

Chronic Poetics and the Poetry of Chronic Illness (in a Global Pandemic)

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ABSTRACT (ENGLISH)

While these are still early days of the global pandemic, already I read calls for academics to simply hunker down and work as if increased focus and drive might be delivered now-as if we are not living through a public health emergency of a scale previously unimaginable. Ellen Samuels writes in "Six Ways of Looking at Crip Time" of how, as a sick young woman physically unable to sustain the strictures of a nine-to-five job, she feared for her future all the while holding out hope that returning to academic life in graduate school and later, hopefully, as a professor, she could live and work in crip time full-time: "It was, and still is, the only way I could see to support myself" Having "crossed some invisible and excruciating threshold from being someone with health problems to being a problem, apparently insolvable" (emphasis original), as a twenty-three-year-old with a disabling illness, she was determined to find a solution. [...]Gravendyk's phrase "chronic poetics" brims with generative potential, especially when focused on the very specific relationship between "chronic illness" and "generative form," for surely the poetry and poetics of chronic illness presents unique insights- not to mention poetic forms-of how to live with uncertainty? In response, I am interested in poetry written by women diagnosed and treated or living with a chronic illness in order to better understand the personal challenge the diagnosis of disease presents to quality of life.

FULL TEXT

Though the length of time over which an experience extends is often the definitional aspect of a "chronic" feature of life, it is a poor descriptor of chronic experience, such as illness, for which the idea of an experiential timeline of onsets and closures is too narrow. Chronicity describes a feature of life that is so persistent that it exceeds conventional markers of time and becomes, along with human sensory capacity more generally, the grounds for one's perception of the world and of "durations."

-Hillary Gravendyk, "Chronic Poetics"

March 15, 2020

Just days after the COVID-19 pandemic was first declared, with the reality that my colleagues and I have sacrificed sleep and regular meals in order to develop an emergency teaching plan so that students can successfully complete our courses online and remotely, I'm already worried about time. To be sure, I do not anticipate having more of it in the coming weeks and months. While these are still early days of the global pandemic, already I read calls for academics to simply hunker down and work as if increased focus and drive might be delivered now-as if we are not living through a public health emergency of a scale previously unimaginable. As if productivity is the solution for all that ails.

I began writing this essay on the poetry and poetics of chronic illness in Canadian women's writing when I was still buoyed by the prospect of a newly acquired and promisingly secure tenure-track job, which I believed would facilitate better and more sustained periods of reading, thinking, writing-not just high-volume teaching and service. These activities-reading, thinking, writing-have quietly animated hours, days, weeks, months when nothing else could. They sustained me through a long period of chronic illness with its attendant and life-changing medical interventions. These are also activities that I've been able to count on when I've been too sick to count on anything else. But I've come to understand that because I was once chronically ill, having lived through a duration of active autoimmune disease and its medical treatments- and could be called to do so again without warning-I'm not sure

that I will ever count myself among the well. In positioning myself as such I've also come to understand that because of chronic illness I have a forever-changed relationship to time, solitude, home, immunity, and care, especially in the context of my scholarly and creative life.

While I worry about conventional notions of time, I'm brought back to considering the profound potential and immense frustrations of working and living in crip time, especially when the university usually enacts anything but. Ellen Samuels writes in "Six Ways of Looking at Crip Time" of how, as a sick young woman physically unable to sustain the strictures of a nine-to-five job, she feared for her future all the while holding out hope that returning to academic life in graduate school and later, hopefully, as a professor, she could live and work in crip time full-time: "It was, and still is, the only way I could see to support myself" Having "crossed some invisible and excruciating threshold from being someone with health problems to being a problem, apparently insolvable" (emphasis original), as a twenty-three-year-old with a disabling illness, she was determined to find a solution. This is where the "beautiful and forgiving" nature of crip time was liberatory in Samuels' life. Embracing the notion that time too can be flexible, can bend to meet disabled bodies and minds-rather than the other way round-allowed Samuels to lie on the floors of university classrooms where her fellow graduate students talked and she listened, staring at the scratched undersides of desks. "And I loved it" she says. "I loved the rhythm of reading and writing and thinking and I realized that this time was also my time, even though it was hard, even though other people didn't get it, even though I was alone"

