

Turning Mad: A First-Person Account

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Abstract

In this commentary, I discuss the ethics of 'lived experience' in Mad activism through a personal exploration of emotion in identity politics. From an autoethnographic standpoint, I reflect on how the experience of anger has contributed to my identity shift from patient advisor to Mad activist. Building on these reflections, I highlight some links between systemic injustice, righteous anger, and radical activism observed across a diversity of spoiled-identity movements. To conclude, I invite the diversity of Mad folks out there to understand, proudly assert, and channel the raw power of that anger into the organizing of emancipatory social change.

Keywords: Righteous anger, Mad Studies, spoiled-identity activism, lived experience, emotion

This paper proceeds in four steps. I begin by sharing some elements of my experience as a mental inpatient and outpatient. Then, I recount my subsequent stint as patient advisor promoting a reformist agenda at the clinic where I had previously received treatment. Third, I reflect on how my moral outrage at the systemic injustice I experienced as I participated in the activities of that clinic's research group gave rise to a persistent sense of righteous anger that drove my shift toward Mad activism. Finally, I highlight that although abundantly described across various spoiled-identity literatures, the theoretical and practical implications of anger in activism remain largely overlooked and deserve further exploration.

Being a mental patient

A few years ago, I was admitted to the psych ward of a mental hospital in Canada. After about three months as an inmate (split between the mood and the psychotic disorder units), I was discharged with a brown bag full of pills and offered a 2-year follow-up at the hospital's first-episode psychosis outpatient clinic. I realized that, just like in the inpatient ward, at the outpatient clinic drugging was the main approach to patients' treatment, whereas social support, talk therapy, or anything other than drugging, was seen by professionals as peripheral and largely optional. Early on, I felt that what that clinic had to offer was foreign to my needs.

I needed meaning and purpose, they gave me labels and drugs.

Beginning in the winter of 2012 and over a period of about two years, I was prescribed at least fifteen different drugs: anxiolytics, antidepressants, antipsychotics, and anticholinergics to mitigate the tremor caused by the antipsychotics. Although I repeatedly expressed concerns about the effects of these drugs on my health, I was asked to blindly comply with this mind-blowing polypharmacological treatment based on the arguments that 'my' psychiatrist knew best and that I lacked insight.¹ Despite my continued experience of various 'side effects,' the deleterious impact of the drugs on my health were systematically downplayed – I was offered simplistic and misleading responses to my sensible questioning of this all-drug approach. In one instance, my psychiatrist said that I should read the long list of possible undesired effects that feature on a bottle of Aspirin and implied that, much like with Aspirin, most of the side effects listed on a box of antipsychotics in reality rarely occurred. Anyone who has ingested antipsychotic drugs at some point in their lives will know how disingenuous this argument is.

About six months into my treatment at that facility, as the drug cocktail I was ingesting on a daily basis was not working as hoped, I was declared 'treatment resistant'. This notion of treatment

¹ The way we usually say "my" psychiatrist always seemed odd to me. I feel that it misrepresents the pervasive sense I experienced throughout my treatment that the psychiatrist assigned to my treatment did not work for me. Rather, the implicit understanding seemed to be that I had to submit to her authority, fit within her templates, and comply with her guidelines. Thus, she did seem to consider me as "her" patient, but I never felt that she was "my" psychiatrist. Having said that, I will stick with the use of "my" psychiatrist to keep a smooth reading.

resistance, I realized, is remarkably biased. If you get better it's because the drugs work, and if you don't it shows you're 'treatment resistant'. Either the drugs get the credit or the patient gets the blame. The answer to treatment resistance, of course, was to increase doses, to add more drugs to the cocktail, or to switch one drug for another. It seems that the less the drugs work, the more they give you.

Around the spring of 2014, I was beginning to feel much better and barely checked any 'symptoms' on my psychiatrist's checklist. By that time, and because of my continued insistence, the number of drugs and the doses I was prescribed had been significantly reduced. Since the early moments of my crisis, I had been engaging intensively in talk therapy and community-based peer support, in which I had much more confidence than the drugs. This helped find meaning to my internal struggles and make tough decisions regarding work and relationships, decisions I had not had the courage to make until that point. For that, I felt proud and gave myself much of the credit for my improved condition. In my view, I was feeling better despite the drugs, not thanks to them.

