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On Ambivalence: Disclosure, Disability, Trauma, and Precarious Affects

Sur l’ambivalence : divulgation, handicap, traumatisme et affects précaires

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Abstract

Following other critical disability studies scholars’ contributions to thinking more capaciously about how disability studies as a field must reckon with experiences of pain and suffering, this autoethnographic article calls for readers to grapple with experiences of disability or chronic conditions that are intimately tied to experiences of trauma. Using storytelling as method, the author explores their shifting affective stances to their lived experiences with epilepsy, autoimmune disorders, mental disability, medical interventions, and trauma over time. Weaving autoethnographic collaged narrative with disability, feminist, and affect theories, the author argues that adopting ambivalence as an affective stance toward disability can make room for the always evolving and contradictory emotions and experiences that impact indivdiuals’ relationships to claiming disability.

Résumé

Pour faire écho aux contributions d’autres chercheuses et chercheurs en études critiques sur le handicap à une réflexion plus approfondie sur la manière dont les études sur le handicap en tant que domaine doivent tenir compte des expériences de la douleur et de la souffrance. Cet article autoethnographique invite les lectrices et lecteurs à se pencher sur les expériences de handicap ou de maladies chroniques qui sont intimement liées aux expériences de traumatisme. En utilisant la narration comme méthode, la personne auteure explore ses positions affectives changeantes face à son vécu avec l’épilepsie, des maladies auto-immunes, un handicap mental et des interventions médicales et des traumatismes au fil du temps. En tissant un récit autoethnographique parsemé de théories sur le handicap, le féminisme et l’affect, la personne soutient que l’adoption de l’ambivalence comme position affective à l’égard du handicap peut faire place aux émotions et aux expériences changeantes et contradictoires qui influencent les relations des individus avec l’appropriation du handicap.

Keywords

Disclosure; Chronic Conditions; Trauma; Claiming Disability; Disability Desire; Affect; Autoethnography

Mots-clés

Divulgation; maladies chroniques; traumatisme; appropriation du handicap; désir de handicap; affect; autoethnographie

I can pass as someone without a disability. I've trained my bodymind to wait until I've clicked "Leave Meeting" on Zoom or turned the key in the lock of my front door, pushing myself until my chronic fatigue flares flood my weekends and days in between teaching. As one of my students wrote in an email near the end of a recent semester to explain a late assignment: "So I'm rolling with the punches and trying to use my anxiety to fight my depression." I wish that I could respond to myself the way I responded to that student: to offer myself flexibility, embrace vulnerability, and take time to truly find and develop radical forms of self-care. But I also hear in my own head that other response about toughening up. If you take a break now, you'll just have double the work tomorrow. Publish or perish. I've cultivated a fucked up ethics of care that I first internalized in my work as a middle school teacher that rewrites what flight attendants have been telling us for years: "Please assist others before placing the mask over your own mouth and nose." The only boundaries I need are the ones I erect within my bodymind and my memory. I creep down the deserted hallways of my department floor at 11pm. When my alarm sounds the next morning, I itch at the telltale welts clustered in angry groups along my arms and legs.

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The intervention I hope to make in this article is born from my personal story and the affective stance from which I experience it and tell it: I feel ambivalence in relation to my disability.

Over the years, I have embodied myriad emotions in response to my lived experiences with and adjacent to disability. And of course, my positionality as a White, queer, cis female academic (among other identities) mediates and affects each encounter and experience in its own right. These affective stances to my disability experiences are not static. They shift and bump up against each other uncomfortably at times. But I have come to embrace that disruptive dissonance as an epistemological and ontological strength: it demands I question the normative and hegemonic. Ambivalence is a productive home for the disruptive dissonance my story demands.