When I first read those words, I did so in immediate recognition. But now they also stir up complicated feelings. Like Ellen Samuels, I also found myself sick in graduate school, and while acutely aware that it often felt impossible, ridiculous even, to continue with a PhD, I had the privilege of navigating the sudden onset of illness in such a way that there was no question of being allowed to continue. I had secured external graduate fellowship funding before getting sick, and would continue to hold it throughout that duration of chronic illness as long as I did not take a medical leave; thus, I could continue if I did not officially declare that I was sick. So I had to work, both at hiding the fact that I was sick and at appearing to be well. (But what is chronic illness if not being healthy and sick at the same time, as Pamela Moss and Isabel Dyck have eloquently argued?) While we should recognize the decidedly gruelling work that can land on our desks as academics, for some this work can also afford possibilities that other occupations disavow and make impossible from the get-go. The key here is: for some. If I had read a line about academia affording possibilities while precariously employed, I would have spat.

Chronic Poetics

Just before her untimely death after a lengthy illness, poet and scholar Hillary Gravendyk was in the process of finalizing an essay for the *Journal of Modern Literature* for a special issue on "Disability and Generative Form." In this posthumously published essay, Gravendyk undertakes a phenomenological engagement with the late poet Larry Eigners work, seeking to account for "disability's role in poetic practice" (1). Demonstrating how attention to both disability studies and formalist discourse "can produce a more flexible mode of criticism" (1), she makes an argument for what she terms "chronic poetics": "What I'm calling chronic poetics extends the reach of disability criticism's relevance to all bodies, not the disabled body alone. Chronic poetics is a phenomenological account of perception and artistic practice that allows the shared conditions of embodiment to emerge from the text" (1). Throughout this essay Gravendyk insists that each of us reconsiders what embodiment is and how we make sense of its register, especially in relation to the twinned creative practices of writing poetry and of reading poems. Where poetic production is concerned, she queries what might be shaped by the reality of living in a disabled body and, obliquely, what might be changed by the experience of illness. Yet it is her insistence that the written page should be understood as more than a record of any writer's embodied experience-let alone a chronically ill or disabled poet's experience-that provides an opportunity to think through the complexities of creatively representing the experience of chronic illness. In fact, Gravendyk's phrase "chronic poetics" brims with generative potential, especially when focused on the very specific relationship between "chronic illness" and "generative form," for surely the poetry and poetics of chronic illness presents unique insights- not to mention poetic forms-of how to live with uncertainty? When, perhaps for the first time, so many are contending with what it might mean to have

one's health rendered precarious, even as others are turning to poetry for comfort and wisdom in these challenging pandemic times, it means something different when a poet writes of her own chronically ill body or mind. In insisting that the poetics of chronically ill people be registered in this historical moment where a virus is not just the backdrop of our lives but a reality lived out in each of our daily interactions, turning to poetry is, from my perspective, essential when considering the relationship between Canadian literature and pandemic.

It is curious that while biomedical research into the management of chronic disease is well established, the experiential knowledge of patients remains undervalued as a means of understanding the impact of living with chronic illnesses. Many chronic illnesses disproportionately affect women, yet an intersectional analysis is too often absent when calculating the societal impact of disease. In response, I am interested in poetry written by women diagnosed and treated or living with a chronic illness in order to better understand the personal challenge the diagnosis of disease presents to quality of life. As such, I am also invested in contributing to further theorizing the unpredictable nature of chronic illness as a "dissonant disability" (Driedger and Owen), something some scholars have sought to do in turning to their own poetry as a means of theorizing. In turning to the poetry and poetics of chronic illness, I wish to more fully explore the ways in which chronic illnesses can be understood as "dissonant disabilities"-to again evoke Diane Driedger and Michelle Owen's generative term-by reading contemporary autobiographical writing by women and published in Canada. Specifically, in this paper I will turn to three collections of poetry- Fionnara MacEoin's *Not the First Thing I've Missed* (ThistleDown, 2014), Anna Swanson's *The Nights Also* (Tightrope, 2010), and Leah Lakshmi Piepzna-Samarasinha's *Bodymap* (Mawenzi, 2015)-in order to illustrate why chronic illness is a poignant site of living in precarity, but also in "collective affinity" (Kafer 13). The poetry and poetics of chronic illness remains a crucial site to explore feminist, queer, and crip experience in giving voice to the intensity of living with mind, body, and/or bodymind unpredictability.

