

## **It's Maddening: Re-Conceptualizing Embodiments of Mental and Physical Distress**

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### **Abstract**

There are ongoing tensions in activist and community groups regarding the suitability of medication for mental distress. These tensions are based on assumptions of separate-but-connected notions of body and mind. Antipsychiatry perspectives resist medicinal interventions only for disablements commonly thought of as 'psychological'. Antipsychiatry activists who claim psychopharmaceutical interventions are scientifically unsubstantiated potentially undermine service user knowledges that draw on a breadth of experiential impacts, both of medication's harm and effectiveness. Furthermore, within a context of neoliberalism it is necessary to remain critical of how demedicalization movements can be coopted by austerity agendas to reduce public spending on healthcare. The article goes beyond body versus mind debates to critically engage with the ethics of embodiment and towards envisioning Mad epistemic justice. Mad epistemic justice would require a repositioning of power structures in healthcare by fundamentally centering service users' needs and expertise.

**Keywords:** Mad Studies, Antipsychiatry, Critical Disability Studies, Chronic Illness, Epistemology

### **Introduction**

The role of psychiatric medications has been an ongoing site of contestation for mental health activism in Britain. Decades of debates apparently unresolvable, the terms of collective understanding

are an important site for further development in Mad Studies. My interest in the topic has been informed by years of activist involvement and from living life with multiple disabilities. I write this article as someone with experience of a chronic illness that spanned across psychological-cognitive-physical divides. To emphasize the interconnectedness of 'physical', 'psychological', and 'cognitive' throughout this paper I interlink theory with reflection on my personal experiences as a Mad activist and academic.

In my early years of mental health activism, I had only experienced what I thought of as predominately mental distress and, at the time, I believed psychiatric medication could at best function as a Band-Aid for deeper psychosocial issues. This changed when I was diagnosed with a benign tumor attached to my brain, a chronic illness called Cushing's Disease (Pituitary Foundation, 2013). Inhabiting a body impacted by long-term Cushing's made it increasingly obvious to me how significantly my emotions were linked to physicality. Cushing's increases levels of the 'stress hormone' cortisol in the body (Santos & Webb, 2016; Sonino, Fava, Raffi, Boscaro, & Fallo, 1998; UCLA Pituitary Tumor Program, 2017); furthermore, Cushing's altered my cognitive experiences too, making concentration difficult, and reducing my short-term memory. I was depressed, chronically ill, and cognitively divergent not as separate-but-connected phenomena but as fundamentally integrated embodiment.

Two years after having an operation to remove the benign tumors, saving my life and 'curing' me of Cushing's, I was invited to speak on a panel about mental health. The event took place at a large activism and arts festival in London, England, and among the three panelists was myself and an activist representative of Speak Out Against Psychiatry (SOAP). As the panel progressed, I spoke of how life-long depression had shaped my life and the moderately beneficial effects I felt from anti-depressant medication. When I raised Cushing's as an aspect of the depression I have experienced, I was interrupted. The SOAP panelist, who believed that mental distress has no neurobiological basis, quipped that the Cushing's had probably been "caused by the medications". This was despite her having no knowledge of my medical history and, likely, little to no knowledge of a rare condition like Cushing's Disease. Antipsychiatry activists in England and Scotland often deny or disapprove of those who voice positive impacts of psychiatric medication, but this moment stood out to me as particularly epistemologically troubling.

Having spoken to many people after this event and in subsequent years, it is clear to me that Mad Studies and Mad Pride movements often lack an integrated approach to psychological, physical,

and cognitive embodiment. Antipsychiatry, arguably, is an exemplar site of where such integrated logic is lacking. This article sets to challenge Mad and antipsychiatry activists and academics who take a totalizing stance against psychopharmaceutical medication. While I value the important contributions made by activists and scholars who have worked to counter psychiatry and psychopharmaceutical interventions, I seek to respectfully challenge aspects of their approach. To be clear, I do not support psychiatry as an institution; however, I do support the use of medication as an assistive technology for experiences commonly thought of as 'psychological distress'. The purpose of this paper is not to engender vast conclusions on embodiment; rather, it aims to pose questions, resist compartmentalization, and contribute to an epistemology rooted in collaborative justice.

Throughout the paper, I raise several concerns with antipsychiatry activists who reject neurobiological aspects of mental health. Firstly, the rejection of a physicality in mental health is a claim of strategic difference to, and in contrast with, physical health. I will then discuss problematics of antipsychiatry approaches that proclaim psychiatric medication lacks evidence of its effectiveness. Lastly, discussion focuses on the risks of antipsychiatry stances being appropriated under neoliberalism.

