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MAKING THE INVISIBLE VISIBLE:

MAPPING CHRONIC PAIN THROUGH ART

by

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Abstract:

This Studio Art thesis explores how I use my art practice as a chronic pain healing process. It draws on the fundamentals of the neuroscience behind pain and the implications of this science for people with chronic pain. People with chronic pain often turn to alternative healing techniques in their search for relief; my own alternative healing approach comes from my art practice of “pain mapping."

The artistic healing process that I have developed takes inspiration from chronically ill artists such as Frida Kahlo and Anna Cowley Ford. The artistic mapping of my pain that I have developed primarily uses the medium of wire, as the fluidity and malleability of this medium speaks to me the most. By using alternative chronic pain healing tools and inspiration from other chronically-ill visual artists, I have developed an arts practice that incorporates pain neuroscience and seeks to address the mental toll that suffering through invisible pain creates. My thesis helps me visualize an otherwise invisible experience and it allows me to create science-informed space for healing.

My art practice focuses on healing tools for chronic pain that draw from the teachings of pain neuroscience and pain psychology. As this paper describes, this topic is highly personal for me: I have struggled with chronic migraines since I was six years old. My migraines have fluctuated in severity at different points throughout my life, but their near constant presence has informed much of the way I move through the world. In college, dealing with my migraines has reached a level of difficulty that is nearly impossible to manage. By the end of each semester I am usually fairly bedridden and wondering whether I will be able to finish the term, and if so, how well my work will reflect my capabilities (if I were not to have devolved into constant pain). During this semester, I have found myself once again in this place, unsure of whether I will pass and move on to the spring semester.

As an artist, my art practice parallels my experience with chronic pain. My experience of pain is the subject of most of the work I create. I have chosen to focus my thesis around this experience for two reasons: the first is that I find the neuroscience of pain incredibly fascinating and understudied, and it offers hope to a world in which one in five people deal with chronic pain[1]. The second is that to write and create art about anything other than my pain experience would feel like a denial of my current state of existence - a state which is extremely physically and emotionally painful, and whose pain is exacerbated by the fact that it is almost entirely invisible.

I came to this exploration of my chronic pain through the visual art tool of “pain mapping.” While I am experiencing pain, I create multimedia "pain maps" that represent the sensations I feel when I am having a migraine. I am interested in whether pain mapping holds the potential to aid in healing from chronic pain, or if it actually serves to focus the sufferer on the

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[1] Dobbs, David. 2021. “How Glial Cells Are Quietly Revolutionizing Chronic Pain Study and Care.” The New York Times. https://www.nytimes.com/2021/11/09/well/mind/glial-cells-chronic-pain-treatment.html.

pain, thus having the opposite effect of heightening it. This is a complicated question that my own experience has not yet clarified for me, and it is one I am eager to continue to explore.

Over the last 17 years I have been to countless doctors and tried numerous different medications to treat my migraines. I have been hospitalized several times when the pain has become so unbearable and long-lasting that my prescription medications are not sufficient to provide me with relief.

Around three years ago, my migraines increased in number and severity. It was the first time in about ten years that I was having migraines every day, sometimes twice a day. As a response, I began to experience intense anxiety attacks surrounding the slightest onset of pain. My debilitating migraines coupled with my exhausting anxiety attacks meant that I remained in bed almost constantly for the fall 2019 semester and had to take medical leave during the spring 2020 semester.

It was only during my medical leave during the spring 2020 semester that I stumbled upon the most basic concepts revolving around pain neuroscience and pain psychology. That spring, while spending almost every day at different doctors' offices, I found an app called *Curable* that targets chronic pain in various forms and introduces tools for dealing with it. *Curable* has been one of my most helpful allies in reducing my chronic pain, and has gotten me interested in the research behind pain neuroscience and pain psychology. The advancements in neuroscience are groundbreaking in their take on pain, and have the potential to completely change the American medical landscape.