There is also an opportunity to explore how poetry, as a genre, is able to illustrate the dissonant and durational qualities of chronic illness. As such, I am interested in exploring the domestic spaces of chronic illness-the places where those who are chronically ill make home and do work-and wondering what can be produced from a site that is often understood as one of both confinement and comfort. By experimenting with what can be said and what is left unsaid about the disabling effects of disease, a chronic poetics works to attend to the embodied, speculative, and gendered dimensions of chronic illness. As such, the context of this essay's production as well as the argument it makes can also be understood as an example of chronic poetics. Gravendyk was also a chronically ill scholar and poet when she first proposed the term: she wrote a formidable piece of literary criticism while chronically ill and died before seeing her own article in print. And in the poem "Eight days asleep," from her collection *Harm* (Omnidawn, 2011), written in intense bursts after major surgery, she alludes to passing, maybe into a long sleep like the title suggests, but also explores the reality that is death: "She left the body trailing its appetites / like a honeymoon. She left the body / permissionless, dreaming" (20). I keep this knowledge close as I revisit her words. For me, this knowledge-that she continued to work while so very sick, having been diagnosed with an interstitial lung disease in her early twenties and then undergoing a double lung transplant at age thirty-remains vital to any discussion of Gravendyk's legacy as a poet and scholar. While I learned these details through Diana Arterian's lyric essay and moving tribute to her life and work, "On the Harmed Body," I think it best to remember that Gravendyk's death should not overdetermine how we understand chronic poetics. Said another way, under conventional circumstances chronic illness does not usually result in premature death; instead, those of us with chronic illnesses may count ourselves among the "unhealthy disabled," rather than the "healthy disabled," to evoke Susan Wendell's important distinction. However, that those of us living with chronic diseases are more susceptible to the deleterious effects of a viral infection-COVID-19 to be sure-and may die from this virus even as we are young and otherwise relatively healthy is a reality that is more palpable than perhaps it ever was. While the mention of chronic illness often conjures images of elderly people, I want to begin again by considering what it means to be a young woman navigating the uncharted terrain of chronic illness. Here, it is especially important to turn to the complexities of mental disability, which engenders its own particular iteration of chronic poetics.

June 8, 2020

I'm returning to this essay amidst a raging global pandemic even as most of Canada seems to have successfully flattened the curve. How long will this reality last? On the phone yesterday my youngest sibling reminded me that if anything good can be gleaned right now, it is that many people are at least exploring the possibility of living and working differently. I'm reminded that various and varied forms of disability arts and culture know much about this, and of living aslant to the required norm Robert McRuer has termed "compulsory able-bodiedness." Even if I'm unable to repeat simple messages of positivity, I remain committed to the idea that a close connection to words is meaningful right now. As Arundhati Roy says in a much-shared photo essay that chronicles the global injustices and violence brought in the wake of COVID-19, "the pandemic is a portal" A portal to other possibilities, I hope, where the future of work and life on this interconnected planet is concerned. And if the pandemic is a portal, poetry too is another type of portal. But not because poetry offers simple solace; instead, because it might break you open in exactly the ways you need it to, providing an entry to another way of being.

