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## Vulvodynia, It's in My Head: Mad Methods Toward Crip Coalition

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### Cover Page Footnote

I am most grateful to the editors of this special issue for making the process of preparing this article one defined by accessibility and care, and to the anonymous peer reviewers for their thoughtful feedback and guidance. I would also like to thank Delaney Nolan for her generous editing support. -- Renee Dumaresque lives in Toronto/Tkaronto where they work at the intersection of creative, critical, and chaotic thought as a community organizer, writer, and PhD student of Social Work at York University.

# Vulvodynia, It's in My Head: Mad Methods Toward Crip Coalition

Renee Dumaresque

**Abstract:** This article employs a mad transdisciplinary approach to autoethnography to detail vulvodynia — or chronic vulvar pain — within the *system* of (dis)ability. Through autoethnography, the self operates as a mobile orientation from which to identify and disrupt the colonial rationalities that differentially construct and narrate vulvodynia across sites of madness and disability. Through historical, discursive, and autoethnographic analysis, I locate vulvodynia's role in various processes of subject, race, and settler-state formation from the nineteenth century up to the neoliberal present.

**Keywords:** feminist disability studies, mad studies, mad autoethnography, transdisciplinary inquiry, vulvodynia, hysteria

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**Content Notification:** This article contains discussion of bodily pain, medical and psychiatric racial and colonial violence, and descriptions of hetero-cis-sexism and sanism within medical encounters.

I begin this discussion by turning to a video titled *Vulvodynia, It's Not in Her Head* (Reynolds 2013). The video lays bare the dominant discourses of vulvodynia — a diagnostic category that captures and, as I will demonstrate, constructs the phenomenon of unexplained chronic vulvar pain (Bornstein et al. 2016).<sup>1</sup> This text gives rise to critical questions that have been raised by scholars across mad and critical disability studies in relation to the construction of narratives and use of stories,<sup>2</sup> including what they produce, what they hide, what labor they perform, by whom, and to what end.

The video is a public service announcement (PSA) made for the Canadian Women's Health Foundation by Pink Buffalo Films, a production company that operates out of Vancouver, BC. Under the direction of Ryan Todd Reynolds, the PSA aims to raise awareness about vulvodynia. The opening shot of a lone woman wandering down a wet street sets the tone: a sleepy, somber atmosphere. The dreary image is accompanied by low, dramatic sounds; single piano notes are played slowly and painstakingly. Over the next minute or so, Reynolds introduces a montage of (mostly white) women who, one assumes, are all living (quietly) with vulvar pain. We meet about fifteen in total, catching sight of them just long enough to gather a silhouette of their situations, each portrayed just a touch more tragic than the last. The women appear mostly alone, in urban environments, or else in intimate settings where they sit visibly isolated and distressed, alongside whom one presumes are their male partners. We see clip after clip of women wandering city streets alone at night; a woman sits quietly in the backseat of a car; an older woman vigorously scrubs a kitchen sink. Reynolds shakes things up a little when he introduces a brunette who takes her frustration out on a boxing bag, and with a downtrodden blonde who walks alongside an indoor swimming pool in a black one-piece bathing suit. The characters are living very similar lives, symbolically and quite literally alone.

The title of the video invokes a common reference to late-nineteenth and early-twentieth century hysteria and captures an experience widely reported in association with vulvar pain: women are told that their pain is all in their head. The answer to this conundrum, according to the message forwarded by the Canadian Women's Health Foundation, is to "speak up," or, as they say, "don't suffer in silence" (Reynolds 2013). This call to action comes through the rhetoric of cinematography, as a clear shift in tone occurs just after the woman by the swimming pool jumps into the water. The image cuts abruptly from the water to another woman who was on screen a few moments earlier, then appearing submissive, who now shoves a man away from her. This continues — one woman buckles over on a sports field, presumably crying out in pain; a woman on another street pushes away another man; the older woman finally drops the scrub brush, literally throws in the towel — until Reynolds brings the piece to a close with a series of tight facial shots. The words "don't suffer in silence" appear under the face of the woman who we saw in the clinic, before the picture cuts to the word "vulvodynia" underneath an image of the woman from the sports field. The last shot features the words "it's not in her head" under the swimmer.

All of the women (my use of gendering language here reflects the film's title) have "taken the plunge" by speaking up about vulvodynia, or in some cases, pushing back against those who have apparently kept them quiet. The close, interpersonal nature of the narrative clips suggests that these subjects are kept quiet by boyfriends and schoolmates, rather than by doctors and a psy-system that bridges, re-produces, and widely distributes the knowledge and practices of medicine, psychiatry, psychology, and other health and "mental health" professions (Rose 1985, 1990) that are situated in a long history of gender and colonial violence (Mills and LeFrançois 2018).<sup>3</sup> The PSA implies that medical professionals are the solution; the obstacle is merely reaching one. It's not lost on me that the only glimpse of a medical presence in the lives of the suffering characters was of one woman sitting alone in an exam room, leaving no medical authority implicated in her struggle; it was her face displayed next to the words "don't suffer in silence," as if to say, *all she had to do was ask*.

I detail the video because it reflects a critical feature of vulvodynia discourse specifically, and madness more generally, and the role that narratives of struggle, empowerment, and resiliency play.<sup>4</sup> In recent years there has been an uptick in content dedicated to raising awareness about vulvodynia that incorporates or is written from the perspective of "people with lived experience"<sup>5</sup> (Voronka 2016, 190). Features in Canadian news sources such as *The Globe and Mail*, *Toronto Star*, and *Vancouver Sun*, to publications like *Cosmopolitan*, *Bustle*, *Guts*, *Autostraddle* and *The Atlantic*, have captured a range of experiences, from the impact of vulvodynia on gender and sexuality, to visiting a doctor with complaints of vulvar pain only to face denial and sexism, and being plugged into (and resisting) a medical system that is defined and defines its subjects by heteronormativity. Trouble is reported in paradise (i.e. in biomedicine and heteropatriarchy), yet the institutions of heteropatriarchy and biomedicine remain intact. As Jijian Voronka (2019, 9) argues regarding the incorporation and translation of mad narratives to justify neoliberal recovery and resiliency frameworks, stories of "lived experience" are often spun and used, not to correct but to advance dominant health agendas and discourses, where the inclusion of (some) "patient" stories operate as evidence of an enlightened institution (Costa et al. 2012; Voronka 2016). It is also notable that those faces depicted as bravely resisting oppressors and calling for more, less, or better "care" — either by speaking for themselves or when spoken for by media and campaign messaging — are largely those of white (or racially anonymous) cis-women.<sup>6</sup> Vulvar pain is rendered intelligible primarily through the reports and positioning of white women, animating Rachel Gorman's (2013) discussion of "Mad nationalism" (269), where mad identity and politics are produced in relation to the theoretical referents and political investments of mad white settlers to result in specific narrative constructions of wrongdoing and ideas of justice.

