



ORIGINAL ARTICLE

Applying a Neurodiversity Lens to Living with Obsessive Compulsive Disorder

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Abstract

I draw on my own experiences receiving therapy for obsessive-compulsive disorder (OCD) as well as my background as a disability rights activist to argue for a model of OCD that is not solely focused on cure as the goal. In my experiences with therapy, I was encouraged to think of OCD as something external to myself and something I had to constantly fight against in order to act in accordance with my “real” self and thoughts. This never sat right with me, given my experiences being developmentally disabled from birth and having seen the futility of attempting to “fight” my cerebral palsy or vision impairment. I entered autistic communities as an adult, and learned strategies for managing distressing traits that did not rely on a cure or demonization of disability. I acknowledge that my disabilities have facets I find painful, frightening, and unhelpful, and I would not choose to experience those aspects. But I do not have a choice, and so drawing on neurodiversity-affirming strategies that I learned in autistic communities, I can both acknowledge traits that I experience as negative and recognize that they are a part of my experience, and not external to me. I hope to think and write an affirming model of OCD into existence as an extension of care to the mad and neurodivergent people who may share similar experiences.

Keywords

OCD, neurodiversity, disability studies, mad pride, social model of disability

History

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¹ Terminology note: As a scholar activist coming out of the independent living and neurodiversity movements of disability rights, I prefer to use identity-first language for myself when I can (disabled, autistic, mad, neurodivergent) instead of person-first language (person with disabilities, person with autism, person with mental illness). I ordinarily prefer to refrain from the pathologizing language of disorder when describing my own impairments, preferring, for example, “neurodivergence” to “mental illness” In the case of the impairments described by “obsessive-compulsive disorder”, I haven’t yet found a non-pathologizing yet concise label, so for brevity’s sake I will use OCD here, but know that I remain critical of the pathology implied in “disorder.”

Upon entering psychotherapy at age 19, in hopes of better coping with intrusive thoughts and anxiety that had gotten steadily more disruptive, one of my first observations was that it was not cut out for people like me; people who were disabled from birth, who did not have a “before self” to go back to that was free of disability or distress. It was also not cut out for aspiring disability studies scholars, people who questioned the medical model which locates the problem to be fixed in individual bodies and minds.² The first therapist I saw believed that I could have what she called “generalized anxiety disorder”, but when I mentioned having specific worries around being a good person or a fear that I would disastrously hurt my friends and brought up the possibility of obsessive compulsive disorder (OCD), she was dismissive, saying that because I wasn’t washing my hands compulsively, the label didn’t fit. In a medical model frame, my diagnosis of OCD by a new therapist a few months later would wrap up the story in a neat bow. I do not subscribe strictly to the medical model, even for a distressing impairment like OCD, so the reality is more complicated. The new therapist corrected the previous one’s oversight, and, as she told it, if I did enough cognitive behavioral therapy (CBT) and exposure to my fears, my OCD would be, if not gone, diminished. Part of my bodymind (to use Margaret Price’s sense of the term)³ was glad to have my initial hunch confirmed, but a large part was nonetheless uneasy at what I saw as increasingly fruitless attempts to rewire my nature. My therapist was not prepared for my insistence that my distressing thoughts and compulsions had a logic: checking alarms made sense in an environment where I needed to wake up on time to receive the care and support I needed to get out of bed. Worries about hurting people were logical extensions of the times I had said or done things that were hurtful due to not interpreting a situation correctly or following social rules I couldn’t discern, often with unpredictable consequences.⁴ These thoughts were undoubtedly exaggerated, but not baseless or illogical.

As time went on, I found myself increasingly frustrated with CBT that advocated ignoring my worries and dismissing them as irrational. As scholar Patricia Friedrich says, CBT “attempts to effect change by focusing on the behaviors and never dwelling on the causes” (Friedrich 2015, p. 61). In therapy, I did learn some helpful coping skills like acknowledging thoughts without having to act on them, but my therapist often urged me to attempt to separate “my thoughts” from “OCD thoughts.” This approach is in line with what Sofia Jeppsson terms the “Realist Solution”, in which patients discover and enforce a strict boundary between themselves and their mental illness.⁵ I couldn’t find the line she insisted was obvious between thoughts coming from my alleged real self and thoughts coming allegedly from my “disorder”. Disability studies scholar Lennard Davis, drawing on the work of multiple researchers of OCD, makes the case that the amount of co-occurring conditions that people

² See Oliver 2013.

