10

RE-WRITING THE MASTER NARRATIVE

A Prerequisite for Mad Liberation

Wilda L. White

Introduction

In the United States, we have the highest rates of unemployment (Henry et al., 2016), the highest rates of disproportionate incarceration (Human Rights Watch, 2006; James and Glaze, 2006), are most likely to be killed by police (Fuller et al., 2015), and die 20 to 25 years prematurely (Walker et al., 2015; Hayes et al., 2015; Siddiqi et al., 2017).

Sixty-eight percent of Americans do not want someone with a mental illness marrying into their family and 58 percent do not want people with mental illness in their workplaces (Martin et al., 2000). While most of us are able and willing to work, surveys of U.S. employers reveal that 50 percent are reluctant to hire someone with a past psychiatric history, approximately 70 percent are reluctant to hire someone currently taking antipsychotic medications, and 25 percent say they would fire someone who had not disclosed a mental illness (Stuart, 2006).

We are the butt of jokes on late night television, scapegoated for gun violence¹ (Obama, 2015; Trump, 2019) and routinely demeaned in the media. The New York Times, America’s newspaper of record, frequently carries headlines such as “Who’s the Real American Psycho?” (Dowd, 2018) or “Is Mr. Trump Nuts?” (The New York Times, 2018).

During his tenure, former President Barack Obama referred to his adversaries as “the crazies,” (Fabian, 2015) and his wife, Michelle Obama (2018:352) who has a reputation for taking the high road, characterized Donald Trump’s birther campaign against her husband as “crazy,” and designed to stir up the “wingnuts and kooks.” For his part, Trump, Barack Obama’s successor, frequently refers to his detractors as “psycho” or “crazy,” and the mainstream media reprint these epithets without a murmur of critique (Johnson, 2017).

Despite this persistent and pervasive marginalization and discrimination, our advocacy focuses almost exclusively on the mental health system and/or critiques of psychiatry. Most advocacy efforts are aimed at increasing “peer” participation in the development of mental health policies, persuading policymakers of the value of a recovery-based, mental health system, and spearheading alternatives to the mainstream mental health system.

Even the burgeoning discipline of Mad Studies delimits its scope as a “critique and transcendence of psy-centered ways of thinking, behaving, relating and being,” (LeFrançois et al., 2013:13).
This hyper-focus on psychiatry and the mental health system has left the many sites of our oppression uncontested. And even in the arena that we do contest – the mental health system – our advocacy typically neither acknowledges nor challenges the root cause of the oppression and discrimination that effectively results in our erasure from society.

Against the backdrop of a psychiatric medical malpractice trial, this chapter introduces the concept of epistemic injustice to illustrate how the failure to focus our advocacy beyond psychiatry and the mental health system facilitates the denial of our basic rights such as the right to redress harm done to us.

The chapter argues that unless and until we, including the discipline of Mad Studies, expand our gaze beyond psychiatry and the mental health system, we will fail in our efforts to liberate ourselves because our oppression is largely rooted in epistemic injustice, an injustice which we must directly confront if we are ever to overcome our oppression both within and beyond the mental health system.

Until we achieve epistemic justice – that is, until society considers us credible witnesses to our own experiences and until we are able to render intelligible to ourselves and others our experiences of oppression – the discrimination and oppression that we experience in all realms of our lives will endure.

**Epistemic injustice**

In 2007, philosopher Miranda Fricker coined the term epistemic injustice to describe the harm that results when, because of prejudice, a person is deprived of her capacity as a “knower” or “interpreter” of her own experience.

Fricker termed the deprivation a person suffers in her capacity as a “knower,” testimonial injustice, and the deprivation a person suffers in her capacity as an “interpreter,” hermeneutical injustice.

Testimonial injustice occurs whenever prejudice causes the hearer to “give a deflated level of credibility to the speaker’s word” (Fricker, 2007:1). A classic example of testimonial injustice is the disbelief with which women are often met when they say they have been raped or sexually harassed. Black people also often find themselves on the receiving end of testimonial injustice during encounters with police or when testifying before juries.