Whereas once, vulvar pain subjects were typically met with invalidation, now they are met with tolerance and inclusion; disbelief has shifted to belief, and shame to liberation – at least so the story goes. Although the connection to hysteria and thereby madness is never made explicit in the PSA, the underlying directive communicated is similar to many “anti-stigma” campaigns related to “mental health,” which, as Kimberley White and Ryan Pike (2013) demonstrate, have become standard for national organizations across “Canada”<sup>7</sup> and beyond. In fact, the PSA was shared on Twitter by @VulvoAwareness using the hashtag #VVLetsTalk (What is Vulvodynia 2015)— clearly taking their cue from the media giants’ #BellLetsTalk campaign for Canadian “mental health” (Bell Let’s Talk, n.d). Nation-wide anti-stigma and “awareness” narratives proliferate what Sunera Thobani (2007) identifies as founding narratives of Canada as the manifestation of liberal inclusion and diversity, while reinforcing biomedical and psy rationalities that essentialize notions of distress (McWade 2019) according to settler colonial logics of race, gender, and class (Gorman 2017). Further, they depoliticize widespread social injustices to enrol people into rather than challenge psy regimes (Gorman and LeFrançois 2018, 110) by, in this case, disseminating the idea that people’s woes are all the result of one big misunderstanding — the misconception that “women’s pain” isn’t real.

To further place the PSA in context, it is significant to know that one of Pink Buffalo’s producer’s reports having lived with vulvodynia, and that their ultimate goal in making the piece was “to attract donations that will help allocate money for research” (Jonathan 2013, par. 8). This is indicative of the neoliberalization of health and “mental health,” whereby not only healthcare is shaped by market rationalities of “choice,” “freedom,” and the bottom-line, but so too are diagnostics, interventions, modes of resistance, and “patient” (or “consumer”) subjectivities (O’Leary and Liat Ben-Moshe 2019; Pitts-Taylor 2010; White and Pike 2013). The mainstreaming of vulvar pain stories and the shift toward inclusive care should thus be examined together; stories of “liberated” vulvar pain subjects are used to propel a new, ostensibly civil and empathetic face of medicine in support of neoliberal interests, similar to how mad stories have been co-opted as mental health marketing materials (Costa et al. 2012). Thus we see that dominant narratives produced by national bodies and major institutions both use and inform the stories told about lived experience while, simultaneously, carving the frame through which stories are heard (Voronka 2019).

As a white vulvar pain subject, I saw myself in the narratives circulated. The difficulty of “awareness” seemed to reflect a main hurdle of mine, after years of pain and a doctor count I had long lost track of. Then, biomedical explanations named my pain “vulvodynia.” Receiving a diagnosis came with a mixed bag of emotions. I was offered the illusion of control that accompanies moments of intelligibility (Farrell and Cacchioni 2012), but the weight of implicit messages, “incurable” and “tragic,” that were deeply embedded in the word chronic sunk the drop of hope that spilled from recognition. Simultaneously, dominant narratives and cultural discourses painted a life lived with pain as a life not worth living (Patsavas 2014, 208). This, in concert with the impact of vulvar pain on my sense of sexuality and gender, shot me into what Alyson Patsavas (2014, 210) articulates as a compulsory quest for pain relief, leaving no room for alternative understandings of pain, nor complex relationships with pain, nor attention to the manifold ways that pain is shaped by — and is used to shape — the discursive, socio-political, and colonial context. The PSA detailed here, despite positioning itself as an oppositional text in support of vulvodynia-subjects, is part and parcel of that compulsory and frustrating search. When pain is positioned as “real,” biomedical rationalities lead one to believe it can and should also be fixable (ibid.).

We are left with pain as a monolith; pain as marketing material. But recently, scholars across fields of cultural studies, the humanities, and social sciences have begun to bring more complexity to mad and disability discourses of pain, including attention to what logics and systems of power pain narratives are at work in selling. Crip, mad, and feminist disability studies thinkers have offered necessary

correctives to the taken-for-granted status of pain in both biomedical and disability theorizing by disrupting discourses of pain as purely biomedical (ibid.), bringing nuance to totalizing crip stories of disability as wholly “good” or “bad” (Kaler 2013), and collapsing the false distinction between the body and mind (Price 2015). However, there remains an absence of disability analysis, especially in relation to chronic vulvar pain, where even feminist inquiries that tackle the medicalization of pain (Farrell and Cacchioni 2012), inadequate healthcare and a heteronormative treatment focus, including the impact of vulvar pain on gender and sexed subjectivities (Ayling and Ussher 2008; Kafer 2006) fail to engage mad or disability thought. Additionally, aside from some ground-breaking scholarship that has traced the historical relationality between pain, anti-Blackness, nation, empire, and gynecology (Cooper Owen 2017; Dudley 2012; Moussa 2019; Snorton 2017), as well as psy disciplines more specifically (Tosh and Carson 2016), there has been a noticeable lack of mad and disability engagement with pain as historically and relationally produced in conjunction with projects of settler colonialism, nation-state, and racial formation. The gap in this type of critical analysis is not specific to pain; similar concerns have been raised across the board in relation to the focus and epistemologies that govern mad and disability studies (Erevelles 2011; Gorman 2016; Meekosha 2011). Julie Avril Minich (2016) has made a particular call for disability analysis to employ “disability studies as a methodology” – an appeal that generated a critical dialogue between Minich (2016, 2017), Jina B. Kim (2017) and Sami Schalk (2017), over two issues of *Lateral: Journal of the Cultural Studies Association*. Together, they call for a reckoning of what, and who, is understood as relevant and contributing to disability critique, and whereby “(dis)ability” is an analytic Schalk created to account for the fluid construction of disability in relation to ability and is engaged as a system in flux across time, place, and subject position.

I address this gap by examining vulvar pain through autoethnography methodology, borrowing from queer (Adams and Holman Jones 2011), critical (Holman Jones 2016) and post-structural (Gannon 2006) applications to centre an analysis of how the self is co-constituted with the socio-political and colonial context in relation to knowledge, power, and material conditions. I demonstrate that a mad transdisciplinary approach to autoethnography can fulfil Minich (2016, 2017), Kim (2017), and Schalk’s (2017) “disability studies as a methodology.” Disability studies as methodology is enacted specifically through a “mad methodology” (Bruce 2017, 306), or what LeFrançois and Voronka (*forthcoming*) offer as a “Mad Studies and Critical Disability Studies-informed mad theory as methodology.” This means that I engage with mad, crip, and disability as “modes of analysis rather than . . . objects of study” (Minich 2016), as well as sites of critical knowledge production and “unstable” sites of identity and subjectivity, which I locate as necessarily feminist and queer (Kafer 2013). This also means that I engage vulvodynia from a positioning that first identifies and then challenges its ties to “Reason” (Bruce 2017, 304),<sup>8</sup> while rejecting the call to confine and be confined by compulsory “common sense,” white scientific taxonomies, and the rigidity that defines post-enlightenment epistemologies and colonial methodologies (Smith 1999). A mad methodology lends itself to a valuing of the “undisciplined:” undisciplined minds and modes of knowledge production.

The autoethnographic impulse to challenge objectivist and totalizing knowledge aligns powerfully with “crip-of-color” (Kim 2017) and mad of colour commitments to expose the colonizing reach of biomedicine and psychiatry, including how it stretches itself out through stories *about* biomedicine and psychiatry (Tam 2013; Voronka 2019). The PSA illustrates that successful autoethnography requires more than the mere relaying of stories, which can be used to support neoliberal, white supremacist, settler colonial rationalities just as easily as they can deepen critical intersectional analysis. Enacting mad autoethnography means that “inexpert” voices are viewed as crucial sources of knowledge, while at the same time, careful attention is placed on discerning the influence of psy discourses on “emerging mad subjectivities” (Gorman and LeFrançois 2018, 110). Approaching discourses of vulvar pain through a mad

approach to autoethnography raises important questions: what logics and political projects currently underpin and work through stories and narratives that characterize vulvodynia? How can the self be employed to deepen, rather than narrow and codify, understandings of madness and disability? These questions are especially pressing for me, while operationalizing autoethnography from the position of a white non-binary person, given the role that narratives play in the construction and consumption of mad and disability categories in service to neoliberal white supremacist settler colonization (Gorman 2013; Tam 2013).