From this site of affective ambivalence, I argue that we need space for more precarious affective relationships to disability. As a disability studies scholar, I am often wary of the embodied tension I experience working within a field that has largely been built upon "arguments for the importance of desiring disability" (Price 274). For a long time, I felt a strong affinity with disability studies but struggled to claim disability and name my own—a discomfort, in reflection, that was born from my uncertainty about my right to identify as disabled and make sense of that identity in relationship to desire. I do not have a complicated relationship with the collective disability pride of political resistance, of the "nothing about us without us" humanizing pride that has dared to suggest that a disabled life is a life worth living. Yet, my impairments, although mediated in social and political ways that negatively affect my experiences of them, are also just difficult in my material and embodied experience of them. The medical model's violent and coercive call for cure erases disability futures, yet, as a critical scholar-activist within disability studies, I often desire a cure for some of my impairments. I have often wondered, as Alison Kafer quips in her introduction to *Feminist, Queer, Crip,* if perhaps my ambivalence, my frequent desires for a cure, and even my desire to locate and make sense of the exigence of my impairments are the types of questions "no self-respecting disability activist or scholar wants" to engage (7).

Disability pride has important origins, tied to hard-fought activist movements calling for accessibility and rights to autonomy. The social model of disability, born from these movements, shifts attention away from disability as individual deficit and toward critiques of social barriers and *disabling* environments. However, this model has also been usefully critiqued by numerous scholars over the years (see, for example, Kafer, 2013; Price, 2014; and Lukin, 2017). In this vein, Kafer argues that "focusing exclusively on disabling barriers, as a strict social model seems to do, renders pain and fatigue irrelevant to the project of disability politics" (7). In other words, an overemphasis on the social model may run the risk of excluding those, like me, who may "simultaneously desire[] to be cured of chronic pain and to be identified and allied with disabled people" (Kafer 6). How can I make sense of pain and fatigue as simultaneously rooted in and distinct from the disabling environments in which I live? Others' contributions to disability studies have provided me useful terrain on which to complicate my own ambivalent relationship with disability (see, for example, Sami Schalk's explorations of disidentification and coalitional politics in her 2013 article, "Coming to Claim Crip").

Furthermore, for many individuals who experience debilitating effects of trauma or live with disabilities born from or alongside trauma, it is necessary to create room for the complexity of our stories and experiences. What does it mean to desire disability, when that disability is perhaps the embodied narrative of a bodymind in pain? How might someone internalize a call to desire disability that is born from trauma? If I were able to isolate the infected tissue of traumatic memory that lives in my body and manifests itself in chronic illness and impairment, would I carve it out?

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Figure 1: A watercolor painting depicts a park filled with trees and greenery. At the center is a roundabout filled with small plants, surrounded by a concrete path. A foot-worn dirt path cuts directly across the roundabout as a shortcut. "Desire Line" by Rachel Tacke.

In wrestling with my relationship to disability several years ago, I became enamored with Sara Ahmed's adoption of "desire lines"—landscape architecture's term for those unofficial paths made by the everyday comings and goings of individuals who "deviate from the paths they are supposed to follow" (19-20). I googled "desire lines" for a conference in 2017 and grabbed a picture that I felt visualized the phenomenon (reimagined as a watercolor painting in Figure 1), which shows a dirt "desire line" shortcut taken directly across a roundabout filled with vegetation on a path in the woods. To me, the shortcut created by so many park visitors, symbolized a sense of creative defiance, a refusal to stick to the path laid out for them. I saw my metaphorical feet treading the same packed dirt.

In grappling with my disability identity, I had become critically invested in exploring how I disclosed disability and trauma, particularly in relation to how those disclosures potentially resisted prescripted narratives of those experiences. In that presentation, I argued that more creative forms of identity disclosures can simultaneously critique the prevailing hegemony and help to compose new ways of being. Someone in the audience said (and I paraphrase here): "But why does it *have* to be creative?" I didn't get, in my gut, the larger critique they seemed to be offering: desire lines are visual markers of the social and ableist norms they seek to deviate from. New and creative forms of disclosure don't alter disability erasure or prejudice, so why must we do the extra labor and sidestep our way through life? As Audre Lorde reminds us, it is often the work of the oppressed to educate the oppressor (114).

Her question festered. In retrospect, I had not thought through what that image (Figure 1) *actually* meant for my own tactics of disclosure at the time. I jumped on Ahmed's adoption of "desire lines" because it did two things for me: 1) it justified my obscured forms of disclosure that I often felt did not fit in disability spaces that foregrounded a pride in explicitly naming disability; and 2) it helped me try to justify my forms of disclosure and embodiment of disability as acts of resistance to dominant narratives. However, my own forms of disclosure are far from a shortcut; they require a lot of complex rhetorical labor. Moreover, I do not always have control over how my bodymind discloses. I had adopted the image and the idea of desire lines without fully interrogating it.