Testimonial injustice is not limited to instances of formal, witness testimony. As conceived by Fricker, testimonial injustice encompasses the full range of speech acts, including asking relevant questions, sharing an opinion, or suggesting a hypothesis. Testimonial injustice arises whenever the relevant statement, question, opinion or hypothesis is disbelieved, ignored, deflected or ridiculed because of prejudice.

Fricker (2007) employed the term “hermeneutical injustice,” to describe what happens when prejudice denies a social group the opportunity to contribute to the pool of knowledge that allows human beings to make sense of and explain their experiences to themselves and others. When a social group has an experience that is unique to that social group, and the group because of prejudice has been denied the opportunity to participate in the creation of the concepts, vocabulary and interpretative tropes necessary to understand, articulate and share that experience, the group is said to be hermeneutically marginalized.

In Fricker’s (2007) conception, hermeneutical marginalization is a prerequisite for a situation to count as a case of hermeneutical injustice. If an experience or condition is not well understood merely because the knowledge has yet to be created, this would not count as a case of hermeneutical injustice, unless the gap in understanding arises from a prejudice that has precluded knowledge creation or knowledge sharing.

77
Psychiatric patients and survivors have been traditionally excluded from creating knowledge about issues that affect us (Wallcraft, 2009:133), although this is not widely known and is itself an example of hermeneutical injustice. Fricker, for example, during a presentation to a group of doctors, once said of people with psychiatric histories:

… if you think they count as a member of a group which is hermeneutically marginalized, I don’t really know how we should think about that, but certainly I’ve had some people say to me who themselves have a history of mental ill health, say we count as such a group. One is hermeneutically marginalized when one has mental illness.

(Fricker, 2015: 00:35:01)

Fricker’s uncertainty aside, there is ample evidence, such as that recounted at the outset of this chapter, that people labeled with mental illnesses are, in fact, hermeneutically marginalized.

When Fricker (2007:149–152) first introduced the concept of hermeneutical injustice, she used as an example the experience of women victimized by sexual harassment before the term “sexual harassment” was coined. Before sexual harassment was given a name, women did not have the language and concepts to grasp and explain their experiences of being sexually pressured in the workplace. Historically, women, owing to prejudice, were excluded from the business of knowledge-creation. As a group, then, women were hermeneutically marginalized. This hermeneutical marginalization created a gap in women’s and society’s shared tools of understanding the experiences of women in the workplace. This lack of shared tools of understanding owing to hermeneutical marginalization is an example of hermeneutical injustice.

Another example of hermeneutical injustice comes from the black feminist movement. In the mid-1970s, five black women sued General Motors alleging discrimination against them as black women. At the time, General Motors hired black men, and it hired white women. It did not hire black women. Because General Motors hired women and it hired men, the court dismissed the lawsuit, reasoning that the law did not contemplate that black women could be discriminated against as “black women.” While black women understood that they suffered discrimination as black women, because they were hermeneutically marginalized, their group understanding was not shared across the social space, including within American jurisprudence.

In 1989, Kimberlé Crenshaw, a UCLA law school professor, re-visited the General Motors case in a law review article and coined the term “intersectionality” to describe the entwined form of oppression black women experience both because of their race and also their sex (1989:139–142). Today, the concept of “intersectionality,” is widely understood across social groups.

Hermeneutical injustice exists both when a marginalized group itself lacks the interpretative tools necessary to understand its own experience, as was the case with women experiencing sexual harassment in the workplace, and also when the marginalized group understands its experience but cannot explain it to those outside the group because of a lack of shared tools of understanding, as was the case with the black women suing General Motors for discrimination against them as black women.

As the foregoing examples illustrate, the harm from epistemic injustice can be significant, depriving people of equal access to employment or a workplace free of harassment. In addition, the capacity to know, reason and inquire is essential to human value. When people are not believed because of prejudice or people cannot themselves understand their experiences or convey them to others because of a dearth of concepts from which to do so, Fricker (2007: 55) argues that the harm is so great it actually prevents people from becoming who they are.
A case study

In 2012, a San Francisco psychiatrist diagnosed me with Attention Deficit Hyperactivity Disorder (ADHD) and prescribed dextroamphetamine, a stimulant, to treat it. At the time, I was 54 years old, held a senior level position at UC Berkeley School of Law, my alma mater, where I earned a six-figure salary. I was also licensed to practice law in three states and was an honors graduate of Harvard Business School. I was debt-free, lived on Telegraph Hill in San Francisco, was in a loving relationship, and was a member of San Francisco’s vibrant squash community.