In my below analyses of personal encounters with medical sites, I produce a fuller, while always partial, account of vulvodynia by engaging mad autoethnography. My examination is rooted in a transdisciplinary orientation, which as China Mills and Brenda A. LeFrançois (2018) demonstrate, shares with mad studies a tendency toward the “irrational.” This supports me to challenge enlightenment logics of knowledge and knowledge production that are bound up in heteropatriarchal, ableist, racial and colonial violence and to unpack how vulvodynia is constructed — and refused — in relation to dynamic networks of power.

### **(Ir)rationalizing Vulvodynia and Hysteria in the “Neuroliberal” Present**

*I land in the cold hard present – and feel a wave of relief, the kind that comes in a moment of honest defeat. My whole body clenches, releases, clenches, releases. Tears fall from my eyes like water from a wrung-out face cloth.*

*Dr. B squats down and lands at my eye level. He says, “Renee . . . we’ve done the whole neurological work up,” as he awkwardly holds out a tissue.*

*My face feels hot and damp. I reach out to take the tissue, unfurling two fingers from my hand, which is tucked up under my folded arms, and then wipe my cheeks.*

*Dr. B rocks forward and pushes his hands off his knees to stand up in front of me. I sit beneath him. He towers, blocking my view of the room like a new building does the sun.*

*He backs up a little and leans against the exam table to my right. “Our bodies are run with electrical wires.” He reaches out one arm and traces the imaginary wires that run along it. “They shoot out mixed messages when overly worked up . . .”*

*I sit quietly and look up at him from the floor.*

*He tucks his hands in his pockets. “Listen,” he says, “I was in a car accident when I was a young man. I couldn’t sleep right for years. Miserable dreams that everyone went up in flames with the car.”*

*His words calm me a little. I unfold my arms and stand up off the floor to sit on the stool behind me.*

*“What you are going through is real. There is a physical explanation for it, but there is nothing seriously wrong with you . . . Sometimes we all need a little help.”*

*I nod, as if to say thank you.*

*“How about we try starting you on a low dose antipsychotic, just for a short trial, to see if that helps calm things? I also think it might be helpful for you to talk with someone.”*

My engagement with madness begins here from the understanding that knowledge and power work together to shape notions of what is reasonable (Mills and LeFrançois 2018). It is through this “Reason” (Bruce 2017) that logics of disability and madness are constructed, and through which the self and experience come to be recognized. My complaints of vulvar pain have often been pierced by a psychiatric gaze – at times explicit and sharp and, at others, cloaked in empathetic sensibilities, such as in the encounter referenced above. Histories of denial and “institutional gaslighting” (Moussa 2019, 124) have characterized biomedical and psy approaches to pain and trauma such that, in the moment above, when my doctor told me that there was a physical explanation for my pain, my understanding of medical violence as defined by denial and disbelief was disrupted and obscured. Having time spent on me in a space where time signifies money left me feeling like I was afforded a certain currency of care and lead me to interpret my doctor's affirmation of my pain as a shift, albeit a small shift, in biomedical dominance. I had also known this doctor for many years. During that time, I also received or encountered: favours called in on my behalf, a prescription written under a different name to protect me from the wrath of future insurance reviews, invalidation, and a non-consensual drug test added to my blood test requisition. These events are significant because they demonstrate the complexity through which power can be animated through, exist alongside, and operate not always in opposition to care (Van Veen, Teghtsoonian, and Morrow 2019). Autoethnography allows me to attend to the way that the complexity and contradictions inherent in these relationships have material effects on one's life.

The relationship between care, power, and knowledge can be more deeply understood by examining the epistemic relationship between hysteria and vulvodynia. My doctor acted in line with the call put forward by the PSA when he affirmed the presence of my pain as real and validated my reported distress. At first glance this may look like progress. This requires further unpacking, however, in light of the title of the PSA, “Vulvodynia, It's Not in Her Head.” The phrase “it's in her head” invokes the disbelief and invalidation in healthcare often associated with late nineteenth-century ideas of hysteria, when women were written off as “mad,” and “mad” meant that complaints of pain had no “real” basis. However, like hysteria, which has been conceptualized in relation to an over-sensitive nervous system (Briggs 2000), vulvodynia is today often associated with “central sensitization,” or a form of nervous system hyper-reactivity, which is regarded as a possible cause or effect of pain, meaning that “central sensitization may not only be responsible for acute pain becoming chronic but may in fact be the cause of the original pain” (Sadownik 2014, 439). Although vulvodynia has been identified in research with a range of factors, such as inflammation and infection, the assertion that pain is also correlated with one's “mood,” “coping,” “sexual function,” (Bornstein et al. 2016, 128), and a predisposition to anxiety, fear, or perfectionism (Brotto, Basson and Gehring 2003 as cited in Sadownik 2014, 439) suggests hysteria and vulvar pain are related by notions of mind-body connection and somatic (ir)rationality that operate both through belief and disbelief regarding pain's ontological status.

Hysteria has been used as a catch-all phrase for various conditions wherein the mind – or brain – and body apparently work in concert to produce symptoms (Arnaud 2015). Although hysteria is most commonly associated with Sigmund Freud's psychoanalytic work with Josef Breuer (1957), Freud's previous partnership with Jean-Martin Charcot, a professor of neuropathology, marks hysteria's early

relationship to neurology (Bogousslavsky 2011). Hysteria has been defined by various discourses and animated by several signifiers, including American psychiatrist George Beard's nineteenth-century articulation of "neurasthenia" as "nervousness," whereby hysteria, and relatedly pain, was regarded as a consequence of white bourgeoisie women's "overcivilization" (Briggs 2000, 246-47).<sup>9</sup> There has been varying emphasis placed on the role of the mind in the manifestation of histrionic, "nervous" or "psychosomatic," symptoms throughout history, in accordance with the dominant knowledge paradigm and political project of the day, and, as Arnaud (2015) notes, narrative interpretations — as well as misinterpretations — of hysteria, appearing across science and literature, have always been critical to producing shifts and overlaps in medical understanding. That the brain would take the place of the mind and the cortex the place of the psyche in the age of "neuroliberalism" — a concept developed by Ghaida Moussa (2019, 155) to unpack the relationship between neuroscience and neoliberalism — is to be expected. I recognize that "neuroscience and psychology go hand in hand when it comes to [vulvodynia]" (156).<sup>10</sup>

This partnership places into context the possibility that my pain could be both affirmed as having a physical explanation and referred for psy interventions, such that "counter-intuitively, the focus on the central nervous system has been taken up as providing scientific proof of the need for psychological interventions" (77). By attending to these parallels, we see how brain-based neuroliberalism is "founded on institutionalized psychological interventions made to mould the brains, thoughts and behaviours of the sick to match neoliberal interests" (152). It wasn't only vulvodynia that was legitimized by neurology, but the psy interventions that accompany it and aim to create more pliable laborers for the neoliberal nation-state.