About a year and a half after that conference, I came back to the idea of desire lines and the question that the audience member asked me as I prepared for a new conference. I was angry—angry about a lot of things that I had lived with or experienced more or less for years, but a new epilepsy diagnosis and its attending medication seemed to push me to the edge. I wasn't sure what to do with the framing of disability desire that had previously ordered my thinking. Where could I fit the anger that now clouded other emotional stances to my experience?

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In the past, I have sometimes made sense of my story through the metaphor of puzzle pieces, but those are prefabricated, cut to have distinct attachments to other pieces. The piece fits or it does not. In this way, perhaps puzzle pieces are too much like the prescriptive thinking I am always trying to disrupt; "each term forms the borders of the other," as Alison Kafer says about the binary that creates disability in contrast to the normative myth of "ability" (6). Too many pieces of my experience do not fit to form a puzzle that coheres in an ableist world.

Instead, I employ the embodied metaphor of quilting. Quilting allows for agentive misfitting: creative mismatching of fabric shapes, patterns, and materials. What may look like dissonance up close can look like constructive contradiction when perceived in its totality. Quilting also requires the labor of stitching each piece to another. Fingers get pricked, wrists get sore. A quilt is embodied and material. It may be a collaborative project. It takes time. Stitches can also be undone and done again, in a recursive process.

In exploring my ever evolving and complex relationship to disability, I echo James Berger's call to foster a productive dialogue between trauma and disability studies, because my story overlaps the boundaries of each—boundaries that have sometimes been too strictly segregated within academia. As I illustrate in the patchworked vignettes that follow, many experiences of disability and trauma are not easily disentangled. Mine is a story of multiple eggs and multiple chickens. Attempts—by myself and others (doctors, friends, therapists)—to map it or make sense of it over time have affirmed the need for multimodal, complex, and embodied forms of meaning-making. Yet despite my epistemic commitments to embrace the multiplicity of experience and diverse knowledge production, I too often seek easier, less complex answers to my own questions about self and experience.

Within this patchworked essay, then, I employ questions-as-method—as Alison Kafer does in *Feminist, Queer, Crip*—in part because the "political/relational model of disability sees disability as a site of questions rather than firm definitions" (11). The sense of multiplicity I want to engender in this piece is also inspired by M. Remi Yergeau's work of storying-as-method in *Authoring Autism*. Adopting autie-ethnography and autistext, Yergeau works to disrupt violent medical and social theories of autism, and "reconfigure what it means to be self-focused and without self, in all of the paradoxicality of that simultaneity" (24). I, too, adopt storying to center the paradoxical simultaneity of emotions, experiences, and my relationship to disability. Jay Dolmage's engagement with *mētis* as an embodied rhetoric of sideways, disabled movement is also central to my method. Dolmage's conceptualization of *mētis* as a "rhetorical apparatus for sideways reading and writing" is based on the ancient Greek god Hephaestus who was characterized by his physical disability and movement (14). I adopt a *mētis* method that requires putting "history back together not as we found it—as a smooth and celebratory space shaped by the victors, performative, clean, and straight—but as a tenuous and temporary collage" (68). As a "tenuous and temporary" collage, this essay is composed of patchworked pieces of story that may create dissonance, even illegibility. I invite you to sit with that dissonance, like I do.

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That anger framed my entire 2019 conference presentation. I was tired of masquerading as OK. There's always a tipping point, and I'd found my anger was just there, bubbling under the surface. More and more frequently, it refused to stay contained. My affects had begun to "bubble out at the seams," in M. Remi Yergeau's words—a bubbling out that carried with it social consequences ("Reason"). The side effects information sheet for my new seizure medication, Keppra, reminded me that my anger could also just be a medically explainable response.