Pain neuroscience and pain psychology arise out of the premise that what we understand as physical pain is as equally an emotional experience as it is a physical experience. Though we have been taught that the mind and body are two separately functioning entities, the reality is that they are inextricably linked. They are linked because all sensory experiences are processed through the brain in order to be felt.

This is equally true for pain as a sensory experience. Pain is processed through multiple different sites in the brain. One such site is the limbic system, which is one of the key locations where emotional and behavioral responses are constructed. The emotional processing that ultimately creates pain is incredibly important in understanding the function of pain. Brains produce pain as a reaction to the danger the brain perceives the human to be in. A body that never experiences pain will not survive for very long; pain serves the essential purpose of telling the conscious mind when it needs to stop what it is doing and take care of itself.

Based on the processing of pain that happens throughout the brain, in equally emotional and physical processing sites, one's brain is instructed on how to react.

> "If there's any reason to think that protection is required, *your brain makes pain.* Your appraisal of the situation is a critical determinant of the pain you feel. Context, thoughts, prior experiences and memories, emotions, and the meaning you assign to your pain all change your experience of it"[2].

Leading pain psychologist Rachel Zoffness emphasizes the way that pain, when thought of simply as the sensory output experience, holds the weight of one’s entire experience and learned brain processing. The experience of pain is like a curtain on a theatre stage, behind which exists all of the cast members, the props, the hours of practice, and each person's individual journey that led them to that show. Due to all the background and historical input that goes into the specific pain we feel in our bodies, pain neuroscience tells us that "*pain is not an accurate indicator of tissue damage.* Pain is an interpretation, your brain's best guesstimate based on all available information"[3].

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[2] Zoffness, Rachel. 2020. *The Pain Management Workbook: Powerful CBT and Mindfulness Skills to Take Control of Pain and Reclaim Your Life*. N.p.: New Harbinger Publications. 10.

[3] Zoffness, *The Pain Management Workbook,* 10.

Chronic pain is defined as pain that exists nearly every day for longer than six months[4]. Though experiences of chronic pain come in all shapes and sizes, the definition provided by artist Johanna Hedva in their writing "Sick Woman Theory" encapsulates much of the pathos of what it means to have chronic pain for me. They write,

> "For those who don't know what chronic illness means, let me help: the word "chronic" comes from the Greek "khronos," Latinized to "chronos," which means "of time" (think of "chronology"), and it specifically means "a lifetime." So, a chronic illness is an illness that lasts a lifetime. In other words, it does not get better. There is no cure. And think about the weight of time: yes, that means you feel it every day"[5].

Hedva's explanation of the definition of chronic illness is incredibly resonant for me because of the emphasis on the lack of cure. As someone who has experienced chronic pain for the majority of their life, it is exhausting when doctors are sure that their new tool or medication will cure me, or when individuals who aren't familiar with my pain give me suggestions on what they know will help me. Unless I, by some miracle, wake up with a completely different, perfectly able-bodied body, my pain is not going anywhere. That said, pain neuroscience emphasizes that while pain itself may be chronic, the pain pathways that cause the severity of pain are plastic. This means that they are, to some degree, changeable.

The plasticity of the brain's pain pathways works in two directions. It is both what causes the learned longevity and severity of chronic pain, and what can undo this longevity and severity. When one's brain experiences pain signals nearly constantly for a sustained period of time, such as with chronic pain, the brain's pain pathways become more carved out than those of a brain not receiving constant pain signals. As pain psychologist Rachel Zoffness puts it, the longer you experience pain, the more your brain "practices" pain through pain pathways. "The more you use

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[4] Watson, Stephanie. 2020. “Chronic Pain Syndrome: Symptoms, Causes, Diagnosis, Treatment.” WebMD. https://www.webmd.com/pain-management/chronic-pain-syndrome-overview.