My doctor's association of his own traumatic experience with somatic sensations captures another trend in vulvodynia discourse, whereby "real" pain is connected to "real trauma." Given that both pain and trauma have been historically invalidated in health encounters, it is understandable how this could be experienced as a productive shift in medicine; however, biomedicine and psy acknowledgment of trauma through DSM criteria must be recognized as supporting the common identification of vulvodynia in relation to "depression" and "post-traumatic stress disorder" (Iglesias-Rios, Harlow and Reed 2015), and the pathologization of trauma is not to be mistaken for a commitment to social justice. Moussa (2019, 94) identifies "liberal feminist" calls for medical recognition of trauma as failing to unhook the broader medical context and epistemologies that differentially constructs and applies diagnoses in relation to race, class, heteropatriarchy, and ongoing colonization. The outcome is a focus on an individual's perceived damage or maladaptive processing, rather than a meaningful address of the damaging effects of social and state violence — in which medicine and psy are deeply implicated (94; Tosh and Carson 2016, 163-5). Furthermore, having my pain or illness acknowledged in the above encounter as "real" might have protected me against being explicitly labelled "hysterical," but pathologies once deemed irrational are now situated in the brain, meaning that my pain is understood as reasonable, with no guarantees that I will be. The objectivity assigned to neuro-medicine enables a subversive form of psychiatrization that, while claiming brain-based distance from psychiatry, and, therefore, innocence from psy violence, continues to differentially construct, define, categorize, and govern populations through signifiers of madness and disability.

The above encounter demonstrates that medical and psy authority are simultaneously obscured and secured with the help of brain-based logics associated with evidenced-based knowledge. With the backing of supposed evidence, doctors' positions as authorities — as arbiters of truth — appears absolute. As White and Pike (2013) state in relation to mental health anti-stigma campaigns, the validation of the real suggests real solutions that are authorized by medicine and psychiatry. Implicit in my doctor's gesture of empathy was the idea that my pain was validated solely by an "experts" quantifiable, physical

measurement. The message was also that the “cure” was to calm down, listen to him to better understand myself, and then talk to someone so I could best manage myself (Teghtsoonian 2009). This was made possible through the neuro-logics of plasticity – the idea that the brain structure can change over time and, in this case, through self-managed intervention – such that the brain, and relatedly pain, and therefore the “neuronal self” (Pitts-Taylor 2010, 636) can be self-managed by good reason and good choices (Moussa 2019).

I, too, was easily seduced by the assurance offered in those knowledge claims. I left the appointment with my doctor and took the prescription, got it filled, and went home, placing my hope in self-help books and a new counselor. Ironically, the medication made me feel so dazed that I spent the better part of the next month in a near-constant state of brain fog,<sup>11</sup> which rendered me entirely unable to “work on myself” or anything else. From bed, I made repeated attempts at assessing the situation, poking my red, swollen vulva with a hand mirror in between episodes of *Sons of Anarchy*. My month in bed ultimately doesn’t sound all that different from that of a nineteenth-century British aristocrat, attending to their histrionic state by way of a bed rest cure. Reading vulvodynia discourse through the framework of neoliberalism reveals how vulvodynia knowledge functions in step with other relations of power, which, as I attend to next, produces different subjects, whom are subjected to different forms of governance, exploitation, and demands for different forms of labour. This supports an understanding that the system of (dis)ability is constructed not alongside, but with, through, and for the broader socio-political colonial context.

### **Mad Imaginaries of Race, Nation, and (Dis)ability: Skin, Sensation, and Sentiment**

*It’s a bone cold day in early January, just weeks after moving to Toronto from St. John’s, Newfoundland. I’m heading up to the office on the 7th floor. I had scoped this man out on the internet before arriving and placed the kind of hope in him that only a person who hasn’t been hurt that bad yet in medicine would.*

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*It’s bright. The walls and all the furniture gleam crisp white, in a minimal, not institutional way. Small succulents add a spot of green in between the chairs that line the wall and a standing desk. I think to myself that someone was paid to assemble this look.*

*We’ve just finished the physical exam and I’m dressed again. I sit on a chair to the side and he stands at his desk, typing, while I tell him the history of what’s been going on.*

*“I’m fairly certain I have vulvodynia,” I say. “I’ve been tested for every STI out there. I even took a trial of Valtrex after a negative swab, just in case —”*

*Doctor D cuts me off, his back turned to me. “No, no, you don’t have an STI, you have what we call vulvodynia, or more precisely, vulvar vestibulitis, as it appears that the irritation is confined to the vestibule. This type of over-sensitization can be the result of nerve damage, among other things.”*

*I feel my eyes swell. “Right, yes. OK.”*

*He turns to face me, his back now leaning against the desk, his arms and feet both crossed. "The good news is I think we can fix it." His voice drops and softens before he goes on, "The tough part is that it may take some time. You'll need to avoid intercourse for a period of about 3 months."*

*A half-cry half-laugh slips out. "Yes, yes, that's fine."*

*"Excellent. I know this is tough."*

*And then a full cry comes. "I've seen over fifteen doctors—"*

In the moment detailed above, there was a readiness with which I was able to render myself intelligible in the diagnostic construction of vulvodynia, not to mention the ease with which my doctor interpolated me as a vulvodynia patient. The slipper fit, so to speak. But to be clear, this "fit" is not reflective of an essential fact so much as a reflection of "racialized medical imaginaries" (Labuski 2017, 166) that racially codifies vulvar pain — and which, as I will detail, is informed by a "neuroliberal" gaze that produces and orders subjects. What the doctor *saw* in the encounter above was a white woman who was very upset, at the end of her rope; I fit his preconceived notion of whom a vulvodynia patient could be. In fact, his imagined idea of the vulvar pain subject as an unaware white woman was so firm that he was unable to even register my saying the word "vulvodynia."

The common opinions, stories, and clinic reports portray vulvodynia as a white middle class phenomenon. This is despite self-reported rates of chronic vulvar pain that are similar across race and ethnicity in select sites in the "United States" (Nguyen, Reese, and Harlow 2015; Reed et al. 2012). In the Canadian context, one of Moussa's (2019) research participants stated, "I don't really know any Black, Indigenous or people of colour who don't have chronic pain" (7) — resonating with other research where Indigenous women have been represented as having the highest rates of chronic pain out of any group (Meana, Cho and DesMeules 2004). In her ethnographic study on vulvar pain, Christine Labuski (2015) identifies a false dichotomy by noting that a resident in the vulvar pain clinic where she conducted her research commented that "vulvar pain is *white* [whereas] pelvic pain is *black*" (61). Labuski is quick to confirm that the literature lines up in support of this "racialized 'story'" which cannot be explained by access to care, as is commonly argued when conditions are thought to shift by race and class, but due to what the medical institution imagines possible for different bodies. In this case, racial difference is conjured via the acuity and precision of sensation associated with each condition, the corresponding repertoire of assumed sexual activity, as well as social indicators such as class and education (Labuski 2015, 61-62) — each suggested by or reflected in the vulvodynia PSA detailed at the start of this article, which, again, was mainly populated by white actors.