³ See Price 2015.

⁴ For a discussion of this phenomenon in autistic people, see Montgomery 2019.

⁵ See Jeppsson 2022.

with OCD have, often with overlapping symptoms, and the difficulty of distinguishing at what point obsessions and compulsions become clinical, makes it hard to pin down OCD as its own discrete entity.⁶ It's no wonder I couldn't find the place where "I" ended and "OCD" began; it's unclear if such a place even exists.

I was given books to read that framed OCD as a malevolent outside force, and framed living with OCD as a constant battle. Therapist and director of The Center for OCD and Anxiety Jon Hershfield says, "Mindfulness and cognitive restructuring matter, but as with any form of obsessive-compulsive disorder, the fight for freedom is staged on the battlefield of exposure with response prevention (ERP)" (2014). I was deeply uncomfortable with the suggestion that I needed to fight my own brain or that I was being held hostage by an outside entity. I was advised to sit with the extreme stress of exposures without "talking back to" my obsessive thoughts, even though I've never been one for ignoring anything that matters to me. Ever the philosopher, I wanted to know why I was having the thoughts I had, even as I realized that arguing with the validity of the thoughts, or trying to disprove them logically, was pointless.

As a budding disability rights activist and scholar of disability studies, I cringed at that attempt to separate part of my bodymind from myself in order to "fix" it. I had been down that road before. As a physically disabled and visually impaired person, doctors and therapists were always pronouncing drastic amelioration right around the corner: if I just worked on walking a bit more, if I just tried harder to read a map, if I just fought harder against the tightness of my muscles and willed my eyes to focus, my disabilities may not be cured, but they would be a much less pronounced presence in my life. Disability rights activist Norman Kunc, who also has cerebral palsy, recalled approaching his childhood therapy as a battle against his impairments: "Well I wanted all those things, to have a good life – so I ended up declaring war on my own body. It was me against my disability; and my disability was my enemy. I was bound and determined that I was going to conquer that disability" (Giangreco, 2003, p. 34). Although he is at least one generation older than me, Kunc's experiences of childhood therapy and the internalized ableism it fostered resonates with my experience. His description of wanting to battle his disability also resonates with Hershfield's description of the need to battle OCD. Whether the supposed enemy was OCD or cerebral palsy, I didn't feel like putting up a fight.

Learning that I was autistic and coming into autistic communities two years prior to my OCD diagnosis, I was no stranger to recognizing that obsessiveness can bring joy as well as pain. I concurred with Lennard Davis when he wrote that "obsession isn't simply a medical category; it is a category of existence" (2009, p. 12). My therapist reacted uneasily to my self-identification as an obsessive person, perhaps wary of encouraging what Friedrich calls

⁶ See Davis 2009, 211.

the “neural pathways” that lead to obsession.⁷ But, whether the topic is my favorite band (The White Stripes) or my consuming fear that I am an evil person, I am obsessive. My first memories are from age 3 or 4, having an autistic obsessive love of ducks in which I memorized facts about them, collected every duck-related object I could find, and begged to see ducks at the pond near my family’s house. These existed alongside pervasive fears that something horrible would happen to my family if I did not repeat an exact bedtime ritual, and that I was somehow making the “wrong” choices of activity during preschool, and consequently, everyone must be angry at me. In therapy I realized that management and reduction of my distressing obsessions and unwanted compulsions was a much more logical goal than an alleged full recovery from a “disorder” that was really just a negative aspect of my nature. As much as I would take a hypothetical cure that eradicated the disturbing intrusive thoughts and time-consuming compulsions without touching my autistic capacity for deep focus and sparkling joy, I do not believe those experiences can be so neatly separated. I have been obsessive as long as I have been conscious of my thoughts, and I have always known that the coin of obsession is two-sided.