At the time the psychiatrist prescribed the stimulant, he told me a potential side effect was “mania” and/or “psychosis,” and after I asked what were the signs and symptoms of “mania” and “psychosis,” he referred me to the Diagnostic and Statistical Manual of Mental Disorders (DSM). While I personally take issue with the DSM’s nosology, I had put myself into the country of Western psychiatry where the DSM was the lingua franca. If I wanted to be understood by my psychiatrist, I felt I had to use his language. Thus, in the language of the DSM, within weeks of starting the dextroamphetamine, I was “manic” and “psychotic,” and did not want to be, and less than a year later, I was also homeless, jobless, penniless, single, and deeply in debt.

According to the DSM, the rulebook to which psychiatry purports to abide, a “manic” episode is a distinct period during which a person’s mood is abnormally and persistently elevated, expansive or irritable with at least three additional symptoms from a list that includes: (a) inflated self-esteem or grandiosity; (b) decreased need for sleep; (c) pressure of speech; (d) flight of ideas; (e) distractibility; (f) increased involvement in goal-directed activities or psychomotor agitation; and (g) excessive involvement in pleasurable activities with a high potential for painful consequences. “Psychotic” features such as “hallucinations” (perceiving things through the senses that are outside the consensus reality) and “delusions” (believing things that are outside the consensus reality) can also be present. The expansiveness, unwarranted optimism, grandiosity and poor judgment that are characteristic of “mania” often lead to an imprudent involvement in pleasurable activities such as buying sprees and foolish business investments (American Psychiatric Association, 2013:123–129).

Over the course of a year, I told my psychiatrist repeatedly that I was “manic” and later “psychotic.” While I was aware of my behavior and activities, I had no power to control them. In fact, I felt somewhat possessed.

I told the psychiatrist I was not sleeping, felt more creative, and was spending more money than I wanted to spend, including buying a brand-new car for a niece. Overnight, I adopted a new goal to raise millions of dollars for the law school. I told him about plans to start a business to end racism and shortly thereafter, I told him I was placed on administrative leave at the law school after delivering a speech at a Gala during which I warned prospective students, who were visiting campus to decide whether to attend the law school, not to attend because the law school was racist. I told him colleagues had begun to call me “crazy.”

The psychiatrist wrote:

Pt. appears to be exercising sound judgment in making decisions; seems to understand risks/benefits/consequences of her actions/behaviors; … able to articulate her thoughts in a way that makes sense and is in keeping with her passion/experiences in life; noted to pt. that many people who have experienced racism may just stay quiet about it or not take action, but that she’s different in a way because it is her calling to take action to address it.
Mad Studies and political organising

I also told him that I took out a $20,000 line of credit to launch my business to end racism, which my friends felt was an expression of “mania,” particularly in the way I was going about it.

The psychiatrist wrote:

Her friend thinks that pt. starting the [business to end racism] represents mania; however, given pt’s lifelong interest in ending racism and fighting for justice, it’s difficult to glean whether this behavior represents grandiosity or bold entrepreneurial vision/normal risk taking.

Friends also directly contacted the psychiatrist to report their observations. One reported that I had “lost a lot of weight, my apartment was a mess, I was not thinking clearly, and was clearly not myself.” The psychiatrist wrote:

I don’t see any clinical evidence of hypomania or mania. … For the most part, when I ask her about the risks, consequences and benefits of the decisions she’s making, she seems to be exercising good reasoning and is able to articulate her thoughts clearly.

A second friend wrote in an email:

Changes that I have witnessed in her attitude and behavior include a shift from risk-avoidant to risk-embracing behavior in relation to her finances and work-life, elevated mood, a sense of greater openness and expansion of possibilities, and a development of a personal relationship to God.

The psychiatrist wrote:

In my opinion, pt may have some degree of hypomania, but even that is not clear to me; she appears to understand the risks that she’s taking and is sound in her thinking about it.

I told him I was communicating with my dead parents and at their instruction I flew cross country to purchase a half-a-million-dollar home for my niece.

The psychiatrist wrote:

Unclear to me if pt is having true manic episode or speaking metaphorically or having more of a spiritual experience.