I know too that those who think thoughtfully about illness, disability, and creative expression have always been at the heart of disability justice movements and have so much to offer right now. Where would we all be without the work of arts and cultural organizations like Sins Invalid with their centring of disabled artists of colour and crip LGBTQ and gender variant folk? In fact, where would we be without a recognition that the disability justice movement has been built by these same bodies? In Sins Invalid's collectively written disability justice primer, *Skin, Tooth, and Bone: The Basis of Movement is Our People*, they write: "Disability justice is a vision and practice of what is yet-to-be, a map that we create with our ancestors and our great-grandchildren onward, in the width and depth of our multiplicities and histories, a movement towards a world in which every body and mind is known as beautiful (26-27)" There is poetry in these words. Poetry is not a discordant voice where disability justice is concerned. In fact, poetry can provide a powerful antidote to the utilitarian, cruel-minded thinking and actions of an ableist society, something we must be on guard against when thinking through the various impacts of COVID-19. I've already heard many times now that the second pandemic will be a mental health crisis; I wonder if we are not already in it?

2. "the next room over"

Fionncara MacEoin is a writer from Saskatoon, Saskatchewan. Prior to the 2014 publication of her first book of poetry, *Not the First Thing I've Missed*, she collaborated with visual artist Nancy Lowry on a chapbook, *Even the Sky Parts*, published by JackPine Press in 2011. She puts forth a vision of the world that is both tender and absurd, using the short poetic line to deliver biting observances of both. Even when the formal subject of the poem might be best described as a meditation on grief or despair, humour still brims to the surface. Always, there is a speaker at the centre of each poem who is alert and made more than a bit uneasy by all that she observes. MacEoin's long poem "the next room over," the second in her debut collection, begins with an assertion of who is rendered visible and who remains invisible where mental disability is concerned:

everyone sees the tragic anorexics
successful manics, the beautiful people
personality disordered charismatic psychopaths
it's the depressives and schizos
no one wants[.] (30)

These stanzas assert that while the suffering imparted by mental illness is often glamorized in the popular imagination-especially when embodied in a very particular way-ongoing disability in the form of depressive disorders and schizophrenia is something "no one wants" (30). Here, the speaker of the poem gives voice to the ableist assumption that a life with disability is implicitly a life no one would ever choose and that, if given a choice, each of us would choose a life free of impairments. But it is because of the pervasiveness of this argument that the speaker of the poem says:

silently, slowly we develop a taste
for our surroundings

the sad soft tone of the elements
and stop imagining a future[.] (30)

Developing a taste for institutional surroundings signals a descent into "dark cellar boring loneliness" where the "stupor of drugs and sad stories" (33) becomes the common element. Grappling with the reality of societal rejection-feeling literally unwanted-the speaker of this poem, "a hard luck story / no one wants to hear" (35), slowly and silently begins to stop imagining her own future. However, in this long poem, as in others that make up MacEoin's collection, interior reflections are paired with observational details. MacEoin's poetics demonstrate a spare blend of short bursts of pedestrian detail situated against deeper contemplation of what reviewer Bill Robertson has termed "anxious vigilance" concerning the "precariousness of mental health" Indeed, MacEoin attends to the daily struggles of maintaining mental health even as the question of futurity remains ever-present for her speaker.

As Alison Kafer has argued, if in the present moment disability is understood as terrible-a fate worse than death-then, on one hand, the future must be oriented to avoid it because in this worldview, absence of disability signals a "good future" On the other hand, the presence of disability signals, in advance, a future no one could or should logically want. In this view, informed by the medical model of disability, impairments are medical problems and "the cure" figures, always, as a desired end goal. I deliberately evoke Kafer's text, *Feminist, Queer, Crip*, as a way to think through strategies to challenge the idea that we have arrived at collective agreement about disability-in the present historical moment and, therefore, in the imagined future. This is important to weave into the argument because in MacEoin's poetry, even as the speaker lives with, and struggles against, "a disease you didn't know you had" (46), she resists a pull to stop imagining her own future. In fact, this speaker lives with full knowledge of a world outside the institution, the domestic space of chronicity that is currently available to her. Attention to the natural world outside the hospital presents itself in moments of survival:

there are the robins
standing
on the rebar
outside your window[.] (31)

Even if this speaker is aware of "walking on some sort of thin ice" she is also aware that it is "not that thin" (31). What she traverses is "crackly" (31)-perceptible and brittle, a surface that separates here from there. For this reason, she decides to instead focus on what is surviving under the ice: "slough / water plants frozen" (31) throughout the winter, plants that have every intention of returning with spring.

