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Chronic Poetics: A Waiting Room of One's Own

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CHRONIC POETICS: A WAITING ROOM OF ONE'S OWN

A Thesis
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts
in
English and Writing Studies

by
Madeleine Simmons
August 2022

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ABSTRACT

This article explores chronic poetics, through my personal lens I take readers on a walk- through of poetry and the discussions surrounding chronic illnesses. I examine the current state of chronic illness and the nuances to its discussion. I analyze chronic illness in the context of disability studies, and touch on the tensions of categorizing chronic illness as a disability. As well as how to best navigate reading chronic poetics, as poets engage in new territories as they form a new language to describe their circumstances. While analyzing multiple poems from different authors, I explore why specifically the vessel of poetry best suits the discussion of chronic illness as authors grapple with all of its obstacles, surroundings, and physical limitations that occur with it.

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DEDICATION

To every poet who I mentioned, and those I didn't get the chance to. This project would not exist without you. Keep writing and sharing your voice. Let us create a communal voice so loud they can no longer ignore us.

TABLE OF CONTENTS

ABSTRACT	iii
ACKNOWLEDGEMENTS.....	iv
JOURNAL ARTICLE: CHRONIC POETICS: A WAITING ROOM OF ONE'S OWN	
From the Waiting Room.....	1
Chronic Illness and Disability.....	8
On Reading	11
Why Poetry?	15
Still in the Waiting Room.....	38
REFERENCES.....	40

JOURNAL ARTICLE

CHRONIC POETICS: A WAITING ROOM OF ONE'S OWN

From the Waiting Room

I write this as I occupy one of the most familiar spaces for poets with chronic illness: the waiting room. I have been nervously occupying the past hour, watching the cooking show on the TV that reminds me that I skipped breakfast so I could be on time for this appointment. The chairs are surprisingly comfortable, but I sit next to a glass shelf full of drug advertisements that promise to be that "magical cure," for which, I'm sure, the office takes a commission. The flimsy dollar tree fall decor contrasts the beach theme of the rest of the office space, as a pumpkin spice scent invades my nostrils despite the face mask I'm wearing. While I appreciate the effort of the decor, compared to the multiple other dreary waiting rooms I occupy, looking at this painting of seashells washing up on the ocean shore does nothing to calm my nerves.

On the contrary, it only aggravates them because I am reminded that I am an ocean. Like the ocean, which is "more than eighty percent unmapped," I live with a chronic condition that very little is known about, as many are (NOAA). Within the depths of this unknown lie the sea monsters of uncertainty, the seemingly endless darkness of mortality.

Elizabeth Harisson describes chronic illnesses as "unpredictable, insidious, and often vague symptoms.... [which] contribute to human suffering

and are easily mistaken for other conditions, misunderstood as resulting from overwork, fatigue, and stress, or they may be misinterpreted as part of normal aging". This is because doctors are only scratching the ocean's surface of what is "known" about chronic illnesses, which is very little. It is easier to dismiss rather than take a closer look, which is why so many are misdiagnosed. At first, I had carpal tunnel syndrome, an ovarian cyst, with doctors chalking it up to "stress" until I finally got the diagnosis of fibromyalgia. Fibromyalgia is "a condition that causes pain all over the body" accompanied by fatigue and sleep, mood and memory issues (CDC).

I have felt incredibly lonely in my journey in the medical-industrial complex, but I'm not alone. Cancer, Diabetes, AIDS, Asthma, Cystic Fibrosis, and Epilepsy are part of a long list of chronic illnesses diagnosed each year. The National Health Council observed that "chronic diseases affect approximately 133 million Americans, representing more than 40% of the total population of this country." Yet despite that number, we see little discussion of this topic in media and academia. Even Virginia Woolf, in 1925, wrote about this problem in her essay *On Being Ill*, "let a sufferer try to describe a pain in his head to a doctor and language at once runs dry" (34). Even today, there is a great deal of difficulty in describing one's pain due to the dearth of nomenclature for describing pain and discomfort. The answer to this lack of language is not answerable solely through medical terminology. Medicine rarely assists us in comprehending pain and suffering or learning to live in uncertainties and instability. We can examine

illness through a medical lens, but other instruments, specifically literature, better serve the experience of illness.

This might sound like an oxymoron, but my diagnosis is a luxury. *What luxury*, do you ask? The luxury of health insurance, the luxury of medicine, the luxury of playing this guessing game we play with doctors. Many do not have access to these facilities. Virginia Woolf famously asserted that "a woman must have money and a room of her own if she is to write fiction," to which I would add the parallel assertion that a chronic poet must have a diagnosis and a waiting room of their own if they are to write poetry.

I do not believe a precise diagnosis is needed to classify an ailment as *chronic*. In some cases, it takes some people a decade or more of chronic suffering before they ever receive a diagnosis; I am lucky to have only spent five years without one. Before the diagnosis left my doctor's lips, I had fibromyalgia. They did not speak it into existence, but merely provided the anchor of a definition to ascribe to my pain. Giving the abstract pain a label provides a sense of meaning to the pain, however slight it may be, and offers an axis around which to orient the pain. We can think of classification as a call to adventure for the poet who finds the urge to write and thus unwind the psychological and physiological inner webbing of a self that feels at the point of annihilation. Rachel Robertson describes it as a "paradox" because the "illness experience is... both highly intimate and profoundly estranging" (Robertson 17), where a diagnosis is just a

particular uncertainty, a *certainty* that your body will behave *uncertainly*. I acknowledge that some writers consider it ableist to look at illness through the lens of a diagnosis. However, I make the affordance here because this is still how chronically ill bodies navigate the world.