I'd been disclosing so long one way, that I needed to try it a different way. On paper, and in front of a small audience, I engaged in acts of more direct disclosure:

> As someone who has carried, for over half of my life, a cadre of diagnoses that suggest I am perhaps over- (or under-) animated, too emotional (or not emotional enough), I am wary to enact this experiment. I have, after all, had close friends and strangers doubt my stories of trauma, and I have found myself changing my narrative to appease their doubts.
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> Once, in a fit of anger, I got into an altercation with a DJ at a bar in Oakland because he wouldn't change a song I found offensive. "Nobody would rape you, bitch," he said, when in that anger I found myself justifying my request through a disclosure of assault.
>
> Another time, floating in a pool with friends after the sun had gone down, I talked about the boy in my childhood, and a friend said, "But isn't that just little kid curiosity?" I'm sure I shrugged my shoulders with a "yeah" and moved on. When my psychiatrist in California first diagnosed me with bipolar disorder, he requested to talk to someone who was close to me. He talked to my partner at the time, who once, after drinking too much, crushed a wine glass in his hands an

> inch from my face. How interesting that after talking to a man who crushed glass in my face about the possible volatility of my moods, the psychiatrist gave me a diagnosis that still sits on my medical record.
>
> However, as Sianne Ngai reminds me in her work on "animatedness," overly emotional bodies are often made Other, and their discourses are swallowed by dominant narratives. So as I navigate this academic work and the disclosures it carries, I ask: What social conditions invite and/or discourage disclosure? And particularly, what emotions compel disclosure? What affects carry disclosures in ways that they will be heard?

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My claim to ambivalence is also a critical reappropriation of the term, which is linked to darker histories. Ambivalence first showed up in the work of Eugen Bleuler, who coined the term schizophrenia in 1911: "I call *dementia precox* schizophrenia because, as I hope to show, the splitting of the different psychic functions is one of its most important features…as the disease becomes distinct, the personality loses its unity" (cited in Ashok, Baugh, and Yeragani 95). Ambivalence, a neologism of the German *equivalenz,* became one of the four central symptoms of schizophrenia, alongside "abnormal associations," "autistic behavior and thinking," and "abnormal affect" (95). Ambivalence was an inherent contradiction, only possible when the self was split.[1]

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[1] Recent work in philosophy has reexamined ambivalence in more capacious ways, including a reframing of ambivalence as an inherently human experience. For example, see Hili Razinsky's 2017 *Ambivalence: A Philosophical Exploration.*

In direct opposition to the violent medical etymology of ambivalence, I argue that ambivalence works as a heuristic for maintaining the integrity of incompleteness. Rather than canceling one another out, contradictory emotions live together. Thus, I define ambivalence as feeling multiple emotions simultaneously, even emotions that may seem paradoxical in relation to each other.

Reflecting on my own experience, I think ambivalence is often read as indifference because ambivalence itself is difficult to *feel* or articulate as a *feeling* because of its multiplicity. Ambivalence is a both/and; it requires me to reckon with misfit pieces and contradiction. Ambivalence exists in liminal spaces even as we are continually and magnetically pulled back to black and white thinking and ways of being in the world.

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When I went back to interrogate "desire lines" more fully, I discovered a whole host of other images that revealed different exigencies. In some, the exigence of a "desire line" was not always obvious. For example, in some images, a dirt path sits parallel to existing pathways. Likely the images did not tell the whole story, but I also realized that I did not need to completely understand any given desire line's exigence. I know from experience to question the *why* of another's story is to question that story's legitimacy. Other images made me begin to question the notion of "desire" itself. I started to see in the images pathways that were better described, perhaps, as "coerced lines": pathways that were forged to avoid danger or created to make more accessible routes when no such access existed.

Figure 2: In this image, a road cuts through a residential area. On the right is a busy street lined with houses. On the left is scrubby lawn that ends in bushes. In the middle of the image, a slim dirt path is worn into grass that runs parallel to a short fence of wood posts that dissects the lawn from the road. On the other side of the fence, the road runs parallel with no sidewalk. The desire line, fence, and road converge in the distance.

Figure 2, “Path desire lines, Beach Road” by philip.mallis depicts a slim dirt path, worn into the grass that runs parallel to a short fence of wood posts connected by metal rods. On the other side of the fence is a road with no sidewalk. Figure 3, “Path of Desire” by bdunnette depicts a steep desire line winding down a grassy incline filled with trees and shrubs to meet the sidewalk at the bottom. To its right is a set of sixteen inaccessible steps.

