patient is not believed to be ill by others, including healthcare professionals (Juuso, et al., 2014). Getting a diagnosis like fibromyalgia might not relieve patients because it does not legitimize their symptoms. Consequently, patients experience a moral judgment of their character and are often characterized as "difficult" patients. Moreover, patients report feelings of shame and blame themselves for the symptoms of pain and for not being able to provide medically relevant information requested by the healthcare professionals.

In Facebook groups, with members suffering from fibromyalgia, they share frustrations with the de-evaluation of fibromyalgia, alleged imaginary symptoms, and healthcare professionals' inability to understand their symptoms despite empathetic efforts (Juuso et al., 2014). Even empathic clinicians could discredit patients' testimonies when they have test results showing no signs of serious illnesses. However, not being granted a proper medical diagnosis causes severe challenges.

A diagnosis marks the official presence of disease and functions to justify disabilities. To be sick without receiving a diagnosis to some extent inhibits the ability to make sense of one's suffering and the communication of one's distress to others. In addition, there are epistemic concerns with not being regarded as a reliable knower of their own symptoms, and being discredited as knowers, may point towards epistemic injustice. We propose that an unfair treatment of patients with fibromyalgia might also relate to the medical culture's disease prestige awarding fibromyalgia as a low rank disease.

Disease prestige

Research has demonstrated that healthcare professionals rank different diseases in a prestige hierarchy (Album et al., 2017). The Norwegian sociologist Dag Album has studied disease prestige in the medical culture since 1990, treating diseases as cultural categories. As such, diseases convey meanings which are not restricted to the "strictly medical", neither for patients nor for healthcare professionals (Album et al., 2017, p. 46).

A comparative analysis of three survey studies of disease prestige conducted in 1990, 2002, and 2014 are presented in Album et al. (2017). In each of these years, a sample of Norwegian physicians was asked to rate 38 diseases on a scale from 1 to 9 according to their prestige. The results showed a remarkable stability in the prestige rank order over 25 years. The top three diseases in all three surveys were leukemia, brain tumor and myocardial infarction. The four lowest ranked were fibromyalgia, depressive neurosis, anxiety neurosis and hepatocirrhosis, with fibromyalgia holding the lowest rank across all the three samples.

The stability of the ranking rests on the following three sets of prestige criteria: (1) the disease and its typical course; (2) the typical treatment; (3) the typical patient. The relevance of these criteria is exemplified with diseases with high prestige as being non-self-inflicted, acute with clear diagnostic signs located in the upper part of the body primarily brain and heart. According to the second group of criteria, high ranked diseases will have active, risky, and high technology treatment leading to effective recovery. The typical patient is young and accept the physician's understanding of the disease, and the treatment is relatively efficient without long-term heavy burdens and helplessness.

By contrast, the categories consistently ranked at the bottom of the prestige hierarchy are not organ specific, and do not have objective diagnostic signs, and efficient therapeutic options are hardly available. Patients' diffuse bodily complaints are challenging for healthcare professionals although for the patient the symptoms are normally not diffuse but "real" and painful. Patients will most often maintain an understanding of their suffering quite different from that of the healthcare professionals (Album et al., 2017).

Album's research illustrates that differences in disease prestige are a significant aspect of medical culture. Understanding these preconceptions is important because disease prestige may influence healthcare decision-making. The lack of prestige might in fact partly explain why patients experience reduced credibility in epistemic interactions with professionals.

Patients complain that they encounter substantial difficulties in their efforts to make themselves understood, while healthcare personnel complain that patients fail to contribute epistemically to the collection of medical relevant data. Consequently, neither group can engage in shared epistemic practices. A patient is vulnerable to epistemic injustice if they struggle to access and employ resources necessary to create the sense of their experiences (Carel and Kidd, 2014). This indicate that there is an epistemic asymmetry but also dependencies towards the medical expert as well as differential power relations, which can increase the vulnerability of patients to epistemic injustice.

Epistemic injustice

Patients' complaints about being marginalized in patient-clinician relationships can be framed as an epistemic problem. Epistemic injustice is a concept which explains why healthcare personnel do not believe what patients tell them, undermining patients as knowers. Epistemic injustice can be a consequence of low disease prestige and negative stereotypes leading to bias against the knower or privileging certain epistemic and practice ideals like EBP, or privileging knowledge derived from medical training and theory. Health personnel might have the very best intentions to trust a patient and believe what the patient is telling them but nevertheless ignore the patient's testimony, for instance because it is not in accordance with medical expertise. Consequently, patient testimonies are not considered credible, and patients are undermined as first-hand knowers. Their reports about their condition are marginalized during medical examination and they encounter difficulties in their efforts to make themselves understood.