The second element for the chronic poet is the waiting room, which I am still waiting in. The waiting room is not just a physical space, but a state of liminality. Liminality is a term in anthropology that describes the quality of uncertainty or confusion in the middle of a rite of passage (Turner). The rite of passage begins when an individual leaves one group to enter another, like a young adult moving out of their parent's home for the first time. In the middle stage, the in-between of two groups, the individual has not yet been given a position in their new group even though they no longer possess one in their previous community (Turner). In the case of the waiting room of chronic illness, this liminality is made permanent. There is no new status to give the chronically ill individual, as it is constantly changing with their changing health, and location changes with their health, from specialist offices to emergency rooms. There is a lack of community within the medical establishment among chronically ill patients, and even a lack of status as a patient, such that only the power dynamic between doctor and patient remains. This creates a perpetual state of liminality, which comes from the chronic poet not being able to insert themselves into a medical society or a society that invasions them, thus leaving them stuck in an uncomfortable transition space. This space forces chronic poets to embody the

ambiguity or disorientation themselves, instead of just experiencing it in passing as most do. Within this broken kind of liminality, the chronic poet *becomes* the waiting room itself. Suppose medical spaces are "where bodies must be invaded in order to heal them"(Mukand x). In that case, we might view healthcare professionals as coming and going from the waiting room/body, invading it in their ways, creating the "more unpredictable than usual" chaos that the chronically ill person must endure (Mukand x). The conditions for the chronic poet to write poetry are born with a diagnosis and a waiting room.

Just as there is a status of luxury to diagnoses and waiting rooms, there is a luxury to being a chronic poet. I assert this privilege not to ignore the pain within the lines of chronic poetics but to understand chronic illness today. With the evolution of medical science, people who would otherwise die from a condition or an illness can live on, with either minimal or heavy reliance on the medical establishment. Many writers with chronic illness in the past never got the chance to describe or understand their predicaments because they died from a lack of modern medicine before they had the chance. Those who did lived short and painful lives. Thus, previous poets have never attained this intrinsically intimate understanding of the body, an understanding that grows every day with new research and data. When Virginia Woolf wrote her essay "On Being Ill," she had no access to the inner workings of the body, which had yet to be discovered. In her essay, she argues that illness should be a "prime theme of literature." Still, she discusses why it's not considered a theme due to a lack of words and

language to communicate with, thus making it impossible to discuss or analyze such a theme (Woolf 4). Medicine has given us the language to discuss it with these labels, but it is inaccessible for many —especially those in countries without universal healthcare. Even I, who have access, find myself barred from understanding my lab results, x-rays, or ultrasounds as healthcare professionals actively avoid giving medical literacy to patients, which creates a lack of autonomy for my body.

Jon Mukand discusses this language barrier in introducing his anthology *Articulations: The Body and Illness in Poetry*. His perspective is familiar in academia; as a medical director of a rehabilitation center and faculty member, he is writing from the position of "doctor," the overseer in the power dynamic between doctor and patient. He describes the medical environment to which the chronic poet must interact, whether or not they are engaging with it in their poems, the chronic poet writes in it. Mukand discusses how once "the border of those benign glass doors is crossed, one has entered a different culture" of medical spaces, and "this place has its language, and the layperson must have an interpreter, which creates a sense of mystery or even secrecy" (x). "Mystery" and "secrecy" are excellent ways of describing the language barrier between patients and healthcare professionals, which widens the gap in the power structure. While "the hospital cannot function without certain linguistic peculiarities," the lack of accommodations, such as a translator, creates "disorientation" from the communication fallout (x). Within this altered mental

state, "patients try to understand the medical environment differently, through intellectualization or withdrawal or hostility, just a few responses" (xx). Therefore, chronic poets are often driven by the need to create a new language for their bodies that is not barred from them. Robertson describes it as "the drive to write about illness.. [that] appears to come from a changed sense of self and the desire to create a form of personal order out of complex and confusing experiences" (13).

However, like the body, this language is not a singular one. In the *Enjambed Body*, Jim Ferris emphasizes the need to let go of any idea of universality if one writes about the particularities of the human body (Ferris 7). Just as someone describes their battle with cancer in one way, someone with diabetes will assign a different set of words to their body. It is also crucial to understand the intersectionality of identities within chronic illness to understand chronic poetics. For example, you cannot understand AIDS without homophobia. The literature written during the AIDS movement created the foundation of what we know today as illness narratives. The LGBTQ+ community rallied to showcase their humanity and rights to the quality healthcare they were denied (Jurecic). There are also racial and ethnic disparities within the healthcare system, with "Black people hav[ing] the highest mortality rate for most leading cancer types, including female breast, prostate, and colon and rectum cancer" (Artiga, Hill, and Tong). In the same vein, "Black, American Indian, and Alaska

Native (AI/AN) women are two to three times more likely to die from pregnancy-related causes than white women" (CDC).

This research is a personal venture, as I am essentially theorizing myself to understand my chronic illness and how poetry has been the best template for me to understand myself when I was thrust into the uncertainty of never getting better. Through poetry, I and many others went from drowning in the ocean to understanding that *we are* an ocean, and that we are *sure of the uncertainty* lurking there. Furthermore, a thorough investigation of poetic discourse and contexts surrounding chronic poets can contribute to a growing body of new language by which to discuss chronic illness. In what follows, I situate chronic illness within the field of disability studies, look at how to navigate through chronic illness while reading about it and how poetry serves to map the uneven terrain of chronic illness with the challenges that come when dealing with the medical system and treatments, social environments, and with a ever-changing physical dis/ability.

Chronic Illness and Disability

I recently attended a workshop, entitled, "Processing Trauma with Zines." As the host welcomed everyone, they made an effort to acknowledge the multiple identities within the room, and they distinguished "those with chronic illness or disability," a subtle but firm separation of the two. Indeed, there is growing tension as some writers are pushing chronic illnesses out of the classifications of

disability. In *Shaping Fractured Self*, however, Rachel Robertson offers a clarifying balm: "I include illness and disability here not to conflate the two or suggest that disability is the same as illness at all. However, while distinct in concept, disability and illness may coexist in an individual and often do" (12). Here, Robertson clarifies the separation but bridges the gap by showcasing the intersectionality of chronic illness and disability.

G. Thomas Couser discusses how illness is "a highly vexed term in disability studies" (105). Similar to Robertson, he views illness and disability as coexisting with a "reciprocal relation" but sees illness as "conceptually distinct from disability in ways that are at the heart of disability studies" (106). He posits that lumping the two together propagates the notion that all disabled people are sick. That idea fits into the medical model of disability studies, which "constructs their condition as requiring medical intervention," as disability is seen as a personal issue (106), for which only medical intervention is needed, rather than societal and/or architectural interventions.