[5] Hedva, Johanna. 2016. “Sick Woman Theory.” johannahedva.com. http://johannahedva.com/SickWomanTheory_Hedva_2020.pdf. 2.

this pathway, the bigger and stronger it gets. The stronger this pathway gets, the better your brain gets at pain! When this happens, we say your brain has become *sensitive*"[6].

When there is sustained tissue damage somewhere in the body, the brain will pick up these signals. However, if the damage lasts long enough, the brain will become so sensitized to the pain signals that it will continue picking them up even after the tissue damage is healed. A brain that has become sensitive to pain signals picks up all future pain signals more readily. As more, smaller pain signals are received, the brain is further sensitized. Without addressing this heightened sensitization, the brain continues down an exponential growth path of reacting to even the smallest pain signals.

The sensitization that occurs in the brains of chronic pain sufferers means that the "entire "danger-detection" system is now on high alert - but it doesn't need to be. In fact, this constant attention to and focus on pain *only makes pain worse.* These warning signals are therefore no longer useful, nor do they protect you. Your nervous system has simply 'gotten good' at pain, so your brain's response is louder"[7]

Though the brain has "gotten good" at pain, it has become bad at assessing actual threats to the body's safety. Pain is not tied to tissue damage any longer, but is instead acting as building blocks,doubling down on itself. Chronic pain continues and grows on itself because the pain pathways have become so sensitized that they respond to even the tiniest stimuli. The plasticity of the pain pathways in the direction of sensitization is what keeps pain stuck and turns it chronic. However, this finding of pain pathway plasticity is groundbreaking in its implications that these pathways can also be reversed with the correct tools and care.

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[6] Zoffness, *The Pain Management Workbook,* 15.
[7] Zoffness, *The Pain Management Workbook,* 16.

Just as pain pathways are plastic and can grow to become increasingly sensitive to pain signals over time, these pain pathways can also be desensitized. The brain's pain pathways become sensitized through attention to all pain signals, even ones that do not arise from harmful situations and do not indicate tissue damage. Pain neuroscience and pain psychology tell us that one of the key tools for desensitizing the brain once pain has become chronic is to distract from the pain[8]. Where giving the pain attention may deepen the pain pathways, ignoring the pain has the effect of telling the brain that the body is in no physical danger.

Ignoring pain, however, is incredibly difficult. Intense pain comes with severe anxiety about the pain, which serves to increase the brain's sense that it is unsafe, which then sends out more pain signals. In order to lower pain, the anxiety surrounding the pain must be lowered as well. Pain neuroscience teaches us that "when *stress and anxiety* are low - your body is relaxed, your thoughts are calm, you perceive or believe that your body is safe - your cerebral cortex and limbic system send signals to your pain dial, lowering the volume on pain so that pain feels less bad"[9]. Reaching a place of low stress and anxiety in the face of pain can seem like a nearly impossible feat for a chronic pain sufferer. In addition to the intense pain experience, the unpredictable nature of chronic pain often means missing work, social events, or any kind of commitment, which is in itself incredibly anxiety-inducing. It makes sense that, with so little control over their lives, chronic pain sufferers feel immensely anxious.

Pain experiences are not entirely physical. Chronic pain arises from even the slightest signaling of pain pathways, which includes equally "emotional" stimuli as it does "physical." Just as pain signals can cause intense anxiety, intense anxiety can cause pain pathways to be triggered and pain to be experienced. This is true with all negative emotions. In the case of anxiety,

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[8] Zoffness, *The Pain Management Workbook,* 21.
[9] Zoffness, *The Pain Management Workbook,* 20.

research shows that "anxiety tends to activate defence mechanisms. Two of the most important are isolation of affect and repression. Isolation of affect is the awareness of emotions in one's head without the experience of the emotions in the body, or 'intellectualizing.' Repression is the unconscious process by which emotions are shunted into the body rather than reaching consciousness at all"[10]. Both of these processes do not allow anxiety to fully play out in the body and mind, which can lead to pain-sensitized pain pathways being triggered. Specifically with repression, the person repressing the anxiety may not even realize that they are feeling anxious, but may feel the experience of pain that is triggered as a result of the anxiety emotion failing to be consciously processed. On the other hand, "when feelings are being experienced consciously to some degree, then, by definition, they are not being somatized to that degree at that moment"[11]. The process of recognizing and making emotions conscious is another tool in decreasing pain, as the emotions cannot then be referred into the body as pain.