After I was fired for the remarks I made at the Gala, I applied for private disability insurance. The disability insurer’s psychiatrist, relying solely on the psychiatrist’s medical records found me disabled due to “mania” and “psychosis.” Thereafter, my psychiatrist retroactively diagnosed me with “mania” and “psychosis.” The psychiatrist wrote:

Things that I saw that I now consider to be features of mania in her are: (1) increased confidence; (2) acting more aggressively; (3) decreased social inhibition, e.g., saying things in contexts where she would have previously exercised greater personal reserve; (4) increased spending; (5) feeling more religious/spiritual than she normally is. … I’m on my toes trying to pick up these clues/symptoms now (I still feel lousy for having missed them the first go around).
In other words, the psychiatrist acknowledged seeing for himself the same signs that I and my friends reported when we told him that I was “manic.”

When I asked him how he could have failed to recognize the “mania” and “psychosis,” which my friends and I pointed out repeatedly, he wrote that because I did not exhibit during sessions with him “racing thoughts, flight of ideas, pressured speech, grandiosity, sense of invincibility, and social disinhibition,” it was difficult for him “to discern the characteristic mental status changes of a manic episode.”

I would go on to learn that I did not meet the DSM criteria for ADHD and the unnecessary prescription of dextroamphetamine had most likely triggered the “mania” and “psychosis,” which abated after I stopped taking the drug. By this time, my savings were gone, and with the loss of my job, so was my $2 million pension and net future earnings. A few months later, I was homeless.

For his part, my psychiatrist inserted a secret, five-page “updated diagnostic formulation note” in my medical records, which purported to diagnose me with narcissistic and paranoid personality disorder based, among other things, on my history of rape, my brother’s diagnosis of schizophrenia, and the following:

She reported to me that she refused to show identification to the police officer because she was concerned that, being black, there was a higher chance that the male officer would mistake her for taking out a weapon instead of her identification — and consequently that a firearm would be discharged against her preemptively.

The psychiatrist hid the updated note from me. I learned about the note months later from records the psychiatrist sent to my disability insurer.

Given the enormity of my loss, I decided to pursue a medical malpractice action. I contacted dozens of lawyers. None was willing to take on a case on behalf of a client with a psychiatric history. I eventually found one lawyer who was willing to meet with me. However, after helping me file the initial lawsuit, he decided not to follow through and in the end, I reluctantly served as my own lawyer.

Once I got to trial, the judge, who was white, was hostile to me and my case at the outset. When I proposed using a written, jury questionnaire to tease out issues of bias based on race, sexuality, gender or psychiatric history, she announced that no such biases existed in San Francisco. During jury selection, she refused to allow me to ask prospective jurors about their own psychiatric histories or experiences with psychiatrists because in her words that was too embarrassing and shameful. Of course, if the case had involved medical malpractice based on a physical ailment, I would have been permitted to ask jurors about their familiarity with the physical ailment and their experiences with medical doctors.

During conferences with the judge, whenever I reported the facts of the case in support of an argument, the judge would turn to opposing counsel and ask, “is that true?” She never asked me whether what my opposing counsel reported was true. She simply accepted it as true even though many times, it was not.

The jury was permitted to ask questions of witnesses during the trial and at one point a juror asked my former psychiatrist what was my diet. He replied without missing a beat that I was a lifelong vegan, which I was not.

Although my psychiatrist had admitted several times in his medical records that he believed the dextroamphetamine had triggered the “psychotic manic” episode, he changed his position at trial and maintained that the episode was an organic process caused by bipolar disorder.
Medical malpractice trials require expert witnesses. My expert witness testified that the psychiatrist’s treatment fell below the standard care because he failed to conduct an assessment to justify the ADHD diagnosis; he unnecessarily prescribed dextroamphetamine for a presumed diagnosis of ADHD; and he failed to recognize and treat the “manic psychosis” that was triggered by the dextroamphetamine.

In the end, the jury sided with my former psychiatrist’s expert witness who testified that amphetamines do not cause “psychosis” and that it was a shame that I had been told that the episode was iatrogenic, when in fact I had the severe and chronic mental illness of bipolar disorder.