Susan Wedell, in "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," addresses Couser and Robertson's concerns, acknowledging that "the relationship between disability and illness is a problematic one" (161). As Couser pointed out, disability activism fights the notion of needing a cure. At the same time, those with chronic illnesses "very much want to have their bodies cured, not as a substitute for curing ableism, but in addition to it" (161). This

gives voice to a conflict in values that ultimately isolates those with chronic health issues within the disability community. Wendell thus suggests the sub-categories of "healthy" and "unhealthy," with unhealthy disableds being those with chronic illnesses. She defines the distinction between the two with her definition of chronic illnesses: "usually, they are understood to be illnesses that do not go away by themselves within six months, that cannot reliably be cured, and that will not kill the patient any time soon" (Wendell 162). Wendell points out that a big reason chronic illnesses are left out of the picture is that Couser mentioned that the inclusion of chronic illnesses "might support those who prefer the individualized, medicalized picture of disability. Thus, in promoting the liberatory vision of social constructionism, it is safer and more comfortable for disability activism to focus on people who are healthy and disabled" (Wendell 161). As Wendell noted, it is easier to leave chronic illnesses out of the discussion than to include them, because opposers would use chronic illness as an excuse to perpetuate a medical model for understanding disability. Indeed, the inclusion of chronic illness in the discussion of disability introduces additional complexity, but there is much to gain in wading into this complexity.

Couser and Wendell's arguments make it clear that the voices of chronic illnesses often have to address two audiences at once, those within and those outside of the disabled community, when trying to overcome the barriers in place. What ultimately needs to happen is a reconciliation and formation of "solidarity between people with chronic illnesses [as] people with other disabilities depend

on acknowledging the existence of the suffering that justice cannot eliminate... [and] acknowledging that illness is not only suffering" (Wendell 171). This suffering includes the "physical or psychological burdens" that come with disabilities and chronic illnesses (162). The potential solidarity of fighting the same battles is often lost in the infighting over nuances. Professor of Sociology Jan Grue discusses that "medicine continues to exert great influence on the social meaning of disability in general and the social valuation of various illnesses and impairments in particular. Whereas specific conditions may be socially valued, the overall category and label of disability connote marginality and stigma" (957). With Grue's insight, we can see that chronic illness and disability are marginalized within the same capacities.

Chronic illnesses, like disabilities, are not going anywhere soon. As long as they are both fighting the same battles, we should honor the different ways people classify them but not let gatekeeping of specific terminologies get in the way of progress. By attending critically to chronic poetics within disability studies, we can bring attention to and counter the history of exclusion done and bring about the recognition that chronic illness, like disability, is a socially and legally constructed identification.

On Reading

Before diving into the poetry, there are some important notes to be made on the means of how to read through chronic poetics. Such as, while the poet is

always the speaker, the speaker is not always the poet. In the same way, we suspend disbelief to enjoy fiction, we must suspend knowing the poet when reading chronic poetics. Ally Day, Assistant Professor of Disability Studies at the University of Toledo, dives deeper into this issue as she reads through Tory Dent's HIV Poetry. She writes, "I want to caution narrative medicine's insistence on knowing and instead propose a practice of feminist bioethics that reads poetry to uncover spaces of unknowing" (92). This draws on race theorist Karla Holloway's understanding of negotiating privacy for women and people of color in medicine (92). Bioethics is a discipline which studies the conceptions of and responses to moral and ethical questions in the medical field. The *bioethics* she references is a way to read by using literature as a guide for ethical practice in biomedicine (92). Bioethics and Disability Studies are not within the same categories because bioethics takes an approach which justifies frameworks like the medical model which are built into medical systems (Day 96). Day, with the help of other theorist such as Jackie Leach Scully, establishing a new version of bioethics grounded in feminist and disability studies.

This "knowing" that Day mentions is a writing approach about the "consistent call to elicit as much personal information as possible from patients to improve treatment protocol and practice," which many medical fields promote, particularly narrative medicine (Day 92). Instead of looking at these poems to *know* the poet and their chronic illness, it needs to be analyzed through the "unknowing" within the piece, as the poets occupy and articulate the liminalities

of their changing bodies. The unknowing comes from many places, such as when the chronic illness first is onset, you do not know what is wrong, but something is wrong, you do not know what as well as the unknowing that comes from the doctor(s) knowledge on your chronic illness. From this unknowing, chronic poets which create accounts that trace through an emotional landscape mimetic to the dailiness of their own lives. This gives readers the experience of deeply understanding the complex nature of chronic illness, from frustrating experiences with the medical system to the fear of picking up a phone call about a tests results.

The second assertion Day makes is that "To read poetry bioethically, we must understand the poem as a body" (94). She elaborates on this by asserting that "as readers, instead of critiquing poetic structure and themes separately, we must move through the poem to demonstrate how poems are bodies, circulating among readers who interpret meaning and structure through their bodily engagements" (94). Day pushes readers to view poems as their own body, reflecting the chronic poet's understandings of their own body in many ways. As readers, we become a part of the poem, as if ingested by it, as we read and ascribe our meanings. Everything is connected and constantly in motion. Thus, as readers, we must develop an intimate understanding of our bodies as we look at chronic poems. Readers co-create meaning because chronic poets create poems that reflect their bodies in various stages; therefore, knowing how our bodies feel helps us to understand the layers of chronic poetics. Chronic Poetics

engage our bodies to take part in the reading process, challenging us to move beyond thought, and even beyond our five senses and into a more profound correspondence within the poet's body as well as ourselves.