The processes of addressing the sensitized pain pathways that create chronic pain are numerous. Pain psychology tells us that if we address our negative, uncomfortable emotions every day, not just when we are in pain, we will learn to experience our emotions consciously and thus be able to release them before they trigger pain. In addition, if we distract ourselves "via *gradual exposure* to small doses of potentially triggering stimuli such as movement, touch, and activity"[12], we will desensitize our pain pathways over time. When pain is triggered, we can learn to coax our bodies into believing that they are safe. The techniques surrounding these broad themes of desensitization are simple, but take patience, space, and commitment. I have chosen to use my thesis as a space for this healing process, as it is a process that already inherently requires

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[10] Abbass, Allan, D. Lovas, and A. Purdy. 2008. "Direct Diagnosis and Management of Emotional Factors in Chronic Headache Patients." *Cephalalgia*, 1308.

[11] Abbass, Lovas, and Purdy, "Direct Diagnosis and Management of Emotional Factors in Chronic Headache Patients." 1309.

[12] Zoffness, *The Pain Management Workbook,* 17

commitment, and learning how to desensitize my pain pathways through art is something I feel passionately about.

In creating this art practice I found myself reflecting on the kinds of work that have influenced me to think about my chronic pain in an artistic capacity. The first artist that came to mind is Frida Kahlo. Kahlo's omnipresence in Western culture has seared her work into my brain, despite little conscious consumption on my part. The constant cultural presence of Kahlo's work has subconsciously validated the portrayal of disability and chronic pain through art as a form of expression. Her work does not shy away from her pain and it is clear that her pain was a key driving force behind her need to create. As one doctor put it, "as Kahlo lived and struggled with chronic pain, painting offered her an opportunity for escape and emotional catharsis"[13]. Though I am using my art practice to work through the pain rather than to escape from it, Kahlo's body of work nevertheless provides important evidence that chronic pain can be processed through art.

The work of artist Anna Cowley Ford centers specifically around the impact of migraine attacks. Ford is primarily a ceramicist who creates life-size busts depicting migraines. Ford's work is incredibly relatable for me and has even further shown me the importance of making the invisible visible through art.

When asked in an interview what her work is trying to convey, Ford replied: "The fracturing of one’s life. The loss of friendships and relationships. The guilt. The impact on one’s mental health - anxiety, depression, suicidal thoughts"[14]. Ford's busts create a very visceral reaction in me. There is a way in which they frighten me, because in looking at them I know

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[13] Antelo, Fernando. 2013. “Pain and the Paintbrush: The Life and Art of Frida Kahlo.” *Journal of Ethics*, May 2013.

[14] Glaser, Angie. 2019. “A Raw Look at Chronic Migraines in "The Dragon That Never Sleeps."” Migraine Again. https://www.migraineagain.com/chronic-migraines-through-art-dragon-never-sleeps/.

exactly what the sensations they convey feel like for me. Even a hint at these sensations puts me on edge, anticipating experiencing them myself; this deeply visceral reaction shows me that her work is successful in its ability to convey the migraine experience. Ford's work proves that it is possible to create a visual representation for an experience that is so deeply isolating and invisible.