In her close engagement with Larry Eigners work, Gravendyk understands that his poetry, not unlike MacEoin's, "asserts the presence of the body among other bodies, a chronic poetics in which the shared conditions of embodiment emerge" ("Chronic Poetics" 3). Eigners conceptualization of embodiment "emphasizes not the transfer of energy from poem to reader but the exchange and circulation of energies in the temporal, contingent body of the text" (3). In fact, writes Gravendyk, "Eigner calls upon this shared sense of embodiment in his poetry as he asks us not to register his physical situation, but to pay attention to our own" (5, emphasis original). This, for me, begins to articulate what a "chronic poetics" might hope to achieve-not that it codifies or translates the experience of being chronically ill but that, through the distillation of poetic language and the use of form, it asks that the reader consider their own potential and limitations. Gravendyk insists that "[t]his idea of a chronic poetics-one that acknowledges simultaneity, chronicity, duration, and other forms of embodied perception-makes use of phenomenology's experiments with and theories of embodiment and consciousness" (7). Through her reading of Eigner's work we, too, witness how his poetry attends "as much to perceptual capacity" as it does to the world "'outside'" himself when he turns his attention to "'birds, sky and weather'" (7). She insists that "Eigner's work relies on the idea that the external and the internal are necessarily entwined at the site of perception: the body" (7). In the poetry of MacEoin the external and internal are also entwined even as they are also separated by windows and walls, the institutional and the domestic world of home, now situated in an aspirational future.

July 28, 2020

I remain writing this essay while the reported daily deaths and new cases of COVID-19 rage in the United States, flare in Vietnam, Spain, and Hong Kong, and spark in BC and Alberta. Even as I listen to CBC News I can't seem to retain the daily updates. Are the numbers in Ontario and Quebec staying much the same or improving just a little? The curve, it seems, remains only just flattened; I'm caught between relief and panic.

In the COVID-19-infused nightmares I have had predictably since midMarch, I'm back in Vancouver in my former endocrinologist's office. He kindly tells me that instead of being in remission for autoimmune disease I'm in fact immunocompromised. This jolts me awake. In the reality lived out in my nightmares, I have been released from my doctor's specialized care without knowing how important this distinction is. It occurs to me that in my waking life every precaution I take to keep myself and others safe is the least I can do. No precaution should be framed as an overreaction, especially as the various provincial economies across Canada reopen for business and the consequences have yet to be contended with.

I'm aware of how fortunate I am at present—living in a strange, augmented iteration of crip time—even if the language of gratitude always seems to fall short. Maybe this is because it tells only a truncated version of a much longer and more complicated story. It's as if the language of gratitude can form the words but doesn't fully account for the grammar of loss that any story of academic success lived out in crip time will surely also tell. If this virus is a natural disaster of our own making, many will survive but a great many others will be cast adrift. Isn't it already immanently evident who has been rendered precarious, expendable even, in these still early days of this global pandemic?

3. "Between Sleep and Sleep"