Fricker's (2007) notion of epistemic injustice describes the ways in which knowledge claims are unfairly dismissed, harming subject's credibility and epistemic capacities. Fricker's basic idea is that a speaker suffers epistemic injustice if prejudice on the hearer's part causes the latter to give the speaker less credibility than he or she would otherwise have (Fricker, 2007, p. 4). Communication depends on the speaker's perceived credibility. If a person lacks credibility his or her testimony will most likely be ignored or treated with suspicion. Epistemic injustice can

manifest in different ways and to different degrees depending on the speaker's status as a knower as well as the hearer's sensitivity. Kidd and Carel (2017) argue that persistent negative stereotypes that affect people with mental illness typically often leads to low credibility. The same might hold for persons with fibromyalgia due to its low prestige. When it comes to healthcare practices, health professionals have a privileged epistemic status and thus risk downplaying patients' testimonies and interpretations. Fricker's study of epistemic injustice focuses primarily on testimonial injustice and hermeneutic injustice, with the former being the primary form of injustice, in her view. Patient testimonies may be excluded from epistemic consideration because they are judged to be irrelevant or insufficiently articulated (Carel and Kidd, 2014, p. 532).

Hermeneutics is the study of interpretation. Interpretations, moreover, are necessary because language and human experience are ambiguous. Hermeneutic injustice is fundamentally harmful because "the subject is rendered unable to make communicatively intelligible something which is particularly in his or her interest to be able to render intelligible" (Fricker, 2007, p. 162). One instance of hermeneutic injustice is when a certain illness experience and symptom interpretation are not accepted as part of the dominant discourse and prevent a patient from expressing and sharing aspects of their experience (Fricker, 2007). Ill persons' hermeneutical resources are not always recognized by healthcare professionals but might nonetheless be essential to their own experiences of illness. Patients trying to express themselves without using medical nomenclature might have an emotional style of communication, which could generate hermeneutic injustice.

In recent years, several researchers have expanded Fricker's theory, exposing epistemic injustice within healthcare. Among them are Kidd and Carel (2017), who provide a philosophical analysis of epistemic injustice related specifically to illness. They argue that illness puts people at risk of epistemic injustice and hence of receiving less effective care. They begin their analysis by detailing epistemic complaints made by patients who have extended experience with modern healthcare. The patients report that professionals do not listen to their concerns; moreover, they experience being ignored and facing difficulties in their efforts to make themselves understood. Meanwhile, healthcare professionals often complain that patients provide medically irrelevant information and make odd statements about their illness. Difficult situations emerge, characterized by deep epistemic inequalities where neither group can engage in an effective epistemic relationship (Kidd and Carel, 2017, p. 173).

In another paper, Carel and Kidd (2014) argue that ill persons are particularly vulnerable to epistemic injustice in Fricker's sense. In line with Chrichton et al., (2017), they argue that Fricker's analytical approach provides an account of why, despite the best of intentions, healthcare professionals often consider patients to be unreliable and distrust what patients tell them (Chrichton et al. 2017). Grim et al. (2019) also confirm that mental healthcare users frequently report negative epistemic experiences such as being ignored, regarded as incredible or excluded from epistemic considerations while meeting with healthcare professionals.

Conceptualizing the gap between disease and illness

Persons suffering from fibromyalgia tend to view themselves as negatively stereotyped which in turn cause professionals to view their testimonies as less credible. In the following, we argue that this might be related to a genuine difference in how professionals perceive the patient's state. Inspired by Toombs' (1990) analysis and Sartre's (2001) (originally from 1943) conceptualization of

four different levels of experience, we will demonstrate the fundamental disparity between different experiences of disease, which might cast light on why patients report epistemic injustice in their interactions with healthcare professionals.