Figure 3: This image is taken at the bottom of a hill, looking up to a white building barely visible on the horizon. On the left is a dirt worn path cutting up through vegetation and a few trees. On the right is a set of sixteen slim, concrete steps with no handrail. A person stands a few steps up with their hands on their hips looking up the steep incline.

These additional images left me reflecting in more cynical ways. Sparked by my active and disruptive bout of anger, and thinking about the role of emotions as both instigating and coercive factors in our disclosures and experiences of disability, I came back to my initial claims about disability and desire with a more critical eye, fueled by that anger, a bit of distrust, and a whole lot of exhaustion. What happens when a “desire line” becomes a “coerced line” or a “survival line”?

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I credit the field of disability studies for giving me the language and complicated critiques I have embodied for more than half of my life—critiques of the medical model and of structural discourses that label disability as deviance—which have had a hand in my choices to self-silence parts of my identity and experience for too many years. Disability studies also introduced me to disability communities and disability culture. Across coffee tables in different cities, brought together with others through academic conferences and workshops, I have had revelatory conversations about new theoretical interventions, born *from* disabled experiences, that consume my thinking and feed my personal and academic reflections. These academic spaces led me to seek out other rich—and just as theoretically thought-provoking—disability communities outside of the exclusionary walls of academia. In these spaces, I have also been able to talk more safely, and without the feeling that I am taking too much from others, about the pros and cons of particular medications, discrimination on various scales, the fear I sometimes have about living alone with an autoimmune condition that could cause a life-threatening flareup out of the blue, or the absurdity of accommodation legalese and forms that serve only as material objects to create space for my own rhetorical labor of both creating and justifying access needs I *actually* need. I have been able to talk about my exhaustion, indignation, joy, annoyance, anger, fulfillment. The pride I have found in disability communities has helped me make sense of myself and my experiences with disability, the medical model, and my own varied impairments. It has also cemented the need for me to name my positionality and privilege as a white academic, and to center intersectional frameworks and stories that complicate exclusionary understandings of disability or erase difference.

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I had done muscle testing before, but this gray-haired woman in drapey clothes whose home sat on a Pacific Northwest rocky beach had come recommended. Some of the things she said made sense. “You just can’t wake up in the morning, I can tell.” She scribbled notes to herself and wrote out another supplement. “You’re overly critical—of yourself and others. It’s just so exhausting.” Then there was talk of gallbladders and methylation and other things I don’t recall. My body told her—translated in numbers and yes/no questions—both its lack and its excesses. “Yours is a complicated one,” she said.

I won’t lie that my inner skeptic was hard at work, but its persistence toward the positivistic “rational” has ebbed significantly in recent years. The “complexity” of my bodymind—i.e., its tendency to misbehave—has been remarked upon by practitioners of all kinds. “Give into the chaos,” my allergist once told me, as she patted my knee. I’ve learned to take any recommendation—regardless of the means of diagnostic inquiry—with a grain of salt. I opt for an approach of throwing spaghetti at the wall and seeing what sticks.

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I have lived with chronic, autoimmune urticaria and angioedema since I was 15 years old. More recent diagnoses of chronic fatigue syndrome and inappropriate sinus tachycardia have been tacked onto my growing list. Sometimes I live inflammation-free for months, but some years I have flareups on a spectrum of severity that last for a year or longer. During my dissertation research, I read Amy Berkowitz’s lyrical essay *Tender Points,* with a small group of five participants. Berkowitz talks about finding the traumatic exigence of her fibromyalgia. I was struck by the line: “To solve this kind of mystery, it seems you need to walk alone into a forest, you need to walk alone until you meet a wolf” (17). That night, I did something very uncharacteristic: I sat down with a journal and wrote about myself. I went to find the wolf. The next morning, I woke up covered from head to toe in hives, my first flareup of that year.

We know that trauma leaves its marks on bodies. I was told that mesial temporal sclerosis—scarring or malformation within the hippocampus—could form due to physical brain trauma, a forceps birth, or meningitis. My mom had some unexplained seizures for a few years shortly after I was born. But, as Claudia Rankine writes in *Citizen*, “the body has memory” (28). In disability studies, we resist binary thinking through the term bodymind—defined by Margaret Price as a “sociopolitically constituted and material entity that emerges through both structural (power- and violence-laden) contexts and also individual (specific) experience” (271). Maybe trauma leaves its mark in other ways. Can traumatic memories destroy neurons in the same way that oxygen deprivation can? What does it mean that my temporal lobe, the part of the brain associated with memories, is scarred?[2] My embodied experiences of pain tell a story of who I am and where I have been. Perhaps the scraps of memory that I cannot disclose must express themselves in other ways. Further reading into temporal lobe epilepsy and trauma after my diagnosis revealed a high rate of medical comorbidities: mood disorders, increased anxiety, severe depression.