Anna Swanson grew up in Vancouver, BC, and now lives in St. John's, Newfoundland, where she works as a librarian. Her debut collection, *The Nights Also*, won both a Lambda Literary Award and the League of Canadian Poets' Gerald Lampert Memorial Award. It is rightly celebrated for its unflinching ruminations on the necessary, if uncomfortable, shifts in identity brought about because of illness. What to make of a yet undiagnosed disease that seemingly seeks to take everything certain away from the speaker at the centre of these poems—school, work, relationships, security? Swanson's response is to engage in a poetics of formal and lyrical variation, never refusing levity nor gravity when it is most called for. Throughout Swanson's section of poems entitled "Between Sleep and Sleep," we find a speaker wake as the eagles call and cry, awake too when a peacock rises with the first slow sun. In the first poem of this section, "Lullaby for small," we get a glimpse into the domestic space of chronic illness. Here, it is a bedroom with "merciful windows," a bed and a bedside table with "a box just large enough for all the doctors' / perfect remedies" (15), remedies that fail, still, to bring about sleep. The windows, while somewhat merciful, function to keep out "whatever weather hits them" (15), and stand as a constant reminder of how limited the speaker's world has become. Curled in her bed, she has been whittled to a fraction of her former self, while her knowledge of the outside world has become reoriented towards the sounds of "falling notes" from the eagles, whose cries are "ripples around a pebble" now "disappeared into dark water" (15). If anger was once a motivating force, she has now "worn out [her] anger" and "there is not much of [her] left" (15). In the final stanza of the poem, the speaker, "small enough to fit in a coat pocket," is taken under by the rippling cries and becomes akin to the pebble with "the dark water closing around it" (15). This lullaby sings of how difficult chronic illness is to live with as a daily practice. It is difficult to keep oneself upright, afloat, attentive to the world outside the window. As Swanson's poems reveal, this can be all the more difficult when an accurate diagnosis and effective treatments remain elusive, while symptoms—fatigue, poor concentration, disordered sleep—remain ever present.

With respect to disabling symptoms of chronic illness, many patients report that fatigue is at the top of their list, followed by poor concentration and disturbed sleep. These material impairments are notoriously difficult to describe even as they are also omnipresent. In writing autobiographically about chronic illness, geographer Pamela Moss describes crushing fatigue: "the kind where your chest hurts and you are so tired that you do not have the energy to breathe" (151). Swanson also uses metaphorical language in her poetry to give voice to this intensity. In "Symptom #1: Fatigue," fatigue takes the speaker down the hall, promising at first some sort of escape only to find the hidden door. Instead of escape, fatigue tosses the speaker in, forcing her to spend time with an old

mattress. Frustratingly, this room is made only of curling wallpaper, which refuses to stay in place and, instead, steadily smothers the speaker even as she tries to keep the seams of the room, and her life, glued and in place. In this poem, fatigue is a very bad friend; lying and cheating, "she goes out, two stepping / with your future" (17). In "Symptom #6: Poor concentration," the mind attempts to complete tasks even if the speaker is unable to. The mind sits with the morning mail, unable to open the crisp envelopes because instead of being equipped with the needed tools to do the job, what is made available is an "old knife made of porridge" (22). Similarly, the mind takes up carpentry only to end up "pounding nails with / a handful of lint" (22). The mind struggles to knit, even when accompanied by roofing hammers clanging out the pattern of "knit one, purl two" (22). In "Symptom #11: Sleep may be disturbed," we enter a reality where there has been no sleep for eighty-nine days. As if provoked-God is also frustrated- the weight of a "cardboard piano box / [filled] with cement" (27) drops and the speaker is flattened. After the drop, and the forced exhalation of the speaker, there is a momentary burst of turbine-like power and then "everything sputters and goes out" (27). Thus, we find the speaker released from a world predetermined by a lack of sleep. Forced through the bed, flat against the floor, she is left "one molecule thick" (27). Now there is "no breath, no terror, no dreams" (27), and this is because sleep finally arrives: "Some would call this sleep, / but you know it's something / holier" (27).

The politics of memory and of memorializing in crip time are also present in Swanson's poems. In "The Argument for remembering," the truth of the speaker's illness experience is revealed through the use of anaphora. Each stanza begins with the word "because" and, as such, becomes the reason to remember. The speaker remembers that while others said "But you look great" (25), she lived with the fear that "I might never sleep again" (25). In another encounter, it is a medical doctor at a walk-in clinic who does the misreading, who "told me I was lazy and it would help if I washed more often" (25). The speaker of this poem continues:

Because, being my mother's daughter, I followed him and repeated what he had said back to him loudly in front of an entire waiting room, and in his couriered letter of apology the doctor said it looked to him as if my hands were dirty, but in retrospect it may just have been the colour of my skin. (25)

This is a painful, profound moment of remembering. Yet it is doubly important for the speaker to chronicle "[b]ecause everyone asks me what I did, but what I did was nothing" (25). From the interior of this poem-from this life lived out in crip time-where "welfare forms, disability benefits applications, request to withdraw from classes after the drop date forms, doctor's notes, proof of rent forms, bank records, personal statements" (25) threaten to take over each waking hour, what patient has the time-or energy-to respond to each racialized microaggression doled out by the field of biomedicine?