Phenomenology studies first-hand experiences, including the study of the relationship between first-hand experience and scientific models. Scientific models are abstract simplifications of complex relations which needs to be related to the “lifeworld”—the world of everyday experience. Toombs (1990) explores the temporality of illness experiences within a phenomenological framework. Her analysis illustrates differences between patients’ experiences and professionals’ articulation of patients’ expressions. Toombs argues that the temporal constitution of illness is important for understanding the way illness is lived by the patient and demonstrates how patients and physicians constitute the temporality of illness according to different phenomenological temporalities (Toombs, 1990, p. 237). While physicians will use the time scale to measure biological processes to determine the diagnosis, patients find time resists measurement as objective time. For instance, they might experience time as standing still or minutes might seem like hours.

According to Sartre, illness is constituted on four different levels. The three first levels represent the way the patient constitutes the illness herself, while the fourth level represents the physician’s conceptualization of illness. The first level is termed the person’s “immediate body sensation”, which is pre-reflective. Experientially, something is not quite right. According to Sartre, consciousness is bodily; the hand and arm *are* pain. On the second level, called the “suffered illness”, the person starts to reflect and comprehend his or her pain. Pain becomes located in the arm, or what Sartre calls an object-pain. “Suffered illness” is still an immediate lived experience. On level three, “disease”, the person starts searching for a cognitive explanation for the pain. It is a reflective experience wherein the painful hand and arm become objects and the person searches for meaning by incorporating knowledge from others. The painful hand and arm are about to be given meaning, maybe as a kind of joint disease or arthritis. At this stage, the person might go to a physician in order to get an appropriate treatment. This fourth level is termed the “disease state” and the illness is constituted as a disease based on pathophysiological facts.

Toombs (1990, p. 236) clarifies the distinction between Sartre’s concepts of “disease” and “disease state” using multiple sclerosis as an example. After getting a physician’s diagnosis of the “disease state”, a patient might conceptualize an alien body sensation like “the dragging of her leg” as “multiple sclerosis”, which could be expressed as: “I am having trouble with my multiple sclerosis nowadays.” However, she does not directly experience her problems as a disruption in the flow of information within the brain, which controls motor functioning, which is the disease identified by the physician. For the physician, the fundamental entity is the damage to the central nervous system, while for the patient, the fundamental entity is the “body painfully lived” which is an alternation and mediation between level 1–3 as described above (Toombs, 1990, p. 236).

Patients are vulnerable to hermeneutical injustice due to their lack of understanding of clinical decision making. They often describe their experiences using non-expert terms and lack the hermeneutical resources available to the physician, which are essential to certain aspects of the diagnostic process. When patients claim that their stance is rejected and that their lived illness-experience is ignored, one might argue that the problem is likely to be grounded in the conceptualization of illness and disease. There is a decisive gap between Sartre’s first three levels, representing the patients’ lived experience, and the fourth, representing the physicians’ conceptualization of illness. This gap

suggests two quite separate experiences, causing harm to patients and their credibility as knowers. This is not to argue that the “objective truth” is in patients’ lived experience of illness. However, as Kidd and Carel, (2017, p. 186) argues “by opening an epistemic space for the lived experience of illness, an important new domain of knowledge—and of further epistemic inquiry and changing of the epistemic balance between patients and healthcare professionals can be revealed.” The patient’s experience of illness might be crucial for the healthcare professional’s understanding of their problems.

Some commentators make a sharp distinction between the phenomenological tradition and historical epistemology. However, there are many affinities between the two traditions illustrated by Georges Canguilhem’s (1966) critical reading of historical conceptions of the normal and the pathological. According to Canguilhem, pathology has—influentially, yet erroneously—been defined through standard quantitative physiological variations. As an alternative, Canguilhem offers a more dynamic conception of physiology in which each (human) body has an internal environment re-iteratively re-establishing individual norms (which Canguilhem coins biological normativity). In fact, the pathological state entails a break-down of the individual ability to create new norms. Pathology, then, generally speaking, is a reduction of the range of norms that an individual can tolerate. In contrast, health is the ability to create new norms corresponding to the shifting environment of the individual.

Canguilhem’s thinking has at least two major implications for the present analysis. First, it challenges the basic distinction between normality and pathology. The morbid state is a normal state in terms of frequency. Consequently, the basic skeptic stance experienced by many patients suffering from fibromyalgia does not reflect the nature of pathology as a phenomenon. More importantly, the pathological is individual and, thus, every patient must be met *as* individuals. Canguilhem concludes his thesis on the normal and the pathological by writing: “Thus, it is first and foremost because men (sic) feel sick that a medicine exists. It is only secondarily that men know, because medicine exist, in what ways they are sick”. (Canguilhem, 1966, p. 229) He goes on to argue: “it is not an objective method which qualifies a considered biological phenomenon as pathological. It is always the relation to the individual patient through the intermediary of clinical practice, which justifies the qualification of the pathological” (Canguilhem, 1966, p. 229). In other words, there does not exist a standard objective test that can be used to override the experience of sickness. For patients suffering with fibromyalgia—their experience is the most robust indicator of pathology.