Hillary Gravendyk also proposes an essential concept to reading chronic poetics, adding to Day's notion of reading the poem as the body. According to Gravendyk, "Chronic poetics is a phenomenological account of perception and artistic practice that allows the shared conditions of embodiment to emerge from the text" (1). Breaking down Gravendyk's definition of chronic poetics, she views it as a philosophical statement that focuses on the lived experience of people with chronic illness, which allows commonalities of experiences of the body to be shared. In her analysis of Larry Eigner's poetry, Gravendyk suggests that the poem is a conduit body for energy to circulate and exchange, rejecting the traditional notion that poems *convey* energy unidirectionally from the writer to the reader (3). Critical to this energy circulation is an attentiveness to the act of reading and an understanding of perception as much as the multiple things that can affect it (7). Building on the work of Merleau-Ponty, Gravendyk believes that the particularity of the body in temporal space allows for many meanings in the poetry, as "our sense of the world is colored by the fact that we experience it through a set of chronic sensory and experiential features of the body" (14). Like Day, the idea of the poem as a body itself emerges, taking on energy that the readers circulate. While Gravendyk does not view the poem as giving power to the readers, its actual reader's input gives life to the poem as it is read, given

meaning, and shared. This idea is very reliant on the state of poetry as a whole, as we choose which poems are taught in classrooms, which poems we read, and the poems that we share with friends. These acts are a type of living that carries on ideas, experiences, and essence. Gravendyk refers to the senses as "chronic." By that, she is touching on the fact that we have certain ways, sensitive and unique, in which we engage the world. Such as, having a favorite fragrance we are pulled or having the gene which causes cilantro to taste like soap. We develop our senses over time until they become a part of our consciousnesses, sometimes unaware of their influence which makes them chronic. Furthermore, Gravendyk notes that the experiences of our body paint our views, and shape the lens through which we view everything; thus, she reminds us to think beyond ourselves when reading chronic poetics. A lot of the reading in chronic poetics deals with illnesses that the readers have not experienced, which demands closer attention to the texts and *extrospection* as opposed to *introspection*, the capacity to feel beyond the self, to extend the self into the chronic body.

Why Poetry?

Pattern-making is one of the vital powers of the writing process. We use words, sentences, and paragraphs to organize, orient, and make sense of, all to construct meaning for ourselves and propose meaning to others. A new pattern is required when an illness, disability, or chronic condition comes into a person's life. Lisa Diedrich suggests, "Illness brings about a shift, a subject crisis, a crisis

of subjectification itself." The individual no longer feels at ease in her own life; no longer at home in her own body. Cade Leebron substantiates this unease in her poem "Ode to the Brain Holes," which for the entirety of the poem gives an optimistic view of her condition, going so far as to thank her illness: "(Thank you for inhabiting me, for making me sick.)" Yet she ultimately arrives at "& I am afraid. Because you are not a hole. You are scar tissue, hardening into something unfillable." This ends with the future uncertainty and the crisis in her changed body, her changed subject position, and self. In Fortesa Latifi's "the cancer diagnosis," she phrases this disorienting unease as "even the most normal of things can betray you." She lists things such as "sunlight; salt; the air between words; your body." What once was is no longer, even "normal" things, even language itself.

The most challenging aspect of creating this new pattern is that the words, sentences, and paragraphs are used to organize the chaos of the body, make sense of this new way of life, and form a new sense of self. Writing about chronic illness and pain is difficult to put into words, let alone stanzas, sentences, and paragraphs. Elaine Scarry claims that "physical suffering does not simply oppose words, but actively destroys it,"(4) Woolf terms this difficulty as a "poverty of the language" (34). Finding language to match one's experience can be even more difficult for those who do not have a precise medical diagnosis and for those who do not even have a framework to explain what is going on in their bodies.

We can feel Max Ritvo's urgency in "Name My Time of Death and See What I Do to You" as he shouts his frustrations with doctors and his body, pressing doctors for an answer:

*Time's up. Break's over. So I put the doctors on the floor again
and ask them for a diagnosis.*

*I've been keeping the doctors in line
on a little tan balance beam—*

*Whenever they reach the end, I pluck them
up by the collar.*

*There is a little sadist in me—or boys
will be boys. I think I just got tired*

*of bad news, and each time
less air getting into my lungs. (1-10)*

Right away, Ritvo creates a setting where he is in charge as he tells the doctors what to do. As well as the physical differences between them, with the speaker being larger than life, they keep the doctors "in line/ on a little tan balance beam" (3-4). Ritvo breaks the line in a place between these two lines in a way that is off beat, knocking readers off balance, placing the readers on the balance beam. The speaker throughout the poem is violent toward the doctors, even calling them "sadist," as if there is enjoyment from these acts of pent-up retribution. Ritvo also uses the phrase "or boys will boys," showcasing the ugliness of his

character. He knows, as many of us, this famously overused excuse for toxic masculinity (7-8). He uses it with the same purpose as the violence, putting all his ugly emotions on display. He is hiding nothing. It also invokes childishness, like a small child who lashes out to make the person who hurt them feel the same way they do, an unhealthy yet seemingly inborn coping mechanism. The doctors have been contorted to represent his pain; he writes, "their legs can only slam forward, crimped / and insanely looped like mine" (15-16). These lines indicate that the violence enacted is what has been done to the speaker's body by chronic illness. As the doctors are contorted to feel a parallel affliction, and in reading it, perhaps we feel it as well. This embodies Day's concept of the poem as body, as this poem is occupied by Ritvo's ewing sarcoma through the violent breakdown that happens through the lines. He creates the appearance of order, two lines coupled together, while the lines themselves read of instability. The speaker's admission, "I think I just got tired/ of bad news, and each time/ less air getting into my lungs," has double meaning due to the way the lines are broken. "I think I just got tired" has one meaning, fatigue of physically and mentally battling cancer, but develops a second meaning with the added line "of bad news" which draws attention to the exhaustive battle chronic illness patients battle within the healthcare system. Many chronic illness sufferers continuously have to navigate the medical system, going to multiple doctors, taking blood tests and biopsies, doing physical therapy, filling out paper work, etc.. It is a laborious process to negotiate the emotional and physical toll of chronic illness, on top of a medical

system that is not set up to comfort people. So when the report comes from the doctors and "the diagnosis comes in underwhelming," which was predicted, but is still disappointing because it is a lot of effort on the person's part to go through the exhaustive medical process (19).