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[2] Dr. Bessel van der Kolk’s book *The Body Keeps the Score*, although potentially problematic when viewed through a critical disability framework, foregrounds the ways that trauma lives in the body. In a little footnote buried within van der Kolk’s text, I found reference to a doctor who has done research on childhood trauma and hippocampal sclerosis in the brain.

I take a free ceramics class as a new faculty member to give myself a form of creative expression as self-care. I've always wanted to try throwing clay—the tactile experiences of art or music have always allowed me to be more present and grounded in the moment in ways that other experiences do not. It's harder than I imagined. Our instructor tells us that clay has memory. It will remember if you tried to cut a corner in its preparation: the act of wedging helps to prepare the clay bodies to align, to make it more durable and malleable at the same time. But wedging is also quite violent: it requires force. The sounds of slamming clay echo in the studio. I break a sweat as I knead the clay. I tell myself that this effort now—wrangling the clay into submission—will make it more durable when I need it to be.

When I get on the wheel, I realize that clay doesn't just have memory, it holds a grudge. We work through our prepared clay to learn the skills of centering. Elbow tucked tightly into my hip, I grip the wheel as I fight the spinning clay. Raising it slowly and bringing it down is a dance of force and finesse. Fail to center and you fail.

We make the beginnings of cups and bowls. They have feet and lips. We personify them because they will become extensions of our bodies, functional tools to eat and drink from. I look at pieces of pottery in my house differently now. I think about the hands that created that curve, the fingernail that may have been the origin of that small, nicked imperfection. These vessels hold memories of their making: past hands and wheels and preparation and sweat. I used to think they were just fragile: a slip of the hand in drying will result in a shattering. But I think differently now, knowing the embodied work of their creation: the wedging and throwing and firing and glazing.

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Sudden onset autoimmune anaphylaxis is also a looming threat. Society has taught me to downplay my disabilities and my emotional reactions to them—a practice that has caused me on more than one occasion to *under*react to potentially life-threatening experiences. Once after a night spent in the hospital—a trip someone called in to 911 for me—a doctor offered a sympathetic joke: "It's too bad you can't get a protective bubble from yourself!" In moments like these, I have watched the god complexes of some doctors splinter as their diagnostic trees come to dead ends. Some hide their uncertainty, some feel okay blaming it on just how much more research we need! I appreciate those doctors who are not afraid to tell me they do not know, but they will talk to others who might. When my allergy specialist told me to "give in to the chaos," I appreciated that more than some of the neurologists I've worked with who refuse to engage in conversation outside of the direct realm of existing medical knowledge. Once, when I asked about the effects of trauma on hippocampal scarring, a neurologist replied: "It's an interesting thought, but we just don't know," she said. "But no one would fund that research." In the next breath, she threatened to medically take my driving away again if I did not start a new medication I was resisting. I gave in.

What is particularly interesting in many of my engagements with doctors is that I have experienced less frequent gendered experiences of being misbelieved, although I have encountered plenty of those, too. I can take pictures of my swollen body and the bruises that form. I have had doctors respond with alarm in office settings when they are able to hear my lack of vocal chord function, witness my labored breathing, feel my racing pulse. After years of working with doctors, I had worked to surround myself with doctors who (sometimes) listen to me—a privilege I carried in my proximity to a research university affiliated hospital and six years with the same GP. I had a doctor trust me enough when I suggested I might have temporal lobe epilepsy to order some tests, even if she told me I likely did not. But it was the petechiae, bitten tongue, bruises, and rug burns on my face that convinced the doctor in the emergency room that my seizures were "legitimate."