Discussion

Distributive and Discriminatory Epistemic Injustice

Epistemic injustice can take on both distributive and discriminatory forms. The distributive form encompasses whether people have fair access to epistemic goods such as education, information, good advice, legal services, and similar resources. The discriminatory form, of course, involves unequal treatment owing to prejudice.

My inability to find a lawyer willing to represent me exemplifies the distributive form of epistemic injustice and also the discriminatory form because my inability was due to my psychiatric history. Discrimination against people with psychiatric histories is so normalized that lawyers freely admit to it. For instance, in a continuing legal education seminar on medical malpractice available on the internet, a New York trial attorney (Oginski, 2014:00:00:25) advises attendees “you should run as fast as possible away” from potential clients with psychiatric histories even where there is a valid basis for a claim, adding that this was the considered opinion of many experienced trial attorneys.

As an attorney, I was technically able to represent myself. However, I was severely disadvantaged as a self-represented litigant. The psychiatrist was represented by three lawyers whose fees and expenses were paid by an insurance company. My psychiatrist’s insurance company even paid him to attend trial. In contrast, I worked alone with no support and the expenses of my under-funded lawsuit were paid by a GoFundMe campaign. And although the law permits a self-represented litigant to testify in narrative form, the judge would not allow me to do so. I was made to ask myself questions and answer them. The irony of a person with a history of “psychosis” effectively talking to herself on the witness stand was not lost on me and likely left a negative impression on the jury.

Testimonial Injustice

The psychiatrist not believing me when I reported that I was “manic” and “psychotic” is an obvious case of testimonial injustice. When I reported the symptoms that were concerning to me, he appointed himself the epistemic authority of my irreducibly subjective experiences of elevated mood, decreased need for sleep, and increased energy.

Not only did he disbelieve my subjective experiences, but also he substituted his judgment for my own. For example, where I said I exercised poor judgment in speaking at the Gala, he wrote that I “appeared to be exercising sound judgment in making decisions.” When I told him I was concerned about the grandiose idea of starting a business to end racism, he not only dismissed my concerns, he enabled the idea, suggesting that I turn to Kickstarter to help finance the endeavor.
Re-writing the master narrative

The jury’s asking my psychiatrist, rather than me, about my diet also exemplifies a form of testimonial injustice which Fricker calls preemptive testimonial injustice. Preemptive testimonial injustice happens where prejudice on the part of inquirers causes them not even to bother asking your view. The juror’s question signaled that I was not viewed as an attorney or an individual with agency from whom information was solicited. Rather, I was a specimen from which data was extracted. In other words, I was epistemically objectified.

In reality, the psychiatrist knew nothing about my diet. Perhaps believing that he was expected to know, he simply invented a response which received no credibility deflation notwithstanding how unlikely it was that a 60-year-old, American woman had been a vegan since infancy. In this instance, the psychiatrist received an inflation of credibility, which is yet another example of testimonial injustice because it arises out of the jury’s epistemic objectification of me.

The judge’s practice of asking the opposing attorney whether what I reported was true is another example of testimonial injustice. In fact, the judge’s question reveals her deep-seated prejudice against me. As an attorney in the American legal system I am considered an officer of the court and as such entitled to the presumption of truthfulness. In my decades of practicing law, a judge had never questioned my veracity. In turning to my opposing counsel as the arbiter of my credibility, she revealed that she herself had no legitimate basis to disbelieve me. She made no credibility judgment. She simply found me inherently untrustworthy based on my status as a self-represented, black woman with a psychiatric history.

The psychiatrist’s expert witness also did not believe my reports of symptoms. This is yet another example of testimonial injustice. Fricker’s conception of prejudice is fairly broad and is defined as a motivated resistance to counter-evidence owing to close-mindedness. Here, I was ultimately vindicated by the disability insurer’s determination that I was experiencing a manic episode, by my psychiatrist’s retroactive diagnosis of the same, and by the catastrophe that befell my life as a result of activities I engaged in while “manic.” However, the psychiatrist’s expert witness resisted this evidence without any rational basis.