With a lack of answers, the speaker goes on to meditate on the unknowing, as they speculate:

*I think there is something in me
more horrible than they're detecting—*

*I think I'd kill to stay alive,
at least myself,*

*and if you can't accept that
you don't know the angel in my blood.*

*What if I ran out of a body to give you?
What would you let me take from you?*

*A star, a raft, a bloody cloth, a bloody cloud,
my body, my body, I'm running for you only,
and my fear is the most beautiful thing I have ever seen. (25-35)*

Ritvo cannot help but think something more is going on, something insidious that technology is not advanced enough to detect, touching on the reality that there is so much unknown about chronic illnesses. He writes in one line, "I think I'd kill to stay alive," which is both an idiom, "I'd kill," and an oxymoron, killing to live, which

signifies how desperately he wants something that cannot exist. He knows the reality is that his condition is chronic and incurable. In the line "my body, my body, I'm running for you only," he plays with words; instead of the body running, he is running, trying to make up for the lack of function in his body. Also, the running falls into the next stanza as he talks about fear because both fear and the act of running induce a fast heartbeat. In the final line, Ritvo leaves his audience with something that seems to contradict the rest of the poem, something hopeful and peaceful as he calls his fear "beautiful." Max Ritvo suffered from Ewing sarcoma, cancer that ultimately took his life. It can seem overwhelming to inhabit chronic poetics as readers because, in instances like this, it is a confrontation with ourselves as we peer into Ritvo, who is staring at the face of death. However, amidst the suffering, he calls it "beautiful."

Most would not use this label to describe fear--maybe sweaty, numbing, or anxious, which are not ruled out when Ritvo calls it beautiful--but he sees beauty in all those things. Not just any fear, but the personal fear that he has felt, his specific fear is a reminder that he lives, that there is some nameable part of his experience, that to have fear is to own something amid a void in the absence of diagnosis or language to describe what is going on, of doctors who have no answers, because to fear means you have something to lose.

Because doctors also struggle to find and understand the language of chronic illness, they created the concept of the pain scale, "from a scale of 1 to

10, what does your pain feel like?" This scale has some uses, but it is nowhere near able to describe the pain which may flare, pulse, spread, throb, buzz, cut, whistle, blot, bulge, slice, dissolve, shout—how to say it? Because what does a level 2 pain feel like? I imagine a stubbed toe when I think of it, particularly in the after moments. They ask this arbitrary question without any proper context. Not all bodies feel pain the same way. The biggest issue with the pain scale is that pain for people with chronic illness is not momentary, like an earthquake; it is constant foreshocks before the earthquake, followed by blackouts and tsunamis. Notice how I use metaphors to describe pain. These are the tools of poetry.

Martha Stoddard Holmes points out that pain is "theorized as an experience that isolates and individualizes" and that "the difficulty of empathizing with another's pain can become hostility toward the person in pain" (Holmes 133). Pain is viewed as private and actively hidden away. Looking at the individual body in pain exacerbates the inclination to see disability as an individual tragedy rather than a social and political identity (Holmes). This is something Couser and Wendell brushed over in their respective discussions on disability and illness. The very lack of discussion further hints at the private nature of pain, the tendency to hide it, to protect it from public view. There is a closed conversation around pain outside and within the disabled community. Thus, Holmes advocates for the need "to acknowledge the experience of pain that may accompany disability without reinforcing the assumption that disability

necessarily entails pain and without presuming that pain defines the boundary between lives worth living and those that are unsupportably miserable" (133).

Just as Holmes acknowledges pain's multi-dimensional part in chronic illnesses , Rachael Mead wrestles with this inwardly private nuance in "What lies beneath my skin":

*The ringing phone ratchets me into tension,
It is everything and nothing,
filling the place poetry used to be.
Management only works in practice, and right now, I'm all about theory.
The circling around guilt drain.
The awareness of performance
— the inability to stop. The anger.
Everything turned inward.
I prefer silence, and when I talk,
it's all repetition. I let the phone ring. (54. 1-11)*

The first stanza begins with the simple, everyday occurrence of a "ringing phone," but for the author, this "ratchets me with tension" (1). It's because of everything that could lie on the other end of the line, resulting from a biopsy, blood work, CT, or MRI scan for someone with chronic illness, or a family member asking for updates, any minefield disguised as a conversation. The list goes on, which is why "it is everything and nothing" for the author because the results could notify her of something and lead to better care or show that nothing is out of the usual, but the pain is still there (2). The results could overwhelm and

consume her as they are "filling the place poetry used to be" (3). For the speaker, poetry cannot compete against the ominous tension of what is or is not beyond the phone call. The speaker begins a descent into a pattern she prefaces: "Management only works in practice / and right now I am all about theory" (4-5). The speaker knows they should be managing their pain along with their feelings and actions, but in this moment, they cannot. This is why they begin with "The circling around guilt drain," and while they have an "awareness of performance," there is an "inability to stop" accompanied by "anger" (6-8). In these lines, we can see the beginnings of the stages of grief, but a version modified by chronic illness. Grief is a typical process for those with chronic illness and a shared pain faced by all—the pain that comes with occupying a liminal space, the pain of unknowing and its possibilities. We see two steps of grief playing out in these lines: first, denial in not picking up the phone, and second, anger. Instead of the next step of bargaining, "everything turned inward," as the speaker looks inside themselves and finds, "I prefer silence," and when they do talk, "it is all repetition" (9-11). Mead uses a lot of end stopped lines within this poem as a formal attempt to stabilize a destabilizing experience. In an attempt to control the experience of their chronic illness, they overly organize the lines. The lines that don't end in punctuation draw attention to the end words "practice," "performance," and "talk." These active words display a series of actions, practicing performance and talking, engaging with the medical system. You cannot be authentic and must know the right thing to say to get the medical attention you need. In these lines,

we see depression begin to take hold of the speaker as they shun the outside world. It becomes more evident, as instead of coming to acceptance, which would lead to picking up the phone, the speaker "let my phone ring," choosing to not outright decline the message nor accept it, having it go to voicemail (11). While the phone, and its call are left in the first stanza the consequences of it play out in the rest of the piece as the speaker works through the grief of the inevitability of having to accept that phone call.