My intrusive thoughts and compulsions ebbed and flowed over the years, with little apparent relationship to whether I was in therapy, taking an SSRI, both, or neither. As I became more conscious of the ways in which an approach that focused on me changing my bodymind failed to help me cope with distress from OCD, I began looking more deeply into work coming out of various (western, English speaking) disability sub-movements. What could I learn about living with OCD from the neurodiversity and Mad Pride movements, as well as cross-disability spaces generally? What if I took the same attitude toward my OCD as I did to my cerebral palsy, autism, and vision impairment, adapting to it and working with it while minimizing aspects I didn’t like, instead of battling it?

Lessons from autistic communities

In this section, I want to discuss ways autistic people deal with distressing or negative aspects of being autistic without focusing on curing autism as a way to illuminate possible parallels of how to deal with OCD without wanting a cure. Rather than present a straightforward list of resources, I’ll direct people who want to know more to the blogger *neurowonderful*, aka Amythest Schaber, and their excellent list of resources and Youtube channel.⁸ I will briefly summarize some points about neurodiversity-affirming ways of dealing with autism along with the ways that I have found them useful in dealing with OCD.

1) *Not thinking of autism as a superpower or a burden.*

As Jessica Penot at *Psychology Today* says, “Many autism advocates argue for a balanced

⁷ Friedrich 2015, 42

⁸ <https://neurowonderful.tumblr.com/autismmasterpost>, <https://www.youtube.com/@neurowonderful>

approach. They believe that autistics must seek supports and accommodations from people outside the disability community. Because autistics need to seek support within the neurotypical world, we can't fully embrace the superpower narrative" (2023). Penot also notes that not every autistic person has an autism-related strength, so the best approach is a balanced one in which the autistic person can accept both strengths and weaknesses and have the support they need. In the OCD literature, Davis and Friedrich both posit possible upsides of OCD,⁹ but, following the autistic community's lead, I think neutrality and access to affirming support is the better option.

2) *Reframing aspects like "obsession" or intense sensory experiences to include joy sometimes.* Autistic advocate Julia Bascom describes the "obsessive joy of autism":

"It's that the experience is so rich. It's textured, vibrant, and layered. It exudes joy. It is a hug machine for my brain. It makes my heart pump faster and my mouth twitch back into a smile every few minutes. I feel like I'm sparkling. Every inch of me is totally engaged in and powered up by the obsession. Things are clear. It is beautiful. It is perfect."

(2011)

In contrast to the way "obsession" is framed negatively, many autistics, including me, think of obsession as being positive, or at least having the capacity to be positive.

3) *Treating only the distressing aspects instead of exclusively waiting for a cure.*

Autistic advocate Kaylene George points out, as many neurodiversity proponents do, that autism is an entire neurology, and "curing" it would completely change who autistic people are as people. There are comorbid conditions that many people do want cured (like epilepsy or gastrointestinal issues) but proponents of autism "cures" often lump those separate aspects in with autism.¹⁰ Similarly, I think that it's impossible to get rid of my capacity for obsessive thoughts and repetitive actions without changing myself in ways I don't want. "Curing" OCD is not meaningful to me; I'd rather minimize distress.

4) *Curating the sensory and social environment instead of changing the bodymind.*

Autistic advocates recognize that some sensory discomfort and meltdowns are inevitable, but that we can make them less frequent or less distressing. For example, autistic activist Judy Endow describes a number of strategies for preventing meltdowns and providing support during them. Her main prevention tactics are not to will meltdowns away, but to assist with things like sensory regulation, setting clear expectations for when events will

⁹ See Davis 2009, 18; Friedrich 2015, 52.

¹⁰ See George 2019.

occur, and developing emotional regulation skills.¹¹ Similarly, in my experience of OCD, distressing thoughts and compulsions are inevitable, but their disruption and negative impact can be lessened if I'm eating, drinking, and sleeping enough, if my sensory system is regulated, and if I'm less stressed about other things in my life.