August 19, 2020

Thinking broadly, what might postcriticism offer the study of Canadian literature, even disability studies, a field that is often designated as "critical" in the first place? (In Canada, we can note the various departments and schools that are named not "Disability Studies" but "Critical Disability Studies" I understand the impulse to name or rename a field of study as "critical" and applaud this if it signals that not only critical theory but also scholarly reflexivity will be put into play. But I've also noted that sometimes this is where a truly self-reflexive approach ends rather than begins.)

In *The Limits of Critique*, Rita Felski offers an example of what a "postcritical reading" of a text might entail. At the outset, it is not a celebratory form of naive reading that can be dismissed easily. Rather than approaching the text as puzzle in need of decoding, as Felski stresses, "we might place ourselves in front of the text, reflecting on what it unfurls, calls forth, makes possible" (12). This shift in the reading of texts-and also in the writing of literary criticism-is not insignificant. Felski believes that this approach is guided not by "idealism, aestheticism, or magical thinking but a recognition-long overdue-of the text's status as coactor: as something that makes a difference, that helps makes things happen" (12).

This idea gives me pause-especially right now as nearly all professors are preparing to teach students online and remotely. In planning to teach my program's Honours seminar, I have selected a number of texts I genuinely hope might act as paradoxical guides in this challenging and uncertain time. Because, of course, we are still very much

living in the early months of this pandemic. What kinds of new thinking might our students do if released from any expectation to either decode or deconstruct the text? Instead of tacitly tasking them to engage in an exercise in fault finding, what if we were to instead ask them to explore the generative possibilities of these texts-through the close connection between reader and writer-as a portal into their lives, not to mention our own?

4. "crip world"

Leah Lakshmi Piepzna-Samarasinha writes in the preface to *Care Work: Dreaming Disability Justice*, "Writing (with) a Movement from Bed," that her own crip writing practice is in community rather than isolation. When she moves to Oakland, California, she describes spending hours writing from her "femme of color bed cave" (10), clad in comfortable pyjama pants with a heating pad to take the edge off chronic pain. As she says, "I did so alongside many other sick and disabled writers making culture" (10). Although not celebrated by the mainstream disability rights movement, "[w]riting from bed is a time-honored disabled way of being an activist and cultural worker" (10). And, Piepzna-Samarasinha explains, "[a]s disability justice was giving birth to itself as a movement, I got to be part of it as a cultural worker, often working from bed" (12). Indeed, Piepzna-Samarasinha, in their own words, is a "queer disabled nonbinary femme writer, educator and disability/ transformative justice worker of Burgher/Tamil Sri Lankan and Irish/Roma ascent" ("Leah Lakshmi"). They have published nine books as author or co-editor, and *Bodymap* (2015) is their third collection of poetry. Originally from Worcester, Massachusetts, they have called Brooklyn, Oakland, and, significantly, Toronto home.

Throughout *Bodymap*, Piepzna-Samarasinha explicitly writes a crip poetics; in the "crip world" section of the collection, we are situated in the present moment of "Lamaze breathing through pain spikes" (22). The speaker struggles "to stay in the palace of words" as she is reduced to "asking for a Vicodin with a shaking hand" (22). Yet this speaker, while confined to bed for long periods of time, is able to ease pain through masturbation, where an orgasm "is better than any prescription pain med" that she can "steal a script for" (26). To "just jerk off and jerk / off and jerk off" keeps her "free" (26), not from pain but from complete reliance on a biomedical system that fails to recognize not only her chronic pain but her identity as a chronically ill woman of colour. This is a speaker who says explicitly "I don't want to date anyone who's not a crip ever again" because she wants "the pleasure of never having to explain"- "sickness, unpredictable tides of fevers and sore hips, microtrembling / butterfly hands and legs" (27), and how these impairments have been shamed, not only by previous partners, but also by friends, family, work, and society at large.