The jury’s decision to side with the psychiatrist’s expert witness is also an example of testimonial injustice when you consider that the evidence was far more compelling that the dextroamphetamine triggered the episode. First, “mania” and “psychosis” are recognized side effects of dextroamphetamine. Second, the episode began within weeks of taking the drug and abated on its own when I stopped. Third, I had never before experienced a spontaneous “manic” episode. Fourth, at the time of trial, I had not seen a mental health practitioner in three years, had received no medical interventions, and showed no psychiatric symptoms, which according to the testimony would be an atypical course for chronic, lifelong bipolar disorder. Fifth, my psychiatrist had admitted in writing on numerous occasions that he believed the dextroamphetamine triggered the episode.

Unlike my expert, the psychiatrist’s expert witness had never examined me. He nevertheless testified that I had chronic, lifelong bipolar disorder and that the “manic” episode was triggered by the loss of my job even though my employer testified that I lost my job because of behavior I engaged in while “manic” and even though both my friends and I reported our concerns to my psychiatrist many months before I lost my job.

The expert witness for the psychiatrist also testified that amphetamines do not cause “psychosis.” On cross-examination I confronted him with the following passage from a report he wrote a few years before trial:

In the 1950s, amphetamines began to be widely distributed for weight loss and the 1960s saw a peak in amphetamine use. However, this widespread consumption also
led to increased recognition of amphetamine’s negative health consequences including amphetamine psychosis.

(Urman-Yotam and Ostacher, 2014:2)

And when I asked him on cross-examination if he warned his patients to whom he prescribed amphetamines that they can cause “psychosis,” he said that he did because it was standard of care to do so.

I ultimately do not know precisely why the jury sided with the psychiatrist. Trials are complicated and there are many factors at play. I was not only a former psychiatric patient, I was also the only black person in the courtroom. As a self-represented litigant, I was also out-lawyered and out-resourced. However, none of that should affect the power of the evidence, which is why I offer this as an example of testimonial injustice. In the final analysis, the power of prejudice appears to have trumped the power of the evidence.

Hermeneutical injustice

The manner in which the psychiatrist’s secret personality disorder diagnosis played out is an example of hermeneutical injustice.

For strategic reasons, I attempted to include as part of my lawsuit the harm I suffered upon discovering the secret personality disorder diagnosis. Essentially, I argued it was a fraudulent diagnosis. In pre-trial proceedings, the psychiatrist’s lawyers opposed this attempt. The judge ultimately sided with the psychiatrist, asking why would a psychiatrist make a fraudulent diagnosis. The judge simply could not imagine a scenario under which a psychiatrist would offer a diagnosis that was motivated by anything other than helping a patient.

Although the judge could not imagine such a scenario, I was well aware through my contacts with other psychiatric survivors that a personality disorder diagnosis is the most charged psychiatric diagnosis of all. “You know you’ve really pissed off a psychiatrist when they diagnose you with a personality disorder,” a fellow psychiatric survivor once told me.

Other psychiatrists also had no difficulty recognizing the secret diagnosis for what it was. The psychiatrist who interviewed me for eight hours and reviewed my records on behalf of my disability insurance company wrote in his report to the disability insurer:

I am skeptical of the fact that … only just before their final session when Ms. White angrily confronted [the psychiatrist] over his failure to note her manic psychosis and treat her appropriately and terminated treatment with him, telling him that she no longer trusted his judgment, did he diagnose her with a personality disorder.

And the psychiatrist who prepared a rebuttal to the personality disorder diagnosis, wrote:

It is worth observing, in my opinion, that there is a conflict of interest here for [the psychiatrist]. In making this diagnosis, he provides an alternative explanation for the suffering that she experienced during her manic episode, one that shifts responsibility for this suffering predominantly to her, thereby mitigating the moral responsibility he might otherwise feel for prescribing her a stimulant medication which, in all likelihood, triggered her mania.

However, owing to the hermeneutical marginalization of psychiatric survivors, I did not have available to me shared concepts, background information, and interpretive tropes to help the
judge understand why a psychiatrist would make a fraudulent diagnosis. As a result, I was unable to hold the psychiatrist accountable.

My psychiatrist not believing me when I reported that I was “manic” and “psychotic” is also an example of hermeneutical injustice, based both on my race and my status as a psychiatric patient.

The psychiatrist rationalized my behavior at the Gala through the lens of race, reasoning that I made the inappropriate comments that led to the loss of my employment based on a “calling to take action to address [racism].”