For my project, I am creating multimedia "pain maps" that represent the sensations I feel when I have a migraine. When I begin to have a migraine, or as soon as I can after one starts, I create a visual representation of the sensations of the pain experience. The word "pain" in "pain map" can be substituted for "sensation." These maps can be done anytime. I have only been creating them when I am experiencing pain, but all they really are are visual meditations on my pain and experiences. I have created these maps over many years, primarily in my journal, using pens, colored markers, and pencils. Though these mediums have been helpful in creating early pain maps, they do not capture the full texture or nuance of my sensory experiences.

During the beginning stages of this thesis, I committed to using mixed-media to try to better represent my pain sensations. I tried painting, drawing, sewing, wire-working and using pastels for my maps. I found that wire is the medium I feel can most accurately express my pain. Wire is a medium I have been working in since I was 19 years old. I first began playing with wire as a way to address my nail-biting and hair-pulling habits by keeping my fingers busy. As I played with it more and more, I made designs that were further intricate and began to see wire as its own art form

To me, wire working allows me to express what is in my head. I never thought I was very good at drawing or painting because I was unable to portray the images in my head. Wire gives me grace while other mediums do not because it is always malleable, which means that if a line doesn't look like what I want it to, I can simply change it. In addition, I love wire because there are very few famous examples of wire artists out there. This means that there is not as much pressure for the wire work I make to look "good," or even look like anything specific. People don't generally have an idea of what wire "should" look like, which gives me the freedom to make whatever I want.

In creating my pain maps, wire has proven to be the medium that conveys my pain sensations best. The malleability of wire means that I can change the map as I work according to how the sensations feel. Additionally, the fluidity of the wire speaks to the long-term, chronic nature of my migraine experiences. One of the ways I am learning to think about my pain is as an exacerbation of feelings that have already been existing within me. The anxiety that surrounds the fear of having a migraine relies on the pain being invisible. This invisibility means that I am forced to express my pain to the world only when my pain is "bad enough" that I can no longer function "normally." Over time, the result is that I begin to fear the circumstances that equal "bad enough," rather than the everyday circumstances that cause me to arrive at this pain. As Johanna Hedva writes,

> "'Sickness' as we speak of it today is a capitalist construct, as is its perceived binary opposite, 'wellness.' The 'well' person is the person well enough to go to work. The 'sick' person is the one who can't. What is so destructive about conceiving of wellness as the default, as the standard mode of existence, *is that it invents illness as temporary.* When being sick is an abhorrence to the norm, *it allows us to conceive of care and support in the same way"*[15].

When I categorize my pain not as an anomaly, but as my body's normal response to emotional and physical stimuli, I am able to bring down the anxiety I feel around each migraine. The fluidity and malleability of wire helps to remind me that my migraines are not isolated incidents of pain but that each of them is a continuation of my overall state of being. These

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[15] Hedva, "Sick Woman Theory," 12.

factors that help me to emotionally cope with my migraines also allow me to best visually represent what the pain sensations feel like.

My pain maps are a healing technique for my experiences with chronic migraines. These maps allow me to portray traumatic and painful experiences in beautiful ways as a form of therapy and to show a visual of an experience that would otherwise be invisible to others. If you experience any form of chronic pain, you know that it is an experience engulfed in fear, anxiety, depression, isolation, and complete overwhelm. Often when I begin to experience the discomfort of a migraine, my mind goes blank as it is swept over with these emotions. These emotions are one of, if not the hardest, parts of, experiencing chronic pain.

Since I started pain mapping around four years ago I have found it to be very therapeutic to target and focus on the specificity of the sensations in my body. What at first may feel like overwhelming pain can be, through mapping, broken down into the individual, specifically located and imagined sensations: a purple spiral that radiates through my left jaw and neck; carbonation traveling upwards behind my left sinus and eye; throbbing green donuts where my spine meets my skull. Articulating the specificity of the sensations I feel, either through words or through visual art, helps to decrease the overwhelming anxiety and sadness surrounding the pain experience, which I have found to be helpful in decreasing the pain itself.