Important context for further understanding the role of medical imaginaries in the racial distinction between vulvar and pelvic pain is highlighted by Khiara M. Bridges (2011). Bridges reads her own ethnographic findings through Dorothy Roberts (as cited in Hoberman 2005, 92) who argues that pelvic pain, or any gynecological complaint from Black and racialized "patients," is often presumed to be caused by a sexually transmitted infection, and relatedly pelvic inflammatory disease (108), an infection of the upper reproductive organs associated with untreated STIs, and therefore with tropes of the unruly, overly sexual, racialized, and poor woman.<sup>12</sup> Bridges (2011) details historical "racial folklore" (Hoberman 2005) about Black women as very active and reproduced in the present through clinic encounters and

teaching moments between doctors and residents. This provides context to the resident's comment above and illustrates how disease and population — and I'll add (dis)ability and population — are dialectically produced, managed, and surveilled through medical imaginaries composed of racial and colonial logics that regenerate, even as they continue to shift. Similar to Labuski (2015, 63), who asks whether the vulvar pain of a Black woman could even be registered as such, I ask, could my doctor have registered pelvic inflammatory disease on my body? He did not ask about sexual activity, and dismissed out of hand my willingness to entertain the idea that my pain was a result of undetected STIs (which would have been an indicator of PID); instead, he went straight to chronic vulvar pain. The material accuracy of the assumption is irrelevant because "the mere imagination of shared pathology does the work of producing a recognizable, apprehensible 'population' out of individual women" (Bridges 2011, 137). This demonstrates that while medical imaginaries construct notions of "disease" and disability, they simultaneously construct population and race. My white, coded as cisgender, educated, and class-privileged subjectivity worked in the clinic encounter to reinforce the racial logics of whiteness and reproduce vulvodinia as a coherent pathology. These narratives also informed my conception of self, along with the stories I have told in making "sense" of my pain (Voronka 2019).

A mad transdisciplinary approach to autoethnography allows me to get to the "so what" of this encounter and to account for how my subjective experience of pain is relationally situated within a broader system of (dis)ability, which, as Minich (2016, 2017), Kim (2017) and Schalk (2017) make clear, is always intertwined with race and class. Bringing this to the surface allows me to name how vulvodinia is relationally produced, recognized, and productive of the very differences it is imagined reflecting. This is made possible because autoethnography demands attention be paid to how the subject is connected to the broader social and political context by grappling with the relationship between self and "Other" (Allen-Collinson 2013): Other diagnostic formation, Other subject, Other site, Other time. With such an approach, "the question, 'what's wrong with me?' turns outward and becomes 'what's wrong with the world?'" (Holman Jones and Harris 2018, 99).

Attending to the historical colonial context of both the US and Canada is necessary to meaningfully appreciate the relationship between diagnostic formation and racial formation (Jasen 1997). Kyla Schuller's (2018) genealogy of race, sex, and science in the nineteenth century offers critical analysis that historicizes present day medical imaginaries<sup>3</sup> by revealing that, while claiming to be "new," the presence of the plastic brain in scientific discourse has a deep colonial history that offers context to interpreting the perceived gulf between white and Black pain, as well as the silence surrounding Indigenous vulvar pain. Black, Indigenous, and even white poor and working-class immigrant women have been historically positioned as less sensate and morally lacking, while the sensitive nervous systems of bourgeoisie white women rendered them particularly susceptible to an overload of "feelings" that confirmed their higher moral, civilizing, and evolutionary potential. Hysteria, and relatedly pain, were thus regarded as the "natural" result of white women's "overcivilization" (Briggs 2000). Schuller (2018) argues that white and Black people were represented as furthest apart on the racial spectrum of "impressibility" — denoting the capacity to accumulate nervous system impressions through sensory experience (7) — while Indigenous peoples were constructed as the "ancestral past" of whiteness and therefore in need of governance (66). Thus, while Black, Indigenous and working-class white women were all understood as less perceptive, they were assigned different potential for self-directed "changeability." This worked as a very convenient theory for white fear over white futurity at a moment characterized by increased colonization (Briggs 2000, 249), and carved a dialectic wherein white women's nervousness, sterility, and "white fragility" emerged in relation to representations of Black, Indigenous and racialized women as "savages," hypersexual, or fertile (247-249).

Today, while vulvodynia should be recognized as contributing to “privileged whiteness” (Labuski 2015, 67), framing the issue through the exclusion of Black and racialized bodies from that diagnosis only results in a call for greater recognition of pain (Labuski 2017); this is limited by a lack of mad and disability analysis that tracks how this history produced differential inclusion in the first place. As Deirdre Cooper Owens (2017) demonstrates, historical analysis allows us to see the central role the field of gynecology played in “racecraft” — “the process that ‘transforms *racism*, something an aggressor does, into race, something the target is’” (Fields and Fields 2012 as cited in Cooper Owens 2017, 110). Disability theorists Rachel Dudley (2012) and Riley C. Snorton (2017) discuss how Black pain and disability were used to build both nineteenth-century American gynecology and US settler nation-state and empire.

Dudley examines the case of Dr. James Marion Sims to illustrate how racialized medical imaginaries undergirded the field of gynecology and, by extension, the American settler colonial and imperial project. Practicing near Montgomery, Alabama in the antebellum South, between 1844 to 1849, James Marion Sims both weaponized and contributed to racialized ideas of pain perception in justifying and enacting atrocious regimes of gynecological experimentation, notably on three enslaved women: Betsey, Lucy, and Anarcha (Cooper Owens 2017, 1). He inflicted invasive procedures, without anaesthetic, on the three women, along with others whose names are unknown, in order to refine a procedure that would correct post-partum vesico-vaginal fistulas. Attending to complications from childbirth was understood as critical to the American political economy, and necessary in order to replenish labour after the ban of the formal slave trade from the African continent in 1808 (Owens 2017, 15). The torturous experiments also honed a surgery that would later be used to rehabilitate white women, whose reproductive health the nation depended on (Dudley 2012). As Snorton (2017) reveals, it wasn't only scientific racism that James Marion Sims mobilized in rationalizing the torture of Black enslaved women; in addition, he pointed to his “love” for the nation-state, echoing Sara Ahmed's (2004) argument that it is love and narratives of love, not hate, that works to materialize white supremacist logics into acts of terror. This demonstrates that medical imaginaries are produced with both racial logics and national imaginaries, and also illuminates the role that sentiment plays to secure differential futures in always insecure, never fully settled, settler states (Stoler 2016). It is safe to say vulvodynia is at work in a social system that produces, taxonomizes, and ranks bodies and minds to meet the needs of white-supremacy and ongoing colonialism.

This history animates what queer, mad, and crip of colour thinkers have theorized about how disability identities, mainstream politics, and the material conditions of disablement are differentially constructed and doled out in accordance with global processes of race, nation, and empire building.<sup>14</sup> The settler colonial imperialist nation-state in accordance with its capital and security needs recognizes and invests in the subjects of liberal, rights-based disability frameworks — their identity and material-corporal resources — in contrast with the targeted debilitation, or “slow wearing down” of those defined as Other by global capitalism (Gorman 2016; Puar 2017, xiv). I call attention to both disabled subjectivities and material disablement within the system of (dis)ability because they are mutually reinforcing, and because the productive effects of this arrangement are exasperated by disability studies scholarship that reinforces essentialized ideas of disability rather than engaging with how disability has and continues to be differentially constructed and mobilized (Gorman 2016). In the case of vulvodynia, the PSA described at the beginning of this article makes it easy to conceive of the white, rights-bearing disabled subject (Gorman 2016) whose “real” pain is used as the gold standard to mark the deserving disabled citizen, in contrast to the pain of white supremacy, settler colonialism and global capitalist violence, or what Gorman (2013) notes is invalidated, “narrated [and often criminalized] as ‘just life’” (277). This reflects a broader trend in mad and disability studies whereby mad/disabled imaginaries and identities are synonymous

with whiteness (Kim 2017) and “white fragility,” which Puar (2017, xiv) confirms, creates an ideal disabled subject against whom all others (and their pain) are adjudicated.