First, I cannot resist noting the irony of the psychiatrist characterizing the remarks that led to my employment termination as consistent with my passion and life experiences and thereafter pathologizing as indicative of a personality disorder my refusal to comply with a police officer’s unlawful demand to see my identification.

Second, no black psychiatrist or perhaps any psychiatrist with any knowledge of how black people negotiate their professional lives would have reached this conclusion. How could I both work at the law school and tell students not to attend and expect to have my job at the end of the day? In this sense, I was harmed by the psychiatrist’s ignorance about how black professionals navigate white professional spaces. While this information is known among black people, owing to hermeneutical marginalization, it was not within society’s common pool of knowledge sufficient to reach the awareness of this psychiatrist.

This example also counts as hermeneutical injustice based on my status as a psychiatric patient. However, to understand this as such requires background information that is simply not within the common pool of societal knowledge, owing ironically to hermeneutical injustice. It was not even within my own ken at the time I attempted to get my psychiatrist to take the reports of my symptoms seriously.

What I have come to understand is that the term “mental illness” connotes not just a state of mental ill health. The term is also deeply ideological and includes a set of beliefs, values and assumptions that shape public opinion, drive mental health policy, and influence treatment decisions. The ideology of mental illness conceptualizes mental illness as extreme, aberrant, often deviant behavior, which makes others uncomfortable and is so simple to recognize that everybody knows.

Thus, while there are 35 unique combinations of symptoms all of which meet the DSM definition of a “manic” episode, practitioners learn to recognize and act upon a single, stereotypical portrayal of “mania.”

A witness for the psychiatrist testified, as follows, about how he was trained to recognize “mania” and “psychosis”:

What I recall from my days in graduate school … is that one of the cardinal signs for manic diagnosis, at least the way that it was taught to me, is that the therapist actually feels the – an oddity, an exaggeration in the way that the client is expressing themselves or a rapidity in their speech, a pressure in their speech; there is sometimes such a fluidity between one idea to another idea to another idea that it starts to feel uncomfortable to the therapist, and that experience is something that we were taught we should pay close attention to as a way of hypothesizing that perhaps we have someone that is having a break with reality.

After the disability insurer’s doctor stepped in, my former psychiatrist readily acknowledged that he had indeed observed the signs of “mania” all along. However, he disregarded them because I did not manifest stereotypical signs such as racing thoughts, pressured speech, distractibility,
and flight of ideas. There is also an unsubstantiated, but dominant clinical and research view that people experiencing “psychosis” have pervasive cognitive, reasoning deficits (Sanati and Kyratsous, 2015), which I also did not exhibit.

Thus, because of the ideology of mental illness and its focus on behavior that is disconcerting to others, my psychiatrist’s recognition of my condition depended on a complex chain of circumstances in which my symptoms were not paramount. How I felt about my symptoms was much less important than how others felt about me. The effect I had on a clinician, the stereotypical manifestation of “mania” and “psychosis,” and an unawareness of my mental state were all more important to a diagnosis of “mania” and “psychosis” than whether my symptoms met DSM criteria or whether I was bothered by them.

In fact, my awareness of my symptoms worked against me because psychiatrists have been incorrectly taught that individuals who are “psychotic” do not typically recognize that they are. To say you are “psychotic” is to prove you are not. The combination of this classic Catch-22 and my ignorance about the ideology of mental illness deprived me of the conceptual tools to convince my psychiatrist that I was, according to his own nosology, “psychotic,” and did not want to be.

Importance of epistemic equality

What I have set out to demonstrate through the example of my trial is that (1) the oppression we experience in the mental health system is not confined to the mental health system but infiltrates every aspect of our lives; and (2) the root cause of that oppression is epistemic injustice.

Fricker (2014) has suggested that social epistemic contribution – the contribution of concepts, meanings, interpretations, beliefs, and knowledge to the pool of shared knowledge – is so crucial to political freedom, freedom of speech, and non-domination, that it is worthy for inclusion on philosopher Martha Nussbaum’s list of central human capabilities. Nussbaum (2000) conceived the list as a description of basic things considered necessary for survival and to avoid or escape poverty or other serious deprivals.