Personal coping mechanisms

Given this theoretical background, I'll dedicate the rest of my paper to specific coping strategies that work for me. Consistent with my experience in neurodiversity spaces, I feel compelled to give a disclaimer that what helps me may not help you or another person, and that's fine. When first pitching this idea to neurodiversity-informed, disabled activists, many people were supportive of my proposed lens, but I was taken aback by how many people thought I was going too far. I was struck by how some criticism I heard mirrored anti-neurodiversity talking points¹²: "You can't really reframe something as bad as OCD.", "Your OCD must not be severe," "I don't see how you can find any upside, or even be neutral, about OCD". These critiques all came from people with OCD, many of whom were otherwise disabled and applied the social model to their other disabilities. I don't mean to "call out" anyone in particular or invalidate their lived experience. Undoubtedly, as with being autistic, the way my particular impairments intersect with white, cisgender, education, economic, and other privileges affects my view and shields me from some oppression that others face. But I do wonder what it is about OCD that makes working with it instead of against it a bridge too far? As disability justice activist and poet Eli Clare says, "We can shift our focus from cure to access, or hold the two in tandem, insisting that our present-day body-minds are as important as any vision of the future" (2017, p. 90). Even if you do strictly want a cure for your OCD or any other madness, I hope you also consider building access into your life where you can. I offer my approaches in the hope that something will resonate with fellow Mad people. You can feel free to take or leave my approaches as you wish, the same way I took what I needed from other frameworks.

Although I didn't find all that much relief from traditional CBT, I borrow aspects from more affirming and solutions-based therapeutic models. I described to some friends how I prefer to engage with my intrusive thoughts not by arguing with them or ignoring them but by asking the thoughts what they need and then deciding if and how I act on that need. A few of them remarked that this approach sounded in line with Acceptance and Commitment Therapy (ACT). According to a widely-cited 2006 paper by Russell Harris, "The goal of ACT is to create a rich and meaningful life, while accepting the pain that inevitably goes with it. 'ACT' is a good abbreviation, because this therapy is about taking effective action guided by our deepest values and in which we are fully present and engaged" (2006, p. 2). Harris would likely take issue with my asking my thoughts what they need, since his stated aim is

¹¹ See Endow 2010.

¹² For more on anti-neurodiversity rhetoric and how it fails, see Ballou 2018.

to make thoughts lose their power by accepting them neutrally without responding to them. Harris might also critique my self-identification as obsessive, but his approach and mine share a focus on accepting life as it is, resistance to the impulse to pathologize thoughts experienced as negative, and a primary concern with concrete solutions that reflect values. Both Harris's approach and mine attempt not to label thoughts as dangerous, abnormal, or illogical, recognizing that although the thoughts may not be accurate, they likely reflect a need or have been helpful in another context. Perhaps I cannot get as much disembodied distance from my thoughts as what Harris terms "the Observing Self" (2006, p. 2), but I can metaphorically listen to my thoughts, give them a fair hearing, and focus on what I want to do.

Asking my thoughts what they need is also drawn from trauma-informed approaches, particularly inner child work. In inner child therapy, the participant copes with trauma by imagining tending to a younger version of themselves, asking and validating what that imagined child needs, and moving forward with an increased understanding of where certain reactions and beliefs may be coming from.¹³ Without consciously intending to, I enact a version of this with my intrusive thoughts. For example, if I'm struggling with the intrusive thought that I might call my friends derogatory names when that does not reflect either my friendship or my general values on how to treat people, I might stop and notice that at the root of the fear is a preoccupation with what kind of friend I am, or how I treat people. I might ask the thought what it needs from me, and if that need would be useful to me and anyone else involved. The thought might lead me to want to perform a compulsion, like asking my friends to reassure me that I'm not a bad person. However, that is often not useful to me in the long term and may cause my friends distress. If I dig beneath the surface level of the thought, the concern is about treating my friends well. An approach to working with that concern that is useful in the long term involves reaffirming my values and dedicating more conscious time to the work of friendship: listening, offering support, reaching out. This does not make the disturbing thoughts or compulsions go away, but it does validate the thought as having a legitimate logical basis (even if exaggerated or incorrect) and allows me to take a concrete step toward something that I and my friends experience as positive.