The denial of the phone call is an act of wanting to not being chronically ill anymore. Of not wanting to go through the monotonous process of hospital visits and phone calls for test results. But the reality is, the speaker can't control that and the depression of that fact takes hold in the second stanza:

*Fear of death drops away like a silk dress
slipping from its hanger. The knife rack,
and the rafters are pregnant with possibility.
I know what to do.
Walk the dog. Sometimes, this is all.
The gum trees raise their lacy fists,
a level of defiance I find impossible.
The glitter of creek water,
the black field of stars.
I put myself in the path of wildness
and let it fill my long and hollow bones (54. 12-22)*

Having detached themselves from the fear of death (12-13), the speaker notes, "the knife rack, / the rafters are pregnant with possibility" (13-14). Something to note with this suicidal depression is that it stems from the pain. As the dress slips from the hanger, so does the speaker's soul drift from their body as they dissociate. Dr. Debra Fulghum Bruce, an award-winning medical writer, notes that "depression magnifies pain" and how "depression and chronic pain share some of the same neurotransmitters... also share some of the same nerve pathways in the brain and spinal cord". Knowing this, we can see that depression and chronic pain go hand in hand, sharing similar paths in the body, which can create a vicious cycle. So this depiction of depression, manifesting as withdrawal from others and suicidal thoughts, directly correlates to the speaker's pain. Clouded by these thoughts, the speaker "know[s] what to do" and takes their dog on a walk (15-16). Once outside, away from the speaker's thoughts and away from the phone, nature provides its analogies: "the gum trees raise their lacy fits,/a level of defiance I find impossible" (17-18). They admire their defiance because they wish to defy their chronic illness and not have to go home and eventually have that phone call.

They understand the inevitability of it. As the speaker takes in "the glitter[ing] of the creek water,/ the black field of stars," the poem ends, "I put myself in the path of wildness / and let it fill my long and hollow bones "(19-22). She especially notes "wildness" instead of "wilderness" about the chaos inside her body, which she accepts in her grieving process, as she gives it permission

to enter her body. Through the process of permitting it, she is reclaiming her autonomy in the process. Autonomy is lost for many in battling an ongoing condition or illness. Mead makes the first and penultimate lines of this stanza a break, bringing attention to her suicidal simile and the wildness she allows to fill her. It puts pressure on the mourning occurring in this piece. By looking at Rachel Mead's piece, we can begin to understand how pain in those with chronic illnesses takes on various shapes. Especially with something as casual as a phone call. Many with chronic illness await the results of lab work that could change their treatment for the better, and it can be quite devastating when it doesn't. Therefore the wait can be nerve wracking, as one's brain turns over the possibilities of good or bad or no news.

Another writer who adds to the conversation about the challenges writing about pain in language is Eula Biss. In her article, "The Pain Scale," she confesses that, "after a year in pain, I no longer knew what it meant to be in pain" (18). Her body came to normalize the sensation of pain, to cope with it, making it even more challenging to describe to doctors. She describes her nerves as having "short memories," making this an obstacle. She also comes to this remarkable recognition: "when I cry from it, I cry over the idea of it lasting forever, not over the pain itself" (19). Biss laments over the persistence of the pain rather than the pain itself. Her revelation comes not from a numbered pain scale but from sitting down and writing out her experience. As "illness is often an

experience of fracture or disordering. Language can help reassemble and reorder our experiences" (Robertson 13).

This reordering can be seen in Jessica Cohen's poem, "The waiting room," as she uses language to describe her encounter (46). The poem opens on "the chairs in the waiting room," describing their uncomfortable nature, "narrow and hard" (1.1-2). Then, she moves the image away from the waiting room, likening the chairs to those in high school, "designed to keep students from falling asleep" (1.4). This comparison highlights two systems (medical and school) that focus on results and quantity over the attention and quality given to its unfortunate victims. Systems people do not choose to be in but are placed in with no alternative. Cohen refers to this system she was birthed into, which reminds her through a hard chair that her body is not functioning as it should.

The second stanza traces how her body moves in the chair, as "ankles rest on one another" (2.1), slowly moving up her body to her "Fingers placed in the ridges /of other fingers" (2.4-5). Then, lastly, her "Head is bowed, spine curved (2.8)." This upward movement through the speaker's body highlights their nervousness and discomfort in the waiting room, a type of unbelonging. Next, Cohen breaks the line on the word "ridges," making the lines as ridged as her body. Ridges is a word usually used for mountains, creating a metaphor between body and earth, as if looking over the ridge of a cliff, which creates anxiety. It also makes us feel rigid, like the rest of their body feels. They constantly shift their

legs, clasping and unclasping their hands, fidgeting, and trying to minimize themselves by hunching over and leaning their head into their body.

Finally, in the third stanza, Cohen focuses on the room, which is just "another waiting room" (3.1), meshing into all other waiting rooms as "another maudlin love song on the radio," which comes to emphasize the "bland" and "monotonous" nowhere of these rooms. In this stanza, the broken liminality of the waiting room mirrors that of the speaker. The love song is maudlin, self-pitying, and tearfully sentimental, echoing how the speaker feels about their predicament in the monotonous routine of chronic illness. The maudlin love song may also suggest one's relationship to self, as the disillusionment of a romantic promise, broken, as broken as the body.

In the fourth stanza, we see a seemingly normal interaction take place that actually isolates the speaker even more in this medical setting. It begins with the receptionist wishing the speaker a happy birthday (4.1). The receptionist invites intimacy by likening the speaker to her daughter, who shares the same birthday. "She tells me this year she will gift money / Daughter and fiancé have a fresh mortgage, you see" (4.3-4). This feels foreign to the speaker, "these concepts feel as far away as wellness" (4.6). The forced comparison of the speaker and the receptionist's daughter makes the speaker look at their life, particularly their support system and future. The receptionist highly supports her daughter, even

going so far as to financially help in her life's endeavors, a daughter who has just bought their first house together. All of this makes the speaker feel out of place.

In stanza five, the speaker recedes to within themselves because of the comparison,

*Newly tired limbs on top
Of years of old paint.
My body interprets the loss that my mind could not
And my mind carries the weight of my body. (5.1-4)*

Cohen makes a play of words, “newly tired limbs” and “old paint” but both draw attention to the fatigue of the speaker. The "old paint" mentioned contrasts with the new paint on the house of the receptionist's daughter, and with it the possibilities of it. Such as getting new jobs in this new location, having children, creating a new life, while the speaker is stuck in their “old paint,” which is worn down by the layers of pain. In the following two lines, the speaker describes how the body can process pain, "the loss," which the mind cannot, and because of this, the mind focuses on the body. An underlying factor in many chronic illnesses is genetic trauma, another word for transgenerational trauma, and the "old pain" here can refer to the pain of past generations up the family tree. Trauma puts pressure on the body, pushing it into physical pain.