Differences in inclusion should also leave us cautious about calls for greater recognition of pain. Gorman (2016, 256) identifies that even when disability recognition does arrive for racialized and colonized subjects, it does not come with the same treatment. Whereas the diagnosis of vulvodynia often comes with an investment in health because the health of the white woman reflects the health of the nation (Dudley 2012), in pain sufferers of color, the risk to self is often interpreted as risk to social security and is managed through pathologization, which rests not (only) on processes of normalization but also criminalization and control (Bridges 2011). In the Canadian settler colonial context, Dian Million (2013) locates the validation and recognition of violence and trauma in neoliberal agendas that aim to further validate settler colonial governance and restrict Indigenous self-determination (cited in Moussa 2019, 143; see also Simpson 2018). Thus, while Native refusal to settler colonial tactics is relentless and ongoing (Million 2013), the call for engagement with the chronic pain of Indigenous women who have experienced violence (Heino 2018) begs the question: what further violence would this enact? This also reveals that racialized and colonial medical imaginaries are not only animated through racially fixed and differential diagnoses but that subjects can be differently signified under the one diagnosis.

Just as Owens (2017) shows how racial narratives traveled in the nineteenth century through medical journals, we can see how race and (dis)ability narratives travel now through texts such as the PSA described at the beginning of this article. But as Stacy Holman Jones (2017) points out, autoethnography is also a text capable of forwarding narratives, one that provides a space to disrupt the stories that “orient” us. Simultaneously, those texts which seek to be disruptive may also have their own normalizing effects when they contain claims of a whole or coherent “alternative” story.<sup>15</sup> Reading my own experience in relation to a range of transdisciplinary literature has revealed the necessity of proliferating my encounters through multiple, sometimes contradictory, lines of thought, because each frame reveals a new story (Gorman 2013). What an analysis of this autoethnographical text, ultimately, reveals is that “care,” in this encounter, is a symptom of the medical imaginaries at work, an extension of Sims’ same terrorizing national love, one where “neuroliberal” tactics of self-management and self-care directed at the white “sensitive” nervous system reflect what Schuller (2018) details as an historical colonial confidence in white people’s ability to self-modulate and self-govern — to adapt — for the “greater good” (Schuller 2018).

### **Instruments of (Im)precision**

*I turn toward a long mirror and begin to undress. I fold my pants and underwear before laying them neatly on the chair against the wall— a habit I haven’t been able to break since it was ingrained in me as proper etiquette when I part-timed as a gynecological teaching associate, teaching medical students how to give pelvic and breast exams, or “well woman exams.”*

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*Dr. D walks to the end of the examination table that I’m laying on. He sits down, then asks me to “slide down” as he goes back and forth with the nurse about what he needs. I lay on my back and place my feet in the footrests.*

*Dr. D hustles me to move down further on the table. “Until your bum hits my hand,” he says.*

*I plop my hips up and down a couple times to shimmy a little closer to the end. "That good?"*

*"Great," he says. Then he lifts the sheet up to just above my knees. I feel him spread my labia. "Yes, things are looking much better, Renee. Very little red."*

*I lift my head, straining my neck to try and peer down the table between my legs to see his face. He looks focused. "Yeah," I say. "I mean, it's hard to say, things really fluctuate. But I guess things seem to be resting at a bit of a lower baseline right now."*

*He looks to the nurse. "Jeanette, can you hand me a small brush?" Then he looks back down. "We'll do the colposcopy now."*

*My mind is racing. I worry I may have overstated my progress.*

*I feel the cold jelly, then feel him insert the speculum. "Have you had intercourse since seeing us last?" he asks.*

*"Yeah," I respond quickly, my voice rising as I finish the word, a little breathy, as if to communicate a question mark.*

*As he pumps the Q-tip in and out of my vagina I imagine him plunging a toilet.*

*"Are you able to reach orgasm?"*

*"Ah," I keep my eyes glued to the ceiling, not bothering to look at him this time. "Sometimes."*

*I see from the corner of my eye that he lifts his head up, slightly squinting from one eye. "Well, that's good."*

*I'm confused. I mean, in a general sense I agree – orgasm, good! – but I sense another invisible equation has just been calculated, and I can't help but hear the sense of completion suggested by his tone: So, I guess we're all done here.*

*I think: I've got to say something. "Yes, but I'm always in a certain amount of pain."*

*"Really?" He sounds genuinely surprised. I've been seeing him for years, but it's like he's hearing this for the first time.*

*\*\*\**

*I leave and walk just around the corner from the clinic and get a sandwich. I call a friend and debrief.*

*"I'm so pissed," I say. "Like, does he actually think people don't have sex in pain? You should have heard him; it was like my orgasm cancelled out my pain."*

*“Baby. I’m really sorry that happened to you. What a super shitty way for him to handle that.” Her voice is warm and soothing. “Ya know, he was probably just trying to make a quick assessment by asking about sex.”*

*I pause. All of a sudden the bit of sandwich in my mouth feels out of place, invasive.*

*Her voice shakes a little. “Not that it makes it OK or anything,” she goes on.*

*My face grows hot. I know that she’s trying to help by telling me that he wasn’t trying to be a jerk, but I’m fuming. I already know why he did what he did, but being reminded of his ‘good reason’ feels like a call to be ‘reasonable’ in my judgement.*

In the above interaction, my doctor attempted to assess the presence or relevance of vulvar pain in terms of whether I had performed intercourse or “reached orgasm” since our last appointment. Such an approach implies that vulvar pain is not only problematic; it is only intelligible in terms of whether it prevents me from being constituted as a white heteronormative subject. This reflects Robert McRuer’s (2006) position that heterosexuality is co-constituted with able-bodiedness, and thus, queerness with disability, so that for my doctor, it was incomprehensible that vulvar pain (disability) could exist in the same space as normative heterosexuality. This partnership is affirmed and naturalized through the diagnostic construction of vulvodynia by way of its ambiguous inclusion in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM5) (2013) under the psychiatric diagnosis “Genito-Pelvic Pain/Penetration Disorder” (GPPPD) (Dias-Amaral and Marques-Pinto 2018). GPPPD, which is listed as a “sexual dysfunction” and involves a slew of conditions associated with painful penetration and fear of penetration, pronounces the contemporary relationship between vulvodynia, psy, and what Native feminists articulate as settler colonial white heteropatriarchy (Barker 2017; Smith 2006). GPPPD captures a system of diagnosis that pathologizes non-normative gender and sexualities, while dictating treatment that revolves around repairing sexual function as defined by white heteronormativity (Tosh and Carson 2016). Like hysteria, which Laura Briggs (2000) notes was associated with a “catalogue of symptoms that ran to seventy-five pages” (247), GPPPD includes a range of “symptoms” and reflects LeFrançois and Diamond’s (2014) claim that diagnostic flexibility extends the reach of psychiatric authority.

The entanglement of “compulsory heterosexuality” and “compulsory able-bodiedness” (McRuer 2006)<sup>16</sup> also produces a system of self-governance in relation to how chronic vulvar pain interrupts the “heterogendering act of penetrative [vaginal] intercourse” (Kaler 2006, 50). This results in gendered and sexed subjectivities that are interpellated as sick, failed, deviant, or queered (Ayling and Usher 2008) when they don’t or can’t perform this heteronormative ritual. Pain subjects are therefore required to seek medical validation and recuperation (Farrell and Cacchioni 2012). However, in the context of neoliberalism, medicalization (and psychiatrization) often disguises itself through its sister discourses of health and wellness, or the “healthisization of sex” (Cacchioni 2007, 306), such that discourses of pathology morph into ones of wellness in much the same way that the PSA reflects how governance can happen under the guise of empowerment, inclusion, and diversity. Hence, sexuality becomes regulated through the rhetoric of self-care, health and “liberation.” Neoliberal governmentality depends on the illusion of choice (Lemke 2000) — of the “flexible” normative subject, fashioning just a touch of difference

(McRuer 2006), such that “compulsion is here produced and covered over, with the appearance of choice (sexual preference) mystifying a system in which there actually is no choice” (7).