But for my psychiatrist, I was doing better because her drugs had prevailed over my 'treatment resistance.' I found that cheap credit-taking awfully disheartening. And when I asked for assistance to wean off drugs, she insisted that I was too fragile and would have to stay on a 'maintenance' dose of the various drugs she was pushing for at least two to five years, or else her 'guidelines' said that I would 'relapse'. At that point, my 2-year follow-up at the clinic was coming to an end. She transferred me to my family doctor and offered me no assistance whatsoever to wean off drugs.

So, I did that on my own.

Becoming a patient advisor

In the last year or so of my follow-up at the outpatient clinic, I started a PhD in organization studies and began a collaboration with the research group attached to the clinic. I wanted to study peer support and patient involvement in psychiatric services through action-research method. They also agreed that I would collect ethnographic data on the research group's activities as part of my thesis. For a while, the clinic's leaders had been saying that they needed a plan to 'engage service users'. I told them I could help them figure that one out. They said good, come on in. Through repeated frustrations, I progressively realized that the clinic's interest in user engagement was essentially

tokenistic: the doctors running the clinic merely wanted to co-opt a few ‘service users’ to give outsiders the impression that the clinic valued ‘lived experience’ and ‘co-constructed’ service improvements with patients, trendy terms nowadays. In reality, however, their ‘engagement’ efforts were set up and managed to prevent patients from gaining a genuine voice or from influencing established research and clinical practices.²

This trend toward ‘engaging’ people with ‘lived experience’ in psychiatric services has gained international prominence in recent decades. Mad researchers have described how ‘user engagement’ is performed by inviting patients to tell their stories in testimonies to fellow patients, their relatives, and ‘mental health’ employees (Costa et al., 2012) or by hiring them as peer workers in existing services (Fabris, 2013; Voronka, 2017). These analyses show how patient engagement is often implemented in ways that primarily serve the interests of psychiatric institutions and professionals (e.g. for legitimization and to attract funding) while offering patients few opportunities to make a meaningful contribution.³ What these authors describe is precisely what I experienced at that clinic. Mostly, it was empty talk and optics management, with no intention to do something real.

At the clinic’s ‘educational’ events, to which the research and clinical staff as well as a few selected service users and relatives were invited, drug companies usually provided lunchboxes for everyone. Behind the reception counter, there was a warehouse full of drug samples provided by the companies’ reps. Pharmas funded the research group’s studies on the efficacy of their products through ‘unrestricted grants’. The research group’s principal investigators, who were also the clinic’s director and assistant director, recruited patients as subjects in their drug studies soon after their admission to the clinic. One study was conducted on the efficacy of an antipsychotic drug which was systematically offered to patients at their first psychiatrist’s visit after they were admitted. Patients, including me, were being told this was a better drug because it provoked “little or no weight gain,” contrary to other newer antipsychotic drugs which cause obesity and diabetes. This was also the

² For an elaborate and illustrative description of ‘user engagement’ as tokenistic co-optation of patients in psychiatric services, see Penney and Prescott (2016, pp. 35-45).

³ My view of what constitutes a “meaningful contribution” is based on Sherry Arnstein’s *Ladder of Citizen Participation* (1969). This well-known model defines three broad levels – nonparticipation, tokenism, and citizen power – at which decision-making power in government agency programs is shared (or not) between the government agents (or in our case, the professionals) administering the program and the citizens (or in our case, the patients) who are its intended recipients.

argument used in the consent form that I signed when I was recruited in that study back in 2013, as I was admitted to the outpatient clinic when I was released from the psych ward.

Later, I became aware that, in parallel with their cumulation of governance, management, research, and clinical functions, these top psychiatrists were receiving personal financial compensations from the three companies that commercialize the drug. In articles they publish in 'scientific' journals, they disclosed these conflicts of interests as advisory, consulting, and speakership fees received from these companies. I found this information because, as a doctoral student, I have access to academic databases that most mental patients either don't have access to, or don't look at. To recruit the number of research subjects they needed to claim statistical validity, they used us, the clinic's patients, as a pool of guinea pigs. They didn't bother to disclose any of their personal conflicts to us, 'their' patients, as they recruited us in their studies and had us sign their consent forms. They called us their 'clients' and, in fact, they used us to test their patrons' products. We put our health at risk in their 'studies' so that they can collect their consulting fees and publish their corrupt articles – what kind of deal is that?