In the final two lines, the speaker closes their eyes and loses track of time as "the love song softens to a murmur" (6.2). This stanza recalls the third, which

houses the broken liminality of the speaker, as the speaker recedes into themselves and their "maudlin" feelings. Time does not exist in the broken liminality of this waiting room, both room and body, as it represents the continuousness of chronic illness' never ending-ness.

We see the struggle of broken liminality, of being stuck in between, in Jill Khoury's "pure o," she takes a formally innovative approach in her poem discussing her obsessive-compulsive disorder. It reads as a stream of consciousness as she demonstrates the breakdown of her mind alongside her body.

*i am only disappointing myself
i myself am only disappointing
only myself am pointing / at i
am this / i am only dis-
appointing / i appoint myself to dismiss
am i myself in blame only / this self-
appointed pointed i / i feint at me
say self i'm disappointed / i disappoint it's
what i do / i'm this / my fragile cellophane membrane
selfish i who is always cleaving to polarities (1-10)*

In these first ten lines, Khoury hyper-fixates on the word "disappoint," breaking the word down slowly as disappointment lingers throughout the piece. The word is dissected but disappointment still lives in the words "pointing" and "appoint." The breakdown of the word coincides with the breakdown of the speaker's "fragile cellophane membrane" body. The speaker spirals through a depressive episode as they are disappointed at their outcomes, openly blaming themselves. The speaker is self-aware, understanding they are "always cleaving to

polarities," which is hypercritical or inflated praise. They use the word "feint," a word used in sword fighting, which also sounds like "faint," giving it double meaning. It also connects to the imagery of taking a stab at themselves. Khoury continues this in the following lines:

*the point / i have / the one and eternal cellar
i have am / this only / this one i halve
only say it and i'll disappoint / it points to
self / i dismiss my quaver / i distill and
am pouring / i miss it / i must / i
distribute distance / distort and
cloak myself / i point at this / a distant crescent
a pointed distinction i anoint / i police
the self / oh no / i only meant primordial
to say this / to say one point but this only
only i (11-21)*

In these lines, Khoury further breaks down their disappointment and a breakdown of themselves. They move from "disappointment" to wondering about the "point" of their existence. They engage in the existential quandary of "the self." They not only feel like a "halve," of who they are, likening it to a "crescent" moon. The use of "halve" is similar to "feint" a word with two meanings because it sounds like "have." They "police" themselves, as well as "distort and/ cloak" to engage in a society with no place for chronic illnesses or disorders. This policing is at the heart of the disappointment, policing that is forced by societal expectations. In a way, they are a crescent because they cannot be wholly themselves in a society that does not accept them. Khoury's piece combines chronic pain and OCD, the physical/mental continuum as a disintegration of mind and body, yet vigorously strives for meaning in the mental spiral. "pure o" visualizes

the disabled body and mind betraying itself through its exhaustive self-quarrel in search of reason in the chaos of their existence.

Poetry is an apt modality to embody the experiences of chronic illness. Pain is difficult to express in language, and chronic illness is unpredictable, so representation is challenging. It is inherently challenging to express pain linearly, as there is a constant interruption within the nervous system; thus, prose cannot give voice to the gaps, stutters, and interweavings at work. Where prose narratives deal with time, continuity, and cause and effect, poetry can accommodate fragments, space, reiteration, dislocation, nonlinear mental processes, and much more. Uncertainty and ambiguity are not just tolerated within poetry but intentionally cultivated.

George Orr discusses in *Poetry as Survival* that "survival begins when we 'translate' our crisis into a language" (4). The crisis for many chronic poets is not just one of the body, but also of the medical system as health professionals actively deny patients medical literacy. In "Leaving the Hospital," Anya Silver describes how once outside those doors, "the world flares back into being—/I exist again, recover myself," as if she had felt nonexistent or disconnected within the medical environment. The language used by doctors and nurses ascribes words to our bodies we do not understand, and bar us from understanding. In this way, doctors take institutionalized acquisition of our bodies through

language. Thus we must create our language in poetry, to reclaim the language of our bodies.

Like Silver, Quinn Eades in "Reverberation" feels unable to live in the hospital system. "They X-ray my lungs as if looking through / me," caring more about the images than the endangered body of Eades (140.1). The enjambment "through/me" disrupts the medical system, and heightens our awareness of the intrusion, almost transgressions, of the body. Instead of being treated like a person, "when I go to hospital they like to press me/ against a lined plate, shivering, breath held, to hunt down" (140.8-9), they are treated like a specimen under a microscope, and in that process are mistaken as the prey instead of a partner in solving the quandary of their body. However, no human is afforded an identity in the medical system, and when Eades reminds them blatantly, putting their trans body on display, it calls out the faults in the system. "Yes, I have nipple rings, I say. And there it is the absence / of noise that is not silence, that comes after speaking, out / of place" (140.16-18). It's not just speaking out but *being* out of place. The standardized medical system has no place for expressions, individuation, no place for nipple rings, which are personalized expressions of the self. Absence comes not from Eades but from the medical system, which has no process in which to intake queer bodies. Margit Shildrick, discusses how the "biological body itself is an effect of language" and that social norms and body representations are in a symbiotic relationship (14-15). The medical model considers each body standard, but Eades' trans body,

prominently his nipple rings, unravel this concept. As it unravels, the mechanisms and grinding gears are on full display. The absence shown is the absence of care in the healthcare system.

We can begin to comprehend the profound change in our sense of self that occurs when the body suffers a substantial alteration if we grasp that our body is our home and is inextricably interwoven with our sense of self and identity. Fractures and disordering frequently accompany illness. Language can assist us in reassembling and reorganizing our experiences. The ability to regain agency and control over one's life is enhanced by telling, and much more so by writing, about one's sickness experience. Susan Hawthorne discusses the loss of agency in "someone's fear" as someone calls an ambulance on her.