At the institutional level, the encounter described above indicates the mechanics through which compulsory heteronormativity and able-bodiedness work in concert with neoliberalism and become invisible through the guise of the mundane and routine. The banality of clinic processes, procedures, and “seemingly benign assessment tools” (Smith 2011, 198), which appear innocuous or bureaucratic at worst, function to aid and abet biomedical and psy governance. My doctor's failure to understand that pain and sex are not mutually exclusive was instantly forgiven, validated, as it fell under the umbrella of institutional assessment. Via the routine of the examination, I was made to feel that I was somehow in the wrong for having an experience that did not equate normative heterosexuality and able-bodiedness; via the routine, I was forced to accept the brusque treatment of my body as a malfunctioning sexual tool to be man-handled and plunged with a Q-tip. Even when my doctor asked if I had had “intercourse,” he meant penetrative vaginal sex, but took intercourse to imply a particular kind of heteronormative sex. In addition to the explicit pressure applied by compulsory heterosexuality and able-bodiedness, the mundane operations of neoliberalism enact a pressure that renders non-compliance to rehabilitation “un-thinkable” (McRuer 2006, 13) for both me and the doctor. My vulnerable position, the totalizing reason of his standardized questions, and the effect produced all left me disoriented about what the real problem was. We were set in motion in a choreographed arrangement. The conversation that I had with my friend after leaving the clinic revealed, in her patient tone, just how neatly white heteropatriarchal neoliberal rationality is equated with “common sense.”

The coarticulation of race and diagnosis demands, however, that attention be paid to the partnership between rehabilitation and “common sense” as a technology of race and ongoing colonialization (see McRuer 2006). We need to be attentive to structural shifts in the system of (dis)ability, and the shifting tactics of compliance that will inevitably come from this. The Canadian Women's Health Foundation's PSA, for example, demonstrates that inclusion, while perhaps mimicking a shift in power, only constitutes a shift in the appearance and operations of power. Inclusive tactics are not confined to the heteronormative subject; discourses of tolerance and inclusion work to ensnare new populations, bringing queer, trans, crip, and mad subjects into neoliberal folds (McRuer 2006) of larger projects connected to “Mad nationalism” (Gorman 2013). I myself, as a non-binary vulvar pain subject, have contributed to organizational projects under the banner of pain-related “gender-inclusivity.” After all, the incorporation of (some) queer and trans disabled subjects is crucial to the self-actualization of the neoliberal nation-state (McRuer 2006; Puar 2007, 2017).

If “inclusion” ensnares more bodies into new modes of governance through shifting forms of “rational thinking” like that which equates rehabilitation with heteronormativity or diversity with what Lisa Duggan (2002) named “homonormativity,” that makes mad thinking not only helpful but crucial in revealing its underlying sinister logics. My mad thinking interrupted the processes of “common sense” in my encounter as I became angry at the “routine”, and I enact it here, again, via a mad approach to autoethnography that allows me to heed Rachel Gorman's (2016, 251) call to move out from what feels “immediate” about my narrative and connect the seemingly mundane details of the interaction above to broader disability relations and socio-political-economic trends and thereby account for how assessment tools, diagnostic criteria, and modes of governance morph, in accordance with the needs of the day.

## Hiding in “Good Reason”

*I feel the sedative kick in, and my muscles ease up a little, soften like hot cement. I notice a slackening of the space where one thought meets the next. I begin to run through my lines once more: ‘Oh yes, Doc, I’m coping quite well. I’m making sure to get outside every day and the routine helps me cope . . .’ I giggle to myself, sitting in the waiting room.*

*I hear my name called. “Renee, right this way.”*

*I get up from my seat and walk to the front of the room, following the young nurse as she takes a right behind a barrier wall that sections off the waiting room and the rooms where the real business happens. We take a path that by now is familiar as I hear voices talking behind closed doors.*

*We land in front of a door that I know signals my stop. I let her walk in first, lead the way, and then follow her in. “I know the drill,” I say. “I’ll get undressed and wait on the table.”*

*She hovers just inside the door. “That’s great.” She tucks her clipboard under her arm and points at the table. “You can leave your top on and there’s a sheet on the bed you can use to cover yourself. The doctor will be by shortly.”*

*She hauls across a curtain as she leaves, and I’m left alone in the clinic room.*

*I pause to look at myself in the mirror. Seeing my blue-white legs and black public hair makes me think of meat in a deep freeze.*

*I turn and walk over to the table, near a window where some light sneaks in. I get up and drape myself in the tissue paper and it makes a familiar crunching noise. I wait 20 minutes until he walks in.*

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*Dr. D starts to greet me before he enters my range of vision. His voice is gruff but honeyed.*

*“How’s our favorite Newfoundlander?” His face and his stride are relaxed. I think that he must be having a good day.*

*I laugh from up on the table, “Ha, hi. Good, yeah. Good. How are you?” My voice is also chemically relaxed.*

*He stops in front of me. “Have you been avoiding us?” He smiles, turns to the nurse who is pulling supplies out from the cupboard under the examination table. She lets out a light laugh, keeps her head down, shaking it just a little. We make eye contact.*

*I laugh and go on to explain how I called to reschedule my last appointment but didn’t get a call back.*

*“Well, we’re happy to have you back,” he says as he turns his back to me and starts moving his mouse around, presumably opening my file. “So, how have things been?”*

*I unleash my script, tell him I’m good — being good.*

*“What did you say you do for a living? You’ve got a great personality. Very level-headed. Rational.”*

*“Well.” I feel satisfied in an ‘ah-ha, got you!’ kind of way.*

My decision to take a sedative before going to this doctor's appointment was informed by the knowledge, obtained from past appointments, that proper care depended on my being viewed as calm and discerning. By reporting my “healthy” coping strategies to my doctor, I knew that I was performing “insight” into my condition and suggesting that I was at work on myself, in alignment with “neoliberal” demands. This type of knowing might be best understood in relation to what Lisa Merri Johnson and Robert McRuer (2014) identify as the everyday knowledge that comes from moving through the world while mad or crip.

If the compulsory nature of compliance is a foundational feature of biomedical and psy power, such that “neoliberal political and economic logics . . . are contingent on compliant queer, disabled bodies” (McRuer 2006, 18), then non-compliance represents a subversive site of refusal. In the appointment above, I was communicating a capacity for “Reason” (Bruce 2017) and knowledge, which is to say, the right kind of knowledge regarding one’s pathological state, and was thereby enacting the performative potential of non-compliance that LeFrançois and Shaindl Diamond (2014) allude to in their writing about mad subjects, who intentionally perform the script of “mental illness” (50-51). Therefore, my performance of sanity — my claim that I was getting outside and regularly seeing a counsellor to cope, in order to act the role of “good patient” — actually constituted an act of subversion. By copying the appearance of psychiatric subjectivity, I was able to position myself outside of psychiatric subjectivity (Mills 2014). The effect was that I repelled psychiatric interpellation and thereby undermined the integrity of “psychiatric truth” (214), which claims that what is discovered under psychiatric observation reveals an objective fact. What my doctor observed was not an objective fact, but rather a performance of his expectations.

By further examining the above encounter through mad autoethnography, centering mad of colour thought, I can identify that my performance of sanity, while it may have fooled the medical gaze and repelled assimilation (Mills 2014), also naturalized madness and disability through what Cynthia Barounis (2009) identifies as the naturalizing power of white masculinity, which I understand as translated through anti-Black notions of “white rationality” (Meerai, Abdillahi and Poole 2016, 24). Barounis (2009) argues that hyper-masculinity can be used to neutralize either queerness or disability and effectively “rehabilitates” the relationship between compulsory heterosexuality and compulsory able-bodiedness. Disability or queerness is repackaged for normative tastes. What this reading reveals about my own situation is that in performing sanity, I relied on, invested in and re-inscribed the standards of white rationality (Meerai et al. 2016). A critical politics of mad refusal must be enacted from an understanding that psy violence takes place in the context of ongoing settler colonialism (Tam 2013), where the sane and rational subject is always constructed in relation to the white masculine subject, and thus, in opposition to the irrationality and deviance ascribed, most notably, to Black, Indigenous, and mad people of color (see Gorman 2017).

## **Madness-in-Relation**

Engaging autoethnography as a mad and critical disability studies methodology means engaging more than just mad experience. A mad method also challenges the rationalities that order knowledge and knowledge production. This does not assign epistemic authority to the mad or disabled subject; writing about lived experience from a mad perspective does not mean the text should be engaged with uncritically — the PSA reveals the dangerous effects that can be produced there. No, it demands attention paid to relationality, where analysis extends beyond articulating the self as produced in the social and political context, to also root in the self as an orientation — a mobile site from which to narrate the system of (dis)ability and provide an always partial account of (in this case) vulvodynia — of “disability-in-relation” (Johnson and McRuer 2014, 141).

To approach disability in relation is to think “from the critical, social, and personal position of disability” (134), but it is also to engage the processes of thinking while mad and crip from within mad thought processes. My scattered focus and the chaotic twists and turns that drive my attention have rendered my mad mind active as a mode of analysis in this inquiry and has been critical to how I have operationalized my transdisciplinary analysis. The mad process I refer to here is not an essentialized one, but one which “produces knowledge where the meaning-making of mad people is centred, but where other meanings emanating from other sources academic or otherwise also can be considered and deconstructed, incorporated or rejected” (Mills and LeFrançois 2018, 506). Said another way, my application of Minich (2016, 2017), Kim (2017), and Schalk’s (2017) method for articulating the system of (dis)ability has been animated by madness at all points of this work.

Using the shifting self as a vantage point has made visible how hysteria works through neoliberal rationalities and brain-based paradigms that are characteristic of contemporary psy arrangements, which produce “new” mad and crip subjectivities, pliable laborers, and governable populations. What this orientation has also revealed is that medical imaginaries are mutable and co-constructed with and for the shifting needs and machinations of race and settler nation-states, a process that is further aid by compulsory able-bodiedness and heteronormativity, along with mad nationalism, even as power (sometimes) disguises itself under the illusion of care. Together, these autoethnographical excerpts reveal how disability can, and indeed must, be engaged from a place of fracture. When mad autoethnographic inquiry is animated by feminist, Black, critical race, queer, Indigenous, and (post)colonial thought to unpack madness and disability it can support the coalitional project of “attuning [oneself] to the varying effects of the political economy of madness on different populations” (Tam 2013, 285). What results from this are the mad and crip stories that, when held in fracture and tension, orient us toward women of colour informed mad and crip coalitions (Kafer 2013; Kim 2017; Minich 2016, 2017; Schalk 2017).

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## Endnotes

1. Vulvodynia reportedly impacts around 16% of “women” living in “America” (Harlow and Stewart 2003). No research has been undertaken to explore the prevalence of vulvodynia in “Canada,” nor the prevalence of vulvar pain within queer, trans, or Two-Spirit communities.

2. In a discussion of how mad stories are incorporated into “mental health” discourses of recovery and resiliency, Jijian Voronka (2019) engages Razack (2004) to distinguish the stories told by individual subjects from the narratives that subsume those stories and assemble them into governing discourses.

3. Throughout this article, ‘psy’ is used as an umbrella term that refers to psychology, psychiatry, psychotherapy, psychoanalysis, and other “mental health” disciplines and knowledge regimes.

4. Lucy Costa et al. (2012) and Voronka (2019) further discuss the appropriation of “recovery” and “resiliency” narratives by neoliberal “mental health” regimes.

5. Voronka (2016) accounts for the dangers associated with the emergent identity category of “people with lived experience” in “mental health” institutions and discourses, arguing that it centres and privileges whiteness in the production of a universal referent.

6. I argue that “just enough” racial diversity in discussions of vulvar pain works to simultaneously obscure and reproduce the vulvar pain subject as a white settler while also supporting the multicultural myth (see also Goldberg 2008).

7. The geographical space referred to as “Canada” is a settler nation-state whose borders and claims to coherency are contested and met by Indigenous refusal and resistance to ongoing occupation and dispossession (Simpson 2014).

8. La Marr Jurelle Bruce (2017) capitalizes “Reason” to discern it from “reason” as “[anti-Black] pretext for the systematic subjugation of persons deemed unreasonable or mad” (304).

9. While I engage the relationship between hysteria, neurasthenia, and white women, Louise Tam (2014) demonstrates this union is not fixed, discussing the mobility of neurasthenia in relation to how it is currently used to pathologize Asian migrant workers in the transnational context.

10. Psy approaches such as “mindfulness” and “cognitive behavioural therapy” are recommended as vulvodynia interventions (e.g., Brotto 2015).

11. Mel Y. Chen (2014) provides an analysis of “brain fog” as a potent site of epistemic potential and refusal.

12. Khiara Bridges (2011) doesn’t discuss vulvar pain, but states that a similar dichotomy exists whereby the pelvic pain of a white woman is assumed to be in relation to endometriosis – which is also associated with white women and was a signifier of civilization in the twentieth century – while Black and racialized women’s pelvic pain is associated with pelvic inflammatory disease.

13. Kyla Schuller (2018) disrupts histories of scientific thought that rely on Darwin’s natural selection to reveal the influence of Lamarckian and neo-Lamarckian notions of impressibility, sensation, and sentiment as a regime of biopower and population management that dominated the nineteenth century by assigning differential capacity to feel, reflect and therefore evolve over time. I argue the “biopolitics of feeling” (Schuller 2018) predicts the contemporary neuro-discourses of plasticity that inform explanations and interventions surrounding vulvodynia.

14. Rachel Gorman’s (2016) “dialectic of *disability-disablement*” and Jasbir Puar’s (2017) “biopolitics of debility” both similarly account for the process whereby the recognition and investment in some white disabled

subjects happens in relation to the targeted and unnamed disablement/debilitation of others to serve the needs of settler colonialism, imperialism, and global capitalism.

15. As Tiffany King (2013, 189-91) outlines in her autoethnography, the white subject has always claimed to define and occupy wholeness in relation to anti-Black and “genocidal” representations of Black and Indigenous people as “chaotic” and “fungible.” Therefore, the risks and potentialities associated with reproducing a coherent story or coherent self shift according to who is speaking (or writing) (see also Robinson 2020).

16. In theorizing *Crip Theory*, Robert McRuer (2006) challenges the taken-for-granted status of heterosexuality and able-bodiedness to argue that what Adrienne Rich (1980) has famously named the system of “compulsory heterosexuality” must be understood as co-constituted with “compulsory able-bodiedness.”

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