Before that treatment episode, I studied business economics and worked several years as an investment analyst. With that background, assessing business models became a second nature. As with everything else, I became interested in the clinic's business model. Early on, I noticed the apparent misalignment between the clinic's services and its clientele's needs. Although I did not have access to its accounting books, the clinic gave all signs of being quite reliant on the industry, given the multiple research and clinical activities there that were funded with pharma money and/or related in one way or another to drug products. There didn't seem to be an activity there in which drug companies were not involved. Looking at the big picture of what was happening there, it seemed clear to me that the doctors running that clinic were serving the industry rather than the clientele.

When I realized that, I felt deeply betrayed.

Turning Mad

The moral outrage that was flowing in my veins as I contemplated what I now saw as a drug-

money gimmick fed a righteous anger that I channeled into Mad activism.⁴ For about two years, I collaborated with the clinic's research group. I relentlessly invited them to make their practices more inclusive and to encourage peer support. In research meetings, I would attempt to bring in the excluded voice of patients and to question service providers' one-sided working assumptions. A few family members also sought to get involved in the clinic's research activities. I was most often the only person with known 'lived experience' sitting at the table and participating in the research group's discussions and activities. I repeatedly argued that the citizenship model of participation I was promoting required the nurturing of a mutual trust that was incompatible with the continuation of the clinic's drug-money gimmick.⁵

Along the way, I started a "no free lunch" initiative, bringing my own lunches at research events and inviting staff members to do as much and reject pharma lunchboxes. About five of them joined my initiative, and the pharma lunchboxes suddenly became less tasty for those who didn't. I also insisted for transparent disclosure of which companies paid for lunchboxes at events. A few staff members supported my request, which forced the doctors who run the clinic to reluctantly do so. Time and again, I advocated for greater integrity and transparency at the clinic. Most often, my views were ignored, minimized, invalidated, silenced. They always resorted to some innovative arguments to finesse away these issues, to awkwardly pretend that they didn't quite know what I was talking about, or to hint that I was exaggerating, making stuff up. It was often suggested that I was the problem: my attitude was oppositional, antagonistic, slanderous. Some of them sought to invalidate my disagreements by floating around that I was possibly manic.

As I grew the sense that my efforts to promote reform in the clinic's practices were futile and came to see their 'user engagement' agenda as empty talk, my belief in patient involvement progressively disintegrated. When they began to intimidate me so that I shut up on the clinic's drug-

⁴ I use the term "Mad activism" in a broad sense that includes a diversity of radical approaches pursued by people who have experienced emotional/perceptive distress and related treatments, denounce psychiatry as oppressive, and/or seek to develop by-and-for alternatives to 'mental health' (see Starkman, 2013). For more, see the Glossary section of *Mad Matters* (LeFrançois, Menzies, & Reaume, 2013, p. 337) which provides useful definitions of terms such as 'Mad nationalism', 'Mad ontology', 'Mad pride', 'Mad Studies' and 'Madness' that are well aligned with my understanding and use of the term "Mad activism".

⁵ Unfortunately, these practices of close proximity with the industry seem to be largely accepted by regulators and entrenched into medical institutions.

money gimmick, I promised them that the more they tried to silence me, the louder I would speak out, which I did. I filed formal complaints to the relevant oversight bodies to denounce their corrupt activities. At that point, my time collaborating with mental health professionals was over. As my political horizon shifted, I began reflecting on how we, ex-mental patients, psychiatric survivors, and all kinds of Mad folks, need to collectively organize in order to render psychiatry obsolete.

Harnessing this righteous anger rooted in my moral outrage, I dropped the patient advisor's reformist agenda and shifted toward a Mad political identity oriented toward a political horizon of radical social change. This identity shift (see Britt & Heise, 2000) allowed me to convert my isolated experience of shame and fear into a collectivized sense of belonging in the vibrant anger and assertive pride that I discovered in the Mad movement. Turning Mad legitimated the full expression of my anger and freed me from the 'mental health' epistemic hegemony.