"[S]omeone's fear calls the ambulance" while she has a seizure which lasts a couple of minutes, but "when the \$1600 ambulance bill arrives / someone's fear is not around to pay" (74. 4,9-10). In telling her story, Hawthorne reclaims the narrative of someone's fear and the literal loss of agency over her body as a seizure takes control. Her seizure did not warrant the full extent of the hospital, and it came at a heavy price tag that she had to pay. While the person who called the ambulance is seen as heroic, Hawthorne's account tells another story.

When illness strikes, we might consider healthcare a necessary and benevolent system. However, in many cases, medical treatments are as difficult to bear as the illness itself, and medical technologies might rob an individual's

autonomy as much as the illness itself. For example, in Andy Jackson's piece, "Nothing Personal," nothing is personal as Jackson is not seen as a person. In the first stanza the doctor performing surgery purposefully ignores his autonomy.

*He leans back against his desk, and asks
if, while he has me under, it would be worth
taking care of that leg too, pointing to it.
He is not talking to me, but my mother.
I'd instead not make this a bigger deal than it is,
so I say don't bother, to her,
who relays this across to the doctor (34.1-7)*

Jackson recreates the image of an impressionable encounter with a surgeon. It sticks with him due to the lack of humanity in the encounter, as the doctor "is talking not to me, but my mother" (34.4). Because he was not able-bodied, he was not in charge of his autonomy. That is why the doctor talks instead to the only other able-bodied person in the room, which is his mother. Instead of correcting the doctor's egregious behavior, Jackson would "rather not make this a bigger deal than it is" (34.5). This is because it is laborious to deal with the medical system. If he were to call the doctor out on his behavior, he would risk dropping him from his care, then going through finding another doctor with a similar behavior pattern because this doctor's disregard for Jackson is not new. Therefore, Jackson does not react to the doctor's behavior because it is something he has become accustomed to with other healthcare providers.

Instead, he enjambes to put tension on the words "asks" and "worth," as both his permission and worth are being stripped from him.

In the next stanza, Jackson is isolated from the rest of the world after his surgery, as this separation parallels how society removes people with chronic illness from it:

*The ceiling floods my Head with whiteness.
Into the corner of my left eye, the television spits.
They've attached weights to my neck and ankles
and suspended them over both ends of the bed.
I will be like this for a week. Until I leave
in a brace with a spine-length scar,
I have only one red button to press. (34.8-14)*

Here again, we see how dehumanizing the medical system is. Here there are no people, just white ceilings, weights, and braces. It is as if there are no people behind it at all. It makes you wonder if anyone would come if he were to push the button, representing his only autonomy. He uses "until I leave" which is a time frame that can vary, as well as questions if leaving will ever come. While he may leave the hospital, he can never leave the medical system. Finally, in the last and third stanza, Jackson shows what seems to be the only actual human encounter he has in the hospital:

*The door is locked, the taps turned on.
Propped on a plastic chair, I am made wet
and clean by a nurse, still too fragile
to do it myself. As she leans over me,
the curtain of her uniform opens an inch,
briefly exposing a hint of the sensitive flesh
of our different positions, how cold it can be. (34.15-21)*

Finally, human contact is made, but only out of necessity. The door to the room is locked for privacy but doubles down on the confinement and isolation. While the nurse is washing him, a sexual encounter occurs as he sees her "sensitive flesh." However, this encounter establishes her and Jackson's "different positions" and the absolute power dynamic. He is "made wet," emphasizing this state he has been placed in as an inanimate object, a state in which he is handled as if he is "too fragile" to be able to handle any responsibility. Nevertheless, at the end of it, he, the nurse, and even the doctor are all made out of the same "sensitive flesh." He is still human despite all the dehumanizing experiences.

In Eades' "Reverberation " and Jackson's "Nothing Personal," we see a fluctuation between order and chaos, coherence and incoherence, as medical therapy shows how it makes them feel isolated and depersonalized. This is not to say that healthcare workers intentionally create that distance, but rather that the

treatment process is often one of estrangement from oneself and others, whether in a hospital or alone at home, and sometimes without others to share the experience with. Another motivation to write about illness and pain is to re-personalize the depersonalizing experience, to claim back one's lost humanity, one's lost voice. The need to write about illness, then, stems in part from a shift in one's sense of self and a desire to build a degree of order out of otherwise chaotic situations—this sense of order being newfound, unlike how the order was inherited, perhaps taken for granted prior to illness.

Still in the Waiting Room

I'm still here, waiting, in the same body but a different waiting room. This one has no tv for me to occupy my time, nor any festive holiday decoration as they have all long passed. The black chairs contrast the bright white walls and blue curtains that line them but are muted by the scuffed, diamond-tiled floors. While I've skipped having breakfast again, it was on purpose this time. I'm waiting in this waiting room for surgery this time. It's supposed to be minor, but the surgeon has no idea what he will find. What if he finds something? What if he finds nothing? He is taking a leap and diving into my ocean, into my body. I'm nervous and anxious as I scan the room looking at families huddled together, chatting as they are waiting on their loved ones, and thinking similar thoughts as mine, a collective unconscious. My partner slips his hand into mine and squeezes it; at this moment, I breathe. I accept the unknown that has taken hold of me. I find strength in these poems I have read and written about. This

research is living and breathing inside me and gives me the strength to face my chronic illness.

Like Max Ritvo, "I think there is something in me / more horrible than they are detecting" (25-26). Like Rachael Mead, I feel "everything turns inward" (54.9). Jessica Cohen perfectly sums this experience up when she mentions that "my mind carries the weight of my body" as my mind shifts through all these thoughts (5.4). These poets use their words to cast light into the darkness surrounding their medical journeys that focus on navigating the unknowns of the body and how medical systems forget to consider the souls that linger there. They use their words to form a language for their chronic conditions and as a platform to showcase their complex humanities, which are often disregarded in the face of the industrial medical complex. Through their pieces, we have seen how poetry resists the measurement and assessment of medical discourse. Yet, the consistency and technique of repetition hail the medical normalization inherent in the lives of those with chronic illnesses.

We have a world to gain by engaging with more chronic poetry; remember that the fear of the unknown is rooted in the reality of the uncertainty of our own lives. However, certainty itself is an illusion. Seeing chronic poets grapple with uncertainty can help us manage our own as they showcase the opportunities to reclaim ourselves through language. It's not too late for illness to claim its spot as a "prime theme of literature" (Woolf 4).

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