Another example of something that has been helped by this kind of approach is my compulsive checking of my alarms, scared I may not wake up in time to get the care support I need to function every day, or that I may oversleep and miss an important work meeting or appointment. First, I recognize that the fear of not having adequate access to care support, and the fear of missing important things because of that lack of access, come from a legitimate place. I have previously struggled with personal care assistants not showing up and subsequently having to miss or reschedule important events. I know that the employment rates for physically disabled and autistic people are abysmally low, and I realize

¹³ See Haupt 2023.

that systemic privilege plays a large part in why I have the relative security I do. That relative security is not airtight. So underneath the worry about waking up on time is a deeper fear of losing vital supports and missing out on activities. While in the midst of the thought, I might initially want to stay up for thirty minutes or more checking my alarm, but what may be more useful in the long term is thinking through and fortifying what supports I have, to the extent I can. Can I hire more backup assistants to minimize the impact of one person not showing up? Can I be open with my doctors or boss that my schedule may be disrupted if I lack care support, and explore options like telehealth or flexible work scheduling? Of course, having these potential options is a function of privileges that not everyone has, but I hope I've sufficiently demonstrated what it looks like to ask my thoughts what they need and practice honoring that need in an affirming way.

I also cope with my OCD by cultivating obsessive joy whenever and wherever I can. I do not go so far as to say OCD can directly be reframed positively the way that some neurodiversity activists positively reframe the traits of autism, ADHD, or bipolar "disorder". Part of the reason for this lies in how OCD is defined. OCD is commonly defined as the experience of obsessive thoughts and urges that cause distress. Using this framing, obsessive thoughts and urges that do not cause distress are either not OCD, or the person experiencing them is an unreliable narrator. As Davis explains:

If your behavior, say the meticulous lining up of objects, is seen as an oddity, you will be distressed that you do it. If it is seen as the useful quality of a master bricklayer then you will not be distressed. In other words, 'marked distress' is not a quality itself but rather a socially defined reaction. The other problem is that the neat distinction between the personality disorder (the person doesn't mind being obsessive) and the disorder (the person minds) is, even in the DSM-IV definition, confused by an acknowledgment that in some cases people 'with OCD' won't be distressed by what they are doing or may even think that what they are doing is actually helpful or valuable. But in that case, they may be seen as having 'poor insight'.

(2009, p. 18)

When understood in this way I cannot claim that OCD has positives because the construct "OCD" cannot have positives. I certainly do not experience graphic, repetitive thoughts of harm as remotely positive. But, following Bascom, I do want to claim the experience of obsession as sometimes positive, and likewise, the experience of repetitive engagement with something. Just because unwanted obsessions and compulsions are distressing does not mean all experiences of obsession and all experiences of repetitive activity are distressing. Stimming, which everyone does, but autistic and other neurodivergent people especially relish or even need, consists of repetitive thoughts, sounds, motions, and actions that bring us joy or help us regulate ourselves in an uncertain, chaotic world. In fact, the

only thing that may separate what gets called obsession/compulsion on one hand and deep focus/stimming on the other is the emotional experience of the person doing them. From personal experience, I can say that I've gotten similar admonishments to "just let it go" or chastisements that I'm "still stuck on that?" in response to both intrusive thoughts (one of the most distressing things I experience) and obsessive interests (one of the most positive and fulfilling things I experience).

Given that both experiences have coexisted in me for my whole life, I'm tempted to say that while "being autistic" and "having OCD" are both accurate descriptors of my neurotype. If I were to be less granular, my neurotype might be just as well described by something like "obsessive/intensive/repetitive", a neutral way of getting at the varying functions of obsession, repetition, and intensity in my life. Since I do not believe negative obsessions, intensity, or repetition are extricable from their positive counterparts, I do not want or believe in a cure that posits a non-obsessive version of me. I likewise do not claim that a condition that is defined by unwanted intrusive thoughts and compulsions is positive. Between these poles, I arrive at "OCD neutrality". I am reminded of Sofia Jeppsson's example of someone with schizophrenia viewing their "frightening and uncanny experiences of derealization, depersonalization and threatening hallucinations..." as a "price worth paying" (2022, p. 302) for having a unique creative outlet and thinking style. In a similar vein, I see my disturbing obsessions and unwanted compulsions as a foil and a "price worth paying" for the depth of joy, wonder, engagement, curiosity, and bodily contentment I have capacity to experience in large part because of my obsessive/intensive/repetitive neurotype.