## **Disrupting the Lines**

The conceptual boundary between physical bodies and cognitive-emotional selves has been a longstanding aspect of Western culture. The taxonomy of disability as 'physical', 'psychological', or 'cognitive' is still prevalent in activist discourse. While I do not intend to suggest a grandiose sameness between all of us labelled within subcategories of disablement, we must acknowledge ways in which such convenient reductionism is deployed. Our everyday lives are regulated by these concepts, yet our everyday embodiments are full of sites where the emotional and physical and cognitive are overlapping, are intertwined, are indistinguishable.

As a cultural practice, the distinctions between physical, psychological, and cognitive are dependent on Western capitalist traditions, adapted over generations. When examined closely the definitional, as well as diagnostic, categories that distinguish these labels apart from each other are inconsistent and inadequate. For example, a lack of sleep is often intertwined with physical exhaustion connected to low mood, and is further connected to cognitive difficulty in concentration. Likewise, I

cannot adequately describe my experience of Cushing's Disease as simply 'physical disability', it is a chronic health condition that does not bare the discreetness of body-mind distinctions. My embodied experience disrupts the segmentation of body from mind, the segmentation of Mad and disability activism, and leads me towards a desire for more liberatory politic.

It is true that many so-called 'physical' health conditions have more overt systems of measurement. The physical, under such logic, should be based on clear scientific evidence. Distinguishing 'mental', 'cognitive', and 'physical' disability is based on a social context which places explanatory power on root causes. The designation of which embodiments are considered 'problems' for medicine to diagnose, treat, and 'cure' is a deeply social issue. All categories of health and disability are situated in a socio-historical context, an ongoing legacy which measures mind-body difference against a 'normality' that is propped up by the white, colonial, cis-hetero-sexism of an idealized optimum embodiment (Clare, 2017; Davis, 2013; King, 2016; Weaver, 2015). There is no disability without the premise of ability—a necessarily unachievable state of socially ambiguous perfection (Campbell, 2009).

The classification of embodiments as disabled or abled cannot be understood as objective and purely scientific phenomenon. The notion that a person is either disabled or abled is itself a false binary constructed by society (Inckle, 2015). As diagnostic processes proclaim increased scientific accuracy, this relegitimization of diagnostic accuracy masks the role of bias and social control (Lewis, 2016; Metzl, 2009). There is no objective, scientific reality that distinguishes mental, physical, and cognitive embodiment. Disability and illness are always an interlocking of body-mind and society. Notions that disability of any kind can ever be objectively scientific relies on the neutralizing of colonial epistemology (Annamma, Connor, & Ferri, 2013; Davis, 2013; Weaver, 2015). Modern Western medicine is situated within a racist colonial history that measures dis/ability according to norms of individualistic functionality, and that which maintains the status quo.

Mad activism as a collective movement needs to ensure that it refuses reductionism and contests health barriers that further some health causes by leaving others behind. I do not advocate for physical, psychological, or cognitive experiences to be subsumed by a grander, monolith replacement category of 'mind-body disability' or just 'disability' (Spandler, Anderson, & Sapey, 2016). Yet, it is the discrepancies and disruptions in where the line is drawn between physical, psychological, cognitive that can help us to reconsider altogether who is drawing the line, what purpose the line

serves, and who ultimately benefits from its existence.

### **Madness in Experiential Knowledge**

Antipsychiatry and critical psychiatry scholars and activists have highlighted potentially dangerous effects of psychopharmaceutical medication (Burstow, 2015; Moncrieff, 2013). They have brought to the fore flaws in scientific research, including the impact of placebo effects (Gøtzsche, 2017; Moncrieff, 2013). Exposing medication's potential harm, the manipulation of scientific research standards, and conditions in which medical regimes (enmeshed with the profiteering of private pharma) coerce people into taking medication is extremely valuable. However, insistence that there is no valid 'scientific' proof as to the effectiveness of medications (Ramsay, n.d.) can negate the very service user expertise antipsychiatry activists claim to champion.

The assertion that psychopharmaceutical medication does more harm than good (Burstow, 2015; Hickey, 2015) speaks over the experiences of service users and Mad people who do find them helpful. The antipsychiatry stance that there is no scientific proof that mental health has neurobiological aspects implies that such 'proof' predominates service user lived experience. Mad Studies asserts a crucial element of its approach is centering the perspectives and experiences of psychiatrised people, yet some scholars and activists still delimit which of these perspectives it will include. Can we not be Mad and critically psychiatrised people, even if we refuse a politic of absolute opposition to psychiatric potentialities?

Speaking from my own experience, I have been forced and coerced to take psychopharmaceutical medication, to attend talk therapy, and to undertake Graded Exercise Therapy (for more on GET, see Spandler & Allen, 2017). In all three of these scenarios, I believe I would have been better off without any intervention at all. Yet, I have also had positive experiences with psychopharmaceutical medication, with talk therapy, and with carefully planned exercise. I would not discard all talk therapy, or all therapeutic exercise, or all psychiatric medications because there are *some* (even many) instances when they can cause harm. The main factor, for me, is the positive experiences that have come from my own initiation of access to them, when professionals have listened to my input as valuable, and where the approach has been appropriately tailored to my needs.