Anger in spoiled-identity activism

During my period of collaborative work with the clinic, I became friends with a dissenting practitioner, a guy with a remarkable intellectual curiosity. Every now and then, we would get together and have long conversations about mental health and beyond. One day, over breakfast, I opened up to him about the depth of my anger – how anger consumed me in the inside. He invited me to further channel my anger into theoretical inquiry, to explore what this anger means and how it could be turned into a positive force for social change. His tip was just what I needed. From there, I began exploring the role of anger in activism, in social movements, in Mad Studies. I paid attention to how spoiled-identity activism drew on anger as a fuel for creative defiance.⁶ I found out that anger runs deep in psychiatric survivor literatures. Four decades ago, the early leader of the ex-patient liberation movement Judi Chamberlin (1977) forcefully connected the collective anger of ex-mental patients to their activist drive to replace the mental health system with survivor-controlled alternatives:

In the mental patients' liberation movement, we have examined the ways in which we

⁶ The term "spoiled identity" refers to the ostracism experienced by members of social identity groups bearing a common, ostensible attribute seen as shameful based on dominant social norms of acceptability, which is brilliantly described in Erving Goffman's (1963) *Stigma: Notes on the Management of Spoiled Identity*.

were treated when we ‘went crazy.’ . . . We came together to express our anger and despair at the way we were treated. Out of that process has grown the conviction that we *must* set up our own alternatives, because nothing that currently exists or is proposed, fundamentally alters the unequal power relationships that are at the heart of the present mental health system. (p. xiii)

The anger felt by mental patients is frequently diagnosed and dismissed as a symptom of ‘mental illness’ (see Sen & Sexton, 2016, p. 168). The pathologizing of emotion is part of an entrenched pattern that allows psychiatry to dominate its clientele through the systemic invalidation of their experiences. Many psychiatric survivors have denounced this invalidation, and some have shown how it is used to repress the agency of patients and submit them to the authority of therapists. Ji-Eun Lee (2013), for instance, writes that “anger is often the starting point of recognizing the injustice around us [psychiatric survivors] and a precondition for taking action” (p. 119). Echoing this ubiquitous patients’ experience of epistemic invalidation, Maria Liegghio (2013) links her anger at seeing the opinions and desires of her elderly mother pathologized, dismissed, and seeing her being treated against her will by mental health professionals to the concept of epistemic violence. Liegghio (2013) defines epistemic violence as an array of “institutional processes and practices committed against persons or groups . . . that deny their worldviews, knowledge, and ways of knowing and, consequently, efface their ways of being” (p. 123).

Mad writers Lee and Liegghio both connect their lived experience of epistemic violence to the anger that drives the mobilization of activist communities engaged in the pursuit of emancipatory social change. Social movement theorist William Gamson (1992) argues that as a response to systemic oppression, activist communities nurture “the *righteous anger* that puts *fire in the belly* and iron in the soul” (p. 32). The role of righteous anger in driving collective action to challenge systemic injustice has been described in many other spoiled-identity activist literatures as well, including but far from limited to feminist consciousness-raising and self-help (Hochschild, 1975; Taylor, 2000), HIV/AIDS treatment activism and queer politics (Gould, 2009), U.S. Afro-American civil rights movements (Morris, 2017), and indigenous peoples’ decolonization movements (West-Newman, 2004). In these writings, the link between systemic injustice, righteous anger, and spoiled-identity activism is often presented as self-

evident and mentioned without further exploration of its theoretical and practical implications.⁷

We still need a much deeper and more contextualized understanding of the meanings and potentialities of anger in spoiled-identity activism. In my experience, anger consumes you in the inside until you channel it into meaningful political action. When turned into activism, righteous anger can become a formidable force for individual and collective emancipation. For the diversity of Mad folks out there, it is critical that we understand our righteous anger and learn to channel its impulse into an array of emancipatory agendas.

My bet is that, with these preliminary reflections, I am merely scratching the surface of a topic of great importance to Mad and other spoiled-identity communities. With this brief commentary, I wish to invite Mad folks to work on this line of inquiry. Let's organize locally in a variety of ways to explore the situated meanings of our anger. Let's proudly assert our shared anger through a diversity of discourses and actions that legitimate it. Harnessing the sheer power of anger may help us reclaim the meanings of our experiences, challenge sanist prejudice, and strengthen our much-needed yet still precarious survivor-controlled settlements.

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⁷ One notable exception to this lack of theorization is found in Gould (2009), who links the mounting anger in HIV/AIDS treatment activism in the mid-1980s (after the U.S. Supreme Court ruled in 1986, in the *Bowers v. Hardwick* case, in favor of Georgia's anti-sodomy statutes against homosexual sex) with the queer communities' expanding political horizons and shifts in tactics, from mainstream advocacy toward increasingly confrontational and disobedient forms of activism.

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