I have always engaged with music as an immensely powerful source of joy and regulation. At every waking moment, unless I am in significant distress, I have what I call an "internal soundtrack" of music that is constantly playing in my head. Any music I've heard enough to remember can be in rotation, though understandably, music I particularly love or listen to often comes up more frequently. Often but not always, the music and/or lyrics relate somehow to what is going on around me. Even when my soundtrack is looping a song I don't especially like, or seems to be stuck on ten seconds of instrumental for hours, I still take great joy that it's there. The rare experience of it going away (usually when I am in significant pain or approaching a meltdown), always compounds my distress. My internal soundtrack is one of my favorite aspects of my bodymind and it always brings me great comfort, sometimes amusement, and a huge knack for making somewhat eclectic playlists at a moment's notice. Imagine my shock upon learning that some people with OCD consider music in their head a distressing symptom in need of eradication. The National Institutes of Health has an entire article on "stuck song syndrome", with the only thing marking these earworms as intrusive (as far as I can tell) is the distress of the person experiencing them. The article recommends standard treatments for OCD like mindfulness, CBT, and ERP, but, crucially, it also states "Unlike CBT, psychotherapy based on using distraction techniques is not standard for classic OCD symptoms, and may even backfire. Yet, distraction is the most

common self-help method for SSS and is often effective” (Euser, Oosterhoff, and van Balkom, 2016, p. 90). I wonder what it is about this manifestation of OCD that makes distraction permissible when it ordinarily wouldn’t be. I wonder what it is about my internal soundtrack that makes my experience of it joyful, necessary, and integral to my being rather than a “syndrome” in need of treatment.

One person’s invasive symptom is another person’s proactive coping mechanism. On days where I feel less able or unable to engage with my intrusive thoughts, it is often helpful to dampen their intensity by filling my mind with my deep loves. This can look like researching a topic that I’m interested in, working on my writing, or talking to a loved one. If I don’t have mental energy for any of those activities, it can look like making a playlist or listening to one I’ve made already. The bubbly, sparkling joy doesn’t negate the barrage of distressing thoughts. They coexist, and listening to music I love deeply is enough to remind me that delight is possible even amidst pain. I cultivate deep loves and joyful deep focus to counteract the unwanted focus that is a hallmark of my intrusive thoughts. I cultivate intentional, joyful repetition (like listening to a favorite song on repeat or engaging in echolalia with friends) to lessen the intensity of the unwanted, distressing repetition of compulsions. The answer to coping with unwanted obsessive and intense experiences, for me, is not to become less obsessive or more stoic; it is to bring more joyful forms of obsession and intensity into my environment as much as I can. It is to let intense, autistic joy become a conscious habit.

Lessons from disability and Mad Studies

In the remainder of the paper, I examine what lessons we can take from mad and disabled communities other than the neurodiversity movement. Other disability and illness communities demonstrate that even outside of the neurodiversity paradigm, there are other, less pathologizing ways of viewing OCD. Interdisciplinary scholar La Marr Jurelle Bruce sees his OCD as fueling the critical, multifaceted “mad methodology” that recognizes interlocked suffering, care, critique, and insight behind his book *How to Go Mad Without Losing Your Mind*:

Put otherwise, this book both suffers and benefits from my own balminess. That suffering lies in the staggering worry, excruciating revision, and the overpowering urge to turn the work over and over and over and over and under and over and under in my mind until my mind is raw and the work feels worn and frayed ... But what of the benefit? ... Madness suffuses the ethical, critical, and radical impetus for *How to Go Mad*. What I mean is that this book is devoutly ethical, trained by a superpowered superego that commands, and relishes, acts of goodness. This book is painstakingly critical, sharing my propensity to question everything, to take nothing for granted, to seek the secrets buried underneath any placid surface, to find fault everywhere, to work

to make it better ... OCD intensifies another elemental force coursing through this book, its most vital feature of all, its care. At the palpitating heart of *How to Go Mad* is care: both careful and caring, both worrisome and loving.

(Bruce 2021, p. 235-6)

Predictably, I note (confess?) that my own OCD prickles uncomfortably at my use (co-opting?) of a black scholar's words to explain my experience which is shaped not just by madness but by white womanhood, the very same white womanhood that continues to harm black people. I decide to accept the discomfort as probably warranted and forge ahead. Like Bruce, while I experience distress stemming from OCD, I fundamentally see it as an impulse to care, an impulse to not harm, or at least to minimize the harm I do. Like Bruce, my OCD informs and shapes my scholarly work, pushing me to dig deeper, to reframe, to struggle toward a better world.