The speaker of these poems reminds us that as chronically ill people we are "like other invalids able to make art" while confined to bed (24). As Kafer has stressed, "collective affinity" (13) can be found in imaginatively joining together as crip people, not because our conditions, symptoms, or diagnoses unite us through essential similarities, but instead because chronic illness and disability can be understood through shared histories of exclusion, isolation, and discrimination in traditional art, literature, and workplaces. Kafer reminds us that because disability should be situated as political, it can also be contested. Disability, then, can be considered a site that is intrinsically contestable. In fact, the call for fixed, stable definitions of disability signals that it remains important to critique the structural forces that decide in advance who is properly disabled and who is not. In the context of chronic illness, this is particularly important because it is not always self-evident who is disabled and who is non-disabled, especially in the context of invisible disabilities. Piepzna-Samarasinha speaks directly to the chronically ill when this poem argues, via its title, that even if "everyone thinks you are so lazy" an appropriate response is: "don't let them" (24). In this poem, productivity-inextricably connected to what are considered legitimate forms of work-is reconceived. A commute is "the daily act of breathing," which is "work as necessary as nine-to-five" (24). As Piepzna-Samarasinha writes, where our work is concerned, "this labour not paid not union" is the work of not only rejecting the slur "lazy" but the work of actively keeping oneself alive. Lazy, then, as a shorthand to describe those who are not considered to be properly productive, stings in exactly the way it is supposed to. Therefore, as disabled people there is a responsibility to not only "make sure you are paid what you are worth" but to pay oneself first (24). At this poem's close, Piepzna-Samarasinha argues: "our survival is / the opposite of lazy" (24, emphasis original).

As Kafer rightly argues, a political-relational model of disability—which Kafer frames as “a friendly departure from the more common social model of disability” (7)—seeks to pluralize understandings of body, mind, and bodymind instability. Yet such a crip politics also refuses to dismiss the medical model of disability because there are individual situations where pharmaceutical treatments and/or surgical interventions might not only be appropriate and effective, but also sought out and desired. In fact, these forms of medicalization can be life-changing as well as life-affirming for many people with disabilities. Thus, in envisioning a political-relational model of disability where women with chronic illnesses are concerned, the goal is to neither oppose nor valorize the role of medicine in our lives. We can desire to have our symptoms alleviated, our mental health issues well managed, and even to be cured of chronic pain, while continuing to be identified as and allied with disabled people.

In a political-relational model of disability, disability continues to no longer singularly reside in individual minds or bodies but in built environments and social patterns that exclude and marginalize. But the problem of disability remains located in inaccessible buildings and discriminatory attitudes. The problem disability presents is solved, then, through social change and political transformation, not simply through accessible spaces, as no manner of ramp has ever been known to cure mental illness or chronic pain. It might be clear, then, how the political-relational model seeks to politicize disability, but let us not forget that it also seeks to articulate how disability is relational, for disability itself exists in relation to notions of normalcy, able-bodiedness, and able-mindedness, thus creating a false binary. In fact, in living with chronic illness we also experience disability through relationships with others. Disability does not occur in isolation from the social world but is brought into being through a hard edge and crackly surface, between here and there, the now and the just-out-of-reach future.

Sidebar

Emilia Nielsen is the author of a scholarly text, *Disrupting Breast Cancer Narratives: Stories of Rage and Repair* (U of Toronto P, 2019), and two collections of poetry. *Body Work* (Signature, 2018) was a finalist for a Lambda Literary Award and the League of Canadian Poets' Pat Lowther Memorial Award, and took third place in the Fred Cogswell Award for Excellence in Poetry. Her first book of poetry, *Surge Narrows* (Leaf, 2013), was a finalist for the Gerald Lampert Memorial Award. She is Assistant Professor of Arts, Medicine, and Healing in the Health and Society Program at York University.

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