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Aside from debilitating itching—much work has been done on debilitating pain, but where is the work on *itching*?—hives leave me with bruises the size of cantaloupes. I have a drug prescription for "intense itching," but it does not stop my itching. Rather, it knocks "me" out so I am not "aware" of my debilitating itching. I still do not know how to make sense of autoimmune disorders and the metaphorical discourses that position the body as "attacking" itself. I often feel anger *at* my body, because I cannot decipher the cryptic (*crip-tic*?) messages it seems to be sending to me. What is the embodied rhetoricity of autoimmune hives? If I am a "bodymind," how can I make sense of rhetorics of autoimmunity that position my body against itself, and thus, against me? I once hurt my shin by walking into a shopping cart. Before the bruise could form, my body released histamines in the area and a hive took over half my leg. Was my body mad at me, the me that had run into the cart? If so, is that not the job of pain already? Who is the "me" here and how can my body be both "me" and distinct from me? I do not have the passcode to unlock the embodied message of inflammation my body sends.

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Voices that have accumulated in my head over the years from doctors, friends, and colleagues have infiltrated my own reactions to my embodied impairments. "Itching" does not carry the rhetorical weight of the embodied experience. Hives do not really seem like a legitimate excuse to miss work. Once, I missed a brunch on a Sunday because my face had swollen to the point that I could not see out of one eye. I had carefully swallowed half of a Benadryl at a time, fearful of choking. I texted an excuse because I could not speak; the only sound in my apartment was the scratchy whistle of my breathing. My friend did not text back. I contemplated going to the ER, but sat alone in my apartment, indecisive, thinking about medical bills, annoyed at the rising fear. My doctor later chastised me for my inaction. I made a joke—I have learned to (or been conditioned to) ease others' reactions to my disabilities through humor and other forms of self-deprecation or emotional reassurance that "I am fine." I could try to disentangle every single affective resonance born from this story alone, but my emotional feeling now in rereading this anecdote is different from when I wrote it, and surely different from the emotions I experienced in the moment of living it. For example, there is less fear in rereading it because the immediacy of that danger has passed, yet there exists the fear of a potential return to a similar moment. Ambivalence captures all of the messy, multiplicity of it. Rather than being a catch-all or a copout, ambivalence refuses a static and singular reading; it reveals the impossibility of disentangling the multiplicity.

Yet in the midst of all of this reflection, I pause to ask myself: Is my connecting of the dots back to my disability's medical origins making me a bad disability studies scholar? What is my orientation to desire? I know in part that as much as I critique the medical industrial complex, it is still a dominant lens through which I view the world and my own bodymind. Despite its eugenicist origins and the histories of violence it has perpetuated, the *Diagnostic and Statistical*

Manual of Mental Disorders (DSM)—"psychiatry's bible"—and other diagnostic systems give me access to medications and interventions that I need. So how can we build narratives of disability that disrupt and nuance the dominant models that structure our lives even as we still need them? Alison Kafer's call for a "political/relational" model of disability similarly invites such nuance: it "neither opposes nor valorizes medical intervention; rather than simply take such intervention for granted, it recognizes instead that medical interventions, diagnoses, and treatments of bodily variations are imbued with ideological biases about what constitutes normalcy and deviance" (6). What forms of care and intervention are elevated and deemed "legitimate" and which are not?

In an anecdote about a particularly bad case of bronchitis, Eli Clare troubles the binary of Western systems of medicine and Indigenous, alternative systems of medicine, both of which were projecting different diagnoses and treatment on his sick body. He writes: "I failed [to make them converge] but quickly realized I didn't need the *single* story that told the entire truth…Rather, in the midst of feeling horrible, what I wanted was increased comfort…and a course of treatment that led back to well-being. 'Rightness' counted for almost nothing" (45 emphasis mine). While Eli Clare approaches bronchitis differently from how he approaches other bodymind difference, I'm highlighting here the impossibility of isolating my daily lived experiences from the larger systems in which they operate, the impossibility of untangling desire and survival.

I echo Margaret Price's call here and ask not only, "What shall we do with pain?" but also, how might so-called "ugly feelings" like anger, fear, and exhaustion help us navigate the desire and survival lines we relationally build in our own lives (Ngai)? Connecting the dots forces me to feel like I need to disaggregate desire and survival, and maybe that’s the problem. Where does desire end and survival begin?