I agree with Fricker. Epistemic justice is fundamental to political freedom and in my estimation, epistemic injustice underlies, among other things, the barbaric practice of psychiatric forced drugging, a separate and inherently unequal mental health system, our underemployment and overincarceration, and the grip of biomedical psychiatry despite its largely conjectural nature.

Epistemic injustice led to the destruction of my health, and the loss of my home, my livelihood, and my savings. And owing to epistemic injustice, I could hold no one to account. I could not retain an attorney to represent me. I could not make the judge and jury understand the harm I suffered or my psychiatrist’s improper motives. I could not even serve as a credible witness to my own experience and witnesses who testified on my behalf were painted with the same broad brush of testimonial injustice.

Trials are ultimately about storytelling through shared tropes, shared concepts and common knowledge. Those who are excluded from the creation and dissemination of interpretive tropes, concepts and knowledge are seriously disadvantaged in such a process, a process that is essential to American democracy and its promise of freedom.

A fundamental tenet of American jurisprudence is due process, meaning notice and an opportunity to be heard. However, the concept of epistemic injustice teaches that it is not enough simply to be heard. One also needs to be believed and understood.

Thus, epistemic justice is foundational. Without epistemic justice – both distributive and non-discriminatory – there can be no other justice. It is impossible to contest the many sites of
Re-writing the master narrative

our oppression if we are not believed and if we cannot render intelligible to ourselves and others the harm that has been done to us sufficient to redress those harms.

Epistemic justice: How do we get there?

Overcoming epistemic injustice necessarily begins with an awareness of its existence. And just as voting rights were for black Americans, epistemic rights for us must be central to our advocacy and scholarship. While we cannot simply demand that people find us credible, there are ways of being in the world and actions we can take that confront hermeneutical injustice, and in the process, transform the social attitudes that perpetuate discrimination and oppression against us.

The rallying cry of consumers/ex-patients/psychiatric survivors – “Nothing about us, without us” – has led some of us to fight solely for the right to be present when decisions are made about us and to require only our lived experience as the price of admission. However, epistemic justice requires more than merely the presence of our lived experience during discussions about us. We must have something useful to say and we must be heard, believed, and understood.

To that end, we must ask more of ourselves and each other. Each of us must offer more than our lived experience or stories of recovery in the venues where our advocacy takes form. We must strive to create theories, concepts, meanings, interpretations, beliefs and knowledge that combine our lived experience with thought, reason, and creativity. And we must disseminate this new knowledge through mainstream media, including social media. We need more letters to the editor, more blogs, more magazine articles, more TED Talks, more YouTube videos, more tweets and more Op-Ed pieces directed to a mainstream audience that challenge the dominant conception of who we are. We must not allow our challenges to be reduced simply to recovery from illness. Rather, we must interrogate the ideology of mental illness, which keeps us underemployed, overincarcerated, prematurely deceased and ghettoized and mistreated in a doctrinaire mental health system.

The burgeoning discipline of Mad Studies has a critical role to play in this regard. However, for the field to contribute to Mad liberation, it must aim higher than transforming the mental health system or adopting alternatives to biomedical psychiatry or replicating other social justice movements and critical studies disciplines that have found a place in society by fitting neatly within society’s tax-paying, law-abiding, we-are-just-like-you-and-want-what-you-want Master Narrative. Invariably, these movements have replicated and perpetuated the oppression of the dominant culture and have left many members of those movements behind.

For true liberation, Mad scholars and activists must re-write the Master Narrative in its entirety, and that narrative must be grounded in difference not sameness, humanity not sanity, and the inherent value of people not the transactional value of money.

Notes

1 Following the October 2015 shooting in Oregon, President Barack Obama said: “And it’s fair to say that anybody who does this has a sickness in their minds, regardless of what they think their motivations may be.” Following the August 2019 mass shootings in Texas and Ohio, President Donald Trump said: “Mental illness and hatred pulls the trigger, not the gun.”


3 Throughout this chapter, except when quoting others, terms of art from Western psychiatry will be enclosed in quotation marks in an attempt to mitigate their violence and underscore that I do not endorse these terms. I used these terms in relation to myself only in the context of trying to be understood by my psychiatrist and others whose mother tongue is the DSM.
Mad Studies and political organising

References


Re-writing the master narrative