Epistemological foundations of EBP

EBP has been the dominant model in medicine and other healthcare practices for about three decades. EBP is structured to diminish the gap between scientific knowledge and clinical practice. Introduced in the early 1990s, it soon became a powerful model influencing healthcare professional education and clinical work. According to its proponents, EBP “de-emphasises intuition, unsystematic clinical experience, and pathophysiologic rationale as sufficient grounds for clinical decision making and stresses the examination of evidence from clinical research” (Evidence-Based Medicine Working Group, 1992). Thus, there is a general shift from basing medicine on the reasoning of the individual clinician in pathophysiologic medicine towards basing it directly on scientific evidence in EBP.

One major reason for introducing EBP was to provide more cost-effective services. In addition, EBP methodologies promote objectivity and reduce bias, typically from clinical trials. According to this perspective, the strength of evidence depends

on the number and severity of biases associated with a given scientific method, leading the EBP proponents to formulate an evidence hierarchy. Usually, systematic reviews of randomized controlled trials (RCT) are considered the most reliable source of evidence. Case studies are considered to be somewhat unreliable and are usually placed near the bottom of the evidence hierarchy. Evidence is made available to practitioners through evidence-based clinical practice guidelines. Thus, adherence to guidelines would appear to promote quality, reduce uncertainty, eliminate inequalities and lead to better patient outcomes.

Tonelli (1998) has questioned the EBP epistemology which “attempts to objectively and deductively apply empirical knowledge to specific cases” (Tonelli, 1998, p. 1235). Greenhalgh et al. (2014) and Wieringa et al. (2017) acknowledge the benefits of EBP, while addressing the critical mismatch between population-derived evidence and the needs of the individual patient. Engebretsen et al. (2016) have argued that epistemic uncertainty can stimulate reflective questioning and clinical imagination sometimes needed in the individual cases. Others have argued that healthcare practices are basically dealing with values and ethical stances which are not emphasized within the EBP framework (Berg and Slaattelid, 2017; Berg, 2019).

Although contemporary evidence-based healthcare models have come to include patient values and clinical expertise, the term EBP suggests that scientific evidence has priority, which has a number of consequences (Haynes et al., 2002). Diseases that are easily operationalized have a higher probability to be defined as evidence-based treatments. Moreover, in a system with limited resources, lack of scientific evidence can be conflated with the lack of symptoms because there are no standardized methods to identify these symptoms. In addition, the objective and alleged value-free stance of EBP is skeptical not only of the individual user's symptoms, but also of the interest organizations proclaiming the right of patients with symptoms like that of fibromyalgia (Häuser et al., 2010). In sum, the antagonism between science and the users' individual experience becomes so strong that the healthcare professionals fail to assess the plausibility of patients' testimonies.

Conclusion

We argue that recognition of epistemic injustice is important if we are to prevent ignoring patients' testimonies and interpretations. There is a need for critical concepts to articulate marginalization of patients as knowers. The education of healthcare professionals is significant to improve students' reflective awareness of the knowledge and attitudes guiding clinical practice. It is notable that patient complaints are documented even though epistemic interaction is premised on a context where comprehensive healthcare reforms have been implemented, ensuring that patient values and preferences should guide all clinical decisions. This paper is an illustration of the complexities related to involving and empowering users of healthcare in a more democratic way and the need for reflection about the ethics of epistemic imbalances.

Data availability

This paper does not contain any data beyond the material in the reference list. All data analyzed are included in the paper.

Received: 10 January 2021; Accepted: 28 September 2021;

Published online: 15 October 2021

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Acknowledgements

We would like to express our gratitude to the Centre for Advanced Study (CAS) at the Norwegian Academy of Science and Letters. Kristin Heggen was fortunate to spend the autumn of 2019 and the spring semester 2020 at this center, which is an independent foundation that furthers excellent, fundamental, curiosity-driven research.

Competing interests

The authors declare no competing interests.

Additional information

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