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Problem List[3] Date Reviewed: 10/25/2022

	Class	*Noted-Resolved*
Bipolar 2 disorder (CMS/HCC)		Unknown – Present
Frontal headache		1/6/2015 – Present
Chronic idiopathic urticaria since 15 years old		3/19/2015 – Present
Eczema		3/19/2015 – Present
GAD (generalized anxiety disorder)		10/25/2015 – Present
Intractable migraine with aura with status migrainous		8/22/2017 – Present
Chronic tension-type headache, not intractable		8/22/2017 – Present
Panic attacks		8/22/2017 – Present
Chronic fatigue syndrome		8/22/2017 – Present
Seizure (CMS/HCC) (Chronic)		4/10/2018 – Present
Angio-edema		4/10/2018 – Present
Synesthesia		4/10/2018 – Present
Temporal lobe epilepsy with mesial temporal sclerosis (CMS/HCC) (Chronic)		9/11/2018 – Present

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[3] A recreation of my health history from my health portal up until October of 2022.

Inappropriate sinus tachycardia		4/15/2021 – Present

Table 1: This chart is a recreation of a medical "problem list" from the author's medical records. Names of diagnoses or treatments are on the left-hand side, and dates are on the right.

When I look at this chart, I feel the multiplicity of ambivalence. My mom was recently diagnosed with superior canal dehiscence syndrome (SCDS) after nearly two decades of debilitating symptoms of vertigo, tinnitus, nausea, and other hearing problems. Although she is currently not electing to have the invasive surgery done to fix the hole in her skull, her diagnosis gave her doctors and other acquaintances in her life medical proof that her symptoms were real. In the same way, this list I carry gives my experience legitimacy. No one is immune to the discourses of the medical model that both legitimize and delegitimize claims to disability. Diagnoses gatekeep, and the field of disability studies is not immune to the deep-rooted reach of these exclusionary discourses. To what extent does “Nothing about us without us” mean I need to justify that I am a part of that “us”?

Yet I neither agree with nor understand some of the data of my medical history. I was on high doses of lithium for years from a potential (mis)diagnosis. How are trauma reactions symptomized? Recorded? (Mis)labeled? (Mis)diagnosed? Read outside of the social contexts in which they’re observed and recorded? Nothing about my record is resolved.

Individual diagnoses strike different affective chords. Synesthesia sometimes grants me a feeling of extra-sensory superpower. Although disconcerting when accompanied by the stomach-plummeting déjà vu of a focal seizure, it can be weirdly pleasing when it surfaces in my “blips”—language I have given to the tiny snippets of electrical activity in my brain, like a skipping CD. Sometimes I can smell and feel turquoise: a beautiful texture that elevates my somatic experiences of water and stones and clothing. I read an overview of a conference presentation that suggests epileptics “feel” music, as scans show how their brain waves can sync with music.[4]

Yet, I am often wary of the temporal “foreverness” of that dash that links a diagnostic date to the ever forward looking “present.” I see new diagnoses have traveled with me to my new medical records. Others have popped up, grown like a wind-blown seed transported into an existing garden. Foreign. Without a diagnostic trail.

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Wrangling with these questions, I return again to my earlier anecdote about the audience member who was, perhaps like me, angry and frustrated with pain and living in a bodymind that is often swimming against the tide. Perhaps this feeling is why conceptual metaphors for living with disability and trauma, like *mētis* or “desire lines,” have been so useful to me. They insist on duality and sideways movement and incompleteness. They let me maneuver through the always-changing affective responses to my own disability and trauma, even masking my responses through theory work. This work is exhausting, and it doesn’t always work, and it might sometimes be more of a “have to” line than a desire line. As I attempt to unravel that which cannot be unraveled, I am already, as Sara Ahmed has argued, inhabiting the world in a different way.

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[4] See American Psychological Association press release on Christine Charyton’s conference presentation, “Music and the Brain: Can Music Help People with Epilepsy?”

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“Path desire lines, Beach Road” by Philip Mallis*,* retrieved from www.flickr.com/photos/84652765@N00/6432035825*,* licensed under CC BY-SA 2.0.

“Path of Desire” by Bdunnette, retrieved from www.flickr.com/photos/122687277@N03/39385694592, licensed under CC BY-SA 2.0.

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