Pain mapping has, for me, been an incredible tool in handling my chronic migraines. However, in learning more about the neuroscience of pain, I am learning that the premise of pain mapping is potentially counterintuitive to healing. Pain neuroscience tells us that distraction from the pain is the best tool for desensitizing pain pathways. In creating pain maps, I am focusing directly on the pain, which pain neuroscience says should further *sensitize* my pain pathways. When I place these two facts side by side I am forced to question whether my approach of pain mapping is helpful, or whether it is a relic of the limited way I've thought about pain until now. What purpose does pain mapping actually serve? I *feel* like it helps me break down the ways my pain actually feels, but based on what I've learned from pain neuroscience, this focus on the pain may actually be sensitizing my pain pathways more.

In thinking about this problem and continuing to create pain maps I've realized the key thing I get from pain mapping: pain mapping creates a visual representation of an incredibly difficult and lonely experience that is otherwise invisible. One of the main articulations for Johanna Hedva's creation of "Sick Woman Theory" is that "Sick Woman Theory is for those who are faced with their vulnerability and unbearable fragility, every day, and so have to fight for their experience to be not only honored, but first made visible"[16]. This reasoning deeply resonates with me. Pain neuroscience is therapeutic for me because it gives me a deeper understanding of a process that otherwise feels overwhelming, completely outside of my control, and unstoppable. Using Hedva's words I realize that pain mapping is therapeutic for me because it provides proof that the outwardly invisible pain that I experience is in fact real. *Pain mapping helps me believe myself when I am in pain.*

While distraction may be good in the long run for desensitizing my pain pathways, I am still operating as someone who has gotten immensely good at acting normal when I am in extreme pain. I spend a lot of time going through the mental gymnastics of how, when I am in pain, I “should” perform this pain to the outside world. If I am at work, or in class, or with friends, the degrees to which I perform pain are all different. As I've grown, I know that it takes more energy to perform pain than it does to simply deal with it in silence. However, when you look normal and talk normally and seem otherwise completely normal, people don't believe you when you say you're in excruciating pain. If I were gushing blood, nobody would question my

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[16] Hedva, "Sick Woman Theory," 8.

need to deal with my injury, regardless of how okay I seemed. Because of this, I have learned in which situations I need to perform pain, and which ones I can simply leave without proving the necessity to those I'm around. This said, I have deeply internalized the world's take on my pain, which is that if it cannot be seen, it is not there, or that it is not that bad. Creating pain maps gives me validation – physical receipts – for all the times I might otherwise have gaslit myself into believing I was fine.

It is hard to move through the world invisibly! I feel this in two parts of my identity: being trans non-binary but still presenting as the world expects me to (as a girl), and in having chronic migraines. Each of these experiences of invisibility can themselves trigger anxiety and thus, potentially, more pain. Art as a manifestation of what outwardly presents as invisible is a vital form of therapy for me.

As I reflect on the journey of this thesis – understanding my pain history, the neuroscience of chronic pain, and the ways that my pain mapping with art facilitates a tool for managing the pain – several questions are still unresolved and feel important to keep exploring. Among them is the contradiction that pain mapping presents. While pain mapping helps me in a number of ways, it is to some degree counterintuitive to pain neuroscience, which says that distraction from pain is what is most helpful in desensitizing pain. How do I validate my pain experiences and work to heal at the same time? Can they exist side by side?

Also, how might pain mapping relate to pain neuroscience education? Is there a way that its embrace by the medical establishment might assist health providers in addressing something I have often observed in my own interactions with them: their implicit bias about invisible and chronic conditions? Might pain mapping help the medical field become more aware, more compassionate, more collaborative with chronic pain patients?

This thesis has resonated with me personally. As I have written, the answers to these questions have extremely personal implications. I am excited to see where I can take my practice next semester, as I continue to explore the frontiers of both the neuroscience of chronic pain and my pain mapping response to the chronic condition that continues to affect my everyday existence.

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