Although I could not find literature that specifically situates OCD within a Mad Pride lens, mad approaches to other madnesses can illuminate less pathologizing ways of viewing OCD. The Hearing Voices Network is a peer-led organization founded by people who hear voices, see visions, or have other atypical sensory phenomena. According to Patrick Bracken, the Hearing Voices Network takes a non-pathologizing approach to atypical sensory experiences and "validates voice hearers' own accounts of their experiences and makes it possible for these experiences to become meaningful" (2001, p. 726). Again we see the importance of validation of the mad person's experience, and the necessity of making an individual, self-imposed meaning. Sofia Jeppsson advocates for what she terms a "Constructivist Solution", in which patients solve the problem of where to draw the boundary between their illness and themselves by constructing the border, rather than discovering it.¹⁴ Constructivism is not de facto anti-pathology, rather it is pro-empowerment. Constructivism gives the power to the patient to make sense of their experiences and decide how to cope with their illness.

Stories and narratives also can have tremendous power as coping mechanisms. Davis recounts meeting a person with OCD who felt comforted and helped by reading Davis's sociocultural exploration of OCD: "In other words, he was telling me that having a new biocultural narrative about his illness, placing it in a social and historical context, was itself of therapeutic use" (2009, p. 237). The stories we tell ourselves and the stories others tell about us can matter deeply. Eli Clare recounts how people with muscular dystrophy who resist pressure to be cured, and people with chronic illness fighting against medical dismissiveness both complicate narratives of non-disabled medical authority:

On the one hand, people with muscular dystrophy resist the notion of body-mind trouble as it is repeatedly foisted on them, and on the other hand,

¹⁴ See Jeppsson 2022, 305

people with [Myalgic encephalomyelitis/chronic fatigue immunity deficiency syndrome] work overtime to have their body-mind trouble acknowledged while doctors and the media ignore and trivialize it. These two dynamics appear to be opposites, but actually they converge, pivoting on the ways the medical-industrial complex wields authority and dismisses what we know about our own visceral experiences. (2017, p. 73).

Even if a mad person wants cure or treatment, this does not mean they have to internalize the ableism of medical professionals or accept without question those professionals' views of treatment and cure.

Disability studies scholar Robert McRuer remarks that people with OCD do not seem to have an active disability rights consciousness, because “ideologies of treatment and ‘cure’ are arguably still the central—and even in some instances the exclusive—organizing principles for people with obsessive-compulsive disorder or some other mental or behavioral disabilities” (2006, p. 214). McRuer does not specifically mention autism, but I have to believe it is a “behavioral disability” in his view. He is certainly not in dialogue with Mad Pride or neurodiversity-affirming work here. Perhaps he also buys into the false, simplistic dichotomy described by Bruce, in which disability is viewed as physical “incapacit[y]” and madness is viewed as mental, “dangerous ... hypercapacit[y]” (2021, p. 13). Just as Bruce complicates strict divisions between medical, social, and cultural models, my piece challenges McRuer’s assertion and attempts to bring in a framing of OCD that is compatible with disability rights. As a mad person, I can go beyond just reclaiming the joyful aspects of repetition, and recognize that the distress cannot be pulled apart from the joy. Like all people, joy and sorrow are expected parts of my human experience, and just because something is distressing does not mean I want it cured.

Understanding OCD as a disability to work with rather than a disorder to overcome opens up new possibilities for reducing distress. I hope that in outlining how I approach my OCD as a neurodivergence and a feature of my bodymind, I present a frame that recognizes it as distressing and disabling yet not in need of a cure. Autistic and otherwise disabled advocates have navigated similar terrain with aspects of their disabilities that are painful or distressing, recognizing that sometimes cure is not possible or desirable. Intrusive thoughts and unwanted compulsions are one side of the obsessive, intensive, repetitive nature that has given me the most profound joy and connection in my life. I can’t have one set of experiences without the other, and I hope that even if someone does want a cure, they can also look for moments of joy and positive intensity in the present.

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