To acknowledge that medication can help in some circumstances for some people does not

minimize, deny, or deflect the reality that medical force, abuse, and coercion exists, as does side effects, placebo effects, and addiction to medications. It is important for Mad Studies to remain critical of mainstream discourses and non-activist spaces where medications are heralded as easy solutions to mental distress. Yet, the ambitions of Mad Studies must go beyond being a contrast to the mainstream, and work towards presenting the complexity and nuance of these topics. Mad Studies should bring to the fore Mad people's experiential knowledge, not as tokens to a narrow narrative schema, but by prioritizing a diversity of direct experience of mental distress and Madness (Faulkner, 2017). Clearly there is a privilege in who is listened to, and who can access forms of treatment/coping, when we can access them and how. These barriers are deep and expansive across all forms of healthcare. To challenge this requires critically engaged and collaborative social justice activism.

### **Neoliberal Cooptation**

The dangers associated with what is often termed the 'medicalization' of distress is its association with neoliberal society (Esposito & Perez, 2014). Pathologizing and medicating difference is a form of social control but so too is the denial of healthcare to those in need.

For many of us with chronic illnesses, a refusal of the neurobiological is an oppressive barrier to accessing essential services. I actively sought a diagnosis for Cushing's Disease but was frequently met with dismissal as doctors patronizingly concluded that my symptoms were the result of emotional trauma. To have Cushing's Disease identified, surgically operated on, and medicated has literally enabled my survival. Diagnosis can help to unlock access to key medical services and is a crucial component of accessing welfare and disability service provision. I say this not because I advocate a politics of 'cure' or assimilationist policy, but because technologies and supports, such as medication for HIV or financial assistance, can allow life and alleviate distress (Clare, 2017). For activists with Cushing's, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia, and other chronic illnesses, a key campaign is for improved medical technologies to identify, treat and support our survival (Brea, 2016).

We must reflect and be wary of how the Mad and antipsychiatry agenda may be easily appropriated for state and corporate profit. Campaigns in the 1960s to deinstitutionalize psychiatric hospitals, for example, may have led to a rise of institutionalization in another form—namely mass

incarceration in the prison industrial complex (Kim, 2016; Rembis, 2014; Stephens, 2014). Crucially, this specifically and disproportionately targets people of color who are more likely than white people to be seen as psychologically disturbed, dangerous, and threatening (Metzl, 2009). Furthermore, private prison firms make substantial profits from the labor inmates undertake. Prisons do not serve or protect, they engender trauma and marginalization for generations of disabled, racialized, and classed others (Ben-Moshe, Segrave, Spivakovsky, & Eriksson, 2017). Beyond an opposition to psychiatry, we must work towards practical ways of resisting an austere-carceral state that is all too willing to cut medical costs and increase profits through prison expansion.

As the UK continues to pursue fiscal austerity, medical provisions are supplied according to what is most cost-effective. Provision of medical care aligns with racist, xenophobic, cis-heterosexist, and classist ideologies of who is 'deserving' of healthcare. In the UK, people who are considering ending their life and seeking help are often turned away from psychiatric and emergency hospital wards, with little to no follow up (The Secret Doctor, 2015). Next to the private profit-driven corporations that are increasingly running public NHS services in England, legal measures are in place to monitor and charge (potentially prohibitive) fees to people with no passport, or non-UK passports, when accessing healthcare (Campbell, 2016; Foster, 2017). As Esposito and Perez describe, neoliberalism promotes "a type of health care system in which health care delivery becomes a commodity as opposed to a right" (2014, p. 419).

Psychiatry, and healthcare more generally, will never be a benevolent provider. I want to disrupt the social order of psychiatry and healthcare, without throwing away the potential of medications to be an assistive technology for Mad people. The fight for Mad people's health includes opposing inequalities in healthcare access as well as challenging the structure of psychiatry and medicine. However, we must remember that the alternatives to the medical-industrial complex are, too, unequally distributed. Such inequalities must be challenged within psychiatry, and its alternatives, as well as broader social structures where the devaluation of marginal lives is deeply entrenched.

## Conclusion

To simply acknowledge the interconnectedness of neurobiological, mental, and cognitive embodiment is not enough when systems of inequality remain adaptable but ultimately intact. We

need to forge ways where Mad people can redefine and redirect psychiatric knowledge and resources. I respect specialist knowledge in neurology and biology and value its potential contributions - we need doctors - but 'care' needs a drastic departure from top-down social control. We need Mad epistemic justice, where our experiences, perspectives, and expertise fundamentally inform the direction of medical intervention and treatment (Leblanc & Kinsella, 2016). We need healthcare that is accessible, actively counters oppression, and that is out of the hands of profiteers, and into the control of those who use